Representaciones cognitivas y emocionales del cáncer y la hipertensión: Aplicaciones del Modelo de Autorregulación en población sana

Antonio del Castillo Godoy

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Débora God

Fdo.: Débora Godoy Izquierdo   Fdo.: Antonio del Castillo Godoy

Fdo.: María Luisa Vázquez Pérez

REPRESENTACIONES COGNITIVAS Y EMOCIONALES DEL CÁNCER Y LA HIPERTENSIÓN: APLICACIONES DEL MODELO DE AUTORREGULACIÓN EN POBLACIÓN SANA

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Facultad de Psicología

Autor
Antonio del Castillo Godoy

Directoras
Dra. Dª. Débora Godoy Izquierdo

Dra. Dª. Mª Luisa Vázquez Pérez

Granada, Noviembre de 2015

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PARTE I:

INTRODUCCIÓN GENERAL

De acuerdo con la OMS (2013), las principales causas de muerte a nivel mundial se relacionan con problemas de carácter cardiovascular. En concreto, esta organización señaló que en 2012 la principal causa de mortalidad fue la cardiopatía isquémica, con un 13.2% de las muertes, seguida de la afección cerebrovascular, con un 11.9%. Además indica explícitamente que un 2% de las muertes se deben a enfermedad hipertensiva. La OMS asimismo muestra que, en comparación con el año 2000, las muertes originadas por cardiopatía isquémica y afección cerebrovascular se habían incrementado en 2012 en más de un millón de casos a nivel mundial y cuando hablamos de enfermedad hipertensiva en alrededor de 200000 casos. En su informe sobre hipertensión (OMS, 2013), se refleja que la hipertensión, al constituir uno de los principales factores de riesgo para este tipo de afecciones, explicaría alrededor del 7% de las muertes y la discapacidad producida a lo largo de la vida de una persona (Lim et al., 2012). En cuanto al cáncer, constituye la primera causa de mortalidad en todo el mundo, con cifras que superan los 8 millones de defunciones por cualquiera de los tipos de cáncer (OMS, 2015), y la tendencia además es que estas aterradoras cifras se incrementen, estimándose que dentro de veinte años el cáncer provoque más de 20 millones de defunciones anuales.

En España, el último informe emitido por el Instituto Nacional de Estadística sobre patrones de mortalidad en 2013 señala que las enfermedades del sistema circulatorio constituyen la primera causa de mortalidad en nuestro país, con un 30.3% del total de las muertes, seguidas del cáncer con un 28.4%. En el caso de los hombres la primera causa fue el cáncer, siendo en el de las mujeres las enfermedades cardiovasculares.

CAPÍTULO 1

El cáncer

1.1. El problema del cáncer: Concepto, epidemiología y posibilidades de prevención

Cuando hablamos de cáncer en general nos estamos refiriendo a un amplio grupo de enfermedades que pueden afectar a cualquier parte del organismo. También se habla de «tumores malignos» o «neoplasias malignas». El cáncer es un término muy amplio que abarca más de doscientos tipos diferentes y cada uno de ellos posee características particulares, que en algunos casos son completamente distintas a las del resto de cánceres, pudiendo considerarse enfermedades independientes, con sus causas, su evolución y su tratamiento específicos. Una característica básica del cáncer es la multiplicación rápida de células anormales que se extienden más allá de sus límites habituales y pueden invadir partes adyacentes del cuerpo o propagarse a otros órganos, proceso conocido como metástasis. El cáncer comienza en una célula. La transformación de una célula normal en tumoral es un proceso multifásico y suele consistir en la progresión de una lesión precancerosa a un tumor maligno. Estas alteraciones son el resultado de la interacción entre los factores genéticos del paciente y tres categorías de agentes externos (OMS, 2015, disponible en www.who.int/mediacentre/factsheets/fs297/.es):

- Carcinógenos físicos, como las radiaciones ultravioleta e ionizantes;
- Carcinógenos químicos, como los asbestos, los componentes del humo de tabaco, las aflatoxinas (contaminantes de los alimentos) o el arsénico (contaminante del agua de bebida);
- Carcinógenos biológicos, como las infecciones causadas por determinados virus, bacterias o parásitos.

El envejecimiento es otro factor fundamental en la aparición del cáncer. La incidencia de esta enfermedad aumenta de forma exponencial con la edad, muy probablemente porque se van acumulando factores de riesgo de determinados tipos de cáncer. La acumulación general de factores de riesgo se combina con la tendencia que tienen los mecanismos de reparación celular a perder eficacia con la edad.

El cáncer constituye uno de los más graves problemas de salud a nivel mundial ya que es una de las principales causas de morbilidad y mortalidad en todo el mundo. La OMS estima que en 2012 hubo unos 14 millones de nuevos casos y 8.2 millones de muertes relacionadas con el cáncer, convirtiéndolo en la primera causa de muerte en el mundo. La tendencia es que la prevalencia de esta enfermedad se incremente, de modo que se prevé que el número de nuevos casos aumente en aproximadamente un

70% en los próximos 20 años, llegando a alcanzar los 22 millones de personas afectadas por esta enfermedad. Son los países subdesarrollados o en vías de desarrollo los que se enfrentan a mayores tasas de incremento de la enfermedad; más del 60% de los nuevos casos anuales totales del mundo se producen en África, Asia, América Central y Sudamérica y estas regiones representan el 70% de las muertes por cáncer en el mundo, mientras en los países desarrollados (Australia, Estados Unidos y Europa occidental) la incidencia de la enfermedad es más alta pero con una mortalidad general de tan sólo un 30%. En concreto, actualmente en la Unión Europea hay estimados 2.66 millones de nuevos casos de cáncer y 1.28 millones de muertes relacionadas por año. Por otra parte, debido a los efectos del crecimiento de la población y el envejecimiento, la carga del cáncer en Europa se prevé que aumente en los próximos años y décadas (OMS, 2015)

De acuerdo con el grado de mortalidad a nivel mundial en el año 2012, los principales tipos de cánceres son:

- Pulmonar (1.59 millones de defunciones);
- Hepático (745000 defunciones);
- Gástrico (723000 defunciones);
- Colorrectal (694000 defunciones);
- Mamario (521000 defunciones);
- Esófago (400000 defunciones).

En 2012, los cánceres diagnosticados con más frecuencia en el hombre fueron los de pulmón, próstata, colon y recto, estómago e hígado mientras que en la mujer fueron los de mama, colon y recto, pulmón, cuello uterino y estómago (OMS, 2015).

En nuestro país, según los últimos datos publicados por el Instituto Nacional de Estadística de 2014, los tumores fueron la segunda causa de muerte en ambos sexos, responsables de 27.5 de cada 100 defunciones. Por sexo, los tumores fueron la primera causa de muerte en los hombres (con una tasa de 296.3 fallecidos por cada 100000) y la segunda causa en mujeres (con 180.0 fallecidas por cada 100000). De acuerdo con esos datos, el cáncer con una mayor incidencia de forma general es el colorrectal (15%), el que produce una mayor mortalidad es el cáncer de pulmón (20.6%) y el que tiene una prevalencia a 5 años más alta es el cáncer de mama (17.9%). En el caso de los hombres, la incidencia más alta es para el cáncer de próstata (21.7%), la mortalidad más elevada para el cáncer de pulmón (27.4%) y la prevalencia a 5 años mayor para el cáncer de próstata (31.4%), mientras que en las mujeres la mayor incidencia, mortalidad y prevalencia a 5 años es para el cáncer de mama (29%, 15.5% y 40.8%, respectivamente) (ver Tabla 1) (Ferlay et al., 2012).

Tabla 1. Cánceres más frecuentes en España en 2012. Extraído de Ferlay et al. (2012).

	Hombre	**Mujer**	**Ambos sexos**
1	Próstata	Mama	Colorrectal
2	Pulmón	Colorrectal	Próstata
3	Colorrectal	Cuerpo de útero	Pulmón
4	Vejiga	Pulmón	Mama
5	Estómago	Ovario	Vejiga

En el documento “Las cifras del Cáncer en España 2014” elaborado por la Sociedad Española de Oncología Médica se destaca que, de acuerdo con un informe de salud de 2013 sobre indicadores de la Organización para la Cooperación y Desarrollo (OECD) en el que se aportan datos sobre cambios en las tasas de mortalidad por cáncer entre 1990 y 2011, en España se ha producido un descenso del 13%, encontrándose en la media de los países de la OECD, pero que es muy inferior a otros países europeos de nuestro entorno o a USA. Sin embargo, a pesar de la reducción en la mortalidad, los casos de cáncer no dejan de aumentar y se espera que para este año 2015 aparezcan en España 227076 nuevos casos, con un crecimiento mayor a costa de la población de más de 65 años (Ferlay et al., 2012).

Una cuestión fundamental y que requeriría de una reflexión profunda por parte de las instituciones de salud a nivel mundial es el papel que los factores conductuales y de estilo de vida juegan en la aparición, evolución y mortalidad asociada al cáncer, y que permitirían reducir la prevalencia de la enfermedad a través de la prevención (primaria, secundaria o terciaria). La OMS estima que aproximadamente un 30% de las muertes por cáncer son debidas a cinco factores de riesgo conductuales: índice de masa corporal elevado, ingesta reducida de frutas y verduras, falta de actividad física, consumo de tabaco y consumo de alcohol. Así, el consumo de tabaco es el factor de riesgo más importante, y es la causa más del 20% de las muertes mundiales por cáncer en general, y alrededor del 70% de las muertes mundiales por cáncer de pulmón. Algunas infecciones crónicas también constituyen factores de riesgo, y son más importantes en los países de ingresos medios y bajos. Otros factores que pueden causar cáncer y que son perfectamente prevenibles serían radiaciones ionizantes y no ionizantes, la contaminación del aire de las ciudades y el humo generado en la vivienda por la quema de combustibles sólidos.

En nuestros días poseemos elevado conocimiento acerca de las causas del cáncer y de cómo podemos prevenirlo y tratarlo. Es posible, por tanto, lograr una reducción y control de la enfermedad aplicando diferentes estrategias orientadas a tres niveles básicos. Primero a través de la prevención, introduciendo cambios en el estilo de vida que afecten a los factores conductuales ya señalados y que constituyen importantes causas de la enfermedad. En segundo lugar, fomentado la detección temprana que permita intervenir sobre el cáncer en las fases iniciales de la enfermedad. Y, por último, aplicando los tratamientos más apropiados de acuerdo con el tipo de cáncer y el estadio de su desarrollo. Muchos cánceres tienen grandes probabilidades de curarse si se detectan tempranamente y se tratan de forma adecuada.

Un ejemplo claro del esfuerzo de las administraciones públicas, en este caso de la Comisión Europea, para la prevención del cáncer, es el llamado Código Europeo Contra el Cáncer desarrollado por la Agencia Internacional para la Investigación sobre el Cáncer (IARC) y la delegación especializada en la enfermedad de la OMS. Dicho código, que va ya por la cuarta edición desde 1987, trata de concienciar a la población sobre la importancia de la prevención de esta enfermedad a través de la propuesta de acciones concretas para ser implantadas en la vida cotidiana, fomentado de ese modo estilos de vida más saludables. Basado en la evidencia científica disponible, el nuevo código establece doce maneras de adoptar estilos de vida más saludables y optimizar la prevención del cáncer en Europa (ver Tabla 2).

El documento hace hincapié en la importancia de evitar el tabaco, el alcohol y la exposición excesiva al sol, así como los beneficios de mantener un peso corporal saludable y la actividad física. También recomienda la participación en programas de detección para el cáncer de intestino, mama y cuello de útero. En esta nueva edición también se incluyen otras recomendaciones importantes para reducir el riesgo de padecer cáncer, como la vacunación contra el virus del papiloma humano, la lactancia materna y la limitación en el uso de la terapia de sustitución hormonal. Igualmente recomienda averiguar la exposición potencial a la radiación de radón en el hogar y la adopción de medidas para reducir sus niveles.

Tabla 2. Código Europeo contra el cáncer resumido. 4ª edición. Comisión Europea (2014).

Doce maneras de reducir el riesgo de cáncer
1. No fume. No consuma ningún tipo de tabaco.
2. Haga que su hogar sea libre de humo. Apoye las políticas libres de humo en su lugar de trabajo.
3. Tome medidas para tener un peso corporal saludable.
4. Realice alguna actividad física en la vida cotidiana. Limite el tiempo que pasa sentado.
5. Mantenga una dieta saludable: - Coma muchos cereales integrales, legumbres, verduras y frutas. - Limite los alimentos altos en calorías (ricos en azúcar o grasa) y las bebidas azucaradas. - Evite la carne procesada: limite la carne roja y los alimentos con alto contenido de sal.
6. Si usted bebe alcohol de cualquier tipo, limite su consumo. No consumirlo es mejor para la prevención del cáncer.
7. Evite el exceso de sol, especialmente en niños. Use protección solar. No tome rayos UVA.
8. En el lugar de trabajo, protéjase frente a sustancias que causen cáncer siguiendo las instrucciones de salud y seguridad.
9. Averigüe si está expuesto a la radiación de niveles naturalmente altos de radón en su hogar. Tome medidas para reducirlo si éstos fueran altos.
10. Para las mujeres: -La lactancia materna reduce el riesgo de cáncer de la madre. Si puede, amamante a su bebé. -La terapia de sustitución hormonal (TRH) aumenta el riesgo de ciertos tipos de cáncer. Limite su uso.
11. Asegúrese de que sus hijos participen en los programas de vacunación para: -Hepatitis B (recién nacidos). -Virus del papiloma humano o VPH (para las niñas).
12. Forme parte en los programas de cribado del cáncer organizados para: -Cáncer de intestino (hombres y mujeres). -Cáncer de mama (mujeres). -Cáncer de cuello de útero (mujeres).

CAPÍTULO 2

La hipertensión

2.1. El problema de la hipertensión. Concepto, epidemiología, riesgos para la salud y posibilidades de prevención

La hipertensión arterial, como su propio nombre indica, se caracteriza por unos niveles elevados de presión de la sangre, que se encuentran por encima de los requerimientos metabólicos del organismo. En este sentido, no existe un acuerdo acerca de los límites entre la normotensión y la hipertensión, variando los criterios en función del autor o de la institución que los propone. Sin embargo, y siguiendo a la Organización Mundial de la Salud (OMS), se podría considerar que la hipertensión se caracteriza por una presión arterial sistólica (PAS) de 140 mmHg o superior y/o una presión arterial diastólica (PAD) de 90 mmHg o superior en una persona que no está siendo tratada con fármacos antihipertensivos (ver Tabla 3). Hay que destacar que los niveles de presión sanguínea se van a ir incrementando con la edad, lo que contribuye a que la hipertensión sea un reductor de la esperanza de vida.

Tabla 3. Clasificación de los niveles de presión arterial*. Adaptado de la Guía Española de Hipertensión Arterial (2005) realizada por la Sociedad Española de Hipertensión-Liga Española para la lucha contra la Hipertensión Arterial (SEH-LELHA).

	Normotensión o Hipertensión controlada			Hipertensión		
Categoría PA	Óptima	Normal	Normal-alta	Grado 1	Grado 2	Grado 3
PAS mmHg	<120	120-139	130-139	140-159	160-179	≥ 180
PAD mmHg	<80	80-84	85-89	90-99	100-109	≥ 110
	**Normal	Prehipertensión		Estadio 1	Estadio 2	

La Guía Europea (ESH/ESC 2003) establece el diagnóstico de hipertensión con cifras de PAS ≥ 140 mmHg y de PAD ≥ 90 mmHg.

* *European Society of Hypertension-European Society of Cardiology Guidelines Committe3*.

** Clasificación de los niveles de presión arterial según *Joint National Committee of Prevention, Detection, Evaluation and Treatment of Hypertension*.

PA: Presión arterial; PAS: Presión arterial sistólica; PAD: Presión arterial diastólica.

De acuerdo con su génesis podemos hablar básicamente de dos tipos de hipertensión:

1) Hipertensión esencial o primaria: Su origen no se puede determinar orgánicamente, se trata, por tanto, de un trastorno de carácter funcional. El 95% de los pacientes hipertensos se englobaría en esta categoría.
2) Hipertensión secundaria: Se debe a un fallo o un daño orgánico. A veces la hipertensión secundaria es el resultado de los propios daños generados por la hipertensión esencial no tratada.

La hipertensión constituye un trastorno cardiovascular que afecta en los países desarrollados a alrededor del 40% de la población (OMS, 2013). En nuestro país la hipertensión constituye también un importante problema de salud pública, de modo que en la población general adulta la prevalencia era hace una década de aproximadamente un 35%, llegando al 40% en edades medias y a más del 60% en los mayores de 60 años, afectando en total a unos 10 millones de individuos adultos (Banegas, 2005). Datos más recientes han mostrado tasas aún más elevadas, de modo que esta enfermedad afecta a más del 47% de los hombre y el 39% de las mujeres con tasas de prevalencia más altas en las regiones del sur (44%) comparadas con otras regiones (Grau et al., 2011; Valdés et al., 2014). Además, las estimaciones sobre las tasas de prevalencia a nivel mundial para el futuro son alarmantes, indicando un incremento de un 60% para el año 2025 (Kearney et al., 2005). Otro problema fundamental cuando hablamos de la prevalencia de la hipertensión tanto en España como en otros países del mundo estriba en que cerca de un tercio de los afectados no son conscientes de ello y sólo un 50% del total de personas con hipertensión se encuentra en tratamiento, de modo que sólo en 1 de cada 3 hombres y en 1 de cada 2 mujeres su hipertensión se encuentra bien controlada por las terapias (Banegas et al., 2011; Félix-Redondo et al., 2011; Guo, He, Zhang y Walton, 2012; Ortíz et al., 2011).

Este trastorno no se puede considerar como una afección severa en sí misma y no se va a ver acompañado de una sintomatología específica, por ejemplo dolor, malestar o fiebre, lo que dificulta su detección. Debido a ello, la hipertensión es conocida como el “asesino silente”, ya que constituye un factor de riesgo de primer orden para el desarrollo de graves enfermedades relacionadas con importantes secuelas e incluso con la muerte, como pueden ser las cardiopatías isquémicas, las patologías cerebrovasculares, la insuficiencia renal o la claudicación intermitente (ver Tabla 4). En este sentido, la hipertensión arterial es uno de los principales factores de riesgo modificables para la cardiopatía isquémica y el principal factor de riesgo para los accidentes vasculares cerebrales, tanto hemorrágicos como trombóticos (OMS, 2013). Los datos procedentes de estudios epidemiológicos prospectivos indican que el riesgo de padecer un problema cardiovascular (incluyendo eventos cardíacos, problemas vasculares y accidentes cerebrovasculares fundamentalmente) se incrementa exponencialmente conforme aumenta el valor de la presión arterial (PA) (Lloyd-Jones et al., 2010; Mancia et al., 2013). Además, la hipertensión es causa frecuente de insuficiencia cardíaca en el adulto y favorece otras enfermedades cardiovasculares (aneurisma disecante, etc.) y renales (Banegas et al., 2009). En nuestro país, el 30.3% de las causas de muerte en 2013 se relacionaron con enfermedades del sistema circulatorio, destacando en primer lugar las enfermedades isquémicas seguidas de las cerebrovasculares, problemas que en muchos casos pueden guardar relación con una elevada presión arterial (INE, 2014).

Tabla 4. Clasificación de la hipertensión según la importancia de las lesiones orgánicas. Adaptado de OMS. Prevención Primaria de la hipertensión arterial. Informe Técnico n.686, Ginebra, 1983.

Fases	Lesiones orgánicas
I	No se aprecian signos objetivos de alteraciones orgánicas
II	Aparece al menos uno de los siguientes signos: Hipertrofia del ventrículo izquierdo Estrechez focal y generalizada de las arterias retinianas Proteinuria y ligero aumento de la concentración de creatinina en el plasma
III	Aparecen síntomas y signos de lesión de distintos órganos a causa de la hipertensión: Corazón: insuficiencia del ventrículo izquierdo Encéfalo: hemorragia cerebral, cerebelar o del tallo encefálico; encefalopatía hipertensiva Fondo de ojo: hemorragias y exudados retinianos con o sin edema papilar Otros cuadros frecuentes en la Fase III, pero no tan claramente derivados de manera directa de la hipertensión: Corazón: angina pectoris; infarto de miocardio Encéfalo: trombosis arterial intracraneana Vasos sanguíneos: aneurisma disecante; arteriopatía oclusiva Riñón: insuficiencia renal

Un problema añadido es el hecho de que un importante porcentaje de individuos, alrededor del 34% de la población adulta (Banegas, 2005; Guo et al., 2011; Marta et al., 2013; Ostrowski, Artyszuk, Lewandowski y Gaciong, 2008; Zhang y Li, 2011), presenta unos niveles de PA no considerados como hipertensivos pero que se encuentran en unos niveles no óptimos que se podrían denominar como prehipertensivos y que, dada la continuidad del riesgo cardiovascular a lo largo de los niveles de PA, hacen que estas personas presenten también riesgo de sufrir eventos cardiovasculares (Banegas et al., 1999; Chobanian et al., 2003). En este sentido, la clasificación realizada en el Séptimo Informe del *Joint National Committee on Prevention, Detection, Evaluation and Treatment of Hypertension* de 2007 acerca del manejo de la hipertensión utiliza el término "prehipertensión" para las categorías de PA con valores de 120-139/80-89 mmHg, con el fin de identificar a aquellos individuos en los que la intervención temprana basada en cambios en el estilo de vida podría reducir la PA y el progreso a hipertensión con el paso de los años.

En general, se podría decir que el grado de conocimiento y de tratamiento farmacológico de la hipertensión arterial en la población general de España es relativamente elevado, pero el control se sitúa aún en cifras inferiores al 40% (ver Tabla 5) y difiere en función del ámbito asistencial y del tipo de encuesta realizada (Banegas, Rodríguez Artalejo, Cruz, Guallar y Rey, 1998; Banegas y Rodríguez Artalejo, 2002; Banegas et al., 2009; Llisterri et al., 2008).

Tabla 5. Prevalencia, conocimiento, tratamiento y control de la hipertensión en adultos en España entre 1980 y 2002. Tomado de Banegas (2005).

	1980	1990	1998	2002
Prevalencia (PAS/PAD ≥ 140/90 mmHG)	30%	35%	35%	35%
Conocimiento en hipertensos	40%	50%	60%	65%
Tratamiento* en hipertensos conocidos	40%	72%	78%	85%
Tratamiento en el total de hipertensos	16%	36%	50%	55%
Control en hipertensos tratados	10%	13%	16%	25%
Control en hipertensos conocidos	4%	9%	13%	21%
Control en el total de hipertensos	2%	5%	8%	14%

* Tratamiento farmacológico.

Por ello, y debido al enorme riesgo para la salud asociado a una PA elevada, y teniendo en cuenta además que las cifras de control de la hipertensión parecen situarse en unos niveles aún demasiado bajos en nuestro país y en el mundo en general, parece lógico pensar en la necesidad de desarrollar actuaciones dirigidas a mejorar el conocimiento sobre la enfermedad así como de prevención y control de la misma no sólo en población hipertensa sino también en población prehipertensa o en riesgo de padecer hipertensión, así como en la población general.

De acuerdo con la elevada prevalencia y los importantes riesgos para la salud asociados a este asesino silente, la prevención de la hipertensión constituye un objetivo fundamental en las políticas de salud pública, ya que si se logra prevenir o disminuir la PA elevada muchos de los riesgos relacionados con ella podrían ser evitados. En este sentido, un buen número de factores de riesgo de carácter controlable han sido bien establecidos, entre los que se incluyen aspectos relacionados con el estilo de vida y el comportamiento como el peso excesivo, patrones de alimentación inadecuados, dietas altas en sal y bajas en potasio, reducida actividad física y consumo de alcohol y tabaco (Chobanian et al., 2003; Dikinson et al., 2006; Forman, Stampfer y Curhan, 2009; Frisoli, Schmieder, Grodzicki y Messerli, 2011; Geleijnse, Kok y Grobbee, 2004; Liu et al., 2012; Lloyd-Jones et al., 2010; Mozaffarian, Wilson y Kannel, 2008; Perk et al., 2012; WHO, 2013). Además, se han identificado factores de riesgo de tipo emocional, incluyendo el estrés (Babu et al., 2014; Backé, Seidler, Latza, Rossnagel y Schumann, 2012; Chida y Steptoe, 2010; Gasperin, Netuveli, Soares Dias-da-Costa y Pattussi, 2009; Landsbergis, Dobson, Koutsouras y Schnall, 2012; Nagele et al., 2014; Rainforth et al., 2007; Sparrenberger et al., 2009), la ansiedad (Olafiranye, Jean-Louis, Zing, Nunes y Vincent, 2011; Player y Peterson, 2011) y la depresión (Meng et al., 2012; Nabi et al., 2011), aunque es necesario señalar que parecen ser factores causales más importantes la presencia de episodios recurrentes (Nabi et al., 2011; Wiehe et al., 2006) o los tratamientos con antidepresivos y no la depresión en sí misma (Delaney et al., 2010; Licht et al., 2009).

La prevalencia de estos factores de riesgo es elevada en la población general y, de acuerdo con la OMS (2013), el aumento de las tasas de incidencia y prevalencia de la hipertensión a nivel mundial puede explicarse por la elevada incidencia de estos factores de riesgo junto con el aumento de la población y el incremento progresivo de su longevidad. Por ello, es fundamental desarrollar actuaciones de prevención tanto primaria como secundaria que reduzcan o minimicen el impacto de estos factores de riesgo de manera especial en la población prehipertensa (Guo et al., 2011). En este sentido, intervenciones dirigidas a la población general que permitan disminuir los niveles de PA van a contribuir a la reducción de la morbilidad, la mortalidad o al menos retrasar el desarrollo de la enfermedad y de los riesgos que ésta conlleva para la salud (Chobanian et al., 2003).

Debido al importante impacto a nivel mundial del cáncer y la hipertensión, las cifras de morbi-mortalidad asociadas a ambas enfermedades y las posibilidades de prevención tanto del cáncer como de la hipertensión, la presente Tesis Doctoral tiene el objetivo de realizar una aportación significativa desde el ámbito de la Psicología de la Salud a la mejora del control de estas "epidemias" a través de un conocimiento profundo de algunos de los factores psicosociales que contribuyen a su prevención, conocimiento ajustado y manejo, siguiendo para ello uno de los modelos teóricos sobre creencias de enfermedad más validados desde el punto de vista empírico, el Modelo de Autorregulación.

CAPÍTULO 3

Las representaciones cognitivas y emocionales de la enfermedad: El Modelo de Autorregulación de Leventhal y colaboradores

3.1. El Modelo de Autorregulación y los modelos de enfermedad: Representaciones cognitivas y emocionales de la enfermedad

En los últimos años ha adquirido gran relevancia en el seno de la Psicología de la Salud el estudio de los distintos factores psicosociales relacionados con el modo en que los seres humanos percibimos la salud y la enfermedad y las diferentes estrategias que adoptamos respecto a ambas. Conocer esas variables reviste una gran importancia de cara al diseño e implementación de estrategias efectivas de intervención para la promoción de la salud, la prevención de la enfermedad, el tratamiento y rehabilitación de enfermedades, la adherencia al tratamiento, la educación al paciente y el asesoramiento familiar. Dentro del conjunto de estos factores destacan los de carácter cognitivo, especialmente las creencias, actitudes y expectativas, ya que dichas variables parecen predecir mejor el ajuste a la enfermedad y sus síntomas que las de carácter “objetivo” relacionadas con la propia enfermedad (Sensky, 1990; Sensky y Catalan, 1992).

Estos factores cognitivos relacionados con la enfermedad están basados en gran medida en los modelos personales o representaciones mentales no especializados que la persona posee sobre la salud y enfermedad en general, o sobre una alteración en particular, y que se derivan de sus creencias, conocimientos y experiencias, así como de las informaciones que han recibido de otros sobre dicho estado (Leventhal, Diefenbach y Leventhal, 1992; Leventhal, Meyer y Nerenz, 1980; Leventhal, Nerenz y Steele, 1984).

Los modelos personales de enfermedad incluyen las diferentes atribuciones y creencias que la persona ha ido construyendo acerca de diferentes aspectos o dimensiones relacionados con la enfermedad. Estas creencias permiten a las personas (enfermos o no) dar sentido a cada condición específica y crear una concepción integrada de la enfermedad en general o de un trastorno en particular, evaluar los riesgos para su salud e iniciar las estrategias y planes de acción necesarios para enfrentarse a ellos. De todo lo dicho anteriormente se puede deducir que las personas actúan a partir de la representación mental que poseen acerca de su enfermedad y no tanto a partir de los síntomas o la evidencia objetiva de la alteración.

Diversos modelos teóricos sobre la conducta en relación con la salud y la enfermedad tienen en cuenta el papel de dichos factores cognitivos (i.e., atribuciones, creencias, actitudes, expectativas…) a la hora de explicar y modificar los comportamientos relacionados con la salud y la enfermedad. En este sentido, en la actualidad, el modelo teórico que más apoyo empírico ha recibido acerca de los modelos individuales de enfermedad, y que constituye la base teórica de esta Tesis

Doctoral, es el Modelo de Autorregulación (SRM, *Self-Regulation Model*) de Leventhal y colaboradores (Cameron y Leventhal, 2003; Diefenbach y Leventhal, 1996; Leventhal, Brissette y Leventhal, 2003; Leventhal y Diefenbach, 1991; Leventhal, Leventhal y Cameron, 2001; Leventhal, Leventhal y Contrada, 1998; Leventhal et al., 1980, 1984, 1992, 1997). La característica más relevante del SRM es que subraya la importancia que tiene la perspectiva de la propia persona sobre sus experiencias con la enfermedad para entender sus esfuerzos para manejar y adaptarse a su condición y sus reacciones emocionales.

Según el SRM, las personas sanas y enfermas *construimos* activamente modelos personales o representaciones mentales no especializadas de la salud y de la enfermedad en general, o de una alteración en particular, para darle sentido y comprender nuestro estado y autorregular nuestras respuestas en relación con la salud y la enfermedad. Dicho de otro modo, los modelos de enfermedad pueden ser entendidos como esquemas mentales autogenerados que orientan todo el proceso de establecimiento e implementación de estrategias muy diversas, tanto conductuales como emocionales, para hacer frente a cualquier amenaza para la salud. Esas estrategias que adoptemos a su vez determinarán la evolución de nuestro estado de salud y sus consecuencias en nuestro bienestar y funcionamiento cotidiano. Según el SRM, somos agentes activos en los procesos de toma de decisiones y solución de problemas en relación con la salud y la enfermedad (Diefenbach y Leventhal, 1996), y mediante procesos de autorregulación manejamos información externa e interna -ya sea congruente con el conocimiento especializado o no- sobre nuestro estado, las amenazas a la salud y las consecuencias de éstas, y ponemos en marcha los comportamientos que estimamos más adecuados para conseguir nuestras metas de protección y promoción de la salud, de prevención de la enfermedad o de tratamiento y rehabilitación de la misma. Las personas utilizamos estas representaciones para evaluar los riesgos para nuestra salud y bienestar, y ejecutar en consecuencia diferentes acciones comportamentales y emocionales para hacer frente a los riesgos percibidos y proteger nuestra salud. En personas enfermas las representaciones de su enfermedad también determinan sus esfuerzos para manejar su condición, controlar las consecuencias de la enfermedad en sus vidas y recuperar la salud, el bienestar y la calidad de vida.

Así, el SRM otorga a estas representaciones “una posición central” en los procesos cognitivos y emocionales que se relacionan con la evaluación e interpretación de la salud/enfermedad y los procesos de adaptación y afrontamiento cuando la salud se ve amenazada (Diefenbach y Leventhal, 1996, p. 34), y las considera como “guías para la acción” más persuasivas incluso que el conocimiento abstracto (p.e., científico-médico) que la persona pueda poseer sobre la enfermedad (Leventhal et al., 1992, p. 144). A su vez, estos comportamientos determinarán en cierta medida las características de la enfermedad y el impacto, en un sentido amplio, que ésta tendrá en el paciente.

Por tanto, para el SRM existe una relación causal directa entre el modelo personal de la enfermedad y las respuestas emocionales y de afrontamiento ante la misma, acciones dirigidas tanto a la solución de problemas como al manejo de las respuestas emocionales en relación con la enfermedad, como por ejemplo búsqueda de ayuda, realización de exámenes médicos, manejo de los síntomas, actividades de autocuidado, cambios en su estilo de vida o autorregulación emocional (Godoy-Izquierdo, López-Chicheri, López-Torrecillas, Vélez y Godoy, 2007; Leventhal et al., 1980, 1984, 1997,1998). El SRM también propone una relación indirecta entre dichas creencias o representaciones y las consecuencias de la enfermedad para el paciente o su familia, como pueden ser la calidad de vida, el bienestar subjetivo o el funcionamiento cotidiano, en la que las acciones de afrontamiento y manejo de la persona, determinadas a su vez en gran medida por dichas creencias personales sobre la enfermedad, juegan un papel mediador. Existe una amplia evidencia obtenida con poblaciones con diferentes enfermedades físicas y mentales que apoya la relación postulada en el SRM entre representaciones de la enfermedad y estrategias conductuales concretas, así como entre éstas y un amplio rango de consecuencias (ver French, Cooper y Weinman, 2006; Hagger y Orbell, 2003; Kaptein et al., 2003; Kucukarslan, 2012; Lobban, Barroclough y Jones, 2003; Mc Sharry, Moss-Morris y Kendrich, 2011; Petrie y Weinman, 1997; para una revisión).

El SRM es un modelo de *feedback* circular en el que las consecuencias de las acciones emprendidas por la persona pueden modificar a su vez las creencias acerca de la enfermedad. El modelo, como ya se ha señalado, parte de la consideración de los individuos como solucionadores activos de problemas que organizan el conocimiento, el procesamiento de la información perceptiva y conceptual referida a las amenazas a la salud de manera episódica y autorregulada mediante un sistema de *feedback* (Beléndez, Bermejo y García Ayala, 2005). Ese *feedback* postulado por el modelo proviene de las consecuencias de las acciones desarrolladas por la persona, que van a actuar como mediadoras y que pueden producir a su vez modificaciones en las representaciones mentales de la enfermedad.

En este sentido, el Modelo de Autorregulación propone que las influencias entre los elementos del modelo se desarrollan en tres fases: El estadío 1 se corresponde con creación de las representaciones cognitivas y emocionales a través de las cuales la persona interpreta y da sentido a un estado de salud o enfermedad concreto; el estadío 2 se refiere a los planes de acción y estrategias de afrontamiento que pone en práctica de acuerdo con sus representaciones, y que incluyen tanto los planes o intenciones de actuación como las actuaciones propiamente dichas, que son las acciones dirigidas tanto a la solución de problemas como al manejo de las respuestas emocionales; y el estadío 3 se relaciona con la evaluación de los resultados de las acciones llevadas a cabo, que pueden modificar las representaciones iniciales del paciente y configurar las respuestas de afrontamiento futuras (Godoy-Izquierdo, López-Chicheri et al., 2007). La interacción entre los distintos estadíos es bidireccional y va tanto de las creencias a las acciones como de las acciones (resultados) a las creencias. En conclusión, de acuerdo con el modelo, el proceso de autorregulación consistiría en tres fases interrelacionadas y recursivas (Leventhal y Diefenbach, 1991).

En la Figura 1 se presenta el proceso de autorregulación que se propone en el modelo con sus tres fases interrelacionadas y recursivas (representaciones cognitivas, acciones y evaluación de los resultados de las acciones), de forma que la vía de las influencias podría ser descendente o ascendente, generando nuevas creencias que guiarán nuevas acciones de afrontamiento que darán lugar a nuevas consecuencias que la persona integrará en su modelo de la enfermedad y valorará para sus futuros intentos de adaptación y manejo de la misma (Leventhal y Diefenbach, 1991; Diefenbach y Leventhal, 1996).

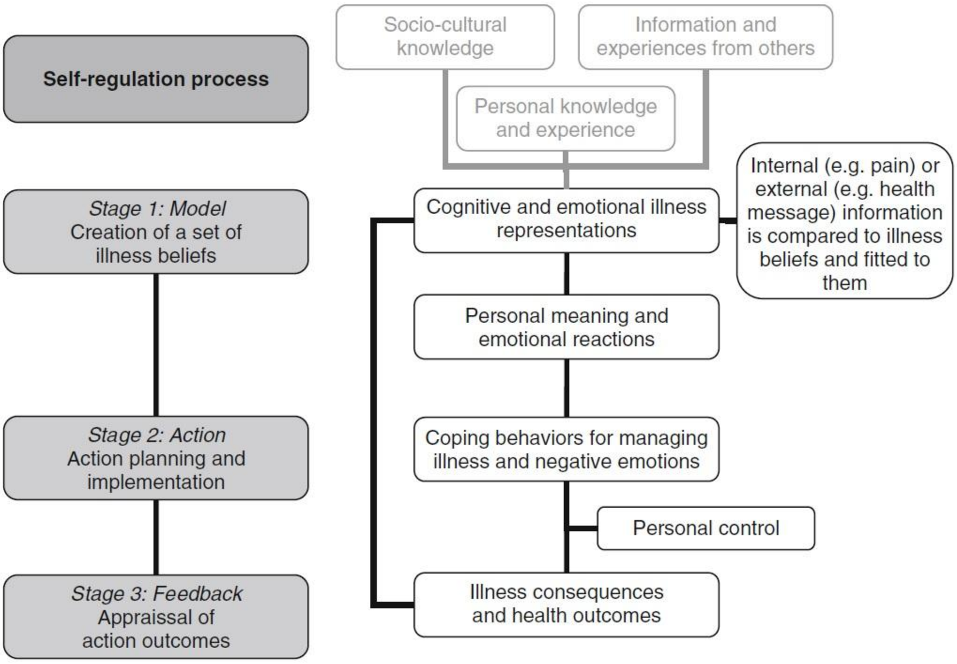

Figura 1. El Modelo de Autorregulación o de Creencias de Sentido Común.

A su vez, estas creencias, aunque consistentes y robustas, son cambiantes y dinámicas, y se alimentan, enriquecen o actualizan constantemente de información procedente de diversas fuentes, como los conocimientos y experiencias personales, tanto directas (p.e., padecer la enfermedad) como indirectas (p.e., tener un familiar que padece la enfermedad), las informaciones recibidas de otros y sus experiencias (p.e., familiares, amigos, profesionales, medios de comunicación, campañas de salud…) y el cuerpo de conocimiento popular y las creencias y normas socio-culturales (Diefenbach y Leventhal, 1996; Leventhal et al., 1980; Leventhal y Diefenbach, 1991).

3.2. Contenidos de los modelos de enfermedad: Dimensiones de creencias y reacciones emocionales

Desde los inicios de la investigación acerca de los modelos personales de la salud y la enfermedad, uno de los objetivos ha sido identificar los contenidos de dichas estructuras mentales. Por ejemplo, Jenkins (Jenkins y Zyzanski, 1968) señaló la existencia de 16 categorías de contenidos para organizar dicha información mientras que para Turk y colaboradores (Turk, Rudy y Salovey, 1986) el objetivo no era otro que confirmar la existencia de una estructura genérica de los modelos personales de enfermedad que pudiera ser aplicada a diferentes desórdenes con independencia de las características sociodemográficas de los individuos, su estado de salud, sus conocimientos acerca de la enfermedad o el impacto de la misma en sus vidas.

En este sentido, el Modelo de Autorregulación postula que existe cierta tendencia común en el modo de organizar las creencias acerca de la enfermedad para construir nuestro modelo personal sobre ella. Así, en relación a los contenidos concretos del modelo personal de una alteración de la salud, según el SRM, éste incluiría las creencias y atribuciones que la persona ha construido sobre su naturaleza, severidad, etiología, síntomas, tratamiento, duración, evolución, pronóstico o consecuencias, entre otros aspectos. Leventhal et al. (1980, 1984, 1992,1997, 1998, 2001,2003) propusieron que los modelos personales de enfermedad incluyen, además de estas representaciones cognitivas, un componente emocional. Las personas hacen de forma paralela representaciones cognitivas y emocionales de la enfermedad para explicar su condición y afrontar sus consecuencias, incluidas las de tipo emocional. Para el SRM, cualquier punto en el proceso de autorregulación se puede asociar a una reacción emocional (Diefenbach y Leventhal, 1996). De hecho, los autores del modelo proponen que "tanto si el componente emocional es una parte integral de las representaciones de enfermedad como si es un componente independiente elicitado por los aspectos cognitivos de las representaciones, la emoción puede tener una doble función": Facilitar o dificultar el comportamiento, de forma que son una parte nuclear del proceso de toma de decisiones (Diefenbach y Leventhal, 1996, p. 30).

La investigación, utilizando una gran variedad de estrategias para evaluar estos esquemas sobre la enfermedad, sugiere que tanto los pacientes como las personas sin alteraciones de la salud organizan o agrupan sus creencias sobre la enfermedad en torno a una serie de temas o componentes centrales o nucleares, que, juntos, forman la percepción integrada que la persona tiene sobre la enfermedad. En un primer momento Leventhal y sus colaboradores propusieron la organización de los modelos personales de enfermedad en torno a cinco dimensiones (identidad, consecuencias, curso, control/cura y etiología). Sin embargo, como veremos a continuación al hablar de la medida de las creencias sobre la enfermedad, la investigación posterior sugirió modificar esa primera propuesta de los autores. De este modo, finalmente las dimensiones propuestas por el Modelo de Autorregulación serían las siguientes (Moss-Morris et al., 2002):

- Identidad: Creencias sobre qué enfermedad es, su nombre o categoría, en qué consiste, cuáles son sus síntomas, cómo se relacionan los síntomas entre sí, cómo se relacionan los síntomas con la "etiqueta" de la enfermedad. Estas creencias indicarían la percepción de las características en la línea de la severidad.
- Etiología: Creencias sobre las causas biológicas (genéticas, inmunológicas, virus o bacterias...), causas psicológicas (comportamientos, hábitos y estilos de vida, factores emocionales como estrés o depresión, características de personalidad...), causas ambientales (conflictos familiares o laborales, estado económico, contaminación ambiental, sustancias...) y causas místicas (suerte, dioses, seres no humanos...) de la enfermedad.
- Duración: Creencias sobre la duración percibida de la enfermedad y sus síntomas (aguda/crónica o permanente, corta/larga duración).
- Evolución: Creencias acerca del carácter cíclico o estable de la enfermedad y sus síntomas.
- Consecuencias: Creencias sobre la gravedad de la enfermedad por sus efectos esperados sobre la mortalidad y morbilidad, secuelas, efectos de la enfermedad sobre el funcionamiento social, emocional o físico, la salud general y el bienestar de la persona que la padece.
- Control personal: Creencias sobre la posibilidad de controlar o influir personalmente en la evolución o solución de la enfermedad. Posibilidad de prevenir la enfermedad o sus características y consecuencias.

- Control por el tratamiento: Creencias sobre las posibilidades de curación de la enfermedad, qué tratamientos o intervenciones existen, eficacia de los tratamientos disponibles.
- Coherencia de la enfermedad: Creencias sobre cómo la enfermedad toma sentido como un todo para la persona. Comprensión acerca de lo que la enfermedad significa.
- Representaciones emocionales: Sentimientos de miedo, ansiedad, preocupación, etc. asociados a la enfermedad.

Como se puede observar, cada una de estas dimensiones incluye representaciones sobre un aspecto de la enfermedad, y unidas configuran la visión (evaluación e interpretación) coherente de la persona sobre la enfermedad y le permiten dirigir el afrontamiento de la misma. Por otra parte, existe un patrón de interrelaciones entre estas dimensiones que suele ser confirmado independientemente de la enfermedad a la que se refieran. Así, creencias más negativas sobre la gravedad de un trastorno en función de sus consecuencias para la salud o la vida cotidiana se asocian estrechamente con representaciones de mayor sintomatología y cronicidad y menor controlabilidad personal o curabilidad, mientras que creencias más fuertes sobre la controlabilidad de una enfermedad se relacionan con percepciones más débiles de cronicidad y consecuencias menos serias para la vida del enfermo y de sus familiares (Hagger y Orbell, 2003; Petrie, Broadbent y Kydd, 2008).

En resumen, las personas construimos representaciones mentales (cognitivas y emocionales) de la enfermedad que padecemos o podemos padecer con el objetivo de dotarla de sentido en una *visión* o interpretación personal de la condición y, a partir de esta interpretación, manejar lo más apropiadamente el problema, por ejemplo buscando información o ayuda profesional, adhiriéndonos a los tratamientos prescritos, modificando nuestros estilos de vida, desarrollando estrategias de ajuste y autorregulación, tanto conductual como emocional, y/o buscando apoyo social, por ejemplo. Estas representaciones integradas de la enfermedad tienen una gran importancia a la hora de definir la experiencia de la enfermedad y sus síntomas y de determinar la relevancia, organización e interpretación de la información sobre la salud y la enfermedad y las respuestas ante las mismas, como la búsqueda de ayuda profesional, las conductas de enfermedad, la relación que se establece con el terapeuta o el seguimiento de los tratamientos.

3.3. Las creencias de enfermedades físicas y mentales: Aplicaciones del SRM

El SRM fue propuesto originalmente -y aplicado fundamentalmente desde entonces- para la enfermedad física (principalmente crónica), siendo actualmente una importante área de investigación en Psicología de la Salud y Medicina Conductual en relación con la influencia de factores psicosociales en la salud física. Aunque sus autores señalaron desde el comienzo que era aplicable también a salud mental (Leventhal et al., 1992), esto no se ha hecho hasta más recientemente, aunque en este caso en menor medida. La Tabla 6 presenta algunas enfermedades para las que se han estudiado las creencias de enfermedad y confirmado la aplicabilidad de los postulados del SRM. Para una revisión, ver Godoy-Izquierdo, López-Chicheri et al. (2007), Hagger y Orbell (2003), Kaptein et al. (2003), Lobban et al. (2003), Petrie y Weinman (1997) y Petrie et al. (2008).

Esta investigación ha encontrado que la estructura propuesta por el SRM se confirma para distintas enfermedades físicas y que lo que cambia es el contenido concreto de las creencias para cada enfermedad y, así, su impacto en la conducta y en las consecuencias de la enfermedad. En el caso de las alteraciones mentales, diversos estudios han confirmado que la estructura dimensional propuesta por el SRM para las representaciones de la enfermedad física es aplicable también a aquéllas, en relación tanto con la complejidad de los modelos (dimensiones y naturaleza) como con sus contenidos (creencias concretas), y ello tanto en pacientes como en familiares de pacientes (Fortune, Smith y Garvey, 2004; Lobban, Barrowclough y Jones, 2005). Por otra parte, Leventhal y Nerenz (1985) sugirieron que la importancia de los diferentes aspectos de las representaciones podría variar dependiendo de la enfermedad concreta, y ello también se ha confirmado en la investigación siguiente.

Tabla 6. Algunos ejemplos de aplicaciones del SRM a enfermedades físicas y mentales.

Enfermedad	Publicaciones
Enfermedades cardiovasculares e hipertensión	Affleck et al. (1987); Bazán et al. (2013); Beléndez et al. (2005); Chen, Tsai y Chou (2011); Chen, Tsai y Lee (2009); Cherrington et al. (2002); Cooper et al. (1999); Cooper et al. (2007); Figueiras y Alves (2007); Figueiras y Weinman (2003); Godoy-Izquierdo et al. (2007); Heckler et al. (2008); Hirani et al. (2005); Hsiao et al. (2012); Lau-Walker (2007); Lopes et al. (2010); McClenahan y Weinman (1998); Meyer et al. (1985); Norfazilah et al. (2013); Petrie et al. (1996); Petrie et al. (2002); Pickett et al. (2014); Rajpura y Nayak (2014); Ross et al. (2004); Weinman et al. (2000)
Diabetes	Awasthi (2011); Barnes et al. (2004); Edgar y Skinner (2003); Griva et al. (2000); Hampson et al. (1990); Lawson et al. (2004); Searle et al. (2007); Skinner et al. (2002); Skinner et al. (2003); Turk et al. (1986)
Cáncer	Anagnostopoulos y Spanea (2005); Buick y Petrie (2002); Cameron (2008); Cameron et al. (2005); Constanzo, et al. (2010); De Castro et al. (2013); De Castro et al. (2015); Dempster et al. (2010); Dempster et al. (2011); Figueiras y Alves (2007); Gercovich et al. (2012); Giannousi et al. (2009); Godoy-Izquierdo et al. (2007); Gould et al. (2010); Henselmans et al. (2009); Hevey et al. (2009); Hoogerwerf et al. (2012); Hopman y Rijken (2015); Letho (2007); Juth et al. (2015); Lancastle et al. (2011); Llewelyn et al. (2006); Llewelyn et al. (2007); Malcarne et al. (1995); Millar et al. (2005); Orbell et al. (2008); Rees et al. (2004); Scharloo et al. (2005); Traeger et al. (2009); Trask et al. (2008); Van Oostrom, et al. (2007a,b,c); Wang et al. (2010)
Artritis y enfermedades reumatoides	Hampson et al. (1994); Murphy et al. (1999); Orbell et al. (1998); Pim y Weinman (1998); Scharloo et al. (1998); Sharpe et al. (2001); Ziarko et al. (2014)
Esclerosis múltiple	Jopson y Moss-Morris (2003); Vaughan et al. (2003)
Fibromialgia	Dijkstra et al. (2001)
Enfermedad de Addison	Heijmans (1999); Heijmans y de Ridder (1999)

Síndrome de fatiga crónica	Chalder et al. (1996); Edwards et al. (2001); Heijmans (1998); Heijmans y de Ridder (1999); Moss-Morris (1997); Moss-Morris (2005); Moss-Morris et al. (1996); Moss-Morris y Chalder (2003); Moss-Morris y Petrie (2001)
Dolor crónico	Glattacker et al. (2013); Hobro et al. (2004); Nicklas et al. (2010)
Gastroenteritis	Parry et al. (2003)
Síndrome del intestino irritable	Holt et al. (2002); Rutter (2001); Rutter et al. (2002); Rutter y Rutter (2002)
Asma	Horne y Weinman (1999); Josep y Rutter (2003); Molloy et al. (2009)
Enfermedad obstructiva pulmonar crónica	Scharloo et al. (1998); Scharloo et al. (2000)
Psoriasis	Fortune et al. (2000); Fortune et al. (2002); Richards et al. (2004); Scharloo et al. (1998); Scharloo et al. (2000)
Epilepsia	Kemp et al. (1999)
Hemofilia	Llewelyn et al. (2003)
Resfriado común y gripe	Godoy-Izquierdo et al. (2007); Glattacker et al. (2012); Lau et al. (1989)
Depresión	Fortune et al. (2004); Lauber et al. (2003); Moss-Morris y Petrie (2001)
Esquizofrenia	Barrowclough et al. (2001); Lobban et al. (2005); Talley (1999)

3.4. Evidencias empíricas sobre la relación entre las creencias de enfermedad, las acciones de manejo de la enfermedad y las consecuencias de la enfermedad

La relación propuesta por el SRM entre creencias más ajustadas y positivas de la enfermedad y estrategias de afrontamiento más adaptativas y eficaces (p.e., adherencia a los tratamientos) ha sido apoyada en diversos estudios, así como la asociación entre estrategias de afrontamiento adaptativas y eficaces y consecuencias más positivas de la enfermedad, como el nivel de salud, el bienestar emocional, la capacidad funcional, el funcionamiento cotidiano y social, el desempeño de roles vitales o la calidad de vida.

Distintos estudios han mostrado la existencia de relaciones concretas entre las estrategias de afrontamiento y determinadas creencias de enfermedad. Así, por ejemplo, se ha hallado una asociación entre la utilización de estrategias de afrontamiento activo, tanto centrado en el problema como dirigido a las consecuencias emocionales de la enfermedad, la reevaluación cognitiva y la búsqueda de apoyo social y las dimensiones de elevada controlabilidad y percepción de curación, baja identidad y sintomatología, no cronicidad y pocas o no graves consecuencias (Awasthi y Mishra, 2011; Croyle y Ditto, 1990; Griva, Myers y Newman, 2000; Hampson, Glasgow y Zeiss, 1994; Heijmans, 1998; Heijmans y de Ridder, 1998, 1999; Hopman y Rijken, 2015; Kemp, Morley y Anderson, 1999; Moss-Morris, Petrie y Weinman, 1996; Orbell et al., 1998; Porrit, Sufi, Barlow y Baker, 2014; Scharlooo el al., 1998; Schiaffino, Shawaryn y Blum, 1998; Wichowski y Kubsch, 1997). Del mismo modo, se ha encontrado una asociación positiva entre las creencias contrarias a las anteriores con estrategias de negación y evitación, no afrontamiento y expresión emocional incontrolada (Godoy-izquierdo, Fajardo et al., 2007; Heijmans, 1998; Hopman y Rijken, 2015; Horowitz, Stephanie y Leventhal, 2004; Kemp et al., 1999; Knowles et al., 2014; Moss-Morris et al., 1996; Moss-Morris, 2005; Scharloo et al., 1998; Ziarko et al., 2014). En un meta-análisis, Hagger y Orbell (2003) confirman las relaciones hipotetizadas por el modelo revisando estudios realizados con diversas alteraciones de la salud física, aunque también señalan, de acuerdo con los resultados obtenidos, que otras variables pueden estar ejerciendo un papel importante.

Hagger y Orbell (2003) en su meta-análisis también mostraron que, de acuerdo con lo propuesto por el Modelo de Autorregulación, las representaciones de enfermedad no sólo se relacionaban con las estrategias de afrontamiento puestas en marcha sino que también ejercen una influencia en las consecuencias de la enfermedad para el paciente, probablemente a través del papel mediador ejercido por los procesos de afrontamiento. En este sentido, consecuencias/resultados más adaptativos de la enfermedad en términos de funcionamiento físico, personal y laboral así como de bienestar psicológico y vitalidad se asociaban con una menor percepción de consecuencias y unos niveles de identidad más débiles, lo que vendría a destacar la importancia de las representaciones de identidad y consecuencias en el bienestar y la calidad de vida de las personas enfermas. Yendo aún más lejos, diversos estudios recogidos en este meta-análisis subrayan la estrecha relación entre consecuencias más positivas de la enfermedad y las percepciones de controlabilidad expresadas por los participantes.

En este sentido, distintos estudios realizados con posterioridad a este meta-análisis ya clásico de Hagger y Orbell han tratado de confirmar en diferentes enfermedades esta influencia propuesta por el SRM de las representaciones de enfermedad en las consecuencias de la misma a nivel físico y mental, en el proceso de recuperación así como en definitiva en el bienestar y calidad de vida de los pacientes (Frostholm et al., 2007; Glattacker et al., 2012, 2013; Knowles et al., 2014; Llewelyn, McGurk y Weinman, 2006, 2007; Millar et al., 2005; Porrit et al., 2014; Rozema et al., 2014; Scharloo et al., 2005; Vaughan, Morrison y Miller, 2003; Ziarko et al., 2014).

Por tanto, los resultados obtenidos en estos estudios han puesto de manifiesto en diferentes enfermedades tanto físicas como mentales la influencia que las creencias de enfermedad en las consecuencias de la misma a través del papel mediador que ejercen las estrategias de afrontamiento y manejo puestas en marcha por el individuo para prevenir la enfermedad en el caso de que esté sano o para recuperar la salud, el bienestar y la calidad de vida en el caso de que esté enfermo.

Cuando hablamos de afrontamiento de la enfermedad, una cuestión clave es la adherencia a las recomendaciones médicas y a los tratamientos prescritos (Hager y Orbell, 2003). En este sentido, si tal y como propone el SRM, las representaciones de enfermedad tienen una influencia en las estrategias de afrontamiento elicitadas por los pacientes y si la adherencia se considera una estrategia de afrontamiento, lógicamente ésta estaría también determinada por el modo en que percibimos y representamos cognitiva y emocionalmente la enfermedad.

La adherencia a los tratamientos farmacológicos y a las recomendaciones médicas son aspectos fundamentales en cualquier enfermedad, pero son aún más relevantes cuando hablamos de enfermedades crónicas, como la hipertensión o enfermedades de larga duración como suele ser el cáncer, ya que este tipo de enfermedades habitualmente requieren, para conseguir resultados satisfactorios, tratamientos a largo plazo y con efectos secundarios importantes, lo que a menudo dificulta una correcta adherencia. Además, la hipertensión es una enfermedad asintomática por lo menos hasta fases muy avanzadas, y este hecho hace aún más difícil que los pacientes se adhieran correctamente a los tratamientos.

En este sentido, con el objetivo de explorar el impacto de las representaciones de enfermedad, de acuerdo con la propuesta del SRM, en la adherencia farmacológica Kucukarslan (2012) llevó a cabo una revisión de la investigación al respecto. La autora encontró que las diferentes dimensiones que conforman los modelos de enfermedad, excepto la dimensión de coherencia, influían bien de forma directa o indirecta en la adherencia a la medicación prescrita. Los resultados también pusieron de manifiesto que la edad, la enfermedad o condición médica concreta o la cultura podrían influir en el impacto de las representaciones de enfermedad en la respuesta de los pacientes a los tratamientos propuestos. Las enfermedades que incluían los estudios revisados fueron asma, hipertensión, diabetes, insuficiencia cardíaca, glaucoma, dolor crónico y tuberculosis.

De acuerdo con esta revisión, creencias más fuertes de identidad se asocian con una mayor adherencia a los tratamientos farmacológicos (Chen et al., 2011; Jessop y Rutter, 2003; Woith y Larson, 2008) aunque también se halló ausencia de dicha influencia en otros casos (Horne y Weinman, 2002). En relación a la dimensión de duración, el impacto de la duración percibida de la enfermedad en la adherencia a los fármacos prescritos poseía un carácter indirecto en lugar de directo y estaba mediado por las percepciones de necesidad del tratamiento (Ross, Walker y Mac-Leod, 2004). En cuanto a la relación entre la percepción de consecuencias de la enfermedad para la vida de los pacientes y la adherencia a la medicación, los resultados son inconclusos y varían a lo largo de los diferentes estudios. Algunos de ellos apoyan que consecuencias más graves percibidas llevan a una mejor adherencia farmacológica (Ross et al., 2004), otros encuentran que creencias más fuertes sobre consecuencias llevan a una peor adherencia (Horne y Weinman, 2002; Molloy et al., 2009) pero otros no han hallado ninguna influencia (Chen et al., 2011; Jessop y Rutter, 2003; Zugelj et al., 2010). También se ha observado una influencia indirecta entre percepción de consecuencias de la enfermedad y adherencia, de modo que percibir consecuencias más severas de su enfermedad se relaciona con una mayor preocupación y percepción de necesidad de tratamiento, lo que lleva a una mejor adherencia (Nicklas, Dunbar y Wild, 2010).

En relación a las dimensiones de control personal y control por tratamiento, creencias más fuertes de control por tratamiento (Chen et al., 2011; Ross et al., 2004; Searle et al., 2007; Zugelj et al., 2010) se relacionaban con una mayor adherencia, mientras que Chen et al. (2011) encontraron una relación positiva y directa entre creencias sobre control personal y adherencia a los tratamientos farmacológicos.

Respecto a la dimensión de curso o evolución, Chen et al. (2009) observaron la existencia de una relación directa y negativa entre la percepción de la enfermedad como cíclica y cambiante y la adherencia a la medicación prescrita. Con respecto a las representaciones emocionales, diversos estudios han hallado una relación negativa con la adherencia farmacológica; así, sentimientos más fuertes de temor, preocupación o tristeza ante una enfermedad se asociaban con una adherencia más pobre (Ross et al., 2004; Zugelj et al., 2010), aunque otros estudios no han hallado relación (Chen et al., 2011).

Finalmente, la dimensión de causas también se ha relacionado de manera directa con la adherencia farmacológica. Por ejemplo, Chen et al. (2009) encontraron que puntuaciones más altas en dicha dimensión se relacionaban con una peor adherencia al tratamiento, mientras que Jessop y Rutter (2003) hallaron que los pacientes que percibían que su enfermedad estaba causada por factores incontrolables y externos mostraban peor adherencia farmacológica.

Por otro lado, la adherencia no se puede considerar únicamente como la toma de la medicación prescrita por el médico en la forma en que este lo indicó, sino que especialmente en enfermedades crónicas o de larga duración se refiere también a realizar determinados cambios a nivel comportamental y en el estilo de vida. En el caso de la hipertensión, esto es especialmente cierto ya que los tratamientos suelen incluir en la mayoría de los casos realizar cambios en la dieta, la actividad física o la autorregulación emocional. En este sentido, la investigación dirigida a conocer la influencia que las representaciones de enfermedad tienen sobre los cambios a nivel comportamental es menor que la dirigida a valorar el papel de éstas en la adherencia farmacológica. Aún así, diferentes estudios han tratado de explorar esa relación mostrando la influencia de las representaciones de enfermedad en la adherencia a cambios comportamentales, asistencia a citas médicas y tratamientos diferentes a la toma de medicación como, por ejemplo, la asistencia a programas de rehabilitación (Barnes, Moss-Morris y Kaufusi, 2004; Cameron et al., 2005; Cooper, Weinman, Hankins, Jackson y Horne, 2007; Heckler et al., 2008; Horowitch, Rain y Leventhal, 2004; Meyer, Leventhal y Guttman, 1985; Orbell, Hagger, Brown y Tidy, 2006; Pickett et al., 2014; Stafford, Jackson y Berk, 2008).

Si dirigimos nuestra atención hacía la población que aún no padece ni ha padecido una determinada enfermedad o alteración de la salud, una cuestión clave en el afrontamiento de los riesgos para la salud es el desarrollo de actuaciones de prevención (Cameron y Moss-Morris, 2004; Cameron y Leventhal, 2003; Leventhal et al., 1980, 1998, 2003, 2011). En este sentido, el SRM postula que en el caso de los no pacientes, sus representaciones tanto cognitivas como emocionales sobre una determinada enfermedad van a jugar un papel clave en los esfuerzos por prevenir su aparición. En este sentido, se espera que la población sana evite riesgos, busque información o ayuda médica, se someta a exámenes o pruebas médicas o adopte nuevos comportamientos de carácter saludable si perciben una enfermedad como prevenible a través de sus propios esfuerzos (Sullivan et al., 2010). Sin embargo, la investigación existente sobre representaciones de enfermedad, de acuerdo con el SRM, y desarrollo de conductas preventivas es escasa y realizada sobre todo con pacientes y poblaciones en riesgo. Aún así, los diferentes estudios que se han desarrollado apoyan este postulado básico del SRM, mostrando que tanto las representaciones cognitivas como emocionales ejercen un papel clave en el modo en que la población sana, así como la población en riesgo o enferma, actúa para prevenir la enfermedad (Ali, Shonk y Saleh El Shayed, 2013; Andersson, Sjöberg, Öhrvik y Leppert, 2009; Cameron, 2008; Chang et al., 2011; Chauan et al., 2007; Claassen, Henneman, Kindt, Marteau y Tinmermans, 2010; Claassen, Henneman, Van der Weijden, Marteau y Tinmermans, 2012; Collins, Dantico, Shearer y Mossman, 2002, 2004; Constanzo, Lutgendorg y Roeder, 2010; Figueiras y Alves, 2007; Honda, Goodwin y Neugut, 2005; Lee, Cameron, Wunsche y Stevens, 2011; McFall, Nonneman, Rogers y Mukerji, 2009; Murray, Murphy, Clements, Brown y Connelly, 2013; Orbell et al., 2006, 2008; Raude y Setbon, 2005; Sabzmakan et al., 2014; Sullivan et al., 2010; Trask, Pahl y Begeman, 2008; Van Oostrom et al., 2007a, 2007b, 2007c).

Distintos estudios han encontrado que representaciones emocionales más fuertes (Cameron, 2008; Figueiras y Alves, 2007; Honda et al., 2005; Orbell et al., 2008), una mayor percepción de consecuencias y síntomas (Cameron, 2008; Weinstein, 2000), un mayor sentido de coherencia (Figueiras y Alves, 2007), la atribución de la enfermedad a causas controlables y especialmente relacionadas con el propio comportamiento (Boudreaux et al., 2010) y mayores percepciones de controlabilidad (Figueiras y Alves, 2007; Sullivan et al., 2010) se asocian con la intención y el desarrollo de conductas de carácter preventivo tanto en población sana como en pacientes y poblaciones de riesgo.

En el caso concreto de las enfermedades objeto de estudio en esta Tesis Doctoral, cáncer e hipertensión, y de acuerdo con lo establecido en los capítulos 1 y 2 de esta Introducción, las posibilidades actuales de prevenir su aparición y desarrollo a través de actuaciones de carácter comportamental y cambios en el estilo de vida son muy elevadas.

En cuanto al cáncer, un aspecto clave de esta enfermedad sería el elevado impacto emocional que ésta genera, aspecto en el que se diferencia sustancialmente de la hipertensión. Diferentes estudios sobre esta cuestión han puesto de manifiesto que el cáncer es una enfermedad que genera un elevado malestar emocional en la población sana (De Castro, Peuker, Laurenz y Figuerias, 2015; Figueiras y Alves, 2007; Orbell et al., 2008) y que ese malestar emocional es similar al que experimenta la población en riesgo (De Castro et al., 2015; Hevey et al., 2009; Lancastle, Brian y Phelps, 2011; Van Oostrom et al., 2007c) y mayor al que manifiestan los pacientes que sufren la enfermedad (Cameron, 2005; Hoogerwert, Ninaber, Willens y Kaptein, 2012; Hopman y Rikjen, 2015; Trask et al., 2008), lo que podría estar relacionado con el proceso de adaptación a la situación y con un afrontamiento centrado en la curación del cáncer. En cualquier caso, el malestar emocional ha sido propuesto como un factor que potencia el desarrollo de comportamientos preventivos (Leventhal et al., 2011), de modo que las representaciones emocionales negativas entendidas como sentimientos más fuertes de preocupación, ansiedad, tristeza o miedo en relación con la enfermedad han sido consideradas como aspectos que podrían favorecer la puesta en marcha de actuaciones de prevención para afrontar los riesgos que supondría contraer una enfermedad (Leventhal et al., 2003). En este sentido, a pesar de que los resultados de los estudios acerca del papel del malestar emocional en la prevención del cáncer son inconclusos, éstos parecen apoyar la idea de que determinado nivel de malestar contribuye al desarrollo de comportamientos preventivos en personas sanas (Cameron, 2008; Figueiras y Alves, 2007; Honda et al., 2005). Sin embargo esta relación entre representaciones emocionales y conductas de afrontamiento, incluidos los esfuerzos de carácter preventivo, parece no poseer un carácter directo sino que representaciones de carácter cognitivo como las percepciones de severidad y vulnerabilidad y las atribuciones causales interactuarían con las representaciones de carácter emocional para influir en las conductas de afrontamiento (Decruyenaere et al., 2000). En cuanto a las percepciones sobre la controlabilidad, Decruyenaere y colaboradores señalan que a mayor confianza en las posibilidades de control el desarrollo de actuaciones preventivas será también mayor.

Si dirigimos nuestra atención hacia la hipertensión, es necesario destacar que diferentes estudios realizados con población sana (Aroian, Rosalind, Rudner y Waser, 2012; Gopinath et al., 2014; Newell, Modeste, Marshall y Wilson, 2009; Peters, Aroian y Flack, 2006; Savoca et al., 2009) han puesto de manifiesto cómo poseer representaciones moderadamente ajustadas acerca de lo que la enfermedad significa y de los riesgos asociados a la misma, de las posibilidades de prevención y de cómo actuar para evitar su aparición no se traducen en la puesta en práctica de conductas preventivas relacionadas con la introducción de modificaciones en determinados hábitos de vida. Este hecho se ha relacionado en dichos estudios con diferentes factores como la dificultad percibida para realizar los cambios necesarios, la falta de recursos, una escasa autoeficacia percibida o aspectos sociales o culturales (Aroian et al., 2012; Gopinath et al., 2014; Newell et al., 2009; Peters et al., 2006; Savoca et al., 2009). Sin embargo es necesario destacar que estos estudios con población que aún no padece la enfermedad se han llevado a cabo con muestras limitadas en cuanto a sus características y minorías étnicas y no han utilizado los instrumentos de evaluación de las representaciones cognitivas y emocionales de enfermedad derivados del SRM. Este problema de falta de coherencia entre las representaciones y las conductas de afrontamiento de riesgos en el caso de la hipertensión hace aún más complejo todo el proceso de prevención primaria de la enfermedad y requeriría de un estudio en profundidad de los factores que influyen en dicha cuestión desde la perspectiva del SRM y utilizando los instrumentos de evaluación propios de dicho modelo, aspecto sobre el que trataremos de arrojar luz en los estudios 4 y 5 de esta Tesis Doctoral.

En definitiva, estos estudios avalan la relación propuesta por el SRM entre representaciones de enfermedad y aspectos comportamentales, de afrontamiento o prevención de la enfermedad y, a través del papel mediador de estos, entre representaciones de la enfermedad y consecuencias de la misma a nivel físico, emocional o de calidad de vida. Sin embargo, como ya hemos señalado, en su mayoría han sido realizados con pacientes o poblaciones de riesgo, por lo que sería recomendable tratar de comprobar la relación predicha por el SRM entre esas variables con poblaciones que no han sufrido ni sufren una determinada enfermedad.

3.5. La influencia de otras variables en las creencias de enfermedad: El papel de las variables sociodemográficas y la experiencia directa o indirecta con la enfermedad

En cuanto a la posible influencia de variables de carácter sociodemográfico tales como el género, la edad o el nivel educativo en los modelos personales de enfermedad, en general los estudios encuentran alguna, aunque limitada, influencia (e.g., Anagnostopoulos y Spanea, 2005; Dunkel et al., 2011; Godoy-Izquierdo et al., 2007; Heijmans y De Ridder, 1998; Lau-Walker, 2004; Lauber, Falcato, Nordt y Rossler, 2003; Lehto, 2007; Sterba y DeVellis, 2009; Wang, Miller, Egleston, Hay y Weinberg,2010).

Sin embargo, haber sufrido la enfermedad (experiencia directa) o tener un familiar enfermo o haber convivido con alguien afectado (experiencia indirecta o familiar) ha sido considerado de forma consistente como un factor que ejerce una contribución relevante a las representaciones de enfermedad (Anagnostopoulos y Spanea, 2005; Buick y Petrie, 2002; Dempster et al., 2001b; Figueiras y Weinman, 2003; Furnham y Chan, 2004; Godoy-Izquierdo, López-Chicheri et al., 2007; Heijmans y De Ridder, 1998; Heijmans et al., 1999; Juth et al., 2015; Lau-Walker, 2004; Lobban, Barrowclough y Jones, 2003; Lykins et al., 2008; Moss-Morris y Chalder, 2003; Moss-Morris y Petrie, 2001; Norfazilah et al., 2013; Orbell et al., 2008; Picket et al., 2014; Weinman et al., 2000, 2003).

3.6. Aplicaciones clínicas del SRM y las creencias de enfermedad

Es fundamental resaltar el carácter aplicado del estudio de las creencias de enfermedad, ya que el conocimiento de los modelos personales no especializados que las personas construimos acerca de la salud y la enfermedad en general y de cada alteración en particular va a ayudar al profesional de la salud en el diseño e implementación de estrategias efectivas de intervención, como por ejemplo promoción de la salud, prevención de enfermedades, educación a los pacientes, mejora de la adherencia al tratamiento, asesoramiento familiar, etc. (Godoy-Izquierdo, Fajardo et al., 2007). En este sentido, dicho conocimiento acerca de los modelos personales que construimos tanto las personas sanas como enfermas va a permitir explicar o modificar el comportamiento de los pacientes frente a su enfermedad, sus respuestas emocionales o de afrontamiento de la misma, su adaptación a su situación, sus actuaciones de automanejo, las consecuencias de la enfermedad en sus vidas y en la de las personas cercanas a ellos, su recuperación de ella y, finalmente, influir en su bienestar y su calidad de vida. Del mismo modo, dicho conocimiento va a ayudarnos a intervenir de forma adecuada en todo el proceso de tratamiento así como la relación entre paciente y especialista de la salud y va a ayudar a los profesionales a diseñar e implementar actuaciones más eficaces en función de estas representaciones personales (Moss-Morris et al., 2002; Sensky, 1997). Además, podría llevar a mejorar el proceso de educación al paciente y la adherencia a los tratamientos, así como la satisfacción de los pacientes, ayudando todo ello al control o recuperación de la enfermedad (Wilson et al., 2002) y a la prevención de posibles complicaciones, recaídas o alteraciones futuras de salud.

Todo ello va a adquirir especial relevancia en el caso de los propios profesionales de la salud, dado que puede existir una enorme distancia entre las creencias sobre la enfermedad de sus pacientes y las consideraciones médicas y el conocimiento especializado (Godoy-izquierdo, Fajardo et al., 2007). Por ejemplo, la severidad de una enfermedad para una persona diagnosticada de la misma puede ser muy diferente de la que cabría esperar a partir de los resultados clínicos o del pronóstico de la misma (Sensky, 1990). Y lo mismo puede decirse respecto a sus causas, evolución, pronóstico. El conocimiento de las creencias personales del paciente y el Modelo de Autorregulación de Leventhal son, además compatibles con el papel activo y colaborador por parte del paciente (Godoy-Izquierdo, Fajardo et al., 2007; Petrie y Weinman, 1997).

Por otro lado, no podemos olvidar que un objetivo central de la investigación en el campo de la Psicología de la Salud es conocer y comprender los factores que influyen en el comportamiento de las personas sanas en relación con la salud y la enfermedad para poder diseñar estrategias adecuadas de intervención en base a dicho conocimiento. De acuerdo con dicho objetivo, conocer los modelos personales de salud y enfermedad de la población sana adquiere una relevancia capital si se desea incrementar la eficacia de las actuaciones en promoción de la salud y prevención de la enfermedad, y no únicamente centrar los esfuerzos en el tratamiento y la rehabilitación de la enfermedad, aunque sin olvidarlos.

3.7. La medida de los Modelos Personales de Enfermedad: El Cuestionario de Percepción de Enfermedad (IPQ), el Cuestionario de Percepción de Enfermedad Revisado (IPQ-R) y el Cuestionario Breve de Percepción de Enfermedad (B-IPQ)

El estudio de las creencias que las personas poseen sobre la enfermedad y la salud ha sido abordado desde múltiples perspectivas metodológicas. En su trabajo original, Leventhal y sus colaboradores utilizaron entrevistas de carácter semiestructurado centradas en las experiencias de los pacientes con una enfermedad concreta con el objetivo de conocer sus representaciones sobre ese trastorno. Aunque dicha aproximación permitía conocer el modelo que los pacientes poseían sobre una enfermedad, también presentaba distintos inconvenientes derivados de la metodología utilizada como, por ejemplo, la excesiva duración de la evaluación, las variaciones en la cantidad y la calidad de las respuestas dadas, la ausencia de estudios psicométricos o las enormes dificultades para conseguir una muestra con un tamaño adecuado para realizar investigación cuantitativa. En contraste con esto, la utilización de cuestionarios permitiría conocer las representaciones acerca de la enfermedad superando los inconvenientes anteriores.

En este sentido, con el objetivo de superar las limitaciones que poseían otras formas de evaluación, a lo largo del tiempo se han diseñado distintos cuestionarios destinados a evaluar las representaciones personales de enfermedad. Sin embargo, estos instrumentos presentaban fundamentalmente el problema de que generalmente no poseían una buena base teórica o no habían sido probados con más de un tipo de pacientes (Weinman, Petrie, Moss-Morris y Horne, 1996). Debido a ello, en 1996 Weinman y colaboradores desarrollaron el Cuestionario de Percepción de Enfermedad (IPQ), dirigido a evaluar las representaciones cognitivas de enfermedad. Este instrumento, basado en el modelo de Leventhal y colaboradores, presenta cinco subescalas que proporcionan información acerca de los cinco componentes fundamentales que forman parte de los modelos personales de enfermedad identificados en la investigación al respecto que ha tratado desde el principio de identificar el contenido de dichas estructuras mentales. El IPQ consta en total de 60 ítems.

La dimensión de identidad es evaluada a través de un listado de quince síntomas, de modo que los participantes deben responder si han experimentando esos síntomas y la frecuencia con la que los han experimentado. Los ítems de las dimensiones de curso, consecuencias y control/cura se presentan en forma de afirmación y el formato de respuesta consiste en una escala tipo Likert con cinco opciones de respuesta que van desde fuertemente en desacuerdo a fuertemente de acuerdo. Por otro lado, la dimensión de causas es evaluada a través de un listado de dieciséis posibles factores que podrían originar la enfermedad y los participantes deben responder de acuerdo con una escala tipo Likert que, al igual que en el caso anterior, abarcaría desde fuertemente en desacuerdo a fuertemente de acuerdo. Los ítems son puntuados de uno a cinco, habiendo ítems tanto de carácter directo como inverso en las dimensiones de curso, consecuencias y control.

El IPQ permite obtener puntuaciones parciales en cada subescala así como una puntuación total. Puntuaciones más altas en las diferentes subescalas indican creencias más fuertes sobre las características evaluadas, mientras que una puntuación total en el IPQ más alta señala una percepción más negativa de la enfermedad. Además de acuerdo con los propios autores, el IPQ permite que le sean añadidos nuevos ítems dirigidos a grupos concretos de pacientes o a determinados problemas de salud (Weinman et al., 1996). La consistencia interna del IPQ y la fiabilidad test-retest son adecuadas (Weinman et al., 1996).

Como ya se ha comentado, existe abundante evidencia acerca de las relaciones estructurales entre los cinco componentes de las representaciones de enfermedad descritos por Leventhal e incluidos en el IPQ (Godoy-Izquierdo, Fajardo et al., 2007; Godoy-Izquierdo, López-Chicheri et al., 2007; Leventhal et al., 1984, 1997; Weinman et al., 1996), así como acerca de las relaciones esperadas entre las percepciones de enfermedad y conductas de afrontamiento concretas como la adherencia a las recomendaciones médicas (e.g., Barnes et al., 2004; Cameron et al., 2005; Chen et al., 2009; 2011; Cooper et al., 2007; Heckler et al., 2008; Jessop y Router, 2003; Leventhal, 2004; Meyer et al.,1985; Molloy et al., 2009; Orbell et al., 2006; Pickett et al., 2014; Ross et al., 2004; Stafford et al., 2008; Weinman et al., 2000; Zujelj et al., 2010), así como con un amplio rango de consecuencias de la misma, como la adaptación funcional del paciente (Heijmans, 1998; Heijmans, de Ridder y Bensing, 1999; Moss-Morris, 1997; Petrie et al., 1996; Scharloo et al., 1998).

Sin embargo, aunque este instrumento ha sido utilizado con éxito en la predicción de diferentes aspectos relacionados con la adaptación y recuperación en distintas enfermedades, el *feedback* proporcionado por la experiencia acumulada por los investigadores utilizando el IPQ parecía señalar la necesidad de revisar el instrumento para mejorar las propiedades de la medida y modificar algunas subescalas (Weinman et al., 1996). Particularmente dos de las subescalas del IPQ, control y curso, presentaban algunos problemas con respecto a su consistencia interna (Weinman et al., 1996). Con respecto a la subescala de control, los análisis parecían apuntar la necesidad de dividirla en dos escalas diferentes, una relacionada con el control personal y las creencias de autoeficacia y la otra referida al control a través del tratamiento o intervenciones terapéuticas disponibles. En relación a la subescala de curso, los hallazgos señalaban la necesidad tanto de incrementar el número de ítems como de incluir algunos ítems nuevos que evaluaran las creencias acerca de la ciclicidad o estabilidad del trastorno, y no sólo su duración corta (enfermedad aguda) o larga/permanente (enfermedad crónica).

Otro componente fundamental del modelo de Leventhal, como son las representaciones emocionales, había sido olvidado en la elaboración del IPQ. Éste originalmente había sido diseñado para evaluar los componentes cognitivos de las representaciones de los pacientes, lo que supone una limitación en su capacidad para describir las respuestas de los pacientes ante la enfermedad (Weinman et al., 1996). Un último problema asociado al IPQ es que no permitía evaluar un aspecto que puede ser importante, como es el grado en el que la representación de la enfermedad que el paciente posee le va a proporcionar una comprensión coherente de la misma, lo que sería de algún modo un tipo de metacognición acerca de la coherencia de la representación de la enfermedad que el paciente posee.

Debido a estas limitaciones del IPQ sus autores desarrollaron algunos años después la versión revisada del mismo, el IPQ-R (Moss-Morris et al., 2002), en la que incluyeron las siguientes modificaciones:

1. La subescala de identidad fue modificada con el objetivo de separar el concepto mismo de identidad de la enfermedad de los procesos de somatización. Así, en lugar de medir la frecuencia percibida de cada síntoma, los

pacientes tienen que identificar, por un lado, los síntomas que experimentan y, por otro, indicar cuáles de esos síntomas creen que están específicamente asociados a su enfermedad.

2. La subescala de causas fue ampliada con un mayor número de ítems, incluyéndose factores psicológicos (conductas, rasgos de personalidad, estado emocional, etc.), factores biológicos (genéticos, infecciosos, inmunitarios, lesiones, edad, etc.), factores ambientales (contaminación ambiental, problemas, otras personas, etc.) y factores externos o incontrolables (suerte, herencia).
3. El IPQ-R incluye una subescala que evalúa la coherencia de la enfermedad, dimensión que ha demostrado ser muy útil para conocer cómo la enfermedad toma sentido como un todo para el paciente y que juega un importante papel en el ajuste a la enfermedad y en la respuesta ante los síntomas.
4. El IPQ-R también incorpora una subescala que permite evaluar las representaciones emocionales, un aspecto fundamental para las conductas de afrontamiento que el enfermo pone en marcha y las consecuencias de las mismas.
5. El IPQ-R divide la subescala de control en dos subescalas diferentes, las de control personal y control por el tratamiento.
6. Por último, en el IPQ-R se ve mejorada la evaluación del curso percibido de la enfermedad, manteniéndose ítems referidos al curso agudo-crónico de la enfermedad (subescala de duración) e incluyéndose otros nuevos para la evaluación de creencias sobre su ciclicidad (subescala de evolución).

En resumen, el IPQ-R evalúa nueve dimensiones relacionadas con la enfermedad derivadas del modelo de Leventhal SRM. Estas dimensiones son 1) Identidad (14 ítems) (e.g., dolor); 2) Duración (5 ítems) (e.g., Mi enfermedad se pasará rápidamente); 3) Consecuencias (6 ítems) (e.g., Mi enfermedad tiene grandes consecuencias en mi vida); 4) Control personal (6 ítems) (e.g., Tengo el poder de influir en mi enfermedad); 5) Control por el tratamiento (6 ítems) (e.g., Mi tratamiento será eficaz para curar mi enfermedad); 6) Coherencia de la enfermedad (5 ítems) (e.g., Mi enfermedad es un misterio para mí); 7) Evolución (4 ítems) (e.g., Mi enfermedad es muy impredecible); 8) Representaciones emocionales (6 ítems) (e.g., No me preocupa mi enfermedad) y 9) Causas (18 ítems) (e.g., herencia). El cuestionario incluye para las dimensiones de duración, consecuencias, control personal, control por el tratamiento, coherencia de la enfermedad, evolución y representaciones emocionales una serie de afirmaciones para las que la persona debe expresar su grado de acuerdo en una escala tipo Likert de cinco alternativas que van desde “Totalmente de acuerdo” a “Totalmente en desacuerdo”, al igual que en el caso del IPQ. Para evaluar la dimensión de identidad se presenta al participante una lista de 14 síntomas y se le pide que responda “Sí” o “No” dependiendo de si piensa que dichos síntomas están relacionados o no con la enfermedad en cuestión, y, en el caso de haberla padecido, se le pide también que indique si los ha experimentado o no. En la escala de causalidad se presenta a la persona un listado de 18 causas y ésta debe indicar su grado de acuerdo con cada una como posible factor etiológico en una escala tipo Likert similar a la anterior. Al igual que ocurre con el IPQ, en la subescala de etiología las causas que puntúan más alto son las consideradas por la persona como los factores etiológicos más relevantes para dicha enfermedad.

Las puntuaciones de cada subescala o dimensión se obtienen sumando o promediando, más frecuentemente, las puntuaciones de cada uno de los ítems que conforman la subescala, teniendo en cuenta que para las dimensiones de duración, control personal, control por tratamiento, coherencia y representaciones emocionales hay tanto ítems directos como inversos. En la escala de identidad, las puntuaciones se obtienen sumando el número de veces que la persona ha contestado “Sí”. Puntuaciones elevadas en las diferentes subescalas indicarían creencias más fuertes.

En relación a las propiedades psicométricas de este instrumento, diferentes estudios han mostrado su adecuada consistencia interna y fiabilidad test-retest (Beléndez et al., 2005; Moss-Morris et al., 2002).

A pesar de las bondades del IPQ-R, en determinados casos su utilización resultaba inadecuada, principalmente por ser poco operativo por su longitud, por ejemplo para pacientes muy enfermos, en aquellos casos en que existe un tiempo limitado para la evaluación o cuando se trata de evaluar a pacientes que tienen habilidades limitadas de lectura o escritura.

Por ello, se puso de manifiesto la necesidad de poder contar con un instrumento más breve y, por tanto, más rápido de responder y que de algún modo superara los problemas asociados al IPQ-R y a la vez permitiera conocer los aspectos fundamentales de las creencias sobre las enfermedades. Un cuestionario más breve además ofrecería la ventaja de permitir estudiar las representaciones de enfermedad en un rango más amplio de pacientes así como en aquellas ocasiones en las que el estudio de los modelos de enfermedad constituyen sólo una parte del estudio de un amplio conjunto de aspectos psicosociales, o cuando las medidas se deben tomar de manera repetida con una determinada frecuencia.

Debido a todo ello, Broadbent, Petrie, Main y Weinman (2006) propusieron un cuestionario abreviado para evaluar las representaciones de enfermedad de acuerdo con el Modelo de Autorregulación y basado en el IPQ-R. El Cuestionario Breve de

Percepción de Enfermedad (Brief-IPQ, B-IPQ) nació, por tanto, con la pretensión de superar las limitaciones ya comentadas de sus predecesores, el IPQ y el IPQ-R, y de modificar el formato de respuesta de los cuestionarios anteriores, pasando de un formato de escala multifactorial tipo Likert a una escala de ítem simple que evalúa las percepciones de enfermedad en una escala lineal continua de 0 a 10 puntos.

En concreto, el B-IPQ está formado por nueve ítems, uno por dimensión evaluada excepto para la dimensión de representaciones emocionales, que es evaluada a través de dos ítems. Desaparece en el B-IPQ la dimensión de evolución (cíclica vs. estable). Los ítems que forman parte del B-IPQ serian los siguientes:

- Consecuencias: ¿Cómo afecta la enfermedad a su vida?
- Duración: ¿Cuánto cree que durará su enfermedad?
- Control Personal: ¿Cuánto control siente que tiene sobre su enfermedad?
- Control por Tratamiento: ¿En qué medida cree que su tratamiento ayuda a mejorar su enfermedad?
- Identidad: ¿En qué medida siente usted síntomas debido a su enfermedad?
- Representaciones Emocionales: ¿En qué medida está preocupado por su enfermedad?, ¿En qué medida lo afecta emocionalmente su enfermedad? (Es decir, le hace sentirse con rabia, asustado, enojado o deprimido)
- Preocupación: ¿En qué medida está preocupado por su enfermedad?
- Causas: Por favor, haga una lista con los tres factores más importantes que usted cree que causaron su enfermedad, enumérelos en orden de importancia.

Como se puede observar, todos ellos, excepto el ítem relativo a la dimensión de causas, se expresan en forma de pregunta y para la respuesta se utiliza una escala que va de cero a diez, donde cero indica que la respuesta a la pregunta es totalmente positiva (i.e., "no/nada en absoluto") y diez que indica que ésta es totalmente negativa (i.e., "mucho/completamente"). Las percepciones acerca de las causas son evaluadas a través de una pregunta con formato de respuesta abierta adaptada del IPQ-R en la que se pide a los participantes que señalen los tres factores causales más importantes para ellos en la génesis de la enfermedad. Las respuestas al ítem de causalidad pueden ser agrupadas luego por el investigador en diferentes categorías como factores psicológicos (e.g., estrés), factores comportamentales (e.g., estilo de vida), factores externos (e.g., contaminación), factores incontrolables o biológicos (e.g., herencia), etc.

En cuanto a las puntuaciones del B-IPQ, éstas son de fácil interpretación, de modo que los incrementos en las puntuaciones de los ítems representan incrementos lineales en la dimensión evaluada.

El B-IPQ, al igual que sus predecesores, presenta una adecuada fiabilidad test-retest y existen asociaciones de moderadas a buenas entre este cuestionario y el IPQ-R en las dimensiones equivalentes (Broadbent et al., 2006). Sin embargo, se han señalado algunas limitaciones de carácter psicométrico en distintos estudios. En primer lugar, parecen existir problemas relacionados con la validez concurrente del B-IPQ en las dimensiones de control personal y control por tratamiento (Broabdent et al., 2006; De Raaij, Schröder, Maissan, Pool y Wittink, 2012; French, Van Oort y Schröder. 2011). También ha sido puesta en cuestión su validez convergente con otras medidas (Bazzazian y Besharat, 2010; Lochting, Garrat, Storheim, Werner y Grotle, 2013). Por otro lado, y dentro de estas críticas a determinados aspectos psicométricos del B-IPQ, se puede señalar la no existencia de evidencia en relación a la validez discriminante de dicho instrumento (French et al., 2011) y la posible falta de validez de contenido (French et al., 2011; Van Oort, Schröder y French, 2011).

Al igual que en el caso del IPQ y el IPQ-R, la versión general del B-IPQ incluye el término "enfermedad" de forma genérica, pero éste puede ser sustituido por la enfermedad concreta que esté siendo objeto de estudio. Del mismo modo, en las dimensiones de control por tratamiento el término tratamiento puede sustituirse por el tipo de tratamiento concreto. Además, al igual que sus predecesores, el B-IPQ permite que puedan ser añadidos nuevos ítems o modificados los existentes de modo que se adapten a grupos concretos de pacientes o a determinados problemas de salud.

Una pregunta clave que se podría plantear es cuándo resulta más adecuado utilizar un cuestionario u otro. En este sentido, el IPQ-R es preferible al IPQ por todas las mejoras introducidas, tanto a nivel de contenido como psicométricas. Además, el IPQ-R ofrece una serie de ventajas relacionadas con la evaluación de la percepción de los síntomas presentes en la enfermedad que no es evaluada en el B-IPQ. Por otro lado, el IPQ-R utiliza más ítems para cada dimensión, lo que permite conocer más profundamente la diversidad de las creencias que la conforman, evalúa específicamente aspectos relacionados con la percepción de curso cíclico de la enfermedad (dimensión no incluida en el B-IPQ) y se muestra más sensible a los cambios en las representaciones sobre la enfermedad. En cuanto a las ventajas de B-IPQ destacan, como ya se ha comentado, su facilidad de aplicación debido a su brevedad y el formato de respuesta, por lo que es muy útil para ser utilizado con poblaciones concretas, como personas muy enfermas, de mayor edad o con limitaciones para responder (e.g., cognitivas, motoras, etc.), cuando la medida de las representaciones de enfermedad forma parte de un estudio con mayor número de variables evaluadas o cuando es necesario tomar medidas repetidas en un corto periodo de tiempo.

A partir del desarrollo de estos instrumentos dirigidos a evaluar las representaciones cognitivas y emocionales que las personas construimos sobre la enfermedad en general y sobre cada alteración en particular de acuerdo con el SRM y debido al enorme interés suscitado por esta cuestión, han surgido otros instrumentos que, basados en los anteriormente citados, han tratado de evaluar estos aspectos en población sana introduciendo diferentes modificaciones sobre la base de estos cuestionarios para adaptar su contenido a personas que no padecen o han padecido una determinada enfermedad (e.g., Godoy y Godoy-Izquierdo, 2006; Figueiras y Alves, 2007).

A continuación se presenta una revisión de las principales investigaciones sobre las representaciones cognitivas y emocionales de las enfermedades cáncer e hipertensión, incluyendo las percepciones que las personas (pacientes, individuos con riesgo, cuidadores y población general sin experiencia con la enfermedad) tienen sobre estas enfermedades así como su relación con conductas de afrontamiento y manejo de la enfermedad y el estado de salud y calidad de vida, siguiendo los postulados básicos del SRM.

Los resultados de la investigación realizada sobre modelos personales de enfermedad en trastornos cardiovasculares, incluyendo la hipertensión, y en cáncer suponen un apoyo a los postulados básicos del Modelo de Autorregulación ya que, en líneas generales, muestran que las representaciones que los pacientes y sus familiares, así como las personas sanas, construyen acerca de sus problemas de salud ejercen una influencia en las estrategias de afrontamiento que utilizan para manejar la enfermedad y su impacto y, a través del papel mediador de éstas, en el nivel de funcionamiento, la recuperación de la enfermedad y finalmente en el nivel de bienestar y calidad de vida de unos y otros.

En este sentido, es necesario destacar, por un lado, la necesidad de llevar a cabo más estudios que profundicen en el conocimiento de las construcciones cognitivas y emocionales que las personas tenemos sobre la hipertensión y cáncer y de las relaciones postuladas por el SRM entre estas representaciones, las acciones ante la enfermedad y las consecuencias de éstas en la salud y la vida en general de las personas, y, por otro, de utilizar el conocimiento emanado de los estudios realizados para desarrollar intervenciones eficaces que conduzcan a una mejora en el abordaje del cáncer por parte de no pacientes, pacientes y cuidadores, así como de las enfermedades de carácter cardiovascular y de la hipertensión en particular, favoreciendo un mejor conocimiento, afrontamiento y recuperación y finalmente un mayor bienestar, que debe ser el objetivo prioritario que guíe la intervención en cualquier ámbito de la Psicología y particularmente en el de la Psicología de la Salud.

CAPÍTULO 4

El modelo de autorregulación y las enfermedades oncológicas (cáncer)

4.1. Aplicaciones del Modelo de Autorregulación al cáncer: Evidencias empíricas

En cuanto a la investigación realizada sobre los modelos personales de cáncer y que utiliza como base teórica el Modelo de Autorregulación, es necesario destacar, al igual que ocurre en el caso de la hipertensión, que el número de estudios es escaso a pesar del enorme problema que esta enfermedad supone para la salud pública a nivel mundial y del impacto que esta enfermedad tiene en pacientes, cuidadores y familiares así como en la población general.

4.1.1. Investigaciones realizadas con pacientes

Es necesario destacar que, a pesar de la escasez de estudios realizados para explorar los postulados del SRM en cáncer, la mayor parte de los mismos se han desarrollado con pacientes. Así, por ejemplo, Cameron y colaboradores (2005) llevaron a cabo un estudio de carácter prospectivo para evaluar el papel de las creencias de enfermedad, los factores de regulación emocional y las características sociodemográficas en la decisión de participar o no en un programa grupal de apoyo de doce semanas de duración para mujeres recientemente diagnosticadas de cáncer de mama. Para ello un grupo de mujeres fueron evaluadas entre dos y cuatro semanas después del diagnóstico a través de un amplio conjunto de pruebas relacionadas con factores cognitivos y afectivos identificados por el Modelo de Autorregulación. En este sentido, se evaluaron el malestar emocional relacionado con el cáncer, las tendencias de evitación, las creencias acerca de la idea de que el cáncer es provocado por el estrés y alteraciones del sistema inmunitario y las creencias sobre el control personal. Además se tomaron medidas de ansiedad, depresión, apoyo social y características demográficas. Los resultados pusieron de manifiesto que el 49% participó en el programa. La participación en el programa estaba guiada por las representaciones de enfermedad y los factores relacionados con la regulación de la emoción identificados por el SRM. La participación fue predicha por creencias más fuertes de que el cáncer era provocado por la alteración del sistema inmunitario, un mayor malestar relacionado con el cáncer, menores tendencias hacia la evitación y una menor edad. Las creencias acerca del control personal sobre la enfermedad no predecían la participación, al contrario de lo que se esperaba. Otros factores como el apoyo social, el nivel educativo, el malestar general o el pronóstico de la enfermedad no actuaban como predictores significativos.

Millar y colaboradores (2005) desarrollaron una investigación de carácter prospectivo de un año de duración para comprobar el nivel de malestar psicológico, las percepciones de enfermedad y la influencia de éstas en el malestar psicológico en mujeres que habían sido operadas de cáncer de mama. Las participantes fueron evaluadas justo después de la operación y a los tres, seis y doce meses. Los resultados obtenidos indicaron una reducción general del nivel de malestar psicológico a los doce meses, aunque éste era aún elevado en ese periodo en un 25% de las participantes. Las pacientes con mayores niveles de malestar se caracterizaban en general por niveles elevados de neuroticismo, mayor conciencia de los síntomas, más temor y unos niveles más pobres de salud general. Los datos también señalaron que el malestar psicológico en el año después de la operación era predicho principalmente por el nivel de malestar justo después de la operación, la conciencia de los síntomas, la percepción del curso de la enfermedad, la salud general y en menor medida por el neuroticismo.

Scharloo y colaboradores (2005) trataron de comprobar qué representaciones de enfermedad de pacientes recientemente diagnosticados de cáncer de cabeza y cuello influían en su calidad de vida. Los resultados mostraron que las percepciones de identidad y una menor edad se asociaban con un mejor funcionamiento físico. El funcionamiento cotidiano estaba relacionado con una menor edad, menos síntomas percibidos y una menor ciclicidad percibida del cáncer. Por otro lado, representaciones emocionales más leves y menores síntomas percibidos se asociaban con un mejor funcionamiento emocional. Finalmente, una menor percepción de ciclicidad se asociaba con un mejor funcionamiento cognitivo.

LLewelyn, McGurk y Weinman (2006) realizaron una investigación con el objetivo de determinar en qué medida la calidad de vida individualizada (sensación individual de calidad de vida) se relacionaba con la calidad de vida estandarizada relacionada con la salud en pacientes de cáncer. Por otra parte, también se trataba de comprobar cuánta de la variación en cada una de las medidas de resultado podía ser explicada por variables de carácter psicológico. Con esa intención se evaluó a pacientes recientemente diagnosticados de cáncer de cabeza y cuello antes de comenzar con el tratamiento así como ocho meses después. Los resultados mostraron que las medidas de calidad de vida estandarizada y las de individualizada correlacionaban sólo parcialmente. El estudio también puso de manifiesto que las representaciones de los participantes acerca de la enfermedad y el tratamiento, especialmente las dimensiones de identidad y duración, así como las estrategias de afrontamiento, se relacionaban de manera importante tanto con la calidad de vida estandarizada como con la individualizada en la medida pretratamiento.

Orbell y colaboradores (2006) realizaron un estudio de carácter prospectivo con el objetivo de explicar la asistencia a la colposcopia y el seguimiento del tratamiento en los siguientes 15 meses en pacientes diagnosticadas de cáncer de útero. Mientras que los componentes del SRM no predijeron las intenciones para completar el tratamiento, sí discriminaron entre diferentes niveles de adherencia. Las participantes fueron clasificadas en tres categorías, asistentes programadas, asistentes puntuales y asistentes que abandonan.

LLewellyn, McGurk y Weinman (2007) desarrollaron una investigación de carácter longitudinal para tratar de comprobar si las representaciones de la enfermedad permitían predecir las consecuencias de ésta a través del tiempo en cuatro aspectos básicos como son la calidad de vida relacionada con la salud, la calidad de vida individualizada, la depresión y la ansiedad, así como para evaluar cómo las creencias de los participantes acerca de la enfermedad y el tratamiento se asociaban con el afrontamiento de la misma. Para ello evaluaron a un grupo de pacientes diagnosticados de cáncer de cabeza y cuello antes del tratamiento, un mes y entres seis y ocho meses después del tratamiento. Los resultados mostraron que las creencias acerca de la cronicidad de la enfermedad se asociaban con depresión después del tratamiento, sin que hubiera relación entre las creencias de los pacientes y la calidad de vida individualizada, la calidad de vida relacionada con la salud y la ansiedad a los seis meses del tratamiento. Por otro lado se halló que las estrategias de afrontamiento y los niveles de satisfacción con la información disponible sobre la enfermedad antes del tratamiento si eran buenos predictores de las consecuencias de la enfermedad a lo largo del tiempo. También se observó que las creencias de los participantes sobre la enfermedad y el tratamiento se relacionaban de manera significativa con el afrontamiento de la enfermedad.

Letho (2007) realizó un estudio para evaluar las atribuciones causales sobre el cáncer de posibles pacientes de cáncer de pulmón. También se exploró la relación entre las atribuciones causales y las percepciones de coherencia y representaciones emocionales antes y después de someterse a cirugía. Los resultados mostraron que fumar fue la causa más frecuentemente señalada en ambos momentos. Otras causas destacadas fueron el comportamiento propio, la polución, la herencia, la edad o la suerte. Después de la cirugía, el comportamiento propio fue considerado como la causa más importante después del consumo de tabaco, algo que no ocurría antes de la misma. En cuanto a la relación entre atribuciones causales y las dimensiones de coherencia y representaciones emocionales halló que la percepción de un accidente o la suerte como causa del cáncer correlacionaba de forma inversa con la dimensión de coherencia. Ninguna de las percepciones de causas correlacionó con las representaciones emocionales. En cuanto a la posible influencia de las diferencias sociodemográficas, encontraron que las mujeres mostraban puntuaciones más altas que los hombres en coherencia antes de la operación. También hallaron que los participantes con mayor nivel educativo señalaban menos causas relacionadas con factores de riesgo en ambos momentos, y que los participantes mostraban mayor coherencia después de la cirugía cuanto mayor era su nivel educativo.

Trask y colaboradores (2008) llevaron a cabo un estudio para valorar las conductas de autoexploración en supervivientes de cáncer de mama entre uno y cuatro años después del diagnóstico así como para examinar los aspectos personales, emocionales, cognitivos y de cuidados de salud que podrían contribuir a esa exploración. En general, las participantes percibían el cáncer de mama como una enfermedad aguda y cíclica, con altas probabilidades de control por tratamiento y no experimentaban altos niveles de emociones negativas. En general, practicaban la autoexploración, la mayoría lo habían hecho en el último mes y el 39% lo hacían más de una vez al mes. La inmensa mayoría afirmaban que un médico o enfermera les habían dicho que debían hacerlo una vez al mes, aunque sólo el 69% expresaba que les habían explicado cómo hacerlo.

Gould, Brown y Branwell (2010) llevaron a cabo un estudio en el que examinaron las asociaciones existentes entre las diferentes dimensiones de los modelos personales de enfermedad en cáncer, el afrontamiento de la enfermedad y el malestar emocional de pacientes recientemente diagnosticadas de cáncer ginecológico. Los resultados mostraron que todas las dimensiones que conforman los modelos personales de enfermedad excepto la de duración (aguda) poseían carácter predictivo con respecto a las alteraciones en el estado de ánimo. Por otro lado, también se halló que las relaciones entre las representaciones de la enfermedad y el humor podrían estar mediadas por las estrategias de afrontamiento utilizadas por las pacientes. En este sentido, existiría una posible vía relacionada con la mayor utilización de estrategias de afrontamiento basadas en la evitación y la negación que mediaría en la relación entre la percepción del cáncer como más cíclico y una menor coherencia en la comprensión de la enfermedad y un humor más negativo.

Henselmans y colaboradores (2009) llevaron a cabo un estudio con el objetivo de examinar el efecto de noticias decepcionantes en la percepción de adaptabilidad del control personal sobre la cura en mujeres con cáncer de mama así como contrastarlo con la adaptatividad del control general sobre su vida. Adicionalmente las creencias y correlatos subyacentes al control sobre la curación fueron también explorados. Para ello, mujeres recientemente diagnosticadas de cáncer de mama fueron evaluadas después de la operación. Como una submuestra se utilizaron también los datos de mujeres antes de la operación y después del tratamiento. La prescripción de quimioterapia después de la operación fue utilizada como un indicador de las noticias decepcionantes. Los resultados pusieron de manifiesto que las noticias decepcionantes no aumentaban ni limitaban la capacidad de adaptatividad de las percepciones de control sobre una enfermedad específica ni de control general. Las participantes manifestaron que el mantenimiento de una actitud positiva, la aceptación del tratamiento y la adopción de un estilo de vida saludable les proporcionaba la sensación de control sobre la curación. Las mujeres con una sensación fuerte de control sobre la cura padecían más habitualmente un cáncer invasivo y eran más jóvenes.

Traeger y colaboradores (2009) realizaron un estudio en el que examinaron las creencias de enfermedad sobre cáncer en hombres que padecían cáncer de próstata dentro de los 18 meses establecidos para completar su tratamiento. El objetivo era conocer en qué medida el ajuste emocional de los supervivientes a un cáncer se ve influenciado por el modo en que los pacientes interpretan los efectos secundarios del tratamiento y otras experiencias relacionadas con el cáncer. Los resultados pusieron de manifiesto que la percepción de mayor control a través del tratamiento, mayor coherencia, menos consecuencias negativas y menores creencias en la personalidad o el comportamiento como causa del cáncer se asociaban con un mayor nivel de bienestar postratamiento. Por otro lado, el estrés vital de los participantes ejercía un efecto mediador en la relación entre las consecuencias percibidas del cáncer de próstata y el bienestar emocional, en el sentido de que la percepción de consecuencias más negativas predecía un menor bienestar especialmente en aquellos hombres con mayores niveles de estrés.

Constanzo, Lutgendorf y Roeder (2010) evaluaron a mujeres que habían padecido cáncer de mama tres semanas y tres meses después de haber concluido el tratamiento con quimioterapia y/o radioterapia con el objetivo de examinar los esfuerzos realizados por las supervivientes para manejar la incertidumbre asociada a padecer cáncer realizando cambios en su estilo de vida. Además, se investigó el papel de las creencias de enfermedad sobre el cáncer en la explicación de dichos cambios después del tratamiento. Los resultados obtenidos sugieren que las supervivientes a un cáncer de mama realizan importantes esfuerzos para introducir cambios en su estilo de vida dirigidos a mejorar su bienestar físico, emocional y espiritual. Los resultados además señalan que las mujeres que creían que su cáncer se relacionaba con consecuencias más graves y que atribuían su desarrollo y la prevención de su recurrencia a un comportamiento saludable o al estrés era más probable que introdujesen cambios en su dieta, incrementasen la actividad física o redujesen el consumo de alcohol y tabaco. En general, los resultados muestran que las supervivientes a un cáncer de mama piensan que poseen un control moderado sobre la enfermedad, perciben que el cáncer implica consecuencias graves o moderadas para su vida y lo consideran una condición más aguda que crónica. Por otra parte, estas mujeres mostraban creencias más fuertes acerca de aquello que provoca la enfermedad y sobre qué deben hacer para evitar su recurrencia.

Gercovich y colaboradores (2012) desarrollaron un estudio para evaluar las asociaciones entre las dimensiones de los modelos de enfermedad sobre el cáncer y la calidad de vida considerando el rol modulador del malestar psicológico en pacientes con cáncer de mama. Observaron que aunque aparecían asociaciones significativas entre las dimensiones de las representaciones de la enfermedad y la calidad de vida, éstas perdían su significación cuando se incluía el malestar psicológico. Las variables que mejor predecían la calidad de vida eran el diagnóstico psicopatológico y el malestar. La subescala de identidad se asoció con la calidad de vida, correlacionando de manera inversa con el funcionamiento social, mientras que la de coherencia se relacionaba de forma positiva con el funcionamiento cotidiano.

Hoogerwerf y colaboradores (2012) llevaron a cabo un estudio para evaluar las representaciones emocionales sobre el cáncer de pulmón y el impacto de la enfermedad. Además de evaluar sus representaciones del cáncer, pidieron a los participantes que dibujaran cómo percibían sus pulmones enfermos para evaluar el ajuste de ese dibujo a la realidad. Las puntuaciones en las diferentes dimensiones de las creencias de enfermedad fueron en su mayoría moderadas. Los pacientes mostraron elevada confianza en las posibilidades de controlar la enfermedad con el tratamiento y no se mostraron especialmente ansiosos o preocupados por padecerla. Señalaron como causas más importantes fumar o la mala suerte. Otras causas también indicadas fueron el trabajo duro, el estrés o la herencia. Los dibujos eran moderadamente ajustados aunque los tumores solían mostrarse más grandes en los dibujos de lo que eran en la realidad. Encontraron correlaciones entre el grado de ajuste del dibujo del cáncer y sus pulmones y puntuaciones en determinadas dimensiones de las creencias de enfermedad. En este sentido, mayores puntuaciones en duración y menores en control por tratamiento se asociaban con un dibujo más ajustado a la realidad.

Hopman y Rijken (2015) desarrollaron un estudio para explorar cómo percibían su enfermedad pacientes con diferentes tipos de cáncer. También fueron examinadas las relaciones entre las representaciones sobre el cáncer de los pacientes con las características de su enfermedad y sus estrategias de afrontamiento. Los participantes en general percibían el cáncer como de larga duración y percibían el tratamiento como efectivo, aunque consideraban que sus posibilidades de control personal eran más bajas. También mostraban una buena comprensión de la enfermedad y no consideraban los factores de tipo psicológico como posibles causas, atribuyendo la enfermedad sobre todo a la suerte. Los participantes con cáncer de piel percibían consecuencias menos negativas mientras que aquéllos que habían sido tratados recientemente percibían consecuencias más negativas y la enfermedad como más crónica. Los participantes con cáncer de piel consideraban también que bacterias/virus, la polución o las alteraciones inmunológicas eran causas del cáncer más que otros pacientes con cánceres menos prevalentes. Por último, las pacientes que sufrían cáncer de mama percibían una mayor influencia de factores psicológicos en el desarrollo de su enfermedad. También encontraron diferencias de acuerdo con el tratamiento recibido, de modo que los pacientes que recibieron sólo tratamiento quirúrgico percibían el cáncer como menos crónico y con menos consecuencias, mientras que los pacientes con una combinación de cirugía y otros tratamientos percibían como causas los aspectos psicológicos en menos proporción.

Finalmente, Dempster et al. (2010) llevaron a cabo un estudio con supervivientes de cáncer de esófago para tratar de determinar si se podrían agrupar en diferentes perfiles de acuerdo con los cambios en sus representaciones sobre el cáncer a lo largo de un año. Los resultados mostraron que los supervivientes mostraban cambios en sus modelos de enfermedad sobre el cáncer después de un año y que podían ser agrupados en diferentes perfiles de acuerdo con esos cambios. Dos de los perfiles mostraron una evolución positiva de esas representaciones, mientras que los otros dos mostraron cambios hacia representaciones de carácter más negativo. Así, los participantes incluidos en el perfil 1 (30.1% de la muestra) mostraban un decremento en identidad, ciclicidad y consecuencias, mientras que aumentaron sus percepciones de control por tratamiento y disminuyeron las de control personal y causas. También vieron incrementada su coherencia. El segundo de los perfiles (28) también mostró una evolución positiva de las representaciones sobre el cáncer. Éstos incrementaron su percepción de control personal, duración y coherencia así como sus representaciones de causas emocionales y externas y disminuyeron sus percepciones de control por tratamiento, identidad, ciclicidad y consecuencias. Los otros dos perfiles evolucionaron hacia representaciones más negativas, el tercero de ellos (23.3% de los participantes) con una disminución de la identidad, duración, ciclicidad, consecuencias, control personal y por tratamiento y coherencia, y el último de los perfiles (18,6%) con un incremento de sus percepciones de ciclicidad, consecuencias y control personal y por tratamiento así como un decremento de las percepciones de causas externas, comportamentales y emocionales y de la coherencia.

Como se puede observar, ninguno de los estudios revisados que tratan de explorar las representaciones acerca del cáncer de acuerdo con el Modelo de

Autorregulación en personas que padecen o han padecido la enfermedad ha sido realizado con población española. Los estudios revisados y realizados en población no española han señalado que las creencias que sobre el cáncer tienen los pacientes son una mezcla de conocimiento médico objetivo y aspectos populares y culturales y que determinan de forma profunda tanto las conductas de manejo de la enfermedad de todos ellos como el estado de bienestar y la calidad de vida de los participantes.

Aunque muchos de los estudios revisados acerca de las representaciones cognitivas y emocionales que sobre el cáncer construyen las personas que padecen esta enfermedad se han dirigido a explorar las relaciones entre las creencias y determinadas conductas de afrontamiento, o aspectos relacionados con el impacto de la enfermedad en el bienestar y la calidad de vida, los que han tratado de conocer cómo son esas creencias no especializadas muestran en general que el cáncer es percibido por los pacientes como una enfermedad con altas probabilidades de control por parte de los tratamientos existentes y menor en el caso de las acciones del propio paciente, de larga duración y que genera reacciones emocionales no excesivamente fuertes.

4.1.2. Investigaciones realizadas con población general sana, población en riesgo y cuidadores

Si el número de estudios dirigidos a explorar los modelos de enfermedad en cáncer en personas que padecen o han padecido la enfermedad es escaso, cuando centramos nuestra atención en el estudio de dichas percepciones en la población sana o poblaciones en riesgo esa cifra se reduce enormemente.

Figueiras y Alves (2007) evaluaron las percepciones acerca del cáncer de piel en una muestra de individuos sanos. Además evaluaron también la afectividad negativa y las actitudes hacia la adopción de un comportamiento preventivo. Los resultados mostraron que en general el cáncer de piel era percibido como una enfermedad escasamente sintomática, de larga duración, cíclica y con graves consecuencias para los pacientes. Las percepciones de controlabilidad personal y por tratamiento fueron de moderadas a altas. Los participantes además poseían una percepción moderadamente buena de su comprensión de la enfermedad. En cuanto a las causas, señalaron los factores relacionados con el estilo de vida más frecuentemente que aspectos psicológicos. Encontraron también que las dimensiones de causas, consecuencias, duración y coherencia explicaban un 11% de la varianza de las actitudes hacia los comportamientos preventivos mientras que las de coherencia, causas y representaciones emocionales explicaban el 8% de la intención de adoptar comportamientos preventivos. Los resultados también mostraron que las dimensiones de las representaciones mostraban un patrón de interrelaciones lógicas: Representaciones emocionales más fuertes correlacionaban positivamente con identidad, una duración más crónica, menor ciclicidad, consecuencias más serias y menor coherencia y negativamente con el control personal y tratamiento. Creencias más fuertes de control por tratamiento se asociaban con menos consecuencias percibidas, una duración menos crónica y un menor número de síntomas asociados a la enfermedad. También encontraron que las atribuciones causales se relacionaban con control personal y por tratamiento y coherencia.

Cameron (2008) llevo a cabo un estudio con estudiantes universitarios de ambos sexos que nunca habían sufrido cáncer de piel para evaluar los contenidos de las representaciones mentales del cáncer de piel y sus asociaciones con la valoración acerca del riesgo de padecerlo, la preocupación y las intenciones y comportamientos de protección ante este tipo de cáncer. Con este objetivo fueron evaluados a través del AIRR (Evaluación de las representaciones del riesgo de enfermedad), una medida de las representaciones de la enfermedad basada en el IPQ-R pero adaptada para evaluar aspectos de las representaciones de riesgo; también evaluaron las imágenes mentales relacionadas con la enfermedad. En relación a los contenidos de los modelos mentales de enfermedad, los resultados pusieron de manifiesto que la mayoría de las imágenes acerca del cáncer de piel manifestadas por los participantes se relacionaban con los atributos representacionales identificados por el SRM: identidad, causas y consecuencias, aunque los contenidos sobre síntomas predominaban sobre el resto.

Se identificó asimismo el modo en que los contenidos de las representaciones de riesgo se asociaban con las evaluaciones de probabilidad y severidad y con la preocupación. Así, los resultados mostraron que las evaluaciones de probabilidad se asociaban positivamente con las creencias acerca de las causas, la identidad y la evolución relacionadas con el riesgo. Además las creencias acerca de un menor control personal se asociaron con mayores valoraciones de probabilidad. Los resultados además mostraron que los atributos de las representaciones mentales, incluidas la viveza de las imágenes y su valencia, predecían las intenciones y los comportamientos ante el cáncer de piel mientras que las evaluaciones de probabilidad y severidad carecían de ese valor predictivo. En este sentido, las imágenes mentales acerca de los síntomas interactuaban con la preocupación para predecir las intenciones relacionadas con la prevención y la detección: la preocupación predecía mayores intenciones para aquellos que poseían imágenes mentales acerca de los síntomas pero no para aquellos que carecían de dichas imágenes.

Wang y colaboradores (2010) desarrollaron una investigación para describir y comparar las creencias de causalidad sobre el cáncer de mama y colorrectal entre mujeres sanas de la población general. Los resultados pusieron de manifiesto que para ambos tipos de cáncer la herencia, seguida de los hábitos de alimentación, fueron consideradas las principales causas. Con respecto al cáncer de mama, las consideradas como más importantes fueron la herencia, seguida de los hábitos de alimentación, la polución y los cambios en el sistema inmunitario. En relación al cáncer colorrectal, las más destacadas fueron la herencia, los hábitos de alimentación y la edad. Se observó que había más probabilidad de considerar la herencia y la polución como causas del cáncer de mama, mientras que había más probabilidad de considerar la dieta, la edad y la falta de ejercicio como causas del cáncer colorrectal. Las participantes que habían sufrido una cirugía de colon consideraban que los gérmenes o virus, pobres cuidados médicos en el pasado, la sobrecarga de trabajo o las preocupaciones eran más causas del cáncer colorrectal. También encontraron diferencias relacionadas con la edad en las atribuciones causales, de modo que las mujeres con 50 o más años consideraban la herencia como causa de ambos tipos de cáncer más frecuentemente que las menores de 50. Las más jóvenes también percibían otros factores comportamentales y psicológicos. Se encontraron también diferencias relacionados con el nivel educativo, de modo que aquellas con mayor nivel de estudios pensaban que la falta de ejercicio tenían mayor peso en el cáncer colorrectal. Por último, encontraron que las mujeres con una historia familiar de cáncer colorrectal era menos probable que creyeran que la ausencia de cuidados médicos en el pasado fuera la causa del cáncer.

Con respecto a los estudios que incluyen tanto población sana como enferma es necesario destacar que el número de estudios realizados desde el SRM, a nuestro conocimiento, es también extremadamente limitado. Algunos de ellos han ido dirigidos a comparar las representaciones sobre el cáncer entre personas que padecían la enfermedad con las de personas sanas mientras que otros han explorado las diferencias en las percepciones sobre el cáncer entre pacientes y sus cuidadores.

En este sentido, Buick y Petrie (2002) desarrollaron una investigación con el objetivo de determinar el ajuste de las percepciones de mujeres sanas acerca de cómo las mujeres que padecen cáncer de mama afrontan la enfermedad. Para ello, se comparó el malestar emocional, estilos de afrontamiento y percepciones de enfermedad de mujeres que recibían tratamiento postquirúrgico para el cáncer de mama y de una muestra de mujeres sanas. Los resultados pusieron de manifiesto la clara incongruencia entre las percepciones que acerca de la enfermedad y su tratamiento poseían las mujeres que no padecían cáncer de mama y las experiencias de las mujeres que sí padecían la enfermedad. En este sentido, las mujeres sanas sobreestimaban el malestar de las pacientes, percibían consecuencias más graves asociadas a la enfermedad y consideraban que las pacientes utilizaban estrategias de afrontamiento basadas en la negación más frecuentemente de lo que lo hacían en realidad.

Anagnostopoulos y Spanea (2005) realizaron un estudio en el que evaluaron las creencias personales acerca del cáncer en mujeres que no padecían la enfermedad o habían padecido un tumor benigno y mujeres con cáncer de mama. Las representaciones del cáncer de mama en la muestra completa incluían creencias sobre un moderado control sobre la enfermedad y un nivel moderado de consecuencias de la misma, y atribuciones causales más fuertes a la suerte que a factores internos, comportamentales o ambientales. Los resultados mostraron que las mujeres que no habían padecido la enfermedad o en las que ésta era de carácter benigno no tenían una representación ajustada de las experiencias con la enfermedad de las pacientes: comparativamente, se caracterizaban por creencias más débiles de controlabilidad así como por una sobreestimación de las consecuencias negativas del cáncer. En relación a la etiología, poseían creencias más fuertes sobre el papel en su inicio de factores ambientales y comportamentales, y más débiles respecto a la suerte, que las participantes que padecían la enfermedad.

Orbell y colaboradores (2008) compararon las representaciones sobre el cáncer, las respuestas de afrontamiento y el estado emocional (ansiedad) de personas que reciben el diagnóstico de cáncer invasivo, de adenoma (o tumor benigno) y de no neoplasia tras una prueba para detectar cáncer colorrectal. Las representaciones acerca del cáncer variaban de acuerdo con el diagnóstico de la prueba; así, los participantes diagnosticados con un cáncer invasivo percibían su resultado como más aterrador y serio que aquellos sin neoplasia y era más probable que creyeran en una mayor eficacia del tratamiento además de percibir una menor duración de la enfermedad. Por otro lado, los participantes diagnosticados de cáncer era menos probable que atribuyeran su enfermedad a factores relacionados con su estilo de vida. Por el contrario, los participantes sin neoplasia percibían la enfermedad como poco sintomática, moderadamente larga, impactante y controlable, aunque indicaron percepciones más fuertes de controlabilidad por el tratamiento que personal. Sus percepciones de coherencia fueron moderadas. Sus atribuciones causales eran más de tipo biológico y psicológico que comportamental. Los participantes con adenoma se distinguieron de los otros dos subgrupos por tener creencias más fuertes de control personal y atribuir más frecuentemente la enfermedad a factores relacionados con el estilo de vida. También se observó que mayores niveles de ansiedad tras el diagnóstico se asociaban con una percepción del cáncer como más amenazante en términos de síntomas así como con representaciones emocionales más fuertes combinadas con una menor percepción de control personal. También hallaron que los esfuerzos por modificar el comportamiento se relacionaban con las creencias acerca del control personal pero no con la severidad de las consecuencias percibidas ni con las atribuciones causales. En concreto, encontraron que estas representaciones predecían las conductas de afrontamiento de los participantes, lo que a su vez predecía la participación en una nueva prueba de *screening* de seguimiento 2 años después entre aquellos que no habían recibido el diagnóstico de cáncer en la primera prueba.

Dempster y colaboradores (2011a) llevaron a cabo un estudio con cuidadores de pacientes con cáncer de esófago para conocer cómo sus percepciones de la enfermedad y estrategias de coping afectaban a su malestar psicológico (miedo a la recurrencia de la enfermedad, ansiedad y depresión). Los cuidadores percibían el cáncer de esófago como una enfermedad crónica y estable, causada principalmente por factores externos en comparación con factores emocionales o comportamentales, con consecuencias graves para el enfermo pero no tanto para el cuidador, y moderadamente controlable tanto por el paciente como por los tratamientos disponibles, aunque en menor medida por los propios cuidadores. Los cuidadores informaron tener una representación moderadamente buena de la comprensión de la enfermedad. Percepciones más fuertes de coherencia, controlabilidad personal y por tratamiento, estabilidad y causalidad externa y percepciones más débiles de consecuencias, así como estrategias de afrontamiento más positivas y funcionales se asociaron a niveles menores de malestar psicológico en los cuidadores.

Dempster y colaboradores (2011b) llevaron a cabo otro estudio para determinar en qué medida las representaciones acerca del cáncer de esófago en supervivientes a la enfermedad y en sus cuidadores permitían explicar los niveles de malestar psicológico de los primeros, en términos de ansiedad y depresión. También trataron de comprobar la posible influencia de variables sociodemográficas y de las estrategias de afrontamiento en esos niveles de malestar. Los resultados pusieron de manifiesto que las representaciones sobre el cáncer de unos y otros eran muy similares, aunque los cuidadores percibían menor controlabilidad personal y atribuciones causales comportamentales y mayores consecuencias de la enfermedad para el paciente, apoyando que la experiencia familiar con la enfermedad tiene una importante influencia en las representaciones sobre la misma. También encontraron que, junto con las percepciones que los propios pacientes tenían, ejercían una importante influencia en el malestar psicológico de los supervivientes. Así, la percepción de la enfermedad por parte de los supervivientes como con consecuencias menos negativas, mayor posibilidad de control personal y causas no relacionadas con el estrés o el estado emocional se relacionaba con menores niveles de depresión y ansiedad. También se halló que las representaciones de los cuidadores ejercían una influencia importante en el malestar de los pacientes, de modo que cuando los cuidadores percibían el cáncer como asociado a consecuencias más graves y bajas posibilidades de control por tratamiento, los niveles de malestar en los supervivientes al cáncer eran más elevados. De hecho, encontraron que las percepciones de los cuidadores moderaban el impacto de las percepciones de los pacientes sobre su bienestar emocional. Por último, también encontraron que las estrategias de afrontamiento positivo se relacionaban con menores niveles de depresión y ansiedad.

De Castro y colaboradores (2013) llevaron a cabo un estudio con el objetivo de comparar las percepciones sobre el cáncer de cuello de útero en mujeres con la enfermedad, mujeres con lesiones precursoras y mujeres sanas. Aparecieron diferencias entre los tres grupos en identidad, evolución y causas. Las mujeres sanas percibían la enfermedad como más sintomática y estable que los otros dos grupos. Con respecto a las causas de la enfermedad, las participantes con cáncer atribuían menos causas psicológicas. Las mujeres con cáncer consideraban que la causa más importante era "el estado emocional, el estrés y las preocupaciones", mientras que el grupo con lesiones precursoras y de mujeres sanas consideraban que eran la actitud personal y el comportamiento. En un estudio subsiguiente, De Castro y colaboradores (2015) compararon las percepciones de enfermedad, el conocimiento del cáncer cervical y las conductas de autocuidado de mujeres con y sin lesiones precursoras. No se encontraron diferencias significativas entre ambos grupos en ninguna de las variables del estudio. Los resultados mostraron que ambos grupos percibían pocos síntomas, elevadas consecuencias y alta controlabilidad y que tenían una comprensión parcial de la enfermedad. En cuanto a las representaciones emocionales, percibían en el cáncer como moderadamente amenazante, y en cuanto a sus posibles causas, asignaban pocas causas de carácter psicológico y más frecuentemente mencionaban factores de riesgo generales.

Juth, Silver y Sender (2015) llevaron a cabo un estudio con adolescentes y jóvenes con cáncer y sus cuidadores (en la mayoría de los casos, sus padres) para examinar el grado en que las percepciones de ambos acerca de la severidad del cáncer eran congruentes con la severidad objetiva de la enfermedad y para comparar las percepciones subjetivas de severidad de pacientes y cuidadores y los síntomas de estrés postraumático relacionados con el cáncer, investigando si las percepciones subjetivas de severidad se relacionaban con el estrés postraumático de ambos grupos.

Puntuaciones más altas en severidad se relacionaban con una mayor duración percibida, mayor control personal sobre la enfermedad, mayores percepciones de control por tratamiento, mayor número de síntomas percibidos, mayor preocupación por sufrir la enfermedad y mayor coherencia. No encontraron, sin embargo, relación entre las percepciones de severidad de pacientes y cuidadores y la severidad objetiva de la enfermedad. Además, los pacientes mostraban una menor severidad percibida que sus cuidadores en todas las dimensiones excepto en control por tratamiento. Comparativamente, los cuidadores mostraron mayores niveles de estrés postraumático. En cuanto a los pacientes, sus síntomas de estrés postraumático eran predichos por sus percepciones de la enfermedad; sin embargo, en el caso de los cuidadores, sus síntomas fueron predichos por sus propias creencias sobre la enfermedad así como por las de los pacientes.

Dentro de este grupo de estudios con personas sanas, una parte de la investigación se ha dirigido a conocer las representaciones que sobre el cáncer poseen poblaciones en riesgo, como demuestran algunos de los estudios presentados hasta ahora. Rees y colaboradores (2004) realizaron una investigación en la que compararon las percepciones de enfermedad de un grupo de mujeres con alto riesgo de sufrir cáncer de mama debido a su historia familiar con las de un grupo control de mujeres sanas sin riesgo establecido. Encontraron que el nivel de malestar con respecto al cáncer de estas mujeres era similar al del grupo control. No obstante, se hicieron evidentes algunas diferencias en las percepciones de la enfermedad entre ambos grupos. Así, las mujeres con un mayor riesgo de sufrir cáncer de mama presentaban una comprensión más coherente del trastorno y tenían una concepción de la enfermedad más cercana al conocimiento médico.

Van Oostrom y colaboradores (2007a) llevaron a cabo una investigación de carácter prospectivo para explorar la contribución de las representaciones de enfermedad, las percepciones de riesgo y el afrontamiento del estrés relacionado con el cáncer al bienestar emocional en individuos no afectados por la enfermedad que fueron sometidos a la prueba genética predictiva para la identificación de la mutación para cáncer de mama o cáncer colorrectal. La evaluación de las variables predictoras se realizó antes de la revelación de los resultados de la prueba. La angustia ante el cáncer hereditario y la preocupación por el cáncer fueron evaluadas antes, dos semanas después y seis meses después de la revelación de los resultados. Los resultados obtenidos confirmaron que las representaciones del cáncer como una enfermedad de larga duración, con consecuencias más serias y una menor coherencia en la comprensión de la enfermedad se relacionaban con todos los comportamientos de afrontamiento, especialmente con el afrontamiento pasivo, que a su vez estaba relacionado con la angustia ante el cáncer hereditario y la preocupación ante el cáncer. Además, una alta percepción de riesgo de desarrollar cáncer también se relacionó con el afrontamiento pasivo y percepciones más pesimistas de la enfermedad, como una duración más crónica, consecuencias más serias y una menor coherencia. Asimismo, se observó que atribuciones causales a aspectos incontrolables de carácter genético se relacionaban con representaciones de la enfermedad menos favorables, con un mayor número de comportamientos de afrontamiento y mayor angustia ante el cáncer. Distintas estrategias de afrontamiento y representaciones cognitivas predecían la preocupación ante el cáncer seis meses después de la revelación del resultado. Uno de los predictores más importantes fue el afrontamiento pasivo. De las dimensiones de los modelos personales de enfermedad, la coherencia fue la que mostró un mayor valor predictivo de la angustia ante el cáncer especialmente a largo plazo.

En otro estudio (Van Oostrom et al., 2007b), exploraron la contribución de las representaciones de enfermedad, el afrontamiento, la experiencia con el cáncer en la familia y el funcionamiento familiar a la angustia ante el cáncer hereditario seis meses después de la revelación de los resultados de la prueba genética predictiva del cáncer de mama y colorrectal en la misma muestra de personas sometidas a dicha prueba. Los resultados mostraron que las experiencias a nivel familiar con el cáncer estaban relacionadas de manera significativa con la angustia ante el cáncer de carácter hereditario, especialmente el número de familiares de primer grado afectados así como tener un padre/madre afectados de cáncer cuando el participante estaba en una edad temprana (menos de trece años). También el modo en que los participantes percibían el cáncer hereditario así como el modo en que lo afrontaban fue relacionado con la angustia ante el cáncer. En este sentido, poseer representaciones emocionales más intensas, una percepción menos coherente del mismo, un menor control percibido sobre la enfermedad y la percepción de consecuencias más negativas se relacionaba con un mayor nivel de angustia. En cuanto a los estilos de afrontamiento, especialmente el afrontamiento pasivo y la autodistracción eran predictores de la angustia ante el cáncer hereditario.

Finalmente, en un tercer estudio (Van Oostrom et al., 2007c) compararon a individuos pertenecientes a familias con una mutación identificada para el cáncer de mama o colorrectal para llevar a cabo recomendaciones para el posterior ajuste de la intervención a las necesidades específicas de los pacientes. El estudio se focalizó en las posibles diferencias con relación a: 1) Las experiencias con el cáncer hereditario en el seno de la familia, 2) las representaciones de la enfermedad, 3) el afrontamiento, 4) las características del sistema familiar y 5) el nivel y el curso del malestar ante el cáncer de carácter hereditario, la preocupación ante el cáncer y la percepción de riesgo, aspectos que fueron evaluados antes, una semana después y seis meses después de la revelación de los resultados de la prueba genética predictiva para el cáncer de ambos cánceres. Los resultados pusieron de manifiesto que, en general, los participantes con mutaciones familiares no diferían en relación al número de experiencias con cáncer en familiares, síntomas de dolor, el curso del malestar ante el cáncer, la preocupación o la percepción de riesgo a través del tiempo. Tampoco se observaron diferencias en las percepciones de enfermedad, respuestas de afrontamiento o características familiares. Estos hallazgos parecen indicar que serían las características individuales las que predecirían el ajuste al examen genético más que el tipo de cáncer. Se observaron diferencias entre ambos grupos en el hecho de que los individuos pertenecientes a familias con mutación para cáncer colorrectal manifestaban una visión más positiva de las consecuencias del cáncer hereditario. Los individuos con familias con mutación para el cáncer de mama mostraban una mayor impotencia ante el riesgo, manifiestan mayor malestar antes de la revelación de los resultados de la prueba y una mayor preocupación. Además los no portadores de dicha mutación mostraron una mayor preocupación ante la posibilidad de sufrir cáncer de mama que los no portadores de la mutación para cáncer colorrectal. Se comprobó que aquéllos además utilizaban más frecuentemente un estilo de afrontamiento pasivo y una comunicación menos abierta con su pareja y sus hijos.

Hevey y colaboradores (2009) llevaron a cabo un estudio con hombres por encima de los cuarenta años con el objetivo de examinar los modelos de enfermedad en cáncer de próstata, el nivel de conocimiento con respecto a la enfermedad y su detección precoz y las intenciones para asistir a la prueba con la que se detecta la presencia del cáncer cuando es ofertada por el doctor o cuando es autoiniciada. Los resultados pusieron de manifiesto que los participantes poseían un conocimiento bastante ajustado acerca del cáncer de próstata así como creencias positivas acerca del chequeo. Éstos percibían la enfermedad cómo crónica, con consecuencias serias y asociada a respuestas emocionales negativas. Entre las causas más comunes del cáncer de próstata los participantes destacaron la edad, factores hereditarios y aspectos relacionados con su estilo de vida (fumar, la dieta, el alcohol, el estrés). Por otra parte, los resultados señalaron que las creencias de enfermedad no se relacionaban con las intenciones para el chequeo, intenciones que eran mayores si este era recomendado por el médico que si era autoiniciado.

Lancastle, Brain y Phelps (2011) realizaron un estudio para valorar en mujeres con riesgo de desarrollar cáncer de ovario debido a sus antecedentes familiares las asociaciones entre los elementos del SRM y los niveles de depresión y ansiedad antes del proceso de evaluación (screening) y determinar otros posibles predictores de ese malestar psicológico. La evaluación se realizó antes de la fase dos de su proceso de evaluación (i.e., antes de la prueba de screening), en la que se les informaba sobre el cáncer de ovario, sus riesgos y las posibilidades de prevención. Los resultados mostraron correlaciones entre las representaciones de enfermedad y el malestar psicológico, de modo que representaciones emocionales más fuertes se asociaban a mayores niveles de malestar, tanto ansiedad, depresión como malestar específico relacionado con el cáncer de ovarios. Además, creencias sobre consecuencias más negativas se relacionaban con mayores niveles de malestar.

El número de estudios sobre representaciones del cáncer en población que no padece ni ha padecido la enfermedad se va a ver reducido de manera importante cuando hablamos de investigaciones realizadas en nuestro país. De hecho, sólo un estudio, a nuestro conocimiento, se ha dirigido a conocer las creencias personales no especializadas sobre cáncer en personas españolas. Godoy-Izquierdo, López-Chicheri et al. (2007) llevaron a cabo una investigación para conocer los modelos personales sobre el cáncer en una muestra de estudiantes universitarios utilizando como instrumento de evaluación la versión española del Cuestionario de Modelos Implícitos de Enfermedad de Turk, Rudy y Salovey (1986). Los resultados obtenidos mostraron que la enfermedad era percibida por la mayoría de los participantes como sintomática y dolorosa, con un importante impacto en la vida del enfermo, duradera con cambios a través del tiempo (i.e., cíclica) y con posibilidad de curación. En dicha investigación, además de evaluarse las representaciones mentales acerca de la enfermedad, se estudió la influencia de la experiencia con la enfermedad, hallándose diferencias en los modelos personales de la enfermedad entre aquellas personas que habían padecido la misma o habían convivido con un enfermo de cáncer y las que no habían padecido la enfermedad y/o no habían convivido con un enfermo de cáncer, lo que es indicativo de la influencia de la experiencia personal en los modelos de enfermedad. En general, las personas con experiencia personal o familiar con la enfermedad demostraban tener esquemas más favorables, benevolentes o positivos de la enfermedad. No obstante, esto no se estudió para el cáncer específicamente, sino para un conjunto de enfermedades consideradas de forma combinada, de forma que es una cuestión aún desconocida.

CAPÍTULO 5

El modelo de autorregulación y las enfermedades cardiovasculares: la hipertensión

5.1. Aplicaciones del Modelo de Autorregulación a las enfermedades cardiovasculares: Evidencias empíricas

Si dirigimos nuestra atención a la investigación realizada en el ámbito de los modelos personales de hipertensión que utiliza como base teórica el Modelo de Autorregulación, hemos de señalar que el número de estudios es escaso a pesar de la relevancia de este problema para la salud pública, de su peligrosidad para la calidad de vida y la longevidad y del apoyo científico que ha recibido el SRM en general para las enfermedades físicas crónicas como la hipertensión. No obstante, comparativamente es más abundante la investigación realizada con respecto a enfermedades cardiovasculares (ver Tabla 6).

Dentro de ese núcleo de investigación, la mayoría de los estudios ha ido dirigida a conocer las representaciones que pacientes con alteraciones cardiovasculares, fundamentalmente infarto de miocardio, poseen acerca de su problema con el objetivo de evaluar si existe alguna relación entre dichas representaciones y las conductas de afrontamiento, incluyendo un aspecto clave como es la adherencia a los tratamientos, desde los programas de rehabilitación cardíaca a las modificaciones en el estilo de vida (Cooper et al., 1999; Cooper et al., 2007; Figueiras y Weinman, 2003; Lau-Walker, 2007; Petrie et al., 1996; Weinman et al., 2000). Del mismo modo, la investigación se ha dirigido a comprobar si dichos modelos de enfermedad ejercen alguna influencia en la recuperación de la enfermedad o las consecuencias de las mismas, incluyendo la salud, el bienestar, la calidad de vida o el funcionamiento de los pacientes en diversas áreas de su vida después de sufrir la alteración cardiovascular (Affleck et al., 1987; Cherrington, Moser y Lennie, 2004; Figueiras y Weinman, 2003; Petrie y Cameron, 2002; Petrie et al., 1996; Weinman et al., 2000).

Otros estudios han tratando de determinar si los modelos de enfermedad que los pacientes con una enfermedad cardiovascular han construido acerca de la misma guardan alguna relación con variables de carácter médico y de severidad de la enfermedad (Affleck et al., 1987; Cherrington et al., 2004; Hirani y Newman, 2006).

Por otro lado, la investigación sobre los modelos personales de enfermedad también posee un importante carácter aplicado, de modo que se han desarrollado intervenciones destinadas a incidir en las creencias que los pacientes construyen sobre su problema cardiovascular con el objetivo final de mejorar su proceso de adaptación y recuperación de la enfermedad y optimizar su funcionamiento y calidad de vida. Por ejemplo, Petrie y Cameron (2002) llevaron a cabo un estudio para determinar si una intervención breve desarrollada en el hospital antes del alta y dirigida a modificar las percepciones de los pacientes después de su primer infarto de miocardio podría conducir a la reducción de la incapacidad después del alta hospitalaria, a una vuelta más rápida al trabajo y a una mejora de la asistencia a la rehabilitación cardíaca. Los pacientes fueron evaluados antes de la intervención y a los tres meses, momento en que también completaron una escala de malestar asociado a los síntomas y fueron preguntados acerca de la frecuencia con la que habían experimentado dolor en el pecho en la semana anterior y la intensidad de ese dolor. Los resultados mostraron que, después de la intervención, los pacientes tenían creencias más leves sobre las consecuencias de la enfermedad y su curso y creencias más fuertes sobre la posibilidad de controlar la enfermedad. Mostraron además menores niveles de malestar asociados a los síntomas. Dichos cambios en sus creencias se mantuvieron a los tres meses. En cuanto a la información recibida sobre el infarto de miocardio, el grupo que recibió la intervención presentó mayores niveles de comprensión sobre su enfermedad y se sintieron mejor preparados para dejar el hospital. Los participantes que recibieron la intervención también vieron más probable su asistencia a la rehabilitación y experimentaron un menor dolor de pecho que los del grupo control.

En cuanto a la investigación realizada con no pacientes, algunos estudios han incluido no sólo a pacientes sino también a sus parejas o familiares, teniendo en cuenta el importante papel que el apoyo social juega en todo el proceso de afrontamiento y recuperación de la enfermedad (Figueiras y Weinman, 2003; McClenahan y Weinman, 1998; Weinman et al., 2000). En estos estudios se ha tratado de conocer sus representaciones sobre la enfermedad, sus estrategias de afrontamiento frente a la misma y las consecuencias de ello tanto para su propio bienestar y calidad de vida como para los del paciente.

Finalmente, aunque en muchos de los estudios anteriormente mencionados se ha explorado si existe algún tipo de influencia de las variables sociodemográficas en los modelos de enfermedad de pacientes con problemas cardiovasculares o sus cuidadores, algunos estudios se han desarrollado con el único objetivo de abordar este aspecto. Así, Dunkel et al. (2011) estudiaron las atribuciones causales de pacientes que iban a ser intervenidos quirúrgicamente para un *bypass* coronario para comprobar si existían diferencias de género en esas atribuciones causales y la existencia de sintomatología depresiva en los pacientes un año después de ésta. Además, se recabó información sobre determinados datos sociodemográficos (edad, sexo, nivel educativo y situación sentimental), así como datos clínicos y de apoyo social. Los resultados pusieron de manifiesto que los hombres atribuían sus problemas cardíacos con mayor frecuencia a su comportamiento relacionado con la salud, mientras que para las mujeres era más probable que la causa de estos problemas fuera el destino/suerte. Por otro lado, los niveles de depresión se mostraban independientes del género y de las variables sociodemográficas y clínicas. La atribución del problema a factores de personalidad, estrés, sobrecarga mental y al destino se mostró asociada a un incremento de la sintomatología depresiva tanto en hombres como en mujeres un año después de la operación. Además, se observó que las asociaciones entre las variables sociodemográficas y clínicas diferían según la edad. Así, se observó que tanto los hombres como las mujeres de mayor edad realizaban mayores atribuciones de su problema a su comportamiento.

5.2. Aplicaciones del SRM a la hipertensión: Evidencias empíricas

5.2.1. Investigaciones realizadas con pacientes

De forma pionera, Meyer, Leventhal y Guttman (1985) realizaron un estudio para conocer las representaciones mentales sobre la hipertensión y determinadas conductas asociadas a la enfermedad. Para ello, se entrevistó a cuatro grupos de participantes: 1) Grupo control de participantes normotensos; 2) Pacientes hipertensos incluidos en tratamiento recientemente; 3) Pacientes hipertensos en tratamiento de forma continuada; y 4) Pacientes hipertensos que habían retomado el tratamiento tras haberlo abandonado. Las hipótesis de partida de este estudio eran: 1) Los pacientes construyen representaciones sobre una elevada presión sanguínea utilizando síntomas concretos y nociones conceptuales, y 2) esas representaciones ejercen una importante influencia en los comportamientos de afrontamiento, en concreto la toma de la medicación y la permanencia o abandono del tratamiento. Para evaluar las representaciones que todos ellos poseían acerca de la hipertensión se utilizó una entrevista con preguntas de final abierto que evaluaban las percepciones acerca de los síntomas, causas, mecanismos fisiológicos y consecuencias de la hipertensión así como el afrontamiento de la enfermedad y la adherencia al tratamiento médico. Se valoró también el control de la presión sanguínea en el grupo de participantes en tratamiento activo.

Los resultados mostraron que la gente, independientemente de su condición, construye creencias sobre la hipertensión. Los participantes, incluidos los del grupo control, consideraban que la hipertensión se asocia con una serie de síntomas que podrían servir para monitorizar elevaciones en la presión sanguínea; además, los pacientes indicaron que la enfermedad podría tener una duración limitada y que era causada por una variedad de condiciones como el trabajo, la familia, el estrés y la dieta. Los resultados mostraron también una evolución en esas representaciones a lo largo del tiempo, de modo que los participantes que llevaban en tratamiento un largo periodo de tiempo consideraban que podían monitorizar sus síntomas mejor. Aquellos pacientes que habían sido incluidos recientemente en el tratamiento decían ser también capaces de monitorizar los síntomas seis meses después de la entrevista inicial. Del mismo modo, se observó que con el paso del tiempo la percepción de la enfermedad como aguda iba evolucionando a crónica. Los resultados también señalaban que las representaciones mentales que los participantes poseían acerca de la hipertensión no eran coherentes ni bien organizadas. Sólo un porcentaje pequeño de los participantes establecía conexiones claras entre los síntomas, causas y mecanismos fisiológicos del problema.

Los resultados también pusieron de manifiesto que las personas que establecían conexiones claras entre esas dimensiones no mostraban una mayor adherencia a la medicación. En cuanto a la posible relación entre las creencias sobre la hipertensión y el comportamiento, se observó que la creencia de que las variaciones en la presión sanguínea se relacionaban con unos síntomas determinados estaba asociada con una mayor adherencia a los regímenes médicos (i.e., ausencia de faltas repetidas y adecuado control de la presión sanguínea). Esa relación entre percepción de síntomas y adherencia al tratamiento se observó para los pacientes que estaban en el grupo de tratamiento continuado. La percepción de que el tratamiento tenía efectos beneficiosos en los síntomas fue crítica en la predicción de la adherencia. La percepción de la existencia de síntomas estaba relacionada además con el abandono del tratamiento en los pacientes tratados recientemente, de modo que aquéllos que señalaban un mayor número de síntomas era más fácil que abandonaran el tratamiento en los primeros meses. Por otro lado, la percepción de la duración de la enfermedad era también un buen predictor del mantenimiento o el abandono del tratamiento. Así, aquéllos que percibían la enfermedad como crónica del grupo de los tratados recientemente era más fácil que permanecieran en tratamiento.

Ross, Walker y Mac-Leod (2004) investigaron las creencias sobre la hipertensión así como sobre la medicación que poseían pacientes hipertensos y si esas creencias influían en la adherencia a la medicación antihipertensiva. La hipertensión era percibida como una enfermedad de larga duración y que podía ser controlada, asociada al mismo tiempo a escasas consecuencias y bajas respuestas emocionales. Los pacientes pensaban también que las causas de la hipertensión eran psicológicas o relacionadas con factores de riesgo conductuales como el tabaco o la obesidad. En general, los participantes pensaban que el tratamiento farmacológico era necesario. Por otro lado, se encontró que una adherencia positiva se asociaba con creencias más fuertes de control por tratamiento a la vez que con creencias más débiles de control personal y consecuencias de la hipertensión y con menores respuestas emocionales. La adherencia también se asociaba positivamente con la percepción de que la medicación es necesaria. Los resultados también pusieron de manifiesto la influencia de la edad y el género en los niveles de adherencia: Los participantes de mayor edad y las mujeres mostraban mejor adherencia al tratamiento.

Heckler y colaboradores (2008) examinaron las creencias, comportamientos y control de la hipertensión en pacientes afro-americanos. Las hipótesis de partida eran que las dimensiones propuestas por el SRM de causas y control se podían incluir en dos modelos diferentes, un modelo de creencia de estrés (i.e., la hipertensión es causada y controlada por factores relacionados con el estrés) y un modelo de creencia médica (i.e., la hipertensión es causada y controlada por factores relacionados con aspectos médicos). De acuerdo con ello, alinearse con un modelo médico conllevaría implicarse en una mayor adherencia así como en cambios en el estilo de vida para controlar la hipertensión, mientras que aquellos pacientes que se adscriben a un modelo de estrés se implicarían en conductas de reducción del estrés y no mantendrían una adecuada adherencia a los cambios en su estilo de vida. El resto de dimensiones propuestas por el SRM se relacionarían también con la adherencia a la medicación, los cambios en el estilo de vida y las conductas de reducción del estrés. La adherencia a la medicación y los cambios en el estilo de vida se esperaba además que estuvieran relacionados con los niveles de presión diastólica y sistólica.

Finalmente, se esperaba que las creencias de enfermedad sobre la hipertensión estuvieran asociadas con la presión sanguínea, de modo que esa relación estuviese mediada por la adherencia a la medicación y los cambios en el estilo de vida pero no por las conductas de reducción del estrés. Los participantes fueron evaluados a través de una entrevista en la que se examinaron sus creencias de enfermedad de acuerdo con el Modelo de Autorregulación y los comportamientos de manejo de la enfermedad categorizados en tres niveles: Adherencia a la medicación, cambios en el estilo de vida y comportamientos de reducción del estrés. También fueron recabados datos demográficos como género, edad, estado civil y nivel educativo así como datos médicos como los años desde el diagnóstico, el número de fármacos antihipertensivos prescritos y los niveles de presión sistólica y diastólica.

Los resultados pusieron de manifiesto que los pacientes que seguían un modelo médico de creencias sobre la hipertensión (por ejemplo, causada y controlada por factores como la dieta, la edad y el peso) mostraban una menor presión sistólica, relación que estaba mediada por los cambios realizados en el estilo de vida (e.g., eliminar el consumo de sal, hacer ejercicio), mientras que aquellos pacientes que tenían creencias sobre hipertensión basadas en el modelo de estrés llevaban a cabo comportamientos de reducción del estrés que, sin embargo, no se relacionaban con los niveles de PA. También se halló que la percepción de mayores consecuencias de la enfermedad se relacionaba con mayores comportamientos de reducción del estrés. Por otro lado, se observó que cambios adecuados en el estilo de vida se relacionaban con una menor presión sistólica pero no con la adherencia a la medicación. Ninguna de las variables se mostró relacionada con los niveles de presión diastólica.

Chen, Tsai y Lee (2009) evaluaron los efectos predictivos que las percepciones de enfermedad tenían sobre la adherencia a los regímenes terapéuticos (medicación y cambios en el estilo de vida, incluyendo dieta insana, dieta sana, ejercicio físico y asistencia a las citas médicas) de pacientes hipertensos. También fueron evaluados aspectos demográficos tales como género, estado civil, nivel educativo, situación laboral y situación familiar, y clínicos como niveles de presión sistólica y diástolica, número de medicamentos prescritos, historia familiar de hipertensión, presencia de otras enfermedades y consumo de tabaco. Los resultados pusieron de manifiesto que creencias más fuertes de control por tratamiento predecían una mayor adherencia a la medicación, mientras que creencias más fuertes sobre control personal se relacionaban con una mayor adherencia a hábitos saludables. En cuanto a las atribuciones causales, se encontró que atribuir la hipertensión a factores de riesgo generales o aspectos psicológicos se asociaba a una mayor adherencia a la medicación prescrita, mientras que las atribuciones a factores de tipo cultural predecían la adherencia al autocuidado. También se encontró que aquellos participantes que manifestaban experimentar síntomas mostraban mayor adherencia a las actividades de autocuidado, mientras que aquellos que no estaban seguros de experimentar síntomas era más probable que autorregularan la toma de su medicación. Finalmente, los resultados mostraron también la influencia de factores sociodemográficos y clínicos, de modo que aquellos participantes de mayor edad, con un mayor nivel educativo y que llevaban más tiempo sufriendo hipertensión era más probable que mostraran mayor adherencia a actividades de autocuidado, mientras que los que vivían con su familia y aquéllos con historia de hiperlipidemia exhibían una mejor adherencia al tratamiento farmacológico.

Figueiras y colaboradores (2010) llevaron a cabo un estudio para conocer cuáles eran las creencias sobre la hipertensión de pacientes hipertensos y su relación con las creencias sobre la medicación, así como para identificar diferentes esquemas de la enfermedad y su posible relación con la elección de la medicación (genéricos o de marca). También se incluyeron datos sociodemográficos como edad, género y nivel educativo. Los resultados mostraron que la hipertensión era percibida como una enfermedad de larga duración, lo que se relacionaba con la creencia relativamente fuerte de los participantes de la necesidad de tratamiento. Las creencias sobre la necesidad de la medicación se relacionaban positivamente con las creencias sobre el control personal y por tratamiento, pero éstas no se relacionaban con las preocupaciones sobre la medicación. Se encontraron también tres *clusters* de esquemas de enfermedad que eran diferentes de acuerdo con la elección de la medicación y al mismo tiempo independientes de variables demográficas. De este modo, pacientes con una visión más negativa de la enfermedad (grupo 1) poseían graves percepciones sobre sus consecuencias, creencias de curso crónico, una creencia fuerte en el control personal y por tratamiento, una identidad fuerte, una preocupación por la enfermedad muy alta y unas representaciones emocionales muy negativas, aunque pensaban que poseían una buena comprensión de su condición. Los pacientes del segundo grupo mostraban diferencias significativas con los del primer grupo, y sus creencias sobre consecuencias, identidad, nivel de preocupación y representaciones emocionales eran menos negativas. Para el tercer grupo había diferencias significativas con los pacientes de los otros dos grupos en todas las dimensiones excepto identidad. Estos participantes mostraban creencias más positivas sobre las consecuencias de la hipertensión, un curso más agudo, creencias más bajas sobre el control personal y por tratamiento, una menor preocupación y comprensión de la enfermedad y unas representaciones emocionales más positivas. Se observó que los pacientes con un modelo más grave sobre la hipertensión era más probable que eligieran medicamentos de marca, y aquéllos con una percepción más positiva en términos de consecuencias, control personal y por tratamiento y representaciones emocionales más positivas era más probable que eligieran fármacos genéricos.

Lopes y colaboradores (2010) llevaron a cabo un estudio para explorar el impacto de las creencias sobre la medicación y las percepciones sobre la hipertensión en el control de la PA y la adherencia a la medicación. Los resultados pusieron de manifiesto la influencia de aspectos sociodemográficos en las creencias de los participantes. Así, aquéllos que tenían 64 años o menos mostraban percepciones más débiles sobre la cronicidad de la hipertensión, mayores creencias sobre el control personal y una menor percepción de la necesidad de tomar la medicación antihipertensiva. Los pacientes que tenían prescrito más de un tratamiento farmacológico presentaban mayor preocupación sobre los medicamentos y percepciones más serias sobre las consecuencias de la enfermedad. Por otro lado, los participantes que además de hipertensión sufrían diabetes mostraban mayores preocupaciones relacionadas con la enfermedad y mayores creencias relacionadas con los efectos secundarios de la medicación. También se encontraron diferencias relacionadas con el género: Las mujeres mostraron creencias menos fuertes sobre el uso excesivo de la medicación que los hombres. Sin embargo, no se encontró que los niveles de PA se relacionasen con las creencias sobre la hipertensión, los tratamientos o cualquier otra de las variables estudiadas.

Chen, Tsai y Chou (2011) quisieron conocer las relaciones entre las representaciones cognitivas y emocionales sobre la hipertensión y la adherencia a la medicación prescrita y a las recomendaciones de autocuidado en pacientes hipertensos. Encontraron que las representaciones sobre identidad se relacionaban de manera tanto directa como indirecta con la adherencia. Así, percibir un mayor número de síntomas llevaba a una menor adherencia a los tratamientos farmacológicos pero además afectaba de forma indirecta a la adherencia a través de su influencia en las dimensiones de causas y control personal y por tratamiento, de modo que los pacientes hipertensos que percibían la enfermedad como más sintomática mostraban puntuaciones más elevadas en la dimensión de causas, especialmente en las de tipo psicológico, y exhibían una menor adherencia a la medicación prescrita. Por otro lado, los pacientes hipertensos que percibían un mayor número de síntomas de la enfermedad expresaban menor confianza en las posibilidades de control personal y por tratamiento, lo que se traducía en menor adherencia tanto a la medicación prescrita como a las actividades de autocuidado. Además se observó que percepciones más negativas de controlabilidad también influían de manera directa en una menor adherencia a los tratamientos farmacológicos y comportamentales prescritos.

Hsiao, Chang y Chen (2012) llevaron a cabo un estudio para explorar los modelos de hipertensión y comprobar si los participantes podrían agruparse de acuerdo con su modelo de enfermedad en diferentes perfiles generales y si esos perfiles predecían la adherencia farmacológica. Los resultados mostraron que la hipertensión era percibida como una enfermedad crónica, con consecuencias negativas, estable, ligada a altas posibilidades de control por parte del paciente y los tratamientos y escaso impacto emocional. También encontraron que los participantes se podían agrupar en tres perfiles diferentes. Los del primero poseían percepciones sobre la hipertensión más positivas pero una menor percepción de controlabilidad. En el segundo perfil, los participantes mostraban unas representaciones más negativas pero mayor control personal. Finalmente, los que formaban parte del tercer perfil mostraban unas representaciones moderadamente negativas y un control y coherencia percibidas elevados. En cuanto a la relación entre representaciones de enfermedad y adherencia, los participantes del cluster con percepciones en general más positivas pero menor percepción de control manifestaban una mayor adherencia al tratamiento farmacológico.

Norfazilah y colaboradores (2013) encontraron que pacientes hipertensos percibían la hipertensión como escasamente sintomática y bastante estable y duradera. Consideraron además que la enfermedad tenía un moderado impacto en sus vidas, aunque se relacionaba con importantes riesgos para la salud. Su compresión de la enfermedad era de moderada a buena y exhibían moderadas reacciones emocionales de malestar. En cuanto a las atribuciones causales, los factores considerados como más relevantes fueron aspectos psicosociales y relacionados con el estilo de vida.

Bazán y colaboradores (2013) llevaron a cabo un estudio con el objetivo de validar el Cuestionario de Percepción de Enfermedad Breve con pacientes hipertensos mejicanos. Los resultados pusieron de manifiesto que la hipertensión era percibida como escasamente sintomática, con impacto en la vida diaria y crónica. También indicaron una baja percepción de controlabilidad, especialmente por parte del propio paciente. Los pacientes hipertensos participantes mostraron una muy baja percepción de comprensión de la enfermedad y exhibieron reacciones emocionales moderadas. Con respecto a los factores causales de la enfermedad, indicaron fundamentalmente aspectos relacionados con el estilo de vida, aunque la herencia también fue considerada como un agente causal importante.

Rajpura y Nayak (2014) realizaron un estudio con el objetivo de evaluar la influencia de las percepciones de enfermedad sobre la hipertensión y de la carga percibida de la enfermedad en la adherencia a la medicación en una muestra de pacientes hipertensos de edad avanzada. Los resultados pusieron de manifiesto que puntuaciones más elevadas en el B-IPQ unidas a una mayor carga de enfermedad percibida se relacionaban con una mejor adherencia. Por otro lado, mayores percepciones de amenazas para la salud de la hipertensión así como creencias más fuertes sobre la necesidad de la medicación contribuían sustancialmente a una adherencia positiva, mientras que un mayor número de preocupaciones específicas sobre la medicación se asociaban también con una mejor adherencia a la medicación. Las causas de la hipertensión más señaladas por los participantes fueron el estrés, el estilo de vida y la herencia.

Pickett y colaboradores (2014) examinaron la relación entre las creencias de hipertensión y los comportamientos de autocuidado (hábitos saludables incluyendo dieta, actividad física, manejo del estrés, control del peso, consumo de tabaco y alcohol, adherencia a la medicación y cumplimiento de las citas médicas) necesarios para el adecuado control de la PA en una muestra de pacientes hipertensos afroamericanos. También se incluyeron datos sociodemográficos tales como género, edad, años de educación y tiempo diagnosticados de hipertensión. Los participantes consideraban como causa más importante de su problema los factores externos que provocaban estrés, y dicha atribución se relacionaba negativamente con la asistencia a las citas médicas. La creencia de que la hipertensión es una enfermedad crónica se relacionaba positivamente con conductas de autocuidado que incluían la asistencia a las citas médicas y la adherencia a la medicación. La mayoría de los participantes se adscribían a un modelo de hipertensión basado en el estrés (i.e., la enfermedad es causada por factores estresantes como el estado emocional, la actitud mental o problemas familiares o por factores externos como la polución, gérmenes o virus). Los participantes pensaban que poseían una comprensión relativamente buena de lo que significa la hipertensión y mostraban unas elevadas percepciones de control personal y por tratamiento, así como creencias moderadas en cuanto a la cronicidad, ciclicidad y consecuencias de la hipertensión en sus vidas.

Se encontró asimismo que los factores sociodemográficos se asociaban con las creencias sobre la hipertensión así como con las conductas de autocuidado. Los participantes con un diagnóstico de hipertensión de más de cinco años era más probable que pensaran que la hipertensión era crónica, mientras que aquéllos que tenían un nivel de ingresos más bajo era más probable que incrementaran su consumo de alcohol y tabaco. Por otro lado, las mujeres atribuían la hipertensión más al estrés, mientras que los hombres pensaban más frecuentemente que estaba causada por la suerte o por factores de riesgo como el consumo de alcohol y tabaco. Los participantes con un menor nivel educativo pensaban en mayor medida que la hipertensión era causada por gérmenes y por el tabaco.

En relación a las representaciones cognitivas y emocionales que sobre la hipertensión posee la población hipertensa española, a nuestro conocimiento sólo un estudio ha abordado esta cuestión utilizando el SRM como base teórica. Así, Beléndez, Bermejo y García-Ayala (2005) desarrollaron una investigación que tenía como objetivo analizar la estructura factorial y la fiabilidad de la versión española del IPQ-R. Sus resultados con respecto a las representaciones que sobre la hipertensión poseía la muestra pusieron de manifiesto que esta enfermedad era percibida por los pacientes como crónica, controlable tanto por parte del propio paciente como a través de los tratamientos existentes, con un curso estable y un bajo impacto emocional. Los participantes también mostraron una percepción bastante coherente de su comprensión de la enfermedad. Como causas más importantes de la hipertensión fueron señaladas las preocupaciones familiares, el estrés, la herencia, la personalidad y los hábitos de alimentación. Los resultados mostraron también diferencias relacionadas con variables sociodemográficas, en concreto con el sexo y la edad. En relación a la primera, se encontraron diferencias para la dimensión de causas. Así, los hombres consideraban que era más probable que la hipertensión fuera provocada por la alimentación y el consumo de tabaco, mientras que las mujeres realizaban más atribuciones causales a aspectos psicológicos. En cuanto a la influencia de la edad, se hallaron diferencias para las dimensiones de identidad y causas. Los participantes más jóvenes percibían la enfermedad como más sintomática y aquellos de mayor edad otorgaban un menor peso a factores psicológicos y relacionados con el estrés en la génesis de la hipertensión.

5.2.2. Investigaciones realizadas en población general sana

El número de estudios sobre representaciones de la hipertensión en población que no padece ni ha padecido la enfermedad se va a ver reducido de manera drástica y, a nuestro conocimiento, sólo dos estudios se han dirigido a explorar estos aspectos utilizando el SRM como base teórica. El primero de ellos es del de Meyer de 1985 ya comentado en el apartado anterior debido a que incluía también a pacientes hipertensos, mientras que el segundo es realizado por Godoy-Izquierdo, López-Chicheri et al. (2007) para conocer los modelos personales sobre la hipertensión en una muestra de adultos jóvenes españoles utilizando como instrumento de evaluación la versión española del Cuestionario de Modelos Implícitos de Enfermedad de Turk, Rudy y Salovey (1986). Los resultados obtenidos mostraron que la hipertensión era percibida por la mayoría de los participantes como una enfermedad escasamente sintomática, severa y con impacto para la vida de los pacientes, de larga duración pero no necesariamente permanente y moderadamente cambiante. Con respecto a las posibilidades de control, era percibida como altamente controlable tanto por el paciente como por los tratamientos existentes y prevenible. En relación a los factores causales, los participantes consideraron como causas fundamentales el estrés, el propio comportamiento o la falta de descanso.

PARTE II:

OBJETIVOS E HIPÓTESIS

CAPÍTULO 6

Objetivo general, objetivos específicos e hipótesis específicas

El objetivo general de esta Tesis Doctoral es comprobar los postulados básicos del SRM en la población general sana, la cual ha sido objeto de menor atención por parte de la investigación en este ámbito que la población enferma, los supervivientes a la enfermedad o poblaciones en riesgo.

El primero de los postulados del SRM a explorar se refiere al modo en que la población general (española) construye sus representaciones de enfermedad y el grado de ajuste de éstas al conocimiento médico-objetivo. También será explorada la influencia de variables de carácter sociodemográfico en las representaciones de enfermedad, así como de la experiencia con la enfermedad, en concreto la experiencia familiar (i.e., tener o haber tenido un familiar diagnosticado con dicha enfermedad).

El segundo de los postulados nucleares del SRM a estudiar se refiere a la relación entre las diferentes dimensiones que forman las creencias sobre la enfermedad, tal y como proponen sus autores, particularmente entre las dimensiones cognitivas y emocionales, y el posible valor predictivo de las primeras sobre las segundas, algo aún no completamente explorado en la literatura.

La tercera de las propuestas del SRM que se pretende comprobar con población general sana se refiere a la relación existente entre las percepciones sobre la enfermedad y las variables conductuales de respuesta ante ésta, en este caso las respuestas de carácter preventivo de afrontamiento del riesgo.

Para ello se llevarán a cabo cinco estudios de carácter transversal. Los dos primeros estudios se llevarán a cabo con personas que no padecen ni han padecido cáncer, mientras que los tres últimos estudios se desarrollarán con personas que no padecen ni han padecido hipertensión.

En el **estudio 1**, el objetivo principal será explorar los modelos personales de enfermedad sobre el cáncer y su proximidad al conocimiento médico-objetivo en población española que no padece ni ha padecido esta enfermedad pero que tienen distinto grado de experiencia familiar con la misma por convivir o haber convivido o no con personas que padecen o han padecido cáncer. El segundo objetivo de este estudio es comprobar la posible influencia de esa experiencia con el cáncer y de otras variables de carácter sociodemográfico como la edad, el género o el nivel educativo en las creencias de enfermedad sobre el cáncer en población sana. Esperamos encontrar que las representaciones sobre el cáncer de los participantes reflejen tanto el conocimiento biomédico existente como creencias laicas o populares sobre esta enfermedad. Además, esperamos que las variables sociodemográficas tengan un impacto limitado sobre los contenidos de dichas representaciones, en tanto que la experiencia de haber convivido con alguien diagnosticado de cáncer ejercerá una influencia más importante sobre las creencias sobre esta enfermedad. En concreto, esperamos que los participantes que han tenido la experiencia de convivir con una persona diagnosticada con esta enfermedad tendrán representaciones del cáncer menos positivas, indicando mayor severidad e impacto de la enfermedad, en comparación con las personas que no han tenido esta experiencia familiar.

El **estudio 2** se centrará en demostrar las relaciones propuestas por el SRM entre las diferentes dimensiones de los modelos de enfermedad. De manera especial, se explorará la relación entre las dimensiones cognitivas y emocionales que conforman las representaciones no especializadas que construimos, en este caso sobre el cáncer. En este sentido, se tratará de explorar el valor predictivo que los aspectos cognitivos pueden tener sobre los aspectos emocionales, es decir sobre el malestar emocional asociado a la posibilidad de sufrir cáncer en personas que no padecen la enfermedad ni la han padecido en el pasado. Ésta es una cuestión prácticamente ignorada en la investigación al respecto, pese a su relevancia. Asimismo, tampoco se conoce la posible influencia de las variables sociodemográficas y de la experiencia con la enfermedad en esta relación, aspecto que también pretendemos explorar. Esperamos encontrar asociaciones robustas entre las dimensiones cognitivas y emocionales de las representaciones de la enfermedad, así como que las primeras predicen las reacciones emocionales al cáncer. También esperamos encontrar que las personas con experiencia familiar muestren mayores niveles de malestar emocional relacionado con la enfermedad, debido a sus creencias más negativas del cáncer, mientras que la influencia esperada de las variables sociodemográficas será mucho menor.

El **estudio 3** irá dirigido a explorar las representaciones que sobre la hipertensión poseen personas sanas que no padecen ni han padecido la enfermedad pero que tienen distinta experiencia familiar con la misma, así como el grado en que dichas representaciones se ajustan al conocimiento médico objetivo. Además, se explorará la influencia de variables sociodemográficas como el sexo, la edad y el nivel educativo así como de la experiencia derivada de convivir o haber convivido con una persona hipertensa en las diferentes dimensiones que conforman, de acuerdo con el SRM, las representaciones de enfermedad. Hipotetizamos que los participantes tendrán representaciones que, como esperábamos en el caso del cáncer, mezclarán conocimiento biomédico y creencias laicas y populares. Esperamos encontrar que las variables sociodemográficas tendrán una influencia limitada en los contenidos de las representaciones sobre esta enfermedad, mientras que hipotetizamos que tener experiencia con la enfermedad tendrá un impacto más notable. En concreto, esperamos que los participantes que han tenido la experiencia de convivir con una persona diagnosticada con esta enfermedad tendrán representaciones de la hipertensión menos positivas, indicando mayor severidad e impacto de la enfermedad, en comparación con las personas que no han tenido esta experiencia familiar.

El **estudio 4** está a su vez compuesto de dos estudios distintos pero relacionados. El principal objetivo del primero de ellos será replicar con una muestra más amplia y heterogénea los hallazgos del estudio anterior, tanto en relación con las representaciones de la enfermedad como con la influencia de las variables sociodemográficas y la experiencia con la enfermedad. En cuanto al objetivo del segundo de los estudios, será explorar las relaciones entre las percepciones sobre la hipertensión, en concreto, las dimensiones cognitivas y emocionales que conforman las representaciones acerca de la enfermedad, las percepciones del riesgo asociado a padecer esta enfermedad y la percepción y práctica de conductas de carácter preventivo en la vida cotidiana para evitar la aparición de la hipertensión. Este objetivo persigue, por tanto, explorar otra de las premisas básicas del SRM, es decir, que existe una relación directa entre las representaciones de la enfermedad y los comportamientos relacionadas con el manejo de la misma, cuestión que no ha sido explorada hasta la fecha en el caso de la hipertensión en personas que no padecen la enfermedad. Esperamos confirmar dicha relación. En concreto, esperamos que representaciones de la enfermedad más negativas se asociarán a percepciones más fuertes de la hipertensión como un factor de riesgo en sí misma para otros problemas de salud, y esto a su vez se asociará con percepciones más positivas de alternativas de acción y la adopción de conductas preventivas.

Finalmente, en el **estudio 5** el objetivo será comprobar si individuos de la población general española podrían dividirse en diferentes perfiles psicosociales multidimensionales en relación a sus modelos de enfermedad o esquemas globales acerca de la hipertensión y considerando también otras variables relevantes como la percepción de riesgos asociados a padecer esta enfermedad o la eficacia percibida de posibles conductas preventivas. En segundo lugar, se tratará de comprobar si cada uno de estos perfiles o agrupaciones de percepciones sobre la hipertensión se asocian a diferentes niveles de actuaciones de prevención de la misma. Como el estudio anterior, este estudio pretende explorar la relación estrecha postulada en el SRM entre percepciones de la enfermedad y conducta. De nuevo, estas cuestiones no han sido exploradas hasta la fecha en población no paciente en el caso de la hipertensión. Esperamos encontrar diferentes perfiles de representaciones de la enfermedad, constituidos cada uno por una configuración particular de percepciones relacionadas con la hipertensión, así como que cada agrupación o perfil se asocie de forma diferente con la realización de conductas preventivas en la vida cotidiana. Más concretamente, esperamos que las configuraciones con percepciones más negativas pero con mayor sentido de controlabilidad se asociarán a una mayor práctica de conductas preventivas en comparación con configuraciones más benevolentes sobre la enfermedad.

Estos objetivos concretos que se pretenden cubrir a través de los diferentes estudios que conforman esta Tesis Doctoral, poseen un marcado carácter aplicado, ya que cada uno de estos cinco estudios pretende contribuir de forma significativa a incrementar el conocimiento sobre la percepción de la enfermedad que poseen las personas sanas y su influencia en su comportamiento relacionado con la salud, de modo que sea posible realizar propuestas y orientaciones para el desarrollo de intervenciones futuras que favorezcan una percepción ajustada y realista de ambas enfermedades y contribuyan a la prevención primaria de las mismas, colaborando de este modo a disminuir la incidencia y prevalencia y el impacto en la salud pública del cáncer y la hipertensión y a mejorar la calidad de vida y el bienestar de las poblaciones a las que vayan dirigidas.

PARTE III:

ESTUDIOS EMPÍRICOS

CAPÍTULO 7

ESTUDIO 1

Illness beliefs about cancer among healthy adults who have and have not lived with cancer patients

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Abstract

Background: Illness representations have been proposed as key determinants for facing health risks and managing disease, and consequently for health outcomes.

Purpose: To know and compare non-specialised illness representations of cancer among adults who had not suffered from cancer and who had/had not lived with cancer patients.

Method: The revised Illness Perception Questionnaire was adapted to assess illness perceptions among healthy people. Cancer representations were explored in a community-based sample of adults of both genders from different educational backgrounds and who had differing experience with cancer, none being a patient.

Results: The participants' beliefs about cancer included both biomedical and folk knowledge. Compared to age, sex and educational level, family experience with cancer (having lived or not with a patient) had the strongest impact on the contents of the representations on cancer. Further, people with a family experience with the disease, compared to those not having a relative diagnosed with cancer, reported significantly more symptoms and stronger emotional impact.

Conclusions: This study allowed us to establish the perceptions on cancer of non-patients with no specialised knowledge. Findings may help in designing and implementing tailored preventive interventions taking into account family experience with the disease, as well as interventions aimed at enhancing family and social care and support given to cancer patients.

Keywords: illness representations, IPQ-R, psycho-oncology, non-patients, prevention, social support

Introduction

The way people perceive health and disease and its relationship with an individual's health and disease-related behaviours has received increased attention. Understanding these issues is important in designing and implementing effective interventions in health promotion, disease prevention, treatment and rehabilitation, treatment adherence management, patient education and family counselling. The most empirically supported theoretical model regarding lay cognitions about disease is the *Self-Regulation Model of Common Sense Illness Representations* (SRM) (1,2). It has been applied to differing physical and mental illnesses, both among patients and non-patients (see 3-6 for a review). Figure 1 displays graphically the SRM proposals.

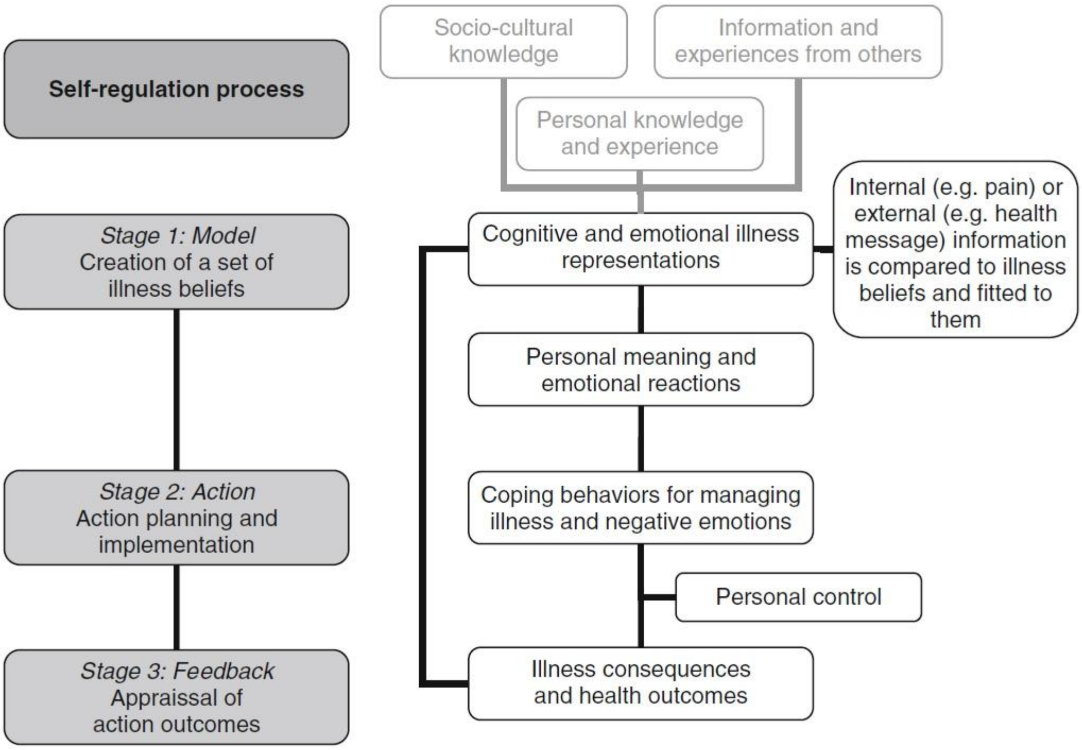

Figure 1: SRM main features and proposals.

Sociodemographic variables such as gender, age or educational level are not usually found to have significant impact on illness beliefs (7-10), although a number of differences have been reported (11-13). However, to have suffered from the disease or to have had an ill relative has been consistently found to be a relevant contributor to illness perceptions (e.g., 3,7-9,14-24). On the other hand, to know the illness beliefs held by healthy people would allow us to understand how a particular illness or health-threatening condition is perceived prior to a possible personal or family experience with the disease. It would also help us understand how these representations are changed by the illness experience, how they relate to specific coping behaviours, adjustment and health outcomes with and without personal or family experience, and how this information can be used to derive interventions aimed at modifying illness beliefs in both patients and non-patients. Furthermore, such knowledge would allow us to inform appropriate preventive and therapeutic interventions. Nonetheless, there are few studies conducted to determine how healthy individuals perceive illnesses, and how their beliefs influence health- and disease-related behaviours (9,10,12,13,18-20,24-27).

Research conducted with cancer patients, survivors and at-risk populations (8,11,15,16,22,28) has pointed out that mixed biomedical and folk information is included in their representations about cancer (29). Research about cancer beliefs among non-specialised, healthy individuals is scarce, and the findings are varied and inconclusive (8,14-16,21,22,28,30,31). When the beliefs about cancer of healthy participants are compared to those of patients or possible future patients, patients and at-risk people have been found to hold a more coherent understanding that is closer to medical knowledge (28), while non-patients hold an overestimated and more unfavourable perception of the disease with more inaccurate beliefs, misconceptions, negative conceptualisations and unrealistic expectations (8). It has been affirmed that healthy people’s perceptions are not an accurate representation of patient experiences (15). However, some authors (28,30) have found that non-patients perceive cancer as a less threatening, distressing and negatively impacting condition as compared to patients.

It has been proposed that direct experience with cancer, i.e., suffering from it, may lead patients to have more positive and realistic perceptions of cancer (8). On the contrary, personal experience shaped by exposure, caring for ill relatives and witnessing the consequences of cancer in the family may help to create inaccurate or more negative cancer perceptions, or to less effectively perceive one’s own risk and cope with it (22,32,33). Only two studies conducted with healthy people took into consideration a family history of cancer for comparison purposes (14,22). Having a family history of cancer has been found to be linked to stronger causal attributions (22). Godoy-Izquierdo et al. (14) explored some SRM’s dimensions in healthy people with and without a relative suffering from cancer and found that family experience of a disease lead to more positive representations on the identity, duration and evolution, consequences and personal and external controllability on the disease.

Thus, the present study was conducted to compare illness representations of cancer among Spanish adults who never had cancer but who had a different family experience with that disease, i.e., the experience of living or not with a cancer patient. With this aim, we used the most widely accepted tool for assessing illness representations, the Revised Illness Perception Questionnaire (34). We expected that the participants' beliefs about cancer would reflect both biomedical and folk knowledge. Further, we expected that the experience of living with someone diagnosed with cancer would influence the representations of this disease.

Methods

Participants

One hundred thirty adults (50% women) 18 to 66 years old (*M*= 39.98; *SD*= 13.82) took part in the study. Table 1 displays their most relevant characteristics. None of the participants had suffered from cancer at the time of the study, and 32.3% (42 participants) had lived or were living with a relative, independently of kinship, who had cancer. This convenient, community-based sample was recruited at random from private households and community settings such as transport stations, work places, parks, health-care services, academic centres and shopping centres.

Table 1: Socio-demographic data of the sample.

		N	%
Age ranges	18-25	27	20.77
	26-35	29	22.31
	36-45	23	17.69
	46-55	28	21.54
	56-66	23	17.69
Educational level (highest completed level)	No formal education	8	6.2
	Primary school	26	20
	Secondary school	41	31.5
	Vocational training and other formal education	12	9.2
	University	43	33.1
Work status	Student	16	12.3
	Employed	76	58.5
	Student & Employed	6	4.6
	Housework	23	17.7
	Unemployed	9	6.9
Marital status	Single	24	18.5
	Short-term relationship (< 3 years)	32	24.6
	Long-term relationship (> 3 years)	62	47.7
	Separated/Divorced	9	6.9
	Widow	3	2.3
Physical or mental disease at the time of the study	Yes	24	18.5
	No	106	81.5

Measures

The participants completed a Spanish-modified version of the Revised Illness Perception Questionnaire (IPQ-R) by Moss-Morris et al. (34). It was adapted to assess illness perceptions among healthy people. The IPQ-R evaluates nine dimensions from Leventhal and colleagues' SRM model and from additional research findings (34) (Table 2). For all the dimensions except identity and causes, partial scores were obtained as the mean of the scores for the items on each subscale (considering direct and inverse items, see Table 2), with higher scores indicating stronger beliefs about disease chronicity, cyclical course, impact and outcomes, personal influence, cure possibilities, perceived understanding and emotional reactions to the disease. Identity was assessed by asking whether a series of symptoms was perceived as characteristic of the disease. The higher the score, the more symptomatic the disease is perceived to be. For the cause subscale, those factors scoring the highest in a series of possible causes are those the person considers to be the most relevant aetiological factors for the illness.

Following previous suggestions (34), we modified the questionnaire to adapt it to non-patients and to make it more complete and better fitted to cancer. Therefore, each reference to "my" illness was substituted by "the" illness or "cancer". For the identity subscale, some new symptoms were added, while others were completed or regrouped. Two new items (#20 and #24 in our tool) were added to assess complementary beliefs about cure for cancer. Item 21 in our version was rewritten to assess beliefs about prevention of the disease. Items measuring the emotional representations dimension also were rewritten to assess emotional distress among healthy people. Items 22 and 25 were completed. Some causes were completed or added to the cause subscale. (See all these changes in Table 2).

The psychometric properties of the IPQ-R have been previously demonstrated among English-speaking and Spanish populations (34,35) and in the context of cancer (31,36,37). Internal reliability for the version used herein is displayed in Table 2.

Procedure

Following approval of the institutional research ethics committee, participants were asked to voluntarily take part and signed an informed consent form. They had been previously informed that the general objective of the study was to learn their beliefs about cancer and not to test their level of knowledge, and specific instructions on how to answer the questionnaire were given. A survey requesting personal and sociodemographic data was also included, which contained questions about whether they had ever suffered from cancer and whether they had ever lived with a relative who was diagnosed with cancer.

A convenience, community-based sample was constructed. Three housing buildings and several community settings per district were selected at random by using a local telephone directory. A person in one out of every three possible households and one out every three persons in the several public settings considered was asked to collaborate and followed the above-mentioned procedure when they accepted. Questionnaires from people suffering or having suffered from cancer were not considered for the analyses.

Statistical analyses

Guided by preliminary analyses conducted to check data and parametric assumptions, we decided to run parametric statistical tests. In addition, following recent recommendations, Cohen's *d* coefficient (38) was calculated for estimations of effect sizes (for equal or different sample sizes).

Results

Non-specialised beliefs about cancer

To establish the contents of illness models for cancer in detail, percentages of responses for each item were obtained. Table 2 shows the most relevant findings along with the descriptive results obtained. The score ranges indicate the variability of the participants' responses.

Influence of gender, age and educational level on cancer representations

No significant differences were found between men and women. We compared five age groups and ANOVAs showed significant differences only for the dimensions of consequences (F=3.386, p<0.05), coherence (F=3.352, p<0.05) and emotional representations (F=2.571, p<0.05). In the Bonferroni's *post hoc* comparisons, significant differences were detected in the consequences dimension between the 18-25 and 56-66 yr old groups (p= 0.010; d= -1.03) and between the 46-55 and 56-66 yr old groups (p= 0.026; d= -0.95), with the older group in both cases showing higher scores. Differences were also found in the coherence dimension between the 18-25 and 56-66 yr old groups (p= 0.034; d= 0.98) and between the 26-35 and 56-66 yr old groups (p= 0.033; d= 0.83), with the older group in both cases showing lower scores. Finally, differences were found in the emotional representations dimension between the 18-25 and 56-66 yr old groups (p= 0.032; d= -0.90), with the older group showing higher scores. Cohen's *d* values for the remaining comparisons were low.

Table 2: Percentages of agreement responses and descriptive results for each subscale.

Dimensions		%
Identity (0-15[a]) (perceived symptoms of cancer) *M*= 9.28; *sd*= 3.70; R= 0-15	Fatigue, tiredness[b]	88.5[c]
	Weight loss	87.7
	Weakness, loss of strength[b]	84.6
	Pain anywhere[b]	83.6
	Breathlessness, respiratory problems[b]	69
	Nausea	67.7
	Fever[b]	66.9
	Stomach-intestine problems[b]	63.1
	Emotional distress, sadness or anxiety[b]	62.3
	Dizziness, vertigo[b]	59.2
	Stiff joints	53.1
	Sleep difficulties	47.7
	Mobility difficulties[b]	46.2
	Tachycardia[b]	38.5
	Delirium and hallucinations[b]	14.6
Timeline (acute/chronic) (1-5) (This illness…) *M*= 3.56; *sd*= 0.62; R= 2-5 *alpha*= 0.62	3. Will last for a long-time	70.7[d]
	2. Is likely to be permanent rather than temporary	43.9
	6. Will improve in time[e] (Item 18 in IPQ-R)	40
	5. Is expected to be for life	23.8
	4. Will pass quickly[e]	7.7
	1. Will last a short time[e]	6.2
Consequences (1-5) (This illness…) *M*= 4.09; *sd*= 0.58; R= 2.33-5 *alpha*= 0.64	7. Is a serious condition	93 [d]
	8. Has major consequences on patient's life	88.5
	12. Causes difficulties for the people close to patients	76.2
	11. Has serious financial consequences	62.3
	10.Strongly affects the way others see patients	35.4
	9. Does not have much effect on patient’s life[e]	6.2
Personal Control (1-5) *M*= 3.23; *sd*= 0.72; R= 1.67-5 *alpha*= 0.80	17. Patients have the power to influence their illness	59.2[d]
	14. What patients do can determine whether their disease gets better or worse	40.8
	13. There is a lot which patients can do to control their symptoms	23.8
	15. The course of the disease depends on the patient	21.5
	16. Nothing the patient does will affect his/her illness[e]	14.6
	18. A patient's actions will have no effect on the outcomes of her/his illness[e]	13.8
Treatment Control (1-5) *M*= 3.67; *sd*= 0.51; R= 1.71-5 *alpha*= 0.48	22. The treatment can control the disease and its negative effects	69.2[d]
	25. Some treatment or intervention exists which is effective in curing this disease (medication, therapy, surgery, rehabilitation...) (Item 20 in IPQ-R)	66.2
	21. The illness can be prevented	53.1
	20. The treatment effectively relieves the symptoms but does not cure the disease (new)	33.9
	19. There is very little that can be done to improve when ill[e]	26.9
	23. There is nothing which can help the patient's condition[e]	8.5
	24. This illness goes away or is cured by its own[e] (new)	5.4
Illness Coherence (1-5) *M*= 3.16; *sd*= 0.91; R= 1.40-5 *alpha*= 0.84	30. I have a clear picture or understanding of the disease	46.9[d]
	26. The symptoms of this disease are puzzling to me[e]	40.8
	27. The disease is a mystery to me[e]	36.9
	28. I don’t understand this illness[e]	33.1
	29. The disease doesn’t make any sense to me[e]	15.4

Table 2. (Continuation)

Evolution (timeline-cyclical) (1-5) *M*= 3.29; *sd*= 0.77; R= 1.25-5 *alpha*= 0.73	34. The patient goes through cycles in which the disease gets better and worse	67.7[d]
	33. The disease is very unpredictable	59.2
	32. The symptoms come and go in cycles	37.6
	31. The symptoms of this disease change a great deal from day to day	28.4
Emotional Representations (1-5) *M*= 3.96; *sd*= 0.80; R= 1.83-5 *alpha*= 0.85	35. I get depressed when I think I have or may have this disease	73.1[d]
	36. When I think on this disease I get upset	73.1
	40. Thinking on having this disease makes me feel afraid	71.5
	39. I feel anxious about the idea of having this disease	68.4
	37. To think on having this illness makes me feel angry	50
	38. I am not worried about this disease or suffering from it[e]	9.2
Causes *alpha*= 0.68	Smoking	92.3[d]
	Pollution, environmental contamination[b]	74.6
	Hereditary, genetic[b]	71.5
	Alcohol consumption[b]	65.4
	Ageing	50.8
	Chance, bad luck	47.3
	Diet, eating habits	39.2
	Poor medical care in one's life	37
	Germs or viruses	30
	Immunity problems[b]	28.7
	One's own behaviour and habits[b]	25.4
	One's own mental attitude and thinkings[b]	22.5
	Stress or worry	22.3
	One's own emotional state	19.2
	Overwork	10.9
	One's own personality	9.2
	Accident or injury	7.7
	Family problems or worries	7
	Other people[b] (new)	0.8

Footnotes: Internal reliability of the IPQ-R version used: 0.73 (Identity dimension excluded from this analysis); Range of possible responses: Identity subscale: 1=Yes, 0=No; Remaining subscales: 1="Strongly Disagree"-5="Strongly agree".

[a] Minimum and maximum possible score in the subscale in the revised questionnaire used in this study.

[b] Symptoms/causes added, completed or regrouped categories

[c] Percentage of people answering "Yes"

[d] Percentage of people answering "Agree" plus "Strongly agree"

[e] Reverse-scored item

The impact of educational level on illness representations was evaluated. We found significant differences only for the dimensions of coherence (*F*=3.714, *p*<0.05) and evolution (*F*=2.891, *p*<0.05). The results of the Bonferroni's *post hoc* comparisons showed significant differences in the coherence dimension scores between the groups with primary and university educational levels (*p*= 0.002; *d*= -1.06), with the university-educated participants scoring higher, and for evolution scores between the groups with primary and university education (*p*= 0.011; *d*= 0.82), with the university-educated participants scoring lower. Cohen's *d* values for the remaining comparisons were low.

Influence of family experience with the disease on cancer representations

When we compared the representations of cancer among participants who had never lived with a person with cancer and those who were currently living with someone with this disease or who had done so in the past, we found that the participants with family experience had significantly stronger beliefs in the identity and emotional representations dimensions, with moderate to high Cohen's *d* values (Table 3). The difference was marginally significant for the illness coherence dimension.

Table 3: Comparisons according to experience with the disease.

DIMENSIONS	EXPERIENCE (N=42)		NO EXPERIENCE (N=88)		*t*	*p*	*d*
	M	*SD*	*M*	*SD*			
Identity	11.19	3.16	8.36	3.60	4.347	0.000**	0.82
Timeline	3.57	0.53	3.56	0.66	0.075	0.940	0.02
Consequences	4.20	0.57	4.03	0.58	1.555	0.123	0.29
Personal control	3.36	0.70	3.17	0.73	1.383	0.169	0.26
Treatment control	3.73	0.35	3.65	0.57	0.930	0.354	0.16
Coherence	3.30	1.02	3.06	0.84	1.774	0.078	0.27
Evolution	3.23	0.86	3.32	0.72	-0.616	0.539	-0.12
Emotional representations	4.28	0.82	3.81	0.76	3.206	0.002**	0.60

** $p< 0.01$

Relationship between gender and experience with the disease

Although no significant differences were found between women and men, a factorial ANOVA was run in order to establish, besides the main effects of family experience and gender, the interactive effects between both conditions. A global score on the IPQ-R obtained by adding all partial scores with the exception of causes dimension were used as dependent variable (the higher the global score, the more robust the beliefs about cancer). Marginally significant effects were found for gender (*F*= 3.444, *p*= 0.066) and no significant effects were found for the interaction of gender and family experience (*F*= 0.028, *p*= 0.867), the main effect for family experience being significant (*F*= 26.347, *p*= 0.000).

Predictors of the illness perceptions on cancer

Finally, in order to establish which factor(s) significantly predicted cancer representations, we conducted a step-wise multiple regression analysis. We considered as the outcome variable the total score obtained by adding all the partial scores, except the causes dimension. Controlling for age, gender and educational level, which did not explain an independent, significant proportion of the predicted variable in the first step, family experience was the only significant predictor, explaining 15.9% of IPQ-R total score (corrected R^2= 0.159; *F*= 25.364, *p*= 0.000). Having a relative diagnosed with the disease increases a person's score by 0.407 units (standardised beta; *p*= 0.000). The interaction of experience and gender did not explain, as expected, a significant proportion of the variance in IPQ-R scores.

Discussion

Although the SRM has been applied to different physical and mental illnesses, there are relatively few studies regarding the non-specialised beliefs that people, particularly non-patients and the Spanish population, hold about cancer. This study focused on establishing the illness cognitions on cancer of healthy adults of both genders with diverse educational backgrounds and family experience with the disease. In summary, we found that the participants' beliefs about cancer were a mixture of medical and folk knowledge. Compared to age, sex and educational level, family experience with the illness, i.e., having lived with a cancer patient, had the strongest impact on the representations of cancer.

Knowing these beliefs will help us to understand how a serious but preventable disease such as cancer is understood by lay healthy people and which beliefs derive from a direct experience with the disease. Inaccurate or exaggerated perceptions about cancer may lead to a failure to adhere to appropriate preventive or screening behaviours, as well as to negative attitudes toward and poorer support to cancer patients (8,15,16). Tailored psychoeducational interventions based on such findings can be designed to address which illness representations should be modified and how in order to create more accurate perceptions of the disease that derive in appropriate preventive and supportive for patients behaviours.

Our descriptive findings on the perceptions that Spanish non-patients hold about cancer demonstrated that cancer is considered a serious disease, with both high and broad impact and major consequences for patients, their relatives and caregivers. The participants considered cancer a highly symptomatic disease with characteristic and localised physical symptoms accompanied by psychological distress. However, some of the symptoms the subjects indicated can be consequences of other processes, e.g., treatment, instead of a symptom of the illness, e.g., nausea. Cancer was also perceived as highly unpredictable and changeable with improvements and relapses over time and as a long-lasting disease, but not necessarily as a chronic or permanent condition. The participants were probably taking into account either the effectiveness of pharmacological, surgical or other therapeutic interventions or the mortality associated to cancer. Unfortunately, this was not specifically dealt with in our study.

Cancer was seen as likely to be cured or alleviated with any of the various existing therapeutic interventions. The representation of cancer as a curable disease may be derived not only from the knowledge of current therapeutic advances but also from information from healthcare institutions, policies' responsibles and the media, which often stress the possibility of overcoming this disease. Participants also believed that patients can influence their illness and symptoms, although cancer was not seen as completely or exclusively depending on patients' actions. One in two participants believed cancer can be prevented. Many perceived causes of cancer are in the patients' power, like smoking, alcohol consumption and dietary habits. Nevertheless, only 25% of participants said a person's "behaviour" is a significant cause of cancer when specifically asked. Uncontrollable causes, such as environmental contamination, heredity or ageing also stood out. Luck or chance was chosen by almost half the sample as an etiological factor, while a relatively small percentage of participants chose immunity problems or viruses as the main cause of the disease. This can be linked to how the disease is treated by healthcare institutions, in the media and in daily life. When the media and public organisations discuss cancer, personal causes such as habits are highly stressed as ways to prevent the disease, while obviating uncontrollable causes. However, given that blame and self-blame are usual when lay people talk about cancer (11,22,39), we tend to diminish our own influence on the onset of cancer while recognising the role of other external and biological causes. On the other hand, due to their impact on patients and family, the symptoms and consequences of cancer are probably often the focus of daily conversations about cancer, with discussions on causes being pushed to the side.

The participants stated they became emotionally disturbed when thinking about having cancer, reporting feelings of sadness and fear of suffering from it. Only a minor percentage of people reported feeling no negative emotions when thinking about having cancer. These people were likely either keeping in mind the progressive demystification of cancer as a fatal disease and the new possibilities for a cure, or they perceive themselves as not vulnerable to the disease.

It is worth mentioning that approximately half the participants considered they hold a good understanding of cancer. The remaining reported being only partially informed about cancer and said they lacked a clear overall picture of it. These beliefs may be reflective of the fact that cancer has been linked to negative and, at times, stereotyped images, leading to attempts to ignore it due to emotional distress, or they may reflect the participants' actual lack of knowledge about the processes, e.g., biological mechanisms, involved in the development or remission of the disease.

Our results support previous findings regarding both the content and fit of beliefs with objective medical knowledge and are very similar to those obtained in a Spanish study (14). In our study, cancer representations were generally accurate but also, sometimes, based on common sense, cultural beliefs and folk knowledge. Other researchers have stated that lay illness cognitions diverge sharply from current medical understanding (8,14,24,28,29). This should be taken into account when designing psychoeducational interventions aimed to adjust cancer beliefs among non-patients, patients and relatives.

Gender, age and educational level have not been previously found to be relevant influences on illness beliefs (7-10), but contradictory findings have been found among cancer patients (8,11). In short, our findings support that sociodemographic variables have little influence on the illness models healthy people construct for cancer. On the contrary, experience with an illness, in terms of suffering from the disease or caring for a patient, has been proposed by the SRM and found to be an important influence on how people construct illness representations (e.g., 7-9,14-24,28,30). In our study, after controlling for sociodemographic variables, personal experience, i.e., living with a patient, was the only significant predictor of cancer representations. Further, patients' relatives or caregivers reported a significantly higher number of cancer-related symptoms and stronger negative feelings of worry, fear or sadness when faced with the possibility of suffering from cancer, something which may be linked to their daily experience with the disease and its consequences as well as to the high heritability of certain types of cancer. Living with a patient probably enables people to have a clearer comprehension of the disease. Anagnostopoulos and Spanea (8) proposed that more positive and realistic reappraisals on cancer can be derived from a direct experience with the disease. Nonetheless, such experience may also lead to create some fatalistic beliefs. Therefore, beliefs must be assessed and adjusted among relatives of patients to assure positive beliefs and efficacious derived behaviours.

Knowing the illness representations non-patients hold would allow health professionals to design individually tailored preventive actions. Our findings provide a basis for new research and interventions aimed at cancer prevention. It is expected that healthy people avoid risks, seek medical care, undergo medical exams or screening tests or adopt new healthy behaviours if they construct the disease as preventable by their efforts. Indeed, it has been proposed that cancer representations influence how an individual behaves to reduce his or her risk of developing the disease. Previous research has established a positive relationship between illness perceptions about cancer among healthy people and their attitudes, intentions and actions regarding future protective and preventive behaviours (21,31,40). Nonetheless, some researchers call for special attention to behaviours that are interpreted as “cancer-detection” rather than “cancer-prevention” actions (15,32). It is expected that more accurate beliefs will lead non-patients to carry out more appropriate and beneficial behaviours to face illnesses before a diagnosis is given. Careful, individually focused revision and discussion of illness beliefs should modify misconceptions and biased, inappropriate and unrealistic expectations. Moreover, our findings suggest that older and less-educated people as well as individuals not having a personal experience with the disease may hold more unrealistic or incorrect beliefs.

Further, social networks can exert an influence not only on the creation of illness beliefs but also in the pursuit of maintaining and promoting health and preventing and managing infirmity. The illness representations of patients’ caregivers, family, friends and other close people can be common-sense misconceptions rather than accurate beliefs, shaping attitudes and responses to the illness and determining the personal experiences with the disease. Research has shown that the coping actions carried out by caregivers and the derived outcomes for caregivers and family members, such as their own well-being, are impacted by caregivers’ illness beliefs (3,13,19,23,27). Moreover, illness beliefs of those close to the patient can also have consequences for patients. Several studies have demonstrated that caregivers’ beliefs are important for patients’ managing behaviours and illness outcomes (3,9,13,17-19,23,26,27).

Furthermore, the reactions to the patient, the support offered to her or him and the quality of the relationships between the patient, caregivers and others are determined to some degree by the illness perceptions of the caregivers and others (3,9,13,15,19,20,23,25). Therefore, illness representations have relevant repercussions on people’s responses to individuals who are ill, the quality and quantity of the help and aid they give to patients, their relationship, their adjustment to the situation, their efforts for coping with the disease and the effects derived from the illness for all of them. It has been stressed (15,16) that the perceptions held by healthy people are not necessarily accurate or congruent with those of ill people. Thus, affective and behavioural responses directed toward ill people may result in inappropriate interpersonal outcomes and support to patients, including negative attitudes toward patients, social disapproval and withdrawal, stigmatisation, etc. Moreover, based on differing illness representations, a lack of fit may exist between patients' needs for support and the support offered by others, i.e., health care professionals, relatives, friends and the community (15,29). Consequently, knowing and improving the accuracy of relatives' and friends' illness beliefs will allow health professionals to develop adapted psychoeducational or counselling interventions for caregivers, family and friends in order to enhance their coping skills as well as those of patients.

Some limitations of our study should be considered for future research. First, the number of studies on cancer representations in Spanish samples is scarce. Thus, we recommend conducting new studies aimed at replicating our results and comparing findings with citizens from other cultural contexts. Second, it would be advisable to increase the number of participants. Third, future research should compare the beliefs of non-patients, caregivers, patients with cancer and people who have suffered from cancer (survivors). Fourth, actual and perceived social and family support that is both given to the patient and received by the patient requires further research. Fifth, neither the type and accuracy of knowledge the participants had nor the sources of said knowledge were considered, and it would be appropriate to compare the beliefs of people with specialised knowledge with those held by lay people to establish possible discrepancies. Sixth, other relevant factors, such as type of cancer, clinical history or specific family history and kinship should be considered in the future. Further, it would be interesting to explore how illness perceptions change over time in response to new influences, such as an individual's personal and/or family experience with the illness.

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CAPÍTULO 8

ESTUDIO 2

Predicting cancer-related emotional distress from cognitive representations of cancer and causal attributions: A study with adults not suffering from cancer with or without family experience with the disease

Abstract

Emotional reactions to a disease are considered by the Self-Regulation Model (SRM) as relevant predictors of illness-related behaviours. In spite of the relevance conceded to the emotional representations of illnesses by the SRM, cancer-related emotional distress among people with no personal experience with the disease has not been sufficiently explored to date. However, emotional responses to cancer are strong among patients, survivors, relatives and carers, and the same is intuitively expected in the community population. The present study explores this issue along with cognitive predictors of emotional responses to suffering from cancer among non-sufferer adults who have or do not have family experience with the disease. Moreover, this aim allows to test the postulates and predictions of SRM regarding the narrow association between all dimensions of illness representations. A convenient, community-based sample of non-sufferers completed the Illness Perception Questionnaire-Revised version indicating their cognitive and emotional representations of cancer. One third of the participants had family experience with the disease. Univariate correlation analyses indicated that emotional representations were associated with beliefs on identity, duration and consequences and with uncontrollable and immunity causal attributions. In multivariate hierarchical multiple regression analyses, illness perceptions emerged as the strongest predictors of cancer-related emotional distress, explaining nearly a third of variance of participants' emotional representations, whilst contributions of family experience and age were significant although more modest. Participants who perceived cancer as a severe illness due to its numerous symptoms and negative influences in patients' health and life, and who held perceptions of a shorter duration of the disease, as well as were more likely to endorse external causes to cancer (marginal effect), reported stronger cancer-related emotional distress when thinking on suffering from the disease. Two interaction terms of cognitive illness representations with the moderators experience with the disease and age also emerged as independent predictors, indicating that those who had family experience with the disease and were older, and hold more negative perceptions on cancer, reported higher emotional reactions to cancer. Findings are discussed in light of the SRM theoretical premises, confirming the interdependence of illness cognitive and emotional representations. Practical implications in terms of emotional-arousing health-related communications for promoting cancer preventive behaviours are also offered.

Keywords: Illness representations, emotional impact, cancer-related distress, IPQ-R, Self-Regulation, healthy adults

Introduction

Emotional distress among cancer patients and their family members

Emotional distress refers to a continuum of psychological symptoms and complaints varying in severity (Strong et al., 2007). Psychological distress following a cancer diagnosis is well documented. It is among the most prevalent and impairing symptoms of cancer patients and includes depression, anxiety, worry, irritability or overall emotional distress (Miller-Reilly et al., 2013). Strong et al. (2007) found that 22% of cancer outpatients demonstrated clinically significant emotional distress in terms of anxiety and depression symptoms, with a distribution skewed towards less distress; while less than 5% of the sample reported no symptoms, 73% indicated some level of emotional distress below clinical cutoff criterion. Younger age, female gender and active disease were found to be predictors of higher levels of emotional distress, whereas cancer type was not related to patients' emotional well-being. Annual prevalence of major depression or generalized anxiety disorder remains affecting to 1 in 5 patients in the fourth year after cancer diagnosis (Burgess et al., 2005), and lifetime prevalence of cancer-related posttraumatic stress disorder (PTSD) is rounding 20% for several types of cancers (Andrykowski & Kangas, 2010).

Routine screening of emotional distress among cancer patients has been encouraged in order to provide them with supportive treatment in psychological services (Vodermaier, Linden & Siu, 2009). Further, it has been also encouraged to identify the psychological processes that cause persistent distress so that a targeted preventive intervention can be provided (Cook et al., 2015). Consequently, psychosocial therapy has become an integral part of cancer care, and several reviews and meta-analyses support its efficacy for promoting short- and long-term emotional well-being and quality of life (QoL) in adult patients with cancer (e.g., Faller et al., 2013; Galway et al., 2012; Osborn, Demoncada & Feuerstein, 2006; Sheard & Maguire, 1999), particularly among those with pronounced clinical symptoms. More emotionally distressed individuals are also more likely to participate in cancer support groups (Cameron et al., 2005; Grande, Myers & Sutton, 2006). It has been stressed that failure to identify and treat psychological distress among cancer patients increases the risk for poor QoL and potential disease-related morbidity and mortality (Andersen et al., 2014; Wagner, Spiegel & Pearman, 2013).

Emotional distress is also prevalent among partners, relatives and carers of patients with cancer (Hodges, Humphris & Macfarlane, 2005; Pitceathly & Maguire, 2003), with some influences of gender (i.e., female), time since diagnosis (i.e., shorter time) and disease status (i.e., higher levels of symptoms, advancing and terminal disease) having stated. Moreover, prevalence rates of clinical cases (Pitceathly &

Maguire, 2003) and levels of psychological distress (Hodges et al., 2005) are comparable to those of patients. Thus, besides their caregiving and supportive role to face the disease, those connected with the patient have also to cope with their own mood disturbances throughout the illness journey; however, they are comparatively less likely to seek help or receive specialized attention, even when the efficacy of interventions is also comparable to those tailored to cancer patients and interventions bring benefits for both the family member and the patient (e.g., Harding, List, Epiphaniou & Jones, 2012; Hopkinson, Bown, Okamoto & Addington-Hall, 2012; Northouse, Willians, Given & McCorkle, 2012).

Furthermore, Strong et al. (2007) stressed that there is limited information about the risk factors for emotional distress in cancer patients, and this is also true for those relating the patient. We wonder whether lay cognitive illness representations on cancer may predispose to cancer-related emotional distress among people who have not received a diagnosis of cancer (but can be diagnosed in the future throughout the life course, given the high annual incidence rates, see Ferlay et al., 2013). Previous findings demonstrate that how the patients perceive their condition and the severity and impact of symptoms influence their emotional distress during the illness trajectory. For instance, drawings of their heart by heart attack patients over the recovery period relate to psychological well-being and functional recovery, including cardiac anxiety and worry about another myocardial infarction (Broadbent, Ellis, Gamble & Petrie, 2006). Furthermore, those relatives and carers of cancer patients who take a more negative view of the patient’s illness and its impact on their lives suffer from higher levels of psychological distress (Pitceathly & Maguire, 2003).

Illness perceptions and cancer-related emotional distress among non-patients

The Self-Regulation Model of Common Sense Illness Representations (SRM) (Cameron & Leventhal, 2003; Diefenbach & Leventhal, 1996; Leventhal, Brissette & Leventhal, 2003; Leventhal & Diefenbach, 1991; Leventhal, Diefenbach & Leventhal, 1992; Leventhal, Leventhal & Cameron, 2001; Leventhal, Leventhal & Contrada, 1998; Leventhal, Meyer & Nerenz, 1980, Leventhal, Nerenz & Steele, 1984; Leventhal et al., 1997) provides a comprehensive theoretical framework for predicting emotional responses to a range of health threats. According to the SRM, people are active decision-makers and problem solvers and play an agentic role in self-regulation. With that aim, both healthy and ill people construct non-specialised models about illnesses which comprise a series of cognitive and emotional representations, in order to create an integrated and meaningful picture of a health-threatening condition. Leventhal et al. (1980) theorized that cognitive beliefs and emotional reactions were parallel, bidirectionally related representations on the disease, interacting with each other in a mutually interfering or facilitating manner. Moreover, illness representations evolve over repeated iterations of the self-regulatory stages (see Del Castillo, Godoy-Izquierdo, Vázquez & Godoy, 2011, figure 1) and hence, they can change as a function of internal or external information. Illness representations include several attributes: identity (the illness label and symptoms), cause (factors responsible for its occurrence), timeline (short- or long-lasting duration and stable or cyclical course or evolution of the illness), consequences (expected outcomes on health status, longevity, emotional well-being or daily functioning), control/cure (personal and treatment control over the illness), coherence (subjective perception of understanding of the disease) and emotional reactions to the disease (emotional distress related to suffering from the disease).

Based on their illness perceptions, individuals self-regulate their behaviour. These illness representations *directly* influence individuals' illness-related problem- and emotion-focused coping actions, conducted for facing perceived risks in order to protect their health, or to manage their condition when already ill for controlling disease-derived consequences and recovering well-being. Cognitive mental representations resulting from cognitive processes activate problem-focused coping such as seeking information, changing lifestyle or adhering to medical recommendations for managing the health threat, when the disease is not present or when it is already developed. Emotional representations resulting from emotional processes drive emotion-focussed coping to handle emotions related to suffering from, or thinking in suffering from the disease, such as managing sadness, seeking social support or denial and avoidance strategies. *Indirectly*, by a mediation path of coping actions, illness representations influence the consequences of illnesses (such as QoL, global functioning or emotional well-being) and the adjustment to the disease (see French, Cooper & Weinman, 2006; Hagger & Orbell, 2003; Kaptein et al., 2003; Kucukarslan, 2012; Lobban, Barroclough & Jones, 2003; Mc Sharry, Mc Sharry & Kendrix, 2011; Petrie & Weinman, 1997; for a review).

Research on cancer-related illness beliefs among non-sufferer individuals, including relatives and careers of patients or survivors, is sparse and the findings are inconclusive (e.g., Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002; Cameron, 2008; De Castro, Aretz, Lawrenz, Bittencourt & Abduch 2013; De Castro, Peuker, Lawrenz & Figueiras, 2015; Del Castillo et al., 2011; Dempster et al., 2011a,b; Figueiras & Alves, 2007; Godoy-Izquierdo, López-Chicheri, López-Torrecillas, Vélez & Godoy, 2007; Graham, Dempster, McCorry, Donelly & Jonnston, 2015; Johansson, Axelsson, Berndtsson & Brink, 2004; Juth, Cohen, Silver & Sender, 2005; Lykins et al., 2008; Orbell et al., 2008; Rees, Fry, Cull & Sutton, 2004; Wang, Miller, Egleston, Hay & Weinberg, 2010). Table 1 summarizes main findings. In general, representations of cancer include perceptions of the disease as with low-to-moderate symptom manifestations, moderate-to-high duration, changeability and consequences, personal and, particularly, treatment control possibilities, and moderate-to-high illness-related emotional reactions. Among aetiological factors, those related to external and uncontrollable causes stand out, followed by lifestyle and behavioural risk factors and, finally, psychological factors. In general, participants reported a moderate, partial understanding of the disease. Wang et al. (2010) explored causal attributions for breast and colorectal cancer among healthy women. They found that, although there were some differences between both illnesses, around 2/3 of the participants attributed cancer to external and uncontrollable factors such as heredity, immune functioning, environmental factors such as pollution and aging and, less frequently, to behavioural factors such as smoking; the remaining causal factors were indicated by 1/3 or less. Curiously, 1/3 of the participants indicated that chance/bad luck was a causal factor, a finding which parallels other results obtained with both patients and non-patients. As Anagnostopoulos and Spanea (2005) stressed, illness representations of cancer may comprise inaccurate information, misconceptions or negative conceptualizations of the disease.

Godoy-Izquierdo et al. (2007) found that Spanish adults from the community (1.2% had ever suffered from cancer) perceived cancer as a serious disease (95.6% of the participants) with particular and localizable symptoms, including pain (81.7%), with a long-lasting (69.2%) and unpredictable evolution (76.7%) with relapses (72.3%) and with important consequences for the patient (95.1%) which impede him(her) from developing his(her) daily activities and roles (68.7%). Cancer was also perceived as controllable by the patients (58.1%) and amenable of a cure (54.7%; medication: 56.1%), although many considered that it is not possible to recover from it and that it is permanent (35.5%). It was moderately related to one's own behaviour (27.7%) and less frequently emotional states (7.6%). Only 35.8% of the sample indicated that it is a preventable disease. A high percentage of participants attributed its evolution to luck or chance (34.3%). A detailed inspection of findings indicate that accurate perceptions based on biomedical knowledge and folk, personal beliefs are mixed and sometimes very divergent.

With the same Spanish sample of non-sufferers of the present study, Del Castillo et al. (2011) found also that participants' beliefs about cancer included both biomedical and folk knowledge. Cancer was perceived as a highly symptomatic and serious disease, with severe, broad impact and major consequences for patients, their relatives and caregivers. The participants considered cancer a long-lasting disease, but not necessarily as a chronic or permanent condition disease, with a unpredictable and changeable course with improvements and relapses. Cancer was also seen as amenable of a cure with any of the various existing therapeutic interventions, and patients were seen as able of influencing their condition depending on their own actions. One in two participants believed that cancer can be prevented. Many perceived that main causes of cancer were related to lifestyle, although only 25% of participants said a person's "behaviour" is a significant cause of cancer when specifically asked. Uncontrollable causes, such as environmental contamination, heredity, or ageing also stood out. Luck or chance was chosen by almost half the sample as an etiological factor, while a relatively small percentage of participants indicated immunity problems or viruses as the main cause of the disease. Approximately half the participants considered they hold a good understanding of cancer; the remaining said they lacked a clear overall picture of it.

Sociodemographic variables such as gender, age and educational level have not been found as strong correlates of illness beliefs, although some influences have been stated (Anagnostopoulos & Spanea, 2005; Del Castillo et al., 2011; Lehto, 2007; Wang et al., 2010). However, having suffered from the disease or having an ill relative consistently emerge as a relevant contributor to illness representations (Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002; Del Castillo et al., 2011; Dempster et al., 2001b; Godoy-Izquierdo et al., 2007; Juth et al., 2015; Lykins et al., 2008; Orbell et al., 2008). Del Castillo et al. (2011) found that, compared to other sociodemographic factors, family experience with cancer (having lived or not with a patient) had the strongest impact on the contents of the representations on cancer. Further, they found that people with family experience with the disease, compared to those not having a relative diagnosed with cancer, reported significantly more symptoms and stronger emotional impact. However, no evidence of the influence of family experience with the disease have been obtained for causal attributions (Wang et al., 2010).

Table 1. Summary of illness representations on cancer endorsed by non-patients.

Study & measure	Sample & cancer type	Cognitive representations								Emotional reactions
		Identity	Duration	Evolution	Consequences	Personal control	Treatment control	Coherence	Causes (factors)	
Rees et al. (2004) IPQ-R	Breast cancer, Women	4.98/17	3.19		3.83	3.25	3.62	3.07		
Anagnostopoulos & Spanea (2005) IPQ	Breast cancer, Women				2.68		Duration/ Cure: 2.54		Chance: 3.68 Internal: 2.65 Environmental: 2.11	
Figueiras & Alves (2007) IPQ-R	Skin cancer, men & women	6.4/17	3.60	3.07	3.83	3.43	3.60	3.10	Risk/lifestyle: 3.04 Psychological: 2.20	3.34
Orbell et al. (2008) IPQ-R[a]	Colorectal cancer, men & women	2.62/10[b]	3.55		2.94	3.82	4.01	3.26	Biological: 3.13 Psychological: 3.00 Behavioural: 2.88	3.21
Del Castillo et al. (2011) (for causes, info reported herein) IPQ-R	All types of cancer, men & women	9.28/15	3.56	3.29	4.09	3.23	3.67	3.16	Uncontrollable: 3.58 Controllable: 3.46 Immunity: 3.14 Chance/accident: 2.67 Psychological: 2.34	3.96
Dempster et al. (2011a) IPQ-R	Oesophageal cancer, carers		3.81	3.04	2.13	2.68	3.34	3.84	Externalized: 3.75 Behavioural: 2.51 Emotional: 2.50	
Dempster et al. (2011b) IPQ-R	Oesophageal cancer, carers		3.84	3.06	For survivor: 3.70 For self: 2.11	For survivor: 3.15 For self: 2.68	3.35	For survivor: 3.84 For self: 3.86	Externalized: 3.77 Emotional: 2.50 Behavioural: 2.50	
De Castro et al. (2015) IPQ-R	Cervical cancer, women		5.02		3.88		4.19	3.38	General: 3.84 Psychological: 2.07	3.23
Juth et al. (2015) BIPQ	All types of cancer, parents of young patients	4.79/10	4.36/10			4.50/10	9.16/10	8.41/10		CONCERN: Caregivers: 8.2/10 Adolescent patients:4.6/10 Young patients:6.2/10

Note. When scores are not reported in the corresponding paper as the average for subscales, we calculated it when possible by dividing the mean by the number of items. For all, responses are in a 1-5 point scale (the higher the score, the stronger beliefs), excepting Identity (symptoms reported/number of total symptoms assessed; [b] reported mean for experienced symptoms in a 0-10 point scale), BIPQ scores (1 item/subscale on a 0-10 point scale) and [a] 1-6 point scale. Only scores obtained by non-patients are showed.

Regarding cancer-related emotional distress, few studies have explored emotional representations of cancer among people not suffering from cancer (see Table 1), which have been interpreted as the emotional response to the illness in non-patients. Among healthy individuals, Figueiras and Alves (2007) found that those who perceive a higher number of symptoms linked to skin cancer, report a more chronic and cyclical timeline for the disease, perceive more serious consequences linked to cancer and lower possibilities of personal and treatment control, and have a more coherent illness model report a stronger emotional representation of the disease. Moreover, emotional representations emerged as significant predictors of intentions to adopt preventive behaviours, though they did not predict attitudes towards preventive actions. As the authors of such study stressed, the importance of emotional representations of a disease is noticeable since this dimension was the most significantly associated with nearly all the other dimensions and may be a particularly salient aspect of the way healthy individuals perceive the nature of serious illness such as skin cancer. This finding may help in informing behavioural interventions aimed at preventing this illness. On the other hand, the causal attribution factors were not found to be related to emotional representation of the illness, a result which is contrary to the relationship found in different groups of patients (Moss-Morris et al., 2002) but agrees with other findings for cancer. For example, in the early period following diagnosis of suspected lung cancer, Lehto (2007) explored the relationship between causal attributions, factored following Moss-Morris et al. (2002) suggestions, and emotional distress. Emotional distress was moderately high among the participants and did not change before and after surgery. None of the causal factors, including psychosocial and behavioural risk factors, immunity factors and chance, was related to or predicted emotional distress at either time point (smoking approached significance after surgery).

Orbell et al. (2008) compared illness representations of patients with colorectal cancer, adenoma and people with no neoplasia after a screening test. Their emotional representations were, in average, higher for cancer participants (3.5) than for people with adenoma (3.3) and no lesions (3.2), with significant differences between healthy participants and cancer patients: Patients with cancer differed from no neoplasia individuals by reporting their condition as more distressing. Moreover, emotional representations contributed to the prediction of avoidance coping, which in turn was associated to participation in a new screening test 2 years later among those participants who were identified as with adenoma or no cancer in the first screening test.

In the study by De Castro et al. (2015), women without premalignant cervical lesions reported a moderate emotional impact of the disease, with no differences found when they were compared to women with premalignant lesions, indicating that both groups perceived the disease as moderately threatening. No differences were found either regarding self-care actions, suggesting that emotional distress did not generate divergences in their behaviour. De Castro et al. (2013) did not found either differences in emotional representations when healthy women, women with premalignant lesions and women with cancer were compared.

Juth et al. (2015) examined cancer-related posttraumatic stress symptoms (PTSS) in dyads of adolescent and young adult cancer patients undergoing treatment and their caregivers. They found that patients' and caregivers' subjective perceptions of illness severity, a composite of illness perceptions including emotional representations as cancer-related concern, were not completely congruent with objective severity of the disease (i.e., medical indicators). Moreover, caregivers reported significantly higher emotional concern (which was very high) and overall subjective perceptions of illness severity and cancer-related PTSS than patients (moderate), yet these findings could be due to age of the participants. Patients' subjective perceptions of illness severity were linked to patients' and caregivers' cancer-related PTSS, while caregivers' perceptions of illness severity were linked only to their own PTSS. No effects of gender and age were found. Unfortunately, emotional representations apart from concern were not explored.

In our previous study, Del Castillo et al. (2011) found that the participants stated they became emotionally disturbed when thinking about having any type of cancer, reporting feelings of sadness and fear of suffering from it. Average score in the emotional distress dimension was very high (see Table 1). Between 68% and 73% of people indicated they felt anxious, depressed or worried when thinking on the possibility of suffering from cancer. Only a minor percentage of people (9%) reported feeling no negative emotions when thinking about having cancer; they were likely either "keeping in mind the progressive demystification of cancer as a fatal disease and the new possibilities for a cure, or they perceive themselves as not vulnerable to the disease" (p. 349). Older people (56-66 yr. old) were found to hold stronger emotional distress compared to younger participants (18-25 yr. old), with no other differences found due to age. No other influence of sociodemographic factors was established. Moreover, participants with family experience with cancer had also significantly stronger emotional representations than those without experience with the disease.

Aims and hypotheses

In spite of the relevance conceded to emotional representations of illness by the SRM, cancer-related emotional distress among people not suffering from cancer have not been sufficiently explored to date. Only a few studies have been found, and even when reported rates of emotional reactions to cancer are comparable, their findings are inconclusive, particularly regarding the influence of sociodemographic variables (not explored, excepting Del Castillo et al., 2011) and the role of having experience with the disease, which has been explored in some of them with contradictory findings, although there is more evidence supporting its influence (family experience: Del Castillo et al., 2011; Juth et al., 2015; personal experience: Orbell et al., 2008) compared to that rejecting it (personal experience: De Castro et al., 2013, 2015). Further, only one study (Figueiras & Alves, 2007) explored the relationships between cognitive and emotional dimensions of illness representations. In order to test the postulates and predictions of the SRM regarding the narrow association between all dimensions of illness representations, the present study explores cognitive predictors of emotional responses to suffering from cancer among non-sufferer adults. Based on the findings of Figueiras and Alves (2007), we expected strong associations between cognitive and emotional representations of cancer, as well as that perceptions on the severity and features of cancer will predict emotional responses to the disease. Moreover, given the influence of experience with the disease in the contents of illness representations, based on the findings of Del Castillo et al. (2011) and other researchers, we expected that healthy people with family experience with the disease would report higher levels of cancer-related emotional distress, while other sociodemographic factors will have no or little influence.

Methods

Participants

One hundred thirty adults (50% women) 18 to 66 years old (*M*= 39.98; *SD*= 13.82) took part in the study. Table 2 displays their most relevant characteristics. None of the participants had suffered from cancer at the time of the study, and 32.3% had lived or were living with a relative, independently of kinship, who had cancer. This convenient, community-based sample was recruited at random from private households and community settings such as transport stations, work places, parks, health-care services, academic centres and shopping centres.

Table 2. Socio-demographic data of the sample.

		%
Age ranges	18-25	20.77
	26-35	22.31
	36-45	17.69
	46-55	21.54
	56-66	17.69
Educational level (highest completed level)	No formal education	6.2
	Primary school	20
	Secondary school	31.5
	Vocational training and other formal education	9.2
	University	33.1
Work status	Student	12.3
	Employed	58.5
	Student & Employed	4.6
	Housework	17.7
	Unemployed	6.9
Marital status	Single	18.5
	Short-term relationship (< 3 years)	24.6
	Long-term relationship (> 3 years)	47.7
	Separated/Divorced	6.9
	Widow	2.3
Current physical or mental disease [a]	Yes	18.5
	No	81.5

[a] No severe mental diseases or cognitive disabling conditions were indicated.

Measures

The participants completed a modified version of the Revised Illness Perception Questionnaire (IPQ-R) by Moss-Morris et al. (2002), which was adapted to assess illness perceptions on cancer among healthy people. The IPQ-R evaluates nine dimensions from Leventhal and colleagues' SRM model and from additional research findings: Identity (symptoms associated with the illness and label); Timeline (duration and chronicity); Evolution (course and temporal changeability or fluctuation of the illness and symptoms); Consequences (effects of the illness on an individual's lifestyle, health and well-being); Personal Control (personal influence on preventing and managing the disease); Treatment Control (availability and efficacy of treatments to manage or cure the disease and its symptoms); Illness Coherence (personal understanding of the disease); Aetiology or Causes (psychological, behavioural, biological, chance and external causes of the disease); and, for the first time in illness representations assessment, Emotional Representations (emotional impact of the disease). The subscale of emotional representations includes perceptions of anger, depression, anxiety, worry, being upset and fear related to the illness. Higher scores indicate greater concern about the illness and, consequently, stronger emotional response to illness.

For all of the dimensions except identity and causes, a series of statements (e.g., “Thinking on having this disease makes me feel afraid”) are included for which the person must express his or her level of agreement on a 1-5 point Likert-type scale from “Strongly disagree” to “Strongly agree”. For all of them, partial scores were obtained as the mean of the scores for the items on each subscale (considering direct and inverse items), with higher scores indicating stronger beliefs about disease chronicity, cyclical course, impact and outcomes, personal influence, cure possibilities, perceived understanding and emotional reactions to the disease. Identity was assessed by asking whether a series of 15 symptoms was perceived as characteristic of the disease (Yes/No). The higher the score, the more symptomatic the disease is perceived to be. For the cause subscale (19 possible causes, plus a blank question on the three main causes as perceived by the participant [not considered in the analyses]), those factors scoring the highest from 1 to 5 are those the person considers to be the most relevant aetiological factors for the illness.

Following previous suggestions (Moss-Morris et al., 2002), we modified the questionnaire to adapt it to non-patients and to make it more complete and better fitted to cancer. Therefore, each reference to “my” illness was substituted by “the” illness or “cancer”. For the identity subscale, some new symptoms were added, while others were completed or regrouped. Two new items (#20 and #24) were added to assess complementary beliefs about cure for cancer. Item 21 was rewritten to assess beliefs about prevention of the disease. Items measuring the emotional representations dimension also were rewritten to assess emotional distress among healthy people. Items 22 and 25 were completed. (See all these changes in De Castillo et al., 2011). Moreover, following factors detected by Moss-Morris et al. (2002), we grouped causes perceptions in: a) *Psychosocial* attributions: Stress or worry, mental attitude (e.g. thinking about life negatively), family problems or worries, overwork, emotional state (e.g. feeling down, lonely, anxious, empty), personality; b) Risk Factors: *Controllable or lifestyle factors*: Diet or eating habits, poor medical care in the past, one's own behaviour *and habits*, smoking, alcohol; *Uncontrollable factors*: Heredity, ageing; c) Immunity: Germs or viruses, pollution *or environmental contamination*, altered immunity; and d) Accident or chance: Chance or bad luck, accident or injury (in italics, changes introduced by the authors).

The psychometric properties of the IPQ-R have been previously demonstrated among English-speaking and Spanish populations (Beléndez, Bermejo & García-Ayala, 2005; Moss-Morris et al., 2002) and in the context of cancer (Figueiras & Alves, 2007;

Giannousi, Manaras, Georgoulias & Samonis, 2009; Hagger & Orbell, 2005), as well as with the sample of this study (see Del Castillo et al., 2011).

Procedure

Following approval of the institutional research ethics committee, participants were invited to voluntarily take part and signed an informed consent form. They had been previously informed that the general objective of the study was to learn their beliefs about cancer and not to gauge their level of knowledge, and specific instructions on how to answer the questionnaire were given. A survey requesting personal and sociodemographic data was also included, which contained questions about whether they had ever suffered from cancer and whether they had ever lived with a relative who was diagnosed with cancer.

A convenience, community-based sample was constructed. Three housing buildings and several community settings per district were selected at random by using a local telephone directory of the town of Granada (Spain). A person in one out of every three possible households and one out every three persons in the several public settings was asked to participate and followed the above-mentioned procedure when they accepted. Data from people suffering or having suffered from cancer were discarded.

Study design and statistical analyses

This is a cross-sectional, correlational study based on self-report data. After checking parametric assumptions, univariate and multivariate analyses were conducted. The associations of cancer-related emotional distress with illness cognitions, age, gender and family experience were examined using univariate Pearson correlations or categorical analyses. Multivariate hierarchical multiple linear regression, using the method of stepwise selection, was subsequently applied to identify independent predictors of emotional distress among the identified correlates.

Results

Descriptive findings have been previously reported (Del Castillo et al., 2011). In the present research, mean scores ± standard deviations for causal factors groupings were as follows: Psychological attributions: 2.34±0.80; Controllable risk factor attributions: 3.46±0.48; Uncontrollable risk factor attributions: 3.58±0.83; Immunity attributions: 3.14±0.72; Chance or accident attributions: 2.67±0.80.

Univariate correlational analyses indicated that emotional representations were associated with identity (r= 0.26, p< 0.01), duration (r= -0.20, p< 0.05) and consequences ($r = 0.44$, $p < 0.01$) dimensions. They were also correlated with uncontrollable perceived causes ($r = 0.21$, $p < 0.05$) and immunity causes ($r = 0.19$, $p < 0.05$). Emotional distress was non-significantly correlated with evolution, perceived personal control, perceived treatment control and coherence dimensions, as well as with psychosocial, controllable and chance/accident causal factors ($p > 0.05$). Scores on emotional distress dimension were also marginally correlated with family experience with the disease ($\lambda = 0.063$, $p = 0.09$) and significantly correlated with age ($r = 0.24$, $p < 0.01$), but were not correlated with gender ($\lambda = 0.045$, $p = 0.223$) and education level (Kendall's *Tau-b*= 0.005, $p = 0.937$).

In order to explore possible independent predictors of cancer-related emotional distress among the correlates previously found, multivariate hierarchical multiple linear regression (MLR) analysis, using the method of stepwise selection, was conducted. In order to test for possible changes in the predictors by introducing sociodemographic data, the IPQ-R dimensions of identity, consequences and duration as well as perceived causes (for maximizing statistical power, a composite score of *external causes* including uncontrollable risk factors and immunity factors was calculated as the average of all the items included in both dimensions, which correlated with emotional distress at $r = 0.27$, $p < 0.01$) were introduced in a first step; experience with the disease was introduced in a next step; finally, age was introduced in a last step. No control variables (gender and education level) were introduced in order to adjust for their effects, given that no other relevant variable was correlated with emotional distress.

Table 3 shows the findings in each model. Illness perceptions emerged as the strongest predictors of cancer-related emotional distress, explaining nearly a third of variance of participants' emotional representations, whilst contributions of family experience and age were significant although more modest. Participants who perceived cancer as a severe disease due to its numerous symptoms and negative influences in patients' health and life but do not perceive it as a long-lasting disease, and who more likely endorsed external causes to cancer (marginally significant), those who had family experience with the disease and those who were older reported stronger cancer-related emotional distress when thinking on suffering from the disease. Furthermore, results indicated that experience with the disease partially explained the relationship between identity perceptions and emotional representations, while age partially explained the relationship between identity and causes with emotional representations.

Thus, the above-mentioned findings pointed to a possible moderation effect of experience with the disease and age in the relationship between cognitive illness perceptions and cancer-related emotional distress. In order to test these possible indirect effects, we used a moderated regression framework (Aiken & West, 1991) to test the association between emotional reactions and the interaction of cognitive illness perceptions with family experience and age. A MLR analysis similar to the previous one was conducted in which family experience and age were substituted by an interaction factor for a composite score of cognitive illness perceptions and family experience and age, separately. Findings are shown in Table 3. Both interaction terms were significant. Participants with stronger negative illness beliefs who also had a family experience with the disease, as well as those who were older, were more likely to experience cancer-related emotional distress when faced with the possibility of suffering from it.

Table 3. Hierarchical multiple linear regression analyses (stepwise procedure).

Model	Cor. R^2	St. Error	*F* (df)	*P*	Stand. *Beta*	t	*p*
FIRST ANALYSIS							
Consequences	0.314	0.66821	15.660	0.000	0.430	5.699	0.000
Duration			(4, 124)		-0.286	-3.834	0.000
External causes					0.171	2.239	0.027
Identity					0.166	2.142	0.034
Consequences	0.327	0.66194	13.438	0.000	0.419	5.594	0.000
Duration			(5, 123)		-0.280	-3.789	0.000
External causes					0.154	2.034	0.044
Identity					0.120	1.478	0.142
Experience[a]					-0.144	-1.833	0.069
Consequences	0.350	0.65065	12.478	0.000	0.382	5.061	0.000
Duration			(6, 122)		-0.257	-3.500	0.001
External causes					0.144	1.929	0.056
Identity					0.143	1.786	0.077
Experience[a]					-0.159	-2.052	0.042
Age					0.171	2.306	0.023
SECOND ANALYSIS							
Consequences	0.350	0.65056	12.484	0.000	0.392	5.167	0.000
Duration			(6, 122)		-0.249	-3.368	0.001
Identity					0.158	1.907	0.059
External causes					0.142	1.885	0.062
CIP X Experience					-0.169	-2.201	0.030
CIP X Age					0.181	2.204	0.029

CIP: Cognitive illness perceptions, a composite score obtained from adding identity, duration, consequences, perceived uncontrollable risk causal factors and perceived immunity causal factors. The higher the score, the more negative perceptions.

[a] Family experience with cancer: Yes= 1, No= 2.

Note. Results of the first and second analyses were very similar for the predictors introduced and consequently only the final model from the second analysis is displayed.

Discussion

This study explored cancer-related emotional distress among adults not suffering from cancer as well as cognitive predictors of emotional responses to suffering from this disease in order to test the relationship between both dimensions of illness representations posited by the SRM and to increase knowledge on illness representations on cancer among non-affected individuals. We found that non-sufferers experience moderately high emotional distress when faced with the possibility of having cancer. Moreover, we found support for the postulates of SRM, demonstrating significant associations between cognitive and emotional representations of cancer as well as that perceptions on the severity and features of cancer predict emotional responses to the disease. Furthermore, experience with the disease and age moderated the relationship of cognitive representations and cancer-related emotional distress.

We found that participants in our study endorsed high cancer-related emotional distress. Others have found more moderate levels of emotional reactions. Figueiras and Alves (2007) found a mean score for emotional representations linked to skin cancer of 3.3. They also found that illness-related emotional distress of healthy people was significantly higher for diseases such as AIDS than for skin cancer, while it was significantly higher for cancer than for diseases such as tuberculosis. Skin cancer may be perceived by non-affected people as less severe than other types of cancer, and consequently illness-related emotional distress may be lower for skin cancer compared to other cancer diagnoses. However, similar levels of emotional reactions to cervical cancer have been found among healthy women (De Castro et al., 2015) and to colorectal cancer among healthy adults (Orbell et al., 2008). Nevertheless, in our study we did not focus on a type of cancer diagnosis but considered cancer in general, and this may explain higher emotional responses to the illness labelled "cancer".

Among cancer patients with varied diagnoses, Hopman and Rijken (2015) have found an average emotional distress rounding 2.5. Hoogerwert, Ninaber, Willens and Kaptein (2012) have also found moderate-to-low emotional reactions to the disease among lung cancer patients, comparable to those of skin cancer, with a score rounding 5 in a 10-point scale. Cameron et al. (2005) found with newly diagnosed breast cancer patients also moderately low cancer-related emotional distress, with a score of 2.8. With long-term breast cancer survivors, participants' emotional representations were lower, with a mean score of 2.2, pointing to that cancer does not elicit strong emotional distress at the long-term among people who had overcome the illness (Trask, Pahl & Begeman, 2008). These findings seem to indicate that patients' emotional representations are more positive or benevolent that non-patients' ones. Personal, direct experience with the disease (i.e., suffering from the illness) has been found to impact robustly cancer-related illness perceptions (Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002; Godoy-Izquierdo et al., 2007; Orbell et al., 2008).

Moreover, with people at risk of colorectal cancer, Orbell et al. (2008) found a mean score on the emotional representations dimension of 3.2. With women at risk of ovarian cancer, Lancastle, Brain and Phelps (2011) found an average score of emotional distress of 3, and with women at risk of cervical cancer, De Castro et al. (2015) found a score of 3.2. With men at risk of suffering from prostate cancer, Hevey, Perlt, Thomas, Maher and Chuinneaga (2009) found an average score of 3.5. With people suspected of suffering from lung cancer, Lehto (2007) found an average score rounding 3.2 before and after surgery. Van Oostrom et al. (2007) found with individuals undergoing genetic susceptibility testing for colorectal and breast and ovarian cancer an average score for emotional representations of their illness of 3.2, with no differences found for both type of diagnoses. All these findings seem to further indicate that emotional representations may also vary depending on the time point in the illness journey. They suggest that not suffering from a disease such as cancer, as well as confirming vulnerability, are associated to stronger emotional reactions to the disease, while diagnosis, treatment and post-treatment phases are progressively related to a decrease of emotional distress, at least in not fatal, advanced and palliative-care cases, probably due to adaptation processes: Patients may report lower emotional impact of the disease because they actively engage in efforts to reinterpret and manage perceived threats (Orbell et al., 2008).

This supposition also agrees with the general favourable evolution of emotional distress and psychological impairment as time from diagnosis or active treatment passes found with cancer patients (e.g., Bárez, Blasco, Fernández-Castro & Viladrich, 2009; Lam et al., 2013) and their relatives (e.g., Wellisch, Ormseth & Arechiga, 2015). Our results also parallel other findings obtained with related measures, such as the Symptoms Representation Questionnaire. Using this indicator, Donovan, Ward, Sherwood and Serlin (2008) established that women with active ovarian cancer scored higher on emotional representations of their symptoms and in general expressed more serious cognitions about their symptoms than long-term survivors. Our findings may explain also why community individuals overestimate cancer patients' emotional distress (Buick & Petrie, 2002).

However, some findings with patients with breast, colorectal and head and neck cancer indicate an average score on emotional representations dimension rounding 3.5 (e.g., Gercovich et al., 2012; Llewellyn, Mc Gurk & Weinman, 2007; Orbell et al., 2008; Scharloo et al., 2005), which contradicts our supposition based on a visual inspection of previous evidence. Besides, when emotional representations of healthy, at risk and ill individuals have been compared, contrary findings have been established, with both no differences found (De Castro et al., 2013, 2015) or even inverse patterns (Orbell et al., 2008). Thus, further research is needed to elucidate the impact of personal experience on the disease on emotional reactions to it.

Besides illness representations regarded with the severity of the illness, we also explored causal attributions and their relationship with emotional reactions to cancer. Regarding perceived causes of cancer, our findings indicated that participants attributed cancer primarily to uncontrollable risk factors such as heredity or ageing and controllable risk factors such as lifestyle including smoking, diet and other habits. Immunity attributions were also considered. Chance, bad luck or accident and injury attributions obtained also a high consideration. Contrarily, psychosocial attributions including mood, personality or stress were the less frequently indicated. Importance attributed to these perceived causes is in line with some previous evidence obtained with non-patients (see Table 1).

Figueiras and Alves (2007) found that perceived causes of skin cancer in a community sample were regarded primarily with general risk factors including lifestyle and at a lower rate with psychological factors, with scores obtained by their participants being very similar (although lower) to scores obtained by the participants in the present study. Wang et al. (2010) found that healthy women attributed breast and colorectal cancer mainly to external and uncontrollable factors such as heredity, immune functioning, environmental factors and aging and, less frequently, to behavioural factors, although chance was also indicated. Anagnostopoulos and Spanea (2005) found with healthy women, women with benign breast conditions and patients with breast cancer higher causal attributions of breast cancer to chance than to environmental and internal and behavioural factors. Comparatively, healthy women held weaker beliefs concerning the role of environmental and behavioural factors in causing breast cancer and expressed greater agreement on the role of chance in the onset and course of the illness. Among carers of oesophageal cancer survivors, Dempster et al. (2011a) found also that external factors were more frequently indicated as causes of such illness, followed by emotional factors and behavioural factors. When these causal attributions were compared to those of patients, carers were found to endorse less frequently behavioural causes than patients did (Dempster et al., 2011b).

De Castro et al. (2013) found that women with cervical cancer indicated less psychosocial causal attributions for cervical cancer than non-affected women, even when they rated emotional factors and mood as the leading cause of their illness, whereas non-patients indicated attitude and behaviour. When women with and without premalignant lesions for cervical cancer were considered (De Castro et al., 2015), general risk factors were much more frequently indicated as causal factors than psychological attributions, and no differences were found between booth groups of participants. Also in the context of screening for cervical cancer, Orbell, Hagger, Brown and Tidy (2006) found that sex-immune factors were indicated more frequently, followed by psychological and behavioural factors. In another study in the context of screening for colorectal cancer, Orbell et al. (2008), found that participants attributed their condition mainly to ageing, along with diet/eating habits, chance/bad luck and stress and worry, with more relevance conceded to biological factors than to psychological or behavioural factors. In the context of screening for breast and colorectal cancer, Van Oostrom et al. (2007) found that the participants indicated heredity much more frequently than chance, ageing, general risk factors and psychological functioning, although they were at risk of family cancer. With patients suspected of lung cancer, Lehto (2007) established that the participants reported general risk factors (including controllable and incontrollable factors), followed by immune and chance/accident attributions to their illness, while psychosocial factors were indicated at a lower rate.

However, our findings contrast with other findings obtained with patients. For instance, Hopman and Rijken (2015) found that cancer patients conceded more relevance to chance/bad luck factors, followed remotely by immunity and general risk factors, psychological attributions and accident/injury attributions. Giannousie et al. (2009) also with cancer patients with several diagnoses under treatment found that patients attributed their illness mainly to external-immunity factors, followed by psychological-internal factors and behavioural-lifestyle factors. Constanzo, Lutgendorf & Roeder (2010) found with breast cancer patients completing treatment that the main causal attributions were environmental factors, heredity, diet, stress or worry and ageing, although 1/3 of participants also indicated chance. Wold, Byers, Crane and Ahnen (2005) found that prostate, colorectal and breast cancer survivors indicated as main causes of their disease genetic factors, smoking, environmental factors and, in a lesser extent, psychological factors, overestimating the impact of some aetiological factors (e.g., pollution) and underestimating the impact of others (e.g., physical inactivity). When patients with colorectal cancer, individuals at risk and healthy people were compared (Orbell et al., 2008), healthy people attributed it more frequently to biological and psychological than to behavioural factors, at risk people indicated more frequently behavioural factors and patients reported less likely behavioural factors.

We found that uncontrollable aetiological factors were more relevant for cancer-related emotional representations. Lehto (2007) proposed that identifying multiple causes including external, uncontrollable and chance factors suggests that although the participants acknowledge personal factors and behaviours as one cause for cancer, they may be insulating themselves from taking direct responsibility. Thus, self-blame and negative emotional consequences are avoided among patients. The lack of a meaningful association between causal attributions and negative emotional responses in her study suggests this possibility. As a consequence, she proposed that understanding factors that contribute to emotional responses to physical illness, such as attributing causes for why the life-threatening illness occurred, may be a key area for the development of focused interventions that may offset negative psychological outcomes.

Similar conclusions were exposed by Lykins et al. (2008). They found that in general, a personal history of cancer was not significantly linked to causal attributions; in contrast, a family history of cancer tended to increase 20-40% on average (for the factor “having a family history of cancer”, 90%) the likelihood of perceiving cancer as caused by both controllable-behavioural and uncontrollable-external specific risk factors. Moreover, an interaction of personal and family experience was observed for controllable causes: While having family experience with cancer did not influenced causal attributions among those with a personal history of cancer (i.e., cancer survivors), for respondents without a personal history of cancer, a family history of cancer markedly increased the tendency to believe controllable factors increased cancer risk. In a similar vein than Lehto (2007), the authors argued that "for those with a personal history of cancer (i.e., cancer survivors), espousing weaker beliefs about cancer causation, particularly downplaying of the influence of personal choice and behaviour in cancer causation, may serve a self-protective function (...) While distancing oneself from personal responsibility for cancer genesis may be anxiety-reducing and protective for cancer survivors, aligning oneself with controllable factors may serve a similar anxiety-reducing function for those possessing a family history (who endorse) strong belief that their family history places them at risk for cancer (...) Individuals want to maintain the belief that they have effective control over their lives, which may cause them to attribute cancer to controllable factors that they themselves can avoid to prevent cancer" (p. 7).

However, our results point that it seems that, among non-patients, perceiving that cancer is out of one's own control elicits stronger emotional reactions to the disease. We did not explore specifically the influence of (personal or) family experience with the disease, but our findings suggest that having family experience with cancer (and older age) makes attributions to uncontrollable causes less relevant for emotional reactions to the illness (see Table 3). Whether uncontrollable causes give way to controllable causes in this scenario is something that future research should explore.

In this study we found that cancer-related emotional distress was associated with perceptions on the severity of the disease, concretely with representations of symptoms (identity), duration (inversely) and consequences of the disease, as well as with uncontrollable perceived causes such as ageing or heredity and immunity causes such as environmental agents and altered immunity. Emotional distress was non-significantly correlated with evolution, perceived personal control, perceived treatment control and coherence dimensions, as well as with psychosocial, controllable and chance/accident causal factors. Our findings partly support previous findings by Figueiras and Alves (2007) with non-patients. With cancer patients, Lancastle et al. (2011) demonstrated that emotional representations inversely correlated with coherence and directly with consequences, psychological factors, risk factors, heredity and aging as causal attributions. Also with patients, Gercovich et al. (2012) found that emotional representations positively correlated with all of the remaining illness perceptions dimensions excepting coherence. With women at risk undergoing cervical screening after an abnormal cervical smear test result, Hagger and Orbell (2005) found that emotional representations correlated with all other dimensions excepting personal control. It was positively associated to identity, duration, consequences and causal attributions, and inversely associated to treatment control and coherence. The authors stated that they confirmed a theoretically predictable pattern of relationships among dimensions of representations. However, Figueiras and Alves (2007) found some contrary findings with healthy individuals, concretely that illness-related emotional distress was positively associated to beliefs on identity, duration, evolution, consequences and also coherence and inversely linked to beliefs on personal and treatment control, whilst no associations were found for psychosocial and risk factor causal attributions. Consequently, they proposed that the dimensions of the IPQ-R appeared to show a pattern of logical inter-relationships, some of which were similar to patterns found in previous studies with patients (Hagger & Orbell, 2003; Moss-Morris et al., 2002). Moss-Morris et al. (2002) explored illness cognitions and emotional representations in patients suffering from several chronic diseases (cancer was not included) and found that illness-related emotional distress was positively associated to beliefs on duration, evolution and consequences and inversely linked to beliefs on personal and treatment control and coherence, whilst no associations were found for identity dimension, a finding which probably is due to the wide range of diseases included. Emotional representations were further correlated with causal attributions of psychosocial, risk factor, immunity and chance nature. However, Lehto (2007) could not also establish any association between emotional representations and causal attributions with suspected patients.

Furthermore, when cancer-related emotional distress was regressed on significant correlates, illness perceptions emerged as the strongest predictors, explaining nearly a third of variance of participants' emotional representations, whilst contributions of family experience and age were significant although more modest. Participants who perceived cancer as a severe disease due to its numerous symptoms and negative influences in patients' health and life and also perceived it as a short-lasting disease (and endorsed more uncontrollable causes, marginally significant), those who had family experience with the disease and those who were older reported stronger cancer-related emotional distress when thinking on suffering from the disease. Our findings support the interdependence between illness cognitive and emotional representations posited in the SRM as theoretical premise. No previous study has been conducted in the context of cancer for testing this issue and thus, our findings should be considered as preliminary and need to be replicated in the future.

Contrary to findings on symptoms and consequences, which are in line with previous findings on associations between emotional and cognitive representations of cancer already discussed, the finding of an inverse relationship between duration and emotional representations might be counterintuitive *a priori*; however, it seems that participants are considering a possible fatal ending of the condition, and in that case the shorter the perceived duration of the illness, the greater emotional negative reactions. With cancer patients, it has been found that cancer is not perceived as a chronic, long-lasting disease, but patients report that they would either die from the disease or be cured (Hoogerwert et al., 2012). Other findings with cancer patients support this hypothesis. For instance, Millar, Purushotham, McLatchie, George and Murray (2005) explored predictors of emotional distress in women with breast cancer during a 12-month period after treatment. They found a general reduction in emotional distress over the 12-month period but also that 25% of patients maintained clinically significant levels of distress throughout the period. Patients with chronically elevated distress were characterised by greater perceived symptom impact (identity dimension) and shorter duration of the disease, both emerging as predictors of emotional well-being of patients during the follow-up period. The more highly distressed patients were more fatalistic and perceived a shorter timeline of their illness: the perception of short illness-duration might imply pessimism about survival (p. 340). Moreover, a mismatch between illness perceptions among survivors of colorectal cancer and their partners was found by Johansson et al. (2014) by which partners perceived the illness as a chronic condition and a permanent life-changing event more frequently than patients did.

In a subsequent analysis we found that experience with the disease and age moderated the influences of cancer illness cognitions on cancer-related emotional distress. Participants who perceived cancer as a more severe, impacting and externally caused disease who also had family experience with the disease reported higher levels of emotional reactions to cancer. A similar pattern was found for older participants. To our knowledge, previous studies have not addressed possible moderation effects of experience with the disease or age in the relationship between cognitive and emotional dimensions of illness representations. Our findings should thus be considered as preliminary results to guide future research hypotheses. Moreover, evidence exploring the relationships between experience with the disease and sociodemographic factors with cancer-related emotional distress among non-affected individuals (and patients) is lacking, so that our findings must be replicated in future research. This is also needed given that contradictory findings have been reported for the influence of age, gender or education level on cancer-related representations (e.g., Anagnostopoulos & Spanea, 2005; Del Castillo et al., 2011; Lehto, 2007; Wang et al., 2010), and although support is more conclusive on family experience with the disease, there is still a scarcity of evidence (e.g., Del Castillo et al., 2011; Dempster et al., 2011b; Godoy-Izquierdo et al., 2007; Juth et al., 2015; Lykins et al., 2008).

Cancer-related emotional distress and the adoption of preventive behaviours

According to the SRM, it is expected that more accurate beliefs will lead non-patients to carry out more appropriate and beneficial behaviours to face health threats before a diagnosis is given (Cameron & Leventhal, 2003; Leventhal et al., 1980; 1998; 2003, 2011). It is also expected that healthy people avoid risks, seek information or medical care, undergo medical exams or screening tests or adopt new healthy behaviours if they perceive a disease as preventable by their efforts (e.g., Figueiras & Alves, 2007; Niederdeppe & Gurmankin, 2007; Sullivan et al., 2010). Research exploring beliefs about an illness and related preventive behaviours is sparse and conducted mostly with patient and risk populations. Concretely in cancer, some studies have addressed this issue and support that illness cognitive and emotional representations powerfully influence preventive efforts among healthy people, at risk individuals and patients (e.g., Cameron, 2008; Constanzo et al., 2010; Figueiras & Alves, 2007; Orbell et al., 2006, 2008; Trask et al., 2008), although contradictory findings have been also reported (De Castro et al., 2015; Hevey et al., 2009). Consequently, it has been confirmed that illness perceptions guide behaviour in relation to prevention.

In particular, emotional distress is proposed to encourage preventive behaviours (Leventhal et al., 2001). Negative emotional reactions are in the first place generated by specific personal experiences with a health threat, rather than cognitive beliefs or verbal statements about it (Decruyenaere, Evers-Kiebooms, Welkenhuysen, Denayer &

Claes, 2000). Illness-related distress has been found to correlate with indicators of negative affect (Figueiras & Alves, 2007). Probably due to its relationship with worry, negative mood and fear of suffering from a disease, emotional representations have been proposed to promote preventive behaviours to face the risk of health threats (Leventhal et al., 2003). Previous findings are inconclusive regarding the role of psychological or emotional distress on cancer preventive efforts among healthy individuals, but in general support it. For instance, Honda, Goodwin and Neugut (2005) found that community people with higher psychological distress were more likely to engage in colorectal cancer screening, which was partially moderated by perceptions of cancer risk. Besides, emotional distress was directly associated to increased likelihood of risk factors such as smoking, physical inactivity and obesity. Cameron (2008) found that people who held more negative perceptions on skin cancer and reported higher worry regarding suffering from it (which was in turn predicted by identity and timeline-moment perceptions) addressed higher intentions of adopting preventive behaviours such as skin self-examination, clinical skin examination and sun protection behaviours. These findings have been replicated when emotional impact has been assessed through emotional representations dimension of the IPQ-R, as herein, as we discuss below.

The SRM provides a framework for identifying the contents of health threats representations and for understanding how these cognitions and associated emotions motivate protective behaviour (Leventhal et al., 2003). These representations elicit emotional arousal such as worry or distress, and both representations and emotions guide decisions to engage in health promoting or disease preventing behaviours. Supporting this, it has been found that emotional reaction to disease (i.e., event-related fear, assessed by selected items from the IPQ-R emotional dimension), along with attributing the health threat to smoking, predicted intentions to quit smoking among individuals with an acute health event at a emergency service and mediated the relationship between perceived illness severity (as assessed by selected items from the IPQ-R) (Boudreaux et al., 2010). Figueiras and Alves (2007) found that emotional distress was a significant predictor of intentions of adopting preventive actions, along with sense of coherence and lower psychological causal attributions; duration, consequences, coherence and lower psychological causal attributions predicted attitudes to preventive efforts. Orbell et al. (2008) found that emotional representations contributed to the prediction of avoidance coping style, which in turn was associated to participation in a new screening test for colorectal cancer 2 years later among those participants who were identified as with adenoma or no cancer in the first screening test. However, contradictory findings have been also reported. For example, emotional reaction to illness did not predict breast self-examination practices among long-term breast cancer survivors; however, participants' emotional representations were low (mean score= 2.2) (Trask et al., 2008). Intentions to attend prostate cancer screening test among at risk men were not predicted by any illness representation, including cancer-related emotional distress (Hevey et al., 2009).

Decruyenaere et al. (2000) elaborated a theoretical framework for understanding the influences of cancer-related emotional distress on preventive behaviours, which can partly explain these contradictory findings. They proposed that cognitive illness perceptions including perceived illness severity and vulnerability and causal attributions, emotional representations including cancer-related distress, and perceptions of controllability interact in influencing coping actions, i.e., preventive behaviours. Concretely, they proposed that the health-threatening situation combined with the cognitive beliefs on it activate illness-related emotional distress. These emotions promote emotion-focussed coping, which can interfere with (i.e., undermine efforts for managing the threat) or facilitate problem-focussed coping (i.e., reduce extreme emotional distress allowing information processing, decision making, etc.). They stated that this will depend on two conditions: type of behaviour and perceptions of controllability regarding the threat. In regards to the first, they affirmed that risk reducing actions (e.g., adopting healthy diet, using sunscreen) are more under control of cognitive processes than of emotional processes, because health is not threatened by this behaviour and thus, emotional distress is elicited at low levels; thus, emotional distress does not interfere with risk reducing actions. Instead, these actions are likely to be facilitated by emotional distress because of their potential for risk reduction and control, and thus emotional distress reduction. Emotional responses are, however, more interfering with disease detection behaviour (e.g., breast self-examination, genetic testing) because of the potential health threat of symptoms detection, which may result in increasing emotional distress. This may lead to distress-induced avoidance of the health behaviour. Thus, a positive linear relationship between emotional distress and health behaviours is expected when they are risk reducing actions (i.e., the higher the illness-related distress, the more likely the behaviour will be adopted), and a curvilinear relationship is expected when they are disease detection behaviour (i.e., low or high levels of distress, compared to moderate levels, are less likely to translate in preventive behaviour).

The second ingredient is perceptions of controllability on the health threat: The higher the perceived control, the more likely the behaviour adoption. They hypothesised that the level of emotional distress interacts with perceived control, so that the optimal level of emotional distress may be different for different subjects: the optimal level of distress for motivating preventive health actions may be lower for persons who hold low perceptions of controllability on the disease. People with strong perceptions of controllability will conduct behaviour changes even in the presence of high levels of emotional distress.

Decruyenaere et al. (2000) concludes that this facilitating or interfering relationship between problem- and emotion-focussed actions based on the interaction of illness cognitions, emotional distress, perceived control and type of preventive behaviour may explain the inconsistent findings established regarding the relationship between emotional distress and health-related behaviour.

Fear appeals and gain vs. loss message framing

Recently, a great interest has been devoted to fear-arousing (fear or threat appeals) and gain-loss message framing in health-related communications and their relationship with preventive efforts and change of health-risk behaviours. The first of these issues is partly based on the Protection Motivation Theory (PMT; Rogers, 1975, 1983), which proposes that the level of induced fear arousal influences the adoption of adaptive responses in a linear way. The premise of PMT is that people are motivated to protect themselves from physical, psychological and social threats. As posited by the PMT, protection motivation is the result of both threat appraisal and coping appraisal. The evaluation of the health threat (perceived vulnerability to the disease and perceived severity of the illness) and the appraisal of the coping responses (perceived response efficacy and perceptions of self-efficacy) result in the intention to perform adaptive responses (protection motivation), or maladaptive responses that place individuals at health risks. Protection motivation is a mediating variable that activate, maintains and guides protective health behaviour in order to reduce the fear arousal induced by the health threat or risk.

Based on this, fear appeals have been broadly used in health research and interventions. A fear appeal posits the risks of conducting inappropriate behaviours or not conducting appropriate behaviours, so that some particular dire consequences will occur. That is, fear appeals rely on a threat to an individual’s well-being that motivates him or her toward action, e.g., increasing control over a situation or preventing an unwanted outcome (Williams, 2012). Meta-analyses such as that by White and Allen (2000) revealed that strong fear appeals produce high levels of perceived severity and susceptibility and are more persuasive than low or weak fear appeals. Research has revealed that more effective fear appeals result from a higher fear arousal motivated from the warning of that if the current behaviour continues, the probability of negative health consequences is high, followed by recommendations to reduce the negativity, i.e., an effective alternative precautionary behaviour that guarantees protection from the predicted aversive health outcome (White & Allen, 2000; Williams, 2012).

PMT has been used as a framework for predicting and adopting several health promoting and protecting behaviours and the intention of behavioural change, including reducing substance (i.e., tobacco, alcohol) use, enhancing exercise, sun protection or condom use or conducting early illness-detection or screening efforts (Baban & Craciun, 2007; Ch'ng & Glendon, 2014; Hall, Bishop & Marteau, 2006; McGowan & Prapavessis, 2010; Pechmann, Zhao, Goldberg & Reibirg, 2003; Plotikoff & Trihn, 2010; Ruiter, Kok, Verplanken & Brug, 2001). Several meta-analyses supports the efficacy of PMT and its components for predicting and changing intention and behaviour (de Hoog, Stroebe & de Wit, 2007; Floyd, Prentice-Dunn & Rogers, 2000; Milne, Sheeran & Orbell, 2000; Sheeran, Harris & Epton, 2014), thus supporting the efficacy of PMT-guided fear-based messages. Based on meta-analytic procedures (Baban & Craciun, 2007; Webb & Sheeran, 2006), it has been determined that its efficacy for predicting intentions and behaviour change is associated to an effect size of 0.69 and 0.46, respectively, being among the most powerful models for generating behavioural change. However, while it has been found that fear appeals may result in attitude and behaviour change there is also the risk of inciting inappropriate levels of fear, instigating maladaptive behaviour in the target group such as denial or defensive avoidance or motivating the wrong audience (Jones & Owell, 2006; Lewis, Watson, Tay & White, 2007; White & Allen, 2000).

PMT, thus, has specified some of the important components of fear-arousing communications. Fear-arousing communications emphasize the negative consequences of health impairing behaviours to motivate individuals to change these behaviours. This relates with the issue regarding message framing. The persuasive impact of fear-arousing messages can be strengthened by taking into account action framing, given that action framing moderates the effects of fear arousal on precautionary motivation (Ruiter, Kok, Verplanken & van Eersel, 2003). Concretely, in their pioneer study on this interaction effect, Ruiter et al. (2003) found that high fear arousal paired with loss information was found to be more persuasive than high fear arousal paired with gain information or low fear arousal paired with either gain or loss information for performing breast self-examination among young women.

According to prospect theory (Kahneman & Tversky, 1979, 1984), individuals are motivated to act according to their perceptions of the risks associated with the outcome of performing a given behaviour. People are more risk-seeking when faced with losses than when faced with gains, because losses are seen as more painful than equivalent gains are seen as pleasurable. Message framing refers to the strategic emphasis of the benefits of performing a behaviour (i.e., gain-framed messages) or the risks of not performing a behaviour (i.e., loss-framed messages). Persuasive health education messages can either stress the positive consequences of performing a healthy behaviour or the negative consequences of not performing a healthy behaviour. There is evidence that messages in different action frames may differ in persuasive effects.

It has been hypothesized that loss-framed messages are more effective than gain-framed messages for persuading health behaviours with high-risk outcomes (e.g., illness detection behaviour such as cancer screening). Alternatively, gain-framed messages are hypothesized to be more effective than loss-framed messages for persuading behaviours with low-risk outcomes (e.g., promoting and preventive behaviours such as physical activity). However, evidence do not completely support this (O'Keefe & Jensen, 2006, 2009). Furthermore, contrary findings have been reported for diet (Brug, Ruitter & van Assema, 2003), condom use (Earl & Albarracin, 2007) or sun protection (O'Keefe & Wu, 2012). A meta-analysis conducted by Gallagher and Updegraff (2012) has found that gain-framed messages are more likely to encourage primary prevention behaviours, whereas no effects of action framing have been found for secondary prevention behaviours such as illness detection or for attitudes and intention change. Moreover, health status may also play a role, given that loss-framed messages seem to be more effective among individuals at high risk (Taber & Aspinwall, 2015) or already ill (Bassett-Gunter, Latimer-Cheung & Martin-Ginis, 2013).

Affect is gaining prominence in health behaviour research (Janssen, Waters, Van Osch, Lechner & de Vries, 2014), and there is progressively more evidence supporting than affective factors may be more strongly related to health-related intentions and behaviours than cognitive factors. Consequently, future research is needed for elucidating the efficacy of fear-appeals and gain- vs. loss-framed messages for the adoption of health promoting or protecting behaviours. Evidence to date suggest that emphasizing the possible gains of health action rather than the possible losses may help to reduce strong emotional reactions and to enhance feelings of control, enhancing the likeliness of behavioural change. It also suggests that moderate-fear arousing communications might play a relevant role in behavioural change, and that both loss- and gain-framed message might contribute to health-related actions implementation; however, the efficacy of the fear-arousing effect of loss-framed communications is in question. Nevertheless, some recent research indicate that emotional context may also play a role. For example, naturally-occurring or induced positive or negative affect increase the persuasiveness of gain-framed and loss-framed messages, respectively (Yan, Dillar & Shen, 2010). In the context of colorectal cancer screening, Ferrer, Klein, Zajac, Land & Ling (2012) have recently found that emotional context moderates the relationship between message frame and behavioural intentions. Contrary to expectations, when action frame is booster affectively, i.e., manipulated in order to increase both anticipated and anticipatory emotions associated with the framed messages by matching the message with a valence-congruent affective state, gain-framed messages have increased persuasiveness compared to loss-framed messages, which were more effective when no emotional booster was introduced. In the context of cancer-related preventive behaviours such as tobacco cessation and sunscreen use, Janssen et al. (2014) have found that affectively-laden risk beliefs (i.e., affect linked to likelihood of getting lung/skin cancer if not quitting smoking or using sunscreen) that cause emotional distress including anticipatory emotions such as worry and anticipated emotions such as regret predicted intentions and behaviours more strongly than cognitive risk beliefs. These findings allow us to identify optimal conditions for using affect-related and gain- and loss-framed messages.

Decruyenaere et al. (2000) stated that inconsistent findings on the relationship between emotional distress and health behaviour can be partly due to how emotional distress is defined and measured (i.e., cancer specific emotional distress is more strongly associated to behavioural indicators than general distress), and we agree with this after reviewing the empirical evidence accumulated to date on this issue. Furthermore, they also argued that the nature of behaviour (i.e., whether it is primarily aimed with promoting health or to protecting health by reducing disease risk, or it is aimed with detecting the presence of a disease for early intervention) is important, and evidence also point at this point. The relationship between cognitive perceptions, illness-related emotional distress and health behaviour is very complex, and may include other factors such as perceived control or self-efficacy (Decruyenaere et al., 2000; Leventhal et al., 1997).

Practical implications

Several practical implications can be derived from our findings. Identifying unhelpful representations and restructuring them as well as establishing and managing illness-related emotional distress, particularly among those with previous experience with cancer such as family experience, may be appropriate interventions to help individuals to change their health-related behaviours in order to encourage promotion and protection behaviours such as adopting an active lifestyle or a healthy diet, using seatbelt, condom or sunscreen or undergoing screening or genetic susceptibility testing. Moreover, the consideration of how illness cognitions and emotional reactions to the disease are constructed and fed in interdependence may help in designing adequate and effective communications for health-related behaviours change. We have confirmed herein the direction of the relationship from cognitive to emotional representations, but some other findings support that cognitive representations can also be transformed by emotional impact of the disease, supporting the interdependence of both dimensions of illness representations. For example, Lehto and Cimprich (2009) explored the relationship between worry and early formation of cognitive representations of illness in individuals with suspected lung cancer over the presurgical and 3-week postsurgical period. They found that higher worry was significantly related to more threatening perceptions of lung cancer. Furthermore, high worry was associated with increased threat and negative contents in cognitive representations of illness over time. Thus, worry may contribute to the formation of negative cognitive representations of illness that can have a detrimental effect on behavioural and adaptive outcomes. Finally, early identification of emotional vulnerable individuals and referral to supportive interventions may reduce future psychological suffering in the face of a diagnosis of cancer.

Limitations

Despite the contributions of the present study, the findings should be accepted with caution. Several limitations of the study justify it. First, the number of studies on cancer illness representations in Spanish samples is scarce, and thus we recommend conducting new studies aimed at replicating our results and comparing findings from other cultural contexts. Second, it would be advisable to increase the number and heterogeneity of participants, ideally constructing a representative sample of the Spanish population. Third, future research should compare the illness cognitive and emotional representations of non-patients, caregivers, patients with cancer, individuals at risk and people who have suffered from cancer (survivors), as well as consider the illness journey. Fourth, it should be recommendable to include behavioural outcomes, such as intentions of behaviour change or adoption of new healthy behaviours and to explore the role of cognitive and emotional cancer representations on behaviour change. Fifth, other relevant factors, such as type of cancer, specific family history and kinship or clinical history should be considered in the future. Finally, it would be interesting to explore how illness perceptions and cancer-related emotional distress change over time in response to new influences, such as an individual’s personal and/or family experience with the illness or a focussed intervention, and to establish its influence on behavioural and emotional outcomes.

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CAPÍTULO 9

ESTUDIO 3

Illness beliefs about hypertension among non-patients and healthy relatives of patients

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Abstract

Objectives: Personal beliefs about illnesses have received increasing interest because these cognitions help to explain and predict preventive and therapeutic coping efforts, adjustment to a disease and health outcomes. We sought to explore and compare non-specialised illness representations of hypertension among adults never suffering from hypertension who had and had not lived with hypertensive patients.

Design: Hypertension representations were explored in a community-based, convenience sample of normotensive Spanish adults of both genders from different educational backgrounds and with different family experience with this illness.

Method: An adapted Illness Perception Questionnaire-R was used to assess such perceptions among healthy people in nine dimensions: Identity, Consequences, Personal Control, Treatment Control, Illness Coherence, Evolution, Emotional Representations and Causes.

Results: The participants' beliefs mixed accurate and folk knowledge. While gender, age and education level had little impact, family experience (having or not having a relative with hypertension) strongly determined the content of hypertension representations. Participants with family experience held significantly stronger beliefs of controllability of the disease, both by patients and treatments, considered the disease as less stable and reported a lower emotional impact when thinking on suffering from hypertension. Family experience was the only significant predictor of illness cognitions.

Conclusions: This study allowed us to know the perceptions of hypertension among non-patients and healthy relatives of patients. Our findings are useful in designing interventions aimed at hypertension prevention, particularly considering family experience with the disease.

Keywords: Illness representations, IPQ-R, hypertension, non-patients, prevention

Introduction

Hypertension is a public health problem in both economically developing and developed nations. Nearly one third of the adult worldwide population has hypertension [1-3]. In Spain, hypertension prevalence in the adult population is currently around 35%, affecting around 10 million people [4]. Although hypertension is not a severe disease by itself, it is considered a “silent killer” because high blood pressure is an important risk factor for other more serious disorders such as cardiovascular, kidney, eye or pulmonary diseases. Thus, hypertension is a major source of morbidity and mortality.

According to the *Self-Regulation Model of Common Sense Illness Representations* (SRM) [5-13], people are active decision-makers and problem solvers and play an agentic role in self-regulation. Both healthy and ill people construct non-specialised models about illnesses which comprise a series of cognitive and emotional representations to create an integrated, comprehensible and meaningful picture of a health-threatening condition. Illness representations derive from several informational sources, including: a) an individual’s knowledge and direct experiences; b) sociocultural knowledge; and c) information and experiences from significant others (e.g., relatives, physicians) [6, 7].

Sociodemographic variables such as gender, age and educational level are not usually significant correlates of illness beliefs in the case of physical diseases [14-16], although a number of exceptions have been reported [17-19]. However, having suffered from the disease or having an ill relative consistently emerges as a relevant contributor to illness representations for physical illnesses [14-16, 20-28].

Individuals use these representations to evaluate the risks for health and well-being, and then direct diverse behavioural and emotional efforts to face the perceived risks and to protect health. Individuals who are already ill use these representations to manage their condition, to control its consequences in their lives and to recover their health, well-being and quality of life. Therefore, as for the SRM illness representations directly influence the illness-related emotion- and problem-focused coping actions and indirectly, by a mediation path of coping, also influence the consequences of illnesses and the adjustment to the disease. There is substantial evidence from populations with different physical and mental illnesses supporting the relationship between illness perceptions and specific coping behaviours (such as adherence to medical recommendations) and between illness beliefs and a wide range of consequences (such as quality of life) [see 29-32 for a review].

Although hypertension is a frequent disease, non-specialised illness beliefs about it have been examined in only a few studies. Research conducted with hypertensive patients [23, 34-41] has shown that their representations of the disease include biomedical knowledge mixed with folk information, and that those representations impact on their illness-related behaviours, such as adherence to treatments. Some of these studies have also examined the impact of sociodemographic conditions on hypertension beliefs. Ross et al. (2004) found that men, compared to women, considered that hypertension has a broader impact on patient’s life, but also held stronger beliefs of personal and treatment control on the disease. Older participants, compared to younger participants, held weaker beliefs on consequences, personal control and emotional impact, but stronger perceptions on treatment control. Wilson et al. (2002) also found that younger participants underestimated mortality associated to hypertension. Research on hypertension beliefs among healthy individuals is very sparse and the findings are inconclusive. Wilson et al. (2002) assessed beliefs about hypertension in an African-American sample including hypertensive patients and healthy people. The disease was perceived by most of the participants, with no discrimination between healthy and hypertensive participants, as symptomatic, caused mainly by stress, heredity and eating habits and treatable with vitamins, home remedies, medication and lifestyle changes. Meyer et al. (1985) sampled 230 individuals, 50 of whom were non-hypertensive, and found that both normotensive and hypertensive participants believed that symptoms were associated with elevations in blood pressure and, consequently could be used to monitor blood pressure elevations, that the disease has a limited duration and that it is caused by a variety of environmental and psychosocial conditions, such as work or family problems, stress and diet.

To our knowledge, only one study has been conducted with Spanish population. Godoy-Izquierdo et al. (2007) investigated illness representations for several diseases (cancer, hypertension, influenza, depression and schizophrenia) in a sample of university students who had or had not had any of those diseases and who did or did not live with a patient suffering from any of them. They utilized a less-used survey for assessing illness beliefs. Approximately 2.5% of the participants suffered or had suffered from hypertension, and 43.5% were living or had previously lived with a hypertensive patient. Most of the participants believed that hypertension had no bodily symptoms, it had a notable impact on patient´s life and it was long-lasting but amenable to cure. A high percentage of participants thought that hypertension was linked to psychological factors, such as stress and emotional activation or lack of rest. These findings are consistent in many respects with those from studies of hypertensive patients [34, 35, 37, 39, 41], but they differ particularly on the identity dimension, as patients tended to believe that high blood pressure manifests through bodily symptoms.

Godoy-Izquierdo et al. (2007) also found for the diseases studied that the illness cognitions of participants who had either personal experience of the diseases or a diagnosed relative were significantly different from those of participants without such a direct or family experience. Compared to participants without a personal or family experience, patients and their relatives perceived the diseases as significantly less chronic and serious, more stable but also recurrent, with fewer or less severe consequences for daily functioning and well-being, as more preventable and controllable, and as more amenable to a cure. These findings imply an essential influence of experience with a disease on lay representations of it.

The present study was conducted to address and compare the illness representations of hypertension among healthy, normotensive Spanish adults who differed in their family experiences with the disease. To our knowledge, no study has considered the impact of sociodemographic factors on the representations of hypertension specifically among healthy people, and we also addressed this issue. We used the most widely accepted SRM-derived tool for assessing illness representations: the revised version [42] of the Illness Perception Questionnaire [43]. Based on previous findings in the above-mentioned illness representations studies, we predicted that the participants' beliefs about hypertension would reflect both biomedical knowledge and folk information. We did not expect that gender, age or educational level would influence hypertension representations. However, we expected that the experience of living with a hypertensive patient would impact the representations of healthy participants.

Methods

Participants

A total of 130 adults (50% women) 18 to 66 years old (*M*= 39.97; *SD*= 13.81) participated. Table 1 displays their most relevant characteristics. At the time of the study, none of the participants had ever suffered from hypertension, and 38.5% (50 participants) had lived or were currently living with any relative who had hypertension. This community-based, convenience sample was recruited at random from private households and community settings such as public transport stations, workplaces, parks, healthcare service delivery locations, academic centres and shopping centres. In 17.7% of cases, participants reported suffering from a physical or mental disease at the time of the study. More frequently reported diseases were depression (30.4%), anxiety (26.1%) and diabetes (17.4%). The other reported illnesses affected only one or two individuals each. No participant reported any severe illness.

Table 1: Socio-demographic data.

		%
Age ranges	18-25	20.8
	26-35	22.3
	36-45	17.7
	46-55	21.5
	56-66	17.7
Educational level (highest completed level)	No formal education	7.7
	Primary school	21.5
	Secondary school	27.7
	Vocational training and other formal education	9.2
	University	33.8
Work status	Student	13.1
	Employed	59.2
	Student & Employed	5.4
	Housework	14.6
	Unemployed	7.7
Marital status	Single	19.2
	Short-term relationship (< 3 years)	23.8
	Long-term relationship (> 3 years)	47.7
	Separated/Divorced	6.9
	Widow	2.3
Physical or mental disease at the time of the study	Yes	17.7
	No	82.3

Measures

The participants completed a Spanish-modified version of the Revised Illness Perception Questionnaire (IPQ-R) by Moss-Morris et al. (2002) adapted to assess illness perceptions among healthy people [21]. The IPQ-R evaluates nine dimensions from Leventhal and colleagues' SRM model and research findings [42]: Identity (symptoms associated with the illness and label); Timeline (duration and chronicity); Consequences (effects of the illness on an individual's lifestyle, health and well-being); Personal Control (personal influence on preventing and managing the disease); Treatment Control (availability and efficacy of treatments to manage or cure the disease and its symptoms); Illness Coherence (personal understanding of the disease); Evolution (course and temporal changeability or fluctuation of the illness and symptoms); Emotional Representations (emotional impact of the disease) and Aetiology or Causes (psychological, behavioural, biological, chance and external causes of the disease).

For all of the dimensions except identity and causes, a series of statements (e.g., "My illness does not worry me") are included for which the person must express his or her level of agreement on a Likert-type scale with five alternatives (from "Strongly disagree" to "Strongly agree"). For all these subscales, partial scores were defined as the mean of the scores for the items on each subscale (considering direct and inverse items, see table 2), with higher scores indicating stronger beliefs about the disease chronicity, cyclical course, impact and outcomes, personal influence, cure possibilities, perceived understanding and emotional reactions to the disease. For the identity dimension, answers to whether each in a series of symptoms was perceived as characteristic of the disease were examined. The higher the score, the more symptomatic the disease was perceived to be. For the cause subscale, those factors scoring the highest in a series of possible causes are those the person considers to be the most relevant aetiological factors for the illness. A global score was calculated by summing the answers to all items excepting those from causes subscale, with higher scores reflecting stronger illness representations.

Following previous suggestions [42, 43], we modified the questionnaire to adapt it to non-patients and to make it more complete and better fitted to hypertension. Therefore, each reference to "my" illness was substituted by "the" illness or "hypertension". For the identity subscale, some new symptoms were added, while others were augmented with additional detail or re-categorised. Two new items (#20 and #24 in our version) were added to assess complementary beliefs about a cure for hypertension. Item 21 in our version was rewritten to assess beliefs about prevention of the disease. Items measuring the emotional representations dimension were also rewritten to assess emotional distress among healthy people. Items 22 and 25 were completed. Some causes were completed or added to the cause subscale (see all changes in table 2).

The psychometric properties of the IPQ-R have been previously demonstrated among English-speaking and Spanish populations [21, 42, 44], as well as in the context of hypertension [44]. The internal reliability of the IPQ-r version used was *alpha*= 0.77 (the identity dimension was excluded from the analysis).

Procedure

After the study was approved by the institutional research ethics committee, participants were asked to take part voluntarily and to sign an informed consent form. They had been informed previously that the general objective of the study was to learn their beliefs about hypertension and not to gauge their level of knowledge. Specific instructions for completing the questionnaire were given. A survey requesting personal and sociodemographic data was also included and contained questions about whether participants had ever suffered from hypertension and whether they had ever lived with a relative who was diagnosed with hypertension.

A community-based convenience sample was constructed. Three housing buildings and several community settings per district were selected at random with a local telephone directory. A person in one of every three possible households and one of every three people in the public settings were asked to participate and followed the above-mentioned procedure when they accepted. Questionnaires from people suffering or having suffered from hypertension were not considered for analysis.

Data analyses

We conducted preliminary analyses to detect errors in data, lost or absent data, or extreme and outlier values and to check parametric assumptions to make decisions on statistical tests. Given that the parametric assumptions were met in the majority of the variables (although Kolmogorov-Smirnov tests were usually significant, no significant Levene coefficients were found), we opted for parametric tests. Descriptive analyses, ANOVAs and *t*-tests for group comparisons and multiple linear regression analyses were conducted. In addition, Cohen's *d* coefficient was calculated to estimate effect size (for equal or unequal sample sizes).

Results

Non-specialised beliefs about hypertension

To establish the contents of illness models for hypertension in detail, descriptive data and the percentages of responses for each item were obtained (see table 2).

Influence of gender, age and educational level on hypertension representations

Women showed stronger beliefs about identity, timeline and coherence for hypertension, while men had stronger beliefs about consequences, personal control, treatment control, evolution and emotional representation. We only found one significant difference: men believed that hypertension has more serious consequences for patients and their families than did women (see table 3). The value of *d* is moderate for this comparison and below 0.3 for the remaining ones.

Table 2: Percentages of agreement responses and descriptive results for each subscale.

Dimensions		%
Identity (0-15^{a}) (perceived symptoms of hypertension) *M*= 5.38, *SD*= 2.51; R= 0-13	Fatigue, tiredness	76.2^{c}
	Tachycardia^{b}	76.2
	Dizziness, vertigo^{b}	74.6
	Pain anywhere^{b}	49.2
	Emotional distress, sadness or anxiety^{b}	43.1
	Weakness, loss of strength^{b}	40
	Breathlessness, respiratory problems^{b}	39.2
	Sleep difficulties	34.6
	Nausea	23.1
	Mobility difficulties^{b}	17.7
	Stiff joints	16.2
	Stomach-intestine problems^{b}	11.5
	Fever^{b}	10
	Weight loss	9.2
	Delirium and hallucinations^{b}	7.7
Timeline (acute/chronic) (1-5) (This illness…) *M*= 3.92, *SD*= 0.65; R= 2.17-5	3. Will last for a long-time	80^{d}
	2. Is likely to be permanent rather than temporary	69.2
	5. Is expected to be for life	63
	6. Will improve in time^{e} (Item 18 in IPQ-R)	17.7
	4. Will pass quickly^{e}	7.7
	1. Will last a short time^{e}	2.3
Consequences (1-5) (This illness…) *M*= 2.87, *SD*=0.57; R= 1.33-5	7. Is a serious condition	59.3^{d}
	8. Has major consequences on patient's life	49.2
	12. Causes difficulties for the people close to patients	14.6
	9. Does not have much effect on patient's life^{e}	12.3
	11. Has serious financial consequences	12.3
	10.Strongly affects the way others see patients	8.5
Personal Control (1-5) *M*= 4.18, *SD*=0.58; R= 2-5	17. Patients have the power to influence their illness	94.6^{d}
	14. What patients do can determine whether their disease gets better	88.4
	or worse	85.4
	13. There is a lot which patients can do to control their	73
	symptoms	8.4
	15. The course of the disease depends on the patient	
	18. A patient's actions will have no effect on the outcomes of her/his illness^{e}	5.3
	16. Nothing the patient does will affect his/her illness^{e}	
Treatment Control (1-5) *M*=3.91, *SD*= 0.45; R= 2.71-5	22. The treatment can control the disease and its negative	85.4^{d}
	effects	76.2
	21. The illness can be prevented	63
	20. The treatment effectively relieves the symptoms but does	
	not cure the disease (new)	38.4
	25. Some treatment or intervention exists which is effective in	
	curing this disease (medication, therapy, surgery,	
	rehabilitation...) (Item 20 in IPQ-R)	10
	23. There is nothing which can help the patient's condition^{e}	3.8
	19. There is very little that can be done to improve when ill^{e}	2.3
	24. This illness goes away or is cured by its own^{e} (new)	
Illness Coherence (1-5) *M*=3.41, *SD*=0.89; R= 1.40-6	30. I have a clear picture or understanding of the disease	51.6^{d}
	26. The symptoms of this disease are puzzling to me^{e}	26.9
	27. The disease is a mystery to me^{e}	23.1
	28. I don't understand this illness^{e}	19.2
	29. The disease doesn't make any sense to me^{e}	7

Table 2: (Continued)

Evolution (timeline-cyclical) (1-5) *M*= 2.83, *SD*= 0.92; R= 1-5	34. The patient goes through cycles in which the disease gets better and worse	34.7
	33. The disease is very unpredictable	33
	32. The symptoms come and go in cycles	29.2
	31. The symptoms of this disease change a great deal from day to day	23.8
Emotional Representations (1-5) *M*= 2.57, *SD*= 0.79; R= 1-5	38. I am not worried about this disease or suffering from it[e]	21.5[d]
	35. I get depressed when I think I have or may have this disease	15.3
	36. When I think on this disease I get upset	13.8
	40. Thinking on having this disease makes me feel afraid	12.3
	39. I feel anxious about the idea of having this disease	11.5
	37. To think on having this illness makes me feel angry	9.2
Causes	Diet, eating habits	86.9[d]
	Stress or worry	84.6
	Smoking	83.9
	Ageing	81.6
	Overwork	76.1
	Hereditary, genetic[b]	73.1
	Alcohol consumption[b]	66.1
	Poor medical care in one's life	51.6
	Family problems or worries	48.5
	One's own behaviour and habits[b]	44.7
	One's own emotions and moods	43
	Accident or injury	41.5
	One's own mental attitude and thinkings[b]	24.7
	Chance, bad luck	22.3
	Pollution, environmental contamination[b]	21.5
	One's own personality	19.3
	Other people[b] (new)	9.2
	Immunity problems[b]	7.7
	Germs or viruses	6.2

Footnotes: Range of possible responses: Identity subscale: 1=Yes, 0=No; Remaining subscales: 1=”Strongly Disagree”-5=”Strongly agree”.

[a] Minimum and maximum possible score in the subscale in the revised questionnaire used in this study.

[b] Symptoms/causes added, completed or grouped in categories

[c] Percentage of people answering “Yes”

[d] Percentage of people answering “Agree” plus “Strongly agree”

[e] Reverse-scored item

Table 3: Comparisons according to gender.

DIMENSIONS[a]	MEN (N=65)		WOMEN (N=65)		*t*	*p*	*d*
	M	*SD*	*M*	*SD*			
Identity	5.32	2.13	5.43	2.86	-0.243†	0.808	-0.04
Timeline	3.9	0.68	3.93	0.62	-0.292	0.770	-0.05
Consequences	2.98	0.66	2.75	0.44	2.414†	0.017*	0.42
Personal control	4.22	0.54	4.15	0.61	0.657	0.513	0.12
Treatment control	3.95	0.43	3.87	0.47	0.945	0.346	0.18
Coherence	3.33	0.93	3.5	0.86	-1.101	0.273	-0.19
Evolution	2.89	0.94	2.78	0.9	0.692	0.490	0.12
Emotional representations	2.66	0.7	2.48	0.88	1.292†	0.199	0.23

[a] Aetiology dimension was not considered for comparison analyses.

† Not considering equal variances. * $p < 0.05$

We considered five age groupings for comparative purposes. In general, as age increased, stronger beliefs were found, with the exceptions of beliefs in the symptoms and coherence dimensions. Although no significant differences were found in the ANOVAs (see table 4), we found marginally significant differences for two dimensions and the following significant differences in pair comparisons, accompanied by moderate to high effect sizes. Bonferroni's post hoc comparisons revealed that participants aged 26-35 yr. indicated significantly more symptoms than did participants aged 56-66 yr. (*p*=0.028, *d*= 0.93), and Games-Howell's test showed that participants aged 18-25 yr. reported a significantly lower level of perceived personal control of the disease than did participants aged 56-66 yr. (*p*=0.047, *d*= 0.78). In the dimension of emotional representations, although the comparison for participants aged 36-45 yr. and 46-55 yr. was non-significant, the *d* value was 0.67, indicating a moderate effect size for this difference.

Table 4: Comparisons according to age.

DIMENSION	18-25 (N=27)		26-35 (N=29)		36-45 (N=23)		46-55 (N=28)		56-66 (N=23)		*F*	*p*
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*		
Identity	5.37	2.40	6.31	2.25	5.56	2.98	5.21	2.42	4.22	2.24	2.385	0.055
Timeline	3.82	0.7	3.97	0.56	4.01	0.65	3.73	0.55	4.09	0.77	1.309	0.270
Consequences	2.78	0.34	2.96	0.8	2.78	0.59	2.86	0.49	2.93	0.56	0.530	0.714
Personal control	3.99	0.6	4.12	0.74	4.16	0.51	4.29	0.51	4.39	0.39	1.915	0.112
Treatment control	3.78	0.35	3.98	0.46	3.97	0.46	3.9	0.54	3.93	0.42	0.818	0.516
Coherence	3.44	0.71	3.52	0.98	3.61	0.87	3.17	0.93	3.33	0.95	0.956	0.434
Evolution	2.57	0.84	2.97	0.88	3.07	1.07	2.77	0.83	2.8	0.97	1.124	0.348
Emotional representations	2.49	0.99	2.44	0.84	2.4	0.75	2.84	0.57	2.69	0.73	1.469	0.216

Participants' education level in the Spanish school system was also considered for comparison purposes. In general, as education level increased, stronger beliefs were found, with the exceptions of consequences and emotional representations dimensions, although university-educated participants usually showed a change in this pattern. ANOVAs showed significant differences for two dimensions and marginally significant differences for another one (see table 5). Bonferroni's posthoc comparisons revealed significant differences for the dimension of timeline for participants with no formal education versus primary education (*p*=0.049, *d*= 1.02) and versus university education (*p*=0.036, *d*=1.25), with participants with higher education scoring higher. In the treatment control dimension, significant or marginally significant differences were found between participants without studies and the remaining participants, such that participants with no education scored lower (*p*= 0.06, *d*= 1.10; *p*= 0.004, *d*= 1.32; *p*= 0.009, *d*= 1.41; *p*= 0.027, *d*= 1.04, respectively). We also found a marginally significant difference in identity beliefs between the participants with primary versus secondary education levels, with primary-educated participants indicating fewer symptoms (*p*=0.102, *d*=0.68). A moderate effect size was also found for the non-significant difference in identity beliefs between participants who had secondary-level education and those with other formal education (*d*=0.67). Although no further significant differences were found, we obtained two other large effect sizes that included the dimension of personal control, in the comparison between participants with no formal education and those with primary studies (*d*= 0.87), and the dimension of timeline, in the comparison between participants without studies and those with other formal studies (*d*= 0.89).

Table 5: Comparisons according to educational level.

DIMENSION	No education (N=10)		Primary (N=28)		Secondary (N=36)		Others (N=12)		University (N=44)		*F*	*p*
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*		
Identity	5.40	3.50	4.57	2.17	6.19	2.52	4.50	2.47	5.45	2.35	2.119	0.082
Timeline	3.4	0.66	4.06	0.64	3.75	0.7	4.04	0.76	4.05	0.48	3.366	0.012*
Consequences	2.95	0.35	2.88	0.57	2.76	0.39	2.61	0.87	2.99	0.63	1.521	0.200
Personal control	3.97	0.55	4.36	0.41	4.21	0.52	4.15	0.60	4.11	0.69	1.243	0.296
Treatment control	3.44	0.44	3.89	0.4	4.01	0.43	4.07	0.45	3.91	0.45	3.827	0.006**
Coherence	3.2	0.72	3.38	0.85	3.54	0.92	3.55	1.2	3.34	0.86	0.491	0.742
Evolution	2.7	0.59	3.0	1.15	2.88	0.91	2.73	1.22	2.74	0.73	0.444	0.776
Emotional representations	2.62	0.52	2.65	0.76	2.7	0.83	2.24	1.03	2.5	0.77	0.936	0.445

* $p < 0.05$ ** $p < 0.01$

Influence of family experience with the disease on hypertension representations

When we compared the representations of hypertension of participants who had never lived with a person with hypertension and those who were currently living with someone with this disease or who had done so in the past, we generally found that those who had experience with the disease had stronger beliefs on all dimensions except consequences and emotional representations. Significant differences were found for the dimensions of personal control, treatment control, evolution and emotional representations (see table 6). Effect sizes were up to moderate for these differences.

Table 6: Comparisons according to experience with the disease.

DIMENSIONS	EXPER. (N=50)		NO EXPER. (N=80)		*t*	*p*	*d*
	M	*SD*	*M*	*SD*			
Identity	5.66	2.58	5.20	2.47	1.016	0.312	-0.18
Timeline	3.99	0.69	3.87	0.62	0.974	0.332	-0.19
Consequences	2.8	0.56	2.9	0.58	-0.975	0.331	0.17
Personal control	4.35	0.53	4.08	0.58	2.641	0.009**	-0.48
Treatment control	4.06	0.41	3.82	0.45	3.040	0.003**	-0.55
Coherence	3.57	0.89	3.32	0.88	1.580	0.117	-0.28
Evolution	3.15	0.93	2.63	0.85	3.232	0.002**	-0.59
Emotional representations	2.35	0.79	2.71	0.77	-2.562	0.012*	0.46

Equal variances assumed for all. * $p < 0.05$, ** $p < 0.01$

Predictors of the illness perceptions on hypertension

Finally, to establish which variable(s), if any among the sociodemographic and family experience variables, significantly predicted hypertension representations, we conducted a step-wise multiple regression analysis. We considered the outcome variable to be the total IPQ-R score obtained by adding all the partial scores (except for the causes dimension) such that the higher the global score, the more robust the beliefs about hypertension. Controlling for age, gender and educational level (none of which explained an independent, significant proportion of the predicted variable in an analysis conducted as a first step), family experience was the only significant predictor, explaining 3.2% of the IPQ-R total score (corrected R^2= 0.032; F= 5.307, p= 0.023). Having a relative diagnosed with the disease increased a person's score by 0.2 units (standardised beta= -0.200; t= -2.304, p= 0.023). Although the influence of family experience is small, it is a significant impact.

Discussion

Although the SRM has been applied to different physical and mental illnesses, there are relatively few studies regarding the non-specialised beliefs that healthy people hold and how their beliefs influence health- and disease-related behaviours [e.g., 16, 21, 27, 41, 45, 46]. This is particularly true for the Spanish population. Furthermore, research specific to hypertension is scarce, although this disease is one of the leading causes of morbidity in the world and one of the main risks factors for serious pathologies such as heart attack, stroke or chronic renal failure. Consequently, healthy people, risk populations, patients, relatives of patients and even health professionals are in need of tailored interventions. This study focused on establishing the representations of hypertension among healthy, normotensive Spanish adults of both genders and with diverse educational backgrounds and varying family experience with the disease. In summary, we found that the participants' beliefs about hypertension were fairly accurate but also deviated from medical knowledge in some respects. Our findings also indicated that there was a little influence of educational level gender and age. However, a personal experience of having lived with a hypertensive patient had a relevant impact on the contents of illness representations.

Descriptive findings indicated that hypertension was considered by non-patients to be a symptomatic, stable and durable (i.e., chronic) disease that is highly controllable by both the patient and by treatments and that has only a moderate impact on the patient's life. Specifically, the participants believed that the patients experience an average of five symptoms related to high blood pressure, such as fatigue or tiredness, tachycardia, dizziness or vertigo (identified by 3 out of 4 participants), and even pain or mood disturbances (identified by almost half of participants). These data stand in contrast to the asymptomatic character of hypertension, the so-called “silent killer”, at least until the disease becomes very advanced. The results are consistent with others’ findings obtained from patients [37, 39, 41] and indicate the necessity for non-specialised people of looking for indicators of the presence of the illness (signs and symptoms) as a way to identify when they are ill or not.

For the majority of the participants, hypertension was seen as a moderately severe, life-long disease that causes some difficulties to patients but not to their families. This perception may derive from the severe pathologies that follow from hypertension and not to hypertension itself, which generally does not have a significant impact on patients’ daily lives. Furthermore, hypertension was perceived as a disease whose development, evolution and recovery are controllable by both the patient and the available treatments. Participants implicated behavioural and psychological factors, such as eating habits, stress and substance abuse (e.g., smoking, alcohol intake) more frequently. Uncontrollable causes, such as age or genetics, were also indicated. This finding may be due to the way hypertension is treated in prevention interventions, where management of controllable psychosocial aspects is emphasised to decrease the impact of other uncontrollable risk factors. Moreover, a very high percentage of the sample believed that available treatments could bring relief from symptoms of the illness; however, hypertension was not perceived as a curable disease.

Regarding its course and evolution, hypertension was perceived as a stable disease, although one out of three people believed that it goes through cycles in which the symptoms increase or decrease. Half of participants affirmed they had poor understanding of the disease. This low level of understanding probably is related to the asymptomatic nature of hypertension and the absence of clear signs of the disease beyond blood pressure tests, at least in the initial disease stages. These circumstances can impede the layperson’s grasp of the disease and its characteristics, although the high incidence and prevalence of hypertension is a reality of our culture.

Regarding the emotional representations, we found that participants did not feel particularly worried, fearful or sad when thinking about developing this disease. This low perceived emotional impact stands in contrast with the fact that almost 6 out of 10 participants considered hypertension a serious illness and almost half of them believed that it has important consequences for patients. Although hypertension has a high incidence and prevalence in the population worldwide and it can be associated with serious or even lethal disorders, this is perceived as only occurring in a relatively low proportion of hypertensive patients. Hence, the vast majority felt that suffering from this illness does not mean experiencing very serious consequences in daily life or general health.

Our results support previous findings regarding both the content and fit of beliefs on hypertension with objective medical knowledge [37-39] and are similar in many respects to those obtained in a Spanish study [23]. In our study, hypertension representations were generally accurate but sometimes they differed from medical knowledge and were based on common sense, cultural beliefs and folk knowledge. Other researchers have stated that laypeople's illness cognitions of diverse physical illness diverge sharply from current medical understanding [14, 21, 23, 37, 39, 41, 47, 48].

Research exploring the influence of sociodemographic factors on lay representations of hypertension is scarce. Contrary to findings by Ross et al. (2004), we have found that sociodemographic variables have little influence on hypertension cognitions. When we examined the impact of gender, we only found that, compared to women, men perceived significantly more frequent or severe consequences of hypertension (i.e., men perceived hypertension as more serious, with a strong and broad impact to patients, their relatives and caregivers). With regard to age, only 2 significant differences in 80 comparisons were found. Some significant differences emerged for educational level, although only regarding the disease timeline and treatment control dimensions. The general tendency of the significant findings was, as expected, that a higher level of formal education led to more accurate beliefs.

As we documented in the Introduction, direct experience with an illness, in terms of suffering from the disease or caring for a patient, is proposed by the SRM and has been found to have an important influence on the construction of illness representations. To date these influences from personal experience with the disease have not been broadly explored in the case of hypertension [e.g., 23, 41]. In our study, after controlling for sociodemographic variables, personal experience (i.e., living with a patient) was the only significant predictor of hypertension representations. Furthermore, patients' relatives or caregivers perceived hypertension as significantly more manageable by both patients and treatments. People who had lived with a hypertensive patient also perceived the disease as significantly more unpredictable and changeable, with improvements and relapses over time. They also reported a significantly lower level of negative feelings of worry, fear or sadness when faced with the possibility of suffering from hypertension themselves. This apparent emotional immunity may be linked to their daily experience with the disease and its consequences.

The SRM proposes that illness-related behaviours, such as adhering to a healthy habit or to drug treatments, are strongly influenced by illness perceptions. Patients and non-patients consider whether such behaviour changes are consistent with what they believe about the illness and its management when deciding on complying with the recommended changes. In the case of hypertension particularly, adherence to behavioural changes has an added importance because inaccurate beliefs about this illness [37-39, 41, 49], particularly about its causes [42], together with its asymptomatic nature, seem to negatively affect adherence to prescribed treatments and preventive or therapeutic behaviours.

It is important to know how a very extended but preventable disease such as hypertension is understood by healthy laypeople and to know which beliefs derive from a direct experience with the disease so that interventions, such as health promotion and disease prevention programmes, can be targeted appropriately. Our findings provide a basis for new research and interventions aimed at hypertension prevention. As the SRM suggests, patients cope with their disease and its impact based on their beliefs and, for example, adhere to treatments, self-regulate emotional distress or adopt self-care activities or changes in lifestyles if they believe something can be done to manage the disease, its symptoms and its consequences for their lives. Similarly, it is expected that healthy people avoid risks, seek medical care, undergo medical exams and adopt new healthy behaviours if they believe they can act to prevent a disease. In our study, 3 out of 4 participants perceived hypertension as a preventable disease. Previous research has established a positive relationship between perceptions about an illness and the attitudes, intentions and actions regarding future protective and preventive behaviours [26, 50-52]. Thus, it is expected that more accurate beliefs will lead non-patients to carry out more appropriate and beneficial actions to face illnesses before a diagnosis is given. Individually focused revision and discussion of illness beliefs should modify misconceptions and biased, inappropriate and unrealistic expectations.

Understanding the illness beliefs held by healthy people would also provide insights as to how a particular illness or health-threatening condition is perceived prior to a possible personal or family experience with the disease. It would help us to understand how these representations are changed by the illness experience; how they relate to specific coping behaviours, adjustment and health outcomes with and without personal or family experience; and how this information can be used to derive preventive and therapeutic interventions aimed at modifying illness beliefs in both patients and non-patients. Furthermore, such knowledge would allow us to inform appropriate preventive and therapeutic interventions, so as the emotional and behavioural managing actions of non-patients and patients could be better adjusted to their respective conditions and result in more positive outcomes in terms of health and well-being and management of risks. Our study also stresses the key role of health psychologists in primary and specialised care and, more broadly in community health policies and campaigns, for educating both laypeople (patients, non-patients, relatives and caregivers) and specialised staff.

However, some limitations of this study should be considered in future research. Given the scarcity of studies on hypertension representations in Spanish samples we encourage researchers to conduct new studies aimed at replicating our results and to include cross-cultural comparison purposes. It would be advisable to increase the number of participants and to include a more heterogeneous sample. Further, sample size made comparisons between groups to have been done with small groups, limiting the statistical power of the analyses. The reliance on self-reported diagnoses of personal and family member hypertension has important limitations, as prevalence may be under- or overestimated. Nonetheless, this procedure has been found to show a moderate to excellent agreement with epidemiological, population-based prevalence in nationwide samples [53-55]. Thus, self-reports are considered valid and an appropriate indicator for the surveillance of hypertension prevalence in the absence of blood pressure measurement. Researchers and health specialists are increasingly obtaining information on chronic illnesses from self-reports [e.g., 56-60]. Future research should also compare the beliefs of non-patients, caregivers, patients with hypertension and people who have suffered from hypertension. Further, neither the type and accuracy of knowledge the participants had nor the sources of said knowledge were considered herein, and it would be appropriate to know and compare the beliefs of people who have significant medical knowledge with those held by people with no specialised knowledge. It would be also interesting to consider participant`s current or future risk of having hypertension due to behavioural or genetic causes. Finally, it would be interesting to explore how illness perceptions themselves change over time in response to new influences, such as an individual’s personal and/or family experience with the illness.

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CAPÍTULO 9

ESTUDIO 4

Hypertension representations in a community-based sample of Southern European non-hypertensive individuals and related preventive perceptions and behaviours

Abstract

Personal beliefs about illnesses have received increasing interest because they help in understanding preventive and therapeutic illness-coping efforts and health outcomes. The present research is composed of two studies. Study 1 was conducted to explore illness representations of hypertension (HT) among normotensive Spanish adults. Study 2 was conducted to explore the associations between HT representations, perceptions of HT as a risk factor itself and perceived and practiced preventive behaviours with the aim of testing the relationship illness perceptions-behaviour predicted by the Self-Regulation Model. A community-based, convenience sample of normotensive adults was recruited. In study 1, an adapted Brief Revised-Illness Perception Questionnaire (BRIPQ) was used to assess perceptions on HT. For the aims of the Study 2, the participants completed the BRIPQ and a series of self-reports on perceptions of HT as a factor risk for other diseases and perceptions and practice of preventive behaviours. Results of Study 1 showed that the participants' beliefs mixed accurate and folk knowledge. Socioeconomic status (SES) and family experience influenced the content of HT representations. In Study 2, almost all of the participants were aware about the severe health problems that HT could generate. Moreover, most of the participants thought that the proposed behaviours help in avoiding high blood pressure, though the proportion of participants that practised those actions was considerably lower. Results also supported that illness perceptions influenced perceptions on HT as a risk factor for further health problems and preventive perceived behaviours and practiced efforts. This study allows us to know the perceptions on HT among non-patients and how these representations influence further perceptions on the disease, possibilities of prevention and preventive actions in daily life. Our findings are useful in designing interventions aimed at HT prevention.

Keywords: Hypertension, Non-patients, Self-Regulation Model, Illness Beliefs, Prevention.

Introduction

Hypertension (HT), systolic/diastolic blood pressure (BP) ≥140/90mmHg, is a serious public-health problem in both economically developed and developing nations (Kearney et al., 2005). The World Health Organization (WHO) in its report "General Information on HT in the World" states that the prevalence of HT has increased in a remarkable way worldwide, to the point that currently, 40% of 25-years-old or older population has an elevated BP (WHO, 2013). In Spain, HT prevalence in the adult population was around 35% a decade ago, reaching 40% in people in their middle-age and over 60% in people over 60 (Spanish Society of Hypertension, 2005). More recent data show even higher rates, affecting up to 47% of men and 39% of women, with slightly higher prevalence rates in the Southern region of the country (44%) compared to other regions (Grau et al., 2011; Valdés et al., 2014). Estimations for future rates of prevalence worldwide are alarming, pointing to an increase by about 60% for 2025 (Kearney et al., 2005). Moreover, as in other nations, in Spain nearly 1/3 of patients does not know that they are affected by the disease, and only 50% is in treatment, with only 1 in 3 of men and 1 in 2 women well controlled by therapies (Banegas et al., 2011; Félix-Redondo et al., 2011; Ortiz et al., 2011). Suboptimal BP control is due to factors under the control of the health system and the health-care provider (e.g., insufficient education and motivation to the patient, reluctance to initiate lifestyle changes or drug treatment) and of the patient (e.g., lack of knowledge and awareness of the relevance of HT, disagreement with recommendations, failure to comply with recommended lifestyle modifications, poor medication adherence, emotional distress) (Düsing, 2006; Khatib et al., 2014). Consequently, a patient-centered approach that tailors interventions aimed at overcoming barriers to adherence has been encouraged for optimizing adherence rates and BP control (Krousel-Wood, Hyre, Muntner & Morisky, 2005).

Although HT is not a severe disease by itself, it is considered a “silent killer” because high BP is an important risk factor for other more serious disorders such as cardiovascular, kidney, eye or respiratory diseases. Thus, HT is a major source of morbidity and mortality, and it has been stated as the first risk factor for global disease burden, explaining 7% of deaths and disability-adjusted life years (Lim et al., 2012). An added problem is that a significant percentage of individuals, 30-50% of worldwide population (Banegas, 2005; Guo et al., 2011; Marta et al., 2013; Ostrowski, Artyszuk, Lewandowski & Gaciong, 2008; Zhang & Li, 2011), has BP levels considered as prehypertensive (a systolic BP of 120-139 mmHg or a diastolic BP of 80-89 mmHg), which arises the risk of, among others, cardiovascular events considering the continuity of the cardiovascular risk over the levels of BP (Huang et al., 2013).

Illness perceptions on HT

According to the Self-Regulation Model of Common Sense Illness Representations (SRM) (Cameron & Moss-Morris, 2004; Diefenbach & Leventhal, 1996; Leventhal, Brissette & Leventhal, 2003; Leventhal & Diefenbach, 1991; Leventhal, Diefenbach & Leventhal, 1992; Leventhal, Leventhal & Cameron, 2001; Leventhal, Leventhal & Contrada, 1998; Leventhal, Meyer & Nerenz, 1980; Leventhal, Nerenz & Steele, 1984; Leventhal et al., 1997), both healthy and ill people construct non-specialised models about illnesses which comprise a series of cognitive and emotional representations, in order to create an integrated, comprehensible and meaningful picture of a health-threatening condition. These illness representations directly influence individuals' illness-related problem- and emotion-focused coping actions (such as adherence to medical recommendations and management of sadness), conducted for facing perceived risks in order to protect their health, or to manage their condition when already ill for controlling disease-derived consequences and recovering well-being; and indirectly, by a mediation path of coping, illness representations also influence the consequences of illnesses (such as quality of life and daily functioning) and the adjustment to the disease (see French, Cooper & Weinman, 2006; Hagger & Orbell, 2003; Kaptein et al., 2003; Kucukarslan, 2012; Lobban, Barroclough & Jones, 2003; Petrie & Weinman, 1997; Mc Sharry, Moss-Morris & Kendrich, 2011 for a review).

Although HT is a frequent disease, non-specialised illness beliefs about it have been examined in a limited number of studies. Research conducted with hypertensive patients (e.g., Bazán, Osorio, Miranda, Alcántara & Uribe, 2013; Beléndez, Bermejo & García-Ayala, 2005; Chen, Lee, Liang & Liao, 2014; Chen, Tsai & Chou, 2011; Chen, Tsai & Lee, 2009; Figueiras et al., 2010; Heckler et al., 2008; Hsiao, Chang & Chen, 2012; Leventhal et al., 1980; Norfazilah et al., 2013; Pickett, Allen, Franklin & Peters, 2014; Ross, Walker & McLeod, 2004) has shown that their representations of the disease include biomedical knowledge mixed with folk information. In general, evidence suggest that individuals suffering from HT perceive the disease as a non- or scarcely symptomatic, but quite stable and highly durable (i.e., chronic) disease that is highly controllable by both the patient and treatments and that has only a moderate impact on the patient’s life, although severe consequences for health are acknowledged. Participants usually also state that they have a moderate to good understanding of the disease and low or moderate emotional representations linked to it. When concern has been explored, moderate to high levels of concern have been found among patients. Although uncontrollable and external factors such as heredity or chance are indicated as causal factors, HT is strongly related to psychosocial factors, with stress and emotional tension standing out, followed by lifestyle and risk behaviours such as unhealthy diet and substance use.

However, percentages of response also offer interesting information. For instance, Bazán et al. (2013) found that only 30% perceived themselves as not suffering from symptoms mostly of the time; 75% of participants affirmed that HT impacts their daily life, and 73% considered it to be a chronic disease but wished it not to be permanent, relating it to the experience of symptoms; 94.5% considered HT to be difficult of being controlled by patients' actions, and 75% referred that their treatment was not sufficiently efficacious; 30% reported to be continuously concerned about their disease and 66% reported to be highly impacted in terms of disease-related emotional distress. However, 99% demonstrated low coherence regarding the illness. Causes were referred mainly to lifestyle factors, but 90% also indicated heredity.

Research has also indicated that the representations that patients hold impact on their illness-related behaviours, such as clinical consultations, choice of treatments or adherence to self-care actions including pharmacologic prescriptions or lifestyle recommended modifications (e.g., Chen et al., 2009, 2011, 2014; Figueiras et al., 2010; Heckler et al., 2008; Hsiao et al., 2012; Pickett et al., 2014; Ross et al., 2004).

These findings are supported with quantitative- and qualitative-methodology research conducted with both adults and the elderly not using the SRM as theoretical background or the main assessment tools derived from it (e.g., Ayalon et al., 2006; delaCruz & Galang, 2008; Fongwa et al., 2008; Frosch, Kimmel & Volpp, 2008; Lukoschek, 2003; Meyer, Leventhal & Guttman, 1985; Schlomann & Schmitke, 2007; Schoenberg & Drew, 2002; Scisney-Matlock, Watkins & Collins, 2001; Wilson et al., 2002). Nevertheless, this research has indicated that patients clearly identify BP elevations with clear symptoms and bodily changes, including headaches, dizziness, warthm/sweating, irritability/nervousness, heart rate changes, fatigue/weakness, nosebleeding, etc. Moreover, patients trust on medication and lifestyle modifications as well as on home remedies (e.g., vitamins, herbs, garlic, vinegar, vegetables and fruits and other foods and drinks) for treating HT. Thus, a deep inspection of illness representations demonstrate that their constructions are based on lay perceptions in a higher extent than on biomedical knowledge.

However, it is important to state that many of these studies have been conducted with restricted samples such as racial minorities or low income social groups.

Some previous research have also examined the impact of sociodemographic conditions on HT beliefs. Table 1 summarizes main findings regarding HT illness representations, demonstrating some, but isolated, influences. However, some other research has not found any influence of sociodemographic factors (e.g., Figueiras et al., 2010). Little, but some, effect of sociodemographic factors has been found also for other illnesses (e.g., Anagnostopoulos & Spanea, 2005; Del Castillo, Godoy-Izquierdo, Vázquez & Godoy, 2011; Heijmans & De Ridder, 1998; Lau-Walker, 2004; Lehto, 2007; Sterba & DeVellis, 2009; Wang, Miller, Egleston, Hay & Weinberg, 2010). Regarding experience with the disease, Norfazilah et al. (2013) found that family history with HT was related to higher B-IPQ global score. Heckler et al. (2008) established no differences due to personal experience (years with the disease), while Picket et al. (2014) found that people with longer experience with the disease (years with diagnosis) were found to hold stronger beliefs just on duration. Having suffered from the disease or having an ill relative consistently emerges as a relevant contributor to illness representations for physical illnesses (e.g., Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002; Del Castillo et al., 2011; Dempster et al., 2001b; Figueiras & Weinman, 2003; Heijmans & De Ridder, 1998; Heijmans, De Ridder & Bensing, 1999; Juth, Cohen, Silver & Sender, 2015; Lau-Walker, 2004; Lykins et al., 2008; Moss-Morris & Chalder, 2003; Orbell et al., 2008; Weinman, Heijmans & Figueiras, 2003; Weinman, Petrie, Sharpe & Walker, 2000).

Table 1. Influence of sociodemographic conditions on HT representations of patients.

Study	Sample	Age and gender	Education and income
Ross et al. (2004)	Patients from UK	Older < younger: consequences, personal control and emotional impact Older > younger: treatment control Men > women: consequences, personal control and causal attributions to general risk factors including behaviour	No differences were established due to education level
Hsiao et al. (2012)	Patients from Taiwan	Older > younger: duration, consequences and illness-related emotional distress Men > women: personal control	No differences were established due to education level
Chen et al. (2011, 2014)	Patients from Taiwan	Age was negatively related to illness identity and causes Men < women: identity and causal attributions to balance of internal-external forces Men > women: personal control and causal attributions to risk factors	
Heckler et al. (2008)	Afro-American patients	Older < younger: consequences and causal attributions to stress-related factors Men < women: consequences and causal attributions	Higher < lower education: identity
Picket et al. (2014)	Afro-American patients	No differences were established due to age Men < women: causal attributions to stress-related factors Men > women: causal attributions to behavioural causes and chance	Education level influenced only some causes perceptions (e.g. tobacco use) No differences were established due to income
Pérez (2014)	Hispanic patients from USA	Older > younger: duration, personal and treatment control and coherence No differences were established due to gender	Higher < lower education: identity, consequences and global score Higher > lower income: duration, personal control and coherence Higher < lower income: identity and global score
Beléndez et al. (2005)	Patients from Spain	Men > women: causal attributions to behavioural factors Men < women: causal attributions to psychological factors Older < younger: identity and causal attributions to psychological and stress-related factors	

Moreover, research on HT beliefs among healthy individuals is very sparse and the findings are inconclusive. Meyer et al. (1985) interviewed individuals with and without HT to know their perceptions on identity, duration, physiological explanations and causal attributions of BP elevations. However, only representations on symptoms were assessed in non-sufferer participants. They found that both normotensive (46%) and hypertensive (>85%) participants believed that elevations in BP are associated with symptoms such as headache, dizziness, warmth, nervousness or heart changes, and, consequently, these manifestations can be used to monitor BP elevations, even when abstractly they perceived HT as a quite asymptomatic disease. Compared to non-patients, more patients identified symptoms with BP elevations and did it more frequently the longer they had been diagnosed as having the disease. Moreover, patients considered the disease as long-lasting (43%) than a curable and short-lasting condition (24%), with one third considering it a cyclical disease (32%); it was also perceived as caused by a variety of behavioural (indicated by aprox. 1/3 of participants) and psychosocial (aprox. 1/4) conditions, such as stress, work or family problems and diet; heredity was also referred (aprox. 1/5).

Wilson et al. (2002), with individual and focus group interviews, assessed beliefs about meaning, consequences, causes and treatment of HT of individuals in a low- to middle-income urban African-American community including hypertensive patients and healthy people, finding many misconceptions on HT. The disease was perceived by most of the participants, with no discrimination between healthy and hypertensive participants, as symptomatic (e.g., headache, dizziness, fatigue/weakness), caused mainly by stress, heredity and eating habits (only 15% related it to an elevated BP) and treatable with medication and lifestyle changes as well as with vitamins, specific foods and drinks or home remedies. Wilson et al. (2002) also found that the older the age, the higher the awareness of HT as a risk factor for premature death, although this knowledge was lower than desirable; younger participants underestimated mortality associated to HT. None of both studies explored other possible influences of sociodemographic factors.

To our knowledge, only two studies have been conducted with Spanish samples in order to know illness beliefs about HT. Godoy-Izquierdo, López-Chicheri, López-Torrecillas, Vélez & Godoy (2007) found that most of the participants (approximately 2.5% suffering or having suffered from HT, and 43.5% living or having lived with a hypertensive patient) believed that HT is a serious disease (53.6% of participants) with no evident bodily symptoms, which has a notable impact on patient´s life (65.9%) and a long-lasting or chronic timeline (48.8%), yet not permanent (75.6%), with changes over time (54.1%) and relapses (44.5%). It was viewed as highly controllable by the patient

(75.6%), amenable to a cure (68.8%), mainly of pharmacologic type (65.3%), and preventable (60.6%). A high percentage of participants thought that HT was caused by psychological factors, such as stress/emotional arousal (67.1%), one's own behaviour (34.4%) or lack of rest (40.9%); however, percentages of agreement with changing behaviour for managing HT were more reduced. Nevertheless, no other descriptive data were reported and no comparison between patients and non-patients was conducted for HT isolated from other diseases. Besides, no exploration of sociodemographic factors was conducted in regards to HT illness representations.

More recently, Del Castillo, Godoy-Izquierdo, Vázquez & Godoy (2013) explored illness representations about HT in individuals not suffering from HT who has ever (38.5%) or had not ever lived with a patient suffering from this illness. Participants perceived HT as a scarcely symptomatic (e.g., fatigue, tachycardia, dizziness), moderately stable but long-lasting disease that is highly controllable by both the patient and, in a lesser extent, available treatments, and that has only a moderate impact on patient’s life. Participants (>75% of participants) frequently indicated behavioural and psychological factors, such as eating habits, stress, substance abuse (e.g., smoking, alcohol intake), as possible causes. Uncontrollable causes, such as ageing (8 out of ten) or heredity (7 out of ten), were also indicated. Moreover, half of participants affirmed that they had a poor understanding of the disease, although average scores indicated a moderate-to-good comprehension of the disease as a whole. Regarding the emotional representations, participants did not feel particularly worried, fearful or sad when thinking about suffering from this disease, indicating a moderate illness-related emotional impact. Del Castillo et al. (2013) also found that sociodemographic variables had little influence on HT representations, with only a few significant differences emerging for age (younger people perceived more symptoms and lower personal controllability than older people), gender (women perceived less consequences than men) and educational level (people with no formal education or Primary studies perceived lower symptoms, duration and personal and treatment controllability than people with higher education level).

Moreover, both studies support the relevance of experience with the disease on the contents of illness representations. Godoy-Izquierdo et al. (2007) found that the illness cognitions of participants who had either personal experience of the disease or a diagnosed relative were significantly different from those of participants without such a direct or family experience, with patients or relatives of patients demonstrating more benevolent cognitions (i.e., less seriousness, long-lasting timeline, cyclical course and consequences, higher controllability, preventability, curability and behavioural causality). However, several diseases were explored simultaneously. Del Castillo et al.

(2013) found that personal experience (i.e., living with a patient) demonstrated a relevant influence on HT representations; it emerged as the unique predictor of illness perceptions (i.e., higher global score on IPQ-R) and led people, compared with those not having this experience, to hold in general more positive HT representations for controllability, apparent or false predictability and emotional impact (i.e., stronger perceptions of changeability and personal and treatment control, lower emotional impact).

Findings obtained with non-hypertensive individuals are consistent in many respects with those from hypertensive patients (e.g., Bazán et al., 2013; Beléndez et al., 2005; Chen et al., 2009, 2011, 2014; Figueiras et al., 2010; Heckler et al., 2008; Hsiao et al., 2012; Norfazilah et al., 2013; Pickett et al., 2014; Ross et al., 2004), but they differ particularly on the identity dimension, as some previous evidence points that patients have a weaker perception that high BP manifests through bodily symptoms. Moreover, findings obtained with both patients and, particularly, non-patients reflect that HT representations were generally accurate but sometimes they differed from medical knowledge and were based on common sense, cultural beliefs and folk knowledge, with in general a poor to moderate self-reported comprehension of the disease, particularly among non-patients.

Illness representations, perceptions of risks and preventive efforts

Given the prevalence of HT and the important health risks related to this *silent killer*, HT prevention is a major public health challenge. If rises in BP are prevented or diminished, many of HT diagnoses and derived risks could be avoided. Dickinson et al. (2006), in a review of randomized controlled trials about lifestyle interventions to reduce raised BP, found that controlling diet, doing aerobic exercise, restricting alcohol and sodium consumption and taking fish oil supplements are effective ways to reduce BP in HT patients.

A number of controllable risk factors for HT have been well-established, including lifestyle and behaviour-related factors such as excessive body weight, suboptimal dietary pattern, high dietary sodium and low dietary potassium, reduced physical activity, smoking and excess alcohol intake (Chobanian et al., 2003; Dikinson et al., 2006; Forman, Stampfer & Curhan, 2009; Frisoli, Schmieder, Grodzicki & Messerli, 2011; Geleijse, Kok & Grobbee, 2004; Liu et al., 2012; Lloyd-Jones et al., 2010; Mozaffarian, Wilson & Kannel, 2008; Perk et al., 2012; Schuit, Van Loon, Tijhuis & Ocké, 2002; WHO, 2013). Furthermore, emotional-distress risk factors have been also identified, including stress (Babu et al., 2014; Backé, Seidler, Latza, Rossnagel & Schumann, 2012; Chida & Steptoe, 2010; Gasperin, Netuveli, Soares & Pattussi, 2009;

Landsbergis, Dobson, Koutsouras & Schnall, 2012; Nagele et al., 2014; Rainforth et al., 2007; Sparrenberger et al., 2009), anxiety (Olafiranye, Jean-Louis, Zing, Nunes & Vicent, 2011; Player & Peterson, 2011) and depression (Meng, Chen, Yang, Zheng & Hu, 2012; Nabi et al., 2011), although it may be the occurrence of recurrent episodes (Nabi et al., 2011; Wiehe et al., 2006) or the antidepressant treatments, not depression itself, the causal factor (Delaney et al., 2010; Licht et al., 2009). Those risk factors are present not only at the adulthood but many years before (Kann et al., 2014; Moreno-Gómez et al., 2012).

The prevalence of these risk factors for HT in the general population is high. The WHO (2013) has stressed that the arise in the incidence and prevalence of HT worldwide may be explained by the higher incidence of these lifestyle risk factors, along with the population increase and their progressive higher longevity. In order to prevent BP levels from rising, primary and secondary prevention should be introduced to reduce or minimize these causal factors in the population, particularly in individuals with prehypertension (Guo et al., 2011). A community approach that decreases BP levels in the general population by even modest amounts has the potential to substantially reduce morbidity and mortality or at least delay the onset of HT and derived health threats (Chobanian et al., 2003). Despite recommendations regarding lifestyle change for HT prevention coming from several institutions and professional associations, there is limited research focused on primary prevention of HT and factors associated to behavioural change.

An important issue directly related to prevention is the perception of risks linked to an illness. Illness risk representations are distinct from illness representations in that they develop from the process of matching characteristics of the self with illness representation attributes (Cameron, 2008). Following Cameron (2008), the attributes of identity, cause and timeline serve as the basis for the generation of likelihood estimates; the attributes of consequences and controllability may serve as the basis for severity estimates; and control over prevention may be an additional, unique attribute of illness risk representations. According to the SRM, it is expected that healthy people avoid risks, seek medical care, undergo medical exams or screening tests or adopt new healthy behaviours if they perceive a disease as preventable by their efforts (e.g., Figueiras & Alves, 2007; Niederdeppe & Gurmankin, 2007; Sullivan et al., 2010). It is also expected that more accurate beliefs will lead non-patients to carry out more appropriate and beneficial behaviours to face illnesses before a diagnosis is given (Cameron & Moss-Morris, 2004; Cameron & Leventhal, 2003; Leventhal et al., 1980, 1998, 2003, 2011). Research exploring beliefs about an illness in physical diseases and related preventive behaviours is sparse and conducted mostly with risk populations, including cardiovascular diseases (CVD) (e.g., Ali, Shonk & Saleh El-Sayed, 2013; Andersson, Sjöberg, Öhrvik & Leppert, 2009; Chauan et al., 2007; Claassen, Henneman, Van der Weijden, Marteau & Timmermans, 2012; Collins et al., 2004; Keller et al., 2013; Lee, Cameron, Wunsche & Stevens, 2011; McFall, Nonneman, Rogers & Mukerji 2009; Murray, Murphy, Clements, Brown & Connolly, 2013; Sabzmakan et al., 2014; Zlot, Valdez, Han, Silvey & Leman, 2010). Some of these studies have used the SRM as theoretical frame and have explored the role of illness perceptions on preventive actions (e.g., Claassen et al., 2012; Lee et al., 2011; Murray et al., 2013; Sabzmakan et al., 2014). In summary, individuals have limited knowledge and awareness of their risk of suffering from HT and insufficient preventive behaviours, but perceived risk and favourable attitudes to preventive efforts as well as stronger perceptions of their efficacy as preventive behaviours more likely translate into the adoption of preventive actions.

Regarding HT prevention in non-hypertensive population, research is scarce and has been conducted mainly with samples limited in their characteristics such as minorities (e.g., Aroian, Rosalind, Rudner & Waser, 2012; Gopinath et al., 2014; Newell, Modeste, Marshak & Wilson, 2009; Peters, Aroian & Flack, 2006; Savoca et al., 2009). It shows that, supporting evidence on CVD prevention, family experience, culture, age and gender influences should be considered. Findings have pointed out that, in general, this population is moderately aware about risk factors for HT and health threats linked to HT and how to prevent the disease, but do not change their life-style in order to avoid HT due to several perceived barriers such as perceived difficulty and lack of resources, low self-efficacy or the negative influences of several factors such as family experience with the disease, culture or family and social support (Aroian et al., 2012; Gopinath et al., 2014; Newell et al., 2009; Peters et al., 2006; Savoca et al., 2009). Nevertheless, none of these studies explored illness representations based on the SRM and their possible influence on preventive perceptions and efforts.

Aims of the present research

The present research is composed of two studies. Study 1 was conducted to explore illness representations of HT among normotensive Spanish adults who differ in their family experience with the disease (i.e., some of them have ever lived with a hypertensive relative, the remaining do not have ever had any relative affected by HT). Based on previous findings (Del Castillo et al., 2013; Godoy-Izquierdo et al., 2007), we expected to find both folk- and biomedical-based representations, and that, compared to sociodemographic conditions such as age, gender and education level, family experience with the disease powerfully contributes to illness cognitive and emotional constructions. Given the controversy on the influence of sociodemographic factors, we did not propose specific hypotheses. For family experience, we expected, based on Del Castillo et al. (2013), that participants with family experience would endorse more positive representations of HT. This study was, thus, conducted to replicate previous findings on the contents of illness perceptions with an European population using a broader and more heterogeneous sample than previous studies with Spanish samples, and both the original IPQ-R (Moss-Morris et al., 2002) and a shorter, adapted brief IPQ-R version derived from it. We also expected to replicate previous findings about the impact of sociodemographic factors and family experience on the representations of HT specifically among healthy people.

Study 2 was conducted to explore the associations between HT representations, perceptions of HT as a risk factor itself for further health problems and perceived and practiced preventive behaviours with the aim of testing the relationship illness perceptions-behaviour predicted by the SRM. As we have detailed before, no study has addressed the relationship between illness perceptions and preventive behaviours in non-hypertensive, healthy general population. Nonetheless, based on previous findings with diverse illnesses (Claassen et al., 2012; Lee et al., 2011; Murray et al., 2013; Sabzmakan et al., 2014) and specifically with HT (Aroian et al., 2012; Gopinath et al., 2014; Newell et al., 2009; Peters et al., 2006; Savoca et al., 2009) we expected an influence of the participants' beliefs about HT in their preventive perceptions and behaviours. Specifically, we predicted that participants who stated main causes of HT as related with controllable factors such as their own behaviours, or hold representations related with higher possibilities of personal control over the onset or prognosis of the disease, would perceive HT as more preventable and, consequently, would more likely accept and engage in preventive behaviours in their daily life. We also predicted that stronger beliefs about identity (i.e., symptoms), consequences, chronicity, stability and coherence and more negative feelings of worry or anxiety would be associated to a higher perception of and engagement in preventive behaviours. On the contrary, we expected that the stronger the perceptions of treatment control, the lower the efforts invested in preventing HT.

On the other hand, to our knowledge there is no study on perceptions of HT as a risk factor for other diseases. Consequently, we addressed this issue specifically. We expected that more negative illness perceptions will contribute to the perception about potential health risks linked to suffering from HT, and this in turn, to the perception and engagement in more preventive behaviours.

Finally, we also expected that older participants, those with higher educational level and those with higher family experience would perceive more potential health risks linked to HT and more possibilities of prevention and, consequently, would more likely engage in daily efforts to prevent this illness.

Methods

Participants

A community-based, convenience sample was recruited at random from private households and community settings such as public transport stations, workplaces, parks, healthcare service delivery locations, academic centres and shopping centres. A total of 450 adults (72.7% women) 18 to 68 years old (M= 36.34, SD= 14.63) participated in this research. Table 2 displays their most relevant characteristics. Participants were mostly of a young age, with almost a half aged between 18-28 years old. We synthesised education level, occupational status and family income in an overall index and derived a composite socioeconomic index for socioeconomic status (SES)[1]. Participants were mainly medium SES level. At the time of the study, none of the participants had ever suffered from HT, although they reported to suffer from other chronic diseases (22.9%, see Table 2), and 58% had ever lived (11.8%) or were currently living (46.2%) with any relative who had HT.

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[1] Criteria for each SES level were as follows: 1) Low: a) no studies, primary or secondary school or vocational training, any work status (particularly domestic work, unemployment or retirement) and monthly family income up to 2000 euros, or b) unemployment with low income level, irrespective of educational level (this group contained mainly participants with low education level and low income level); 2) Medium: a) no studies, primary or secondary school or vocational training, any work status (particularly studying, employment or retirement) and monthly family income higher than 2000 euros, or b) university studies (any grade), any work status and monthly family income lower than 2000 euros (this group contained mainly participants with low-to-medium education level and high income level, or with high education level and low income level); 3) High: a) university studies (any grade), b) studying, employment or retirement, and c) monthly family income higher than 2000 euros (this group contained mainly participants with high education level and high income level who were studying, employed or retired). These criteria allowed to form three levels of SES which corresponded to SES levels in Spain derived from social indicators such as family income, occupation and education level according to data from the National Institute of Statistics (INE, 2012), and by which approximately 24.5-26.5% of Spanish citizens would have a low SES level, 45.5-52.5% would have a medium SES level, and 23-28% would have a high SES level. We decided to compute in indicator of SES because this measure of an individual's or family's economic and social position based on education, income, work status or occupation is considered a strong predictor of health-related factors, including health-related behaviours, risk factors and health outcomes (e.g., health problems, mortality, incapacity).

Table 2: Socio-demographic data.

Variable		%
Age ranges	18-28	47.8
	29-48	21.7
	49-68	30.5
Marital status	No current relationship, of which	30.2
	Single	20.9
	Separated/Divorced	6.7
	Widow	2.7
	Short-term relationship (< 1 year)	7.3
	Long-term relationship (> 1 year)	62.4
Socioeconomic status	Low	25.3
	Medium	48.4
	High	26.2
Educational level (highest completed level)	No formal education	1.1
	Primary school	11.1
	Secondary school and other formal education	11.1
	Vocational training	9.3
	University-Grade	63.6
	University-Postgrade	3.8
Occupational status	Housework	8.2
	Unemployed	8.7
	Student	46.9
	Retired	2.9
	Employed	33.3
Monthly family income	< 1000 euros	21.1
	1000-2000 euros	43.8
	2000-3000 euros	24.9
	>3000 euros	10.2
Relative with HT	Yes, currently	46.2
	Yes, in the past	11.8
	No	42
Relative patient kinship (more frequently reported)	Mother	20.6
	Father	20.5
	Grandfather/Grandmother	19.1
	Brother/Sister	5.4
	Uncle/Aunt	2.6
	Intimate partner/Spouse	1.8

Table 2: (Continued).

Physical or mental disease at the time of the study	No	77.1
	Yes, of which	22.9
Type of illness (Remaining illnesses were indicated by less than 1%)	Hypothyroidism, hyperthyroidism	4.5
	Cardiovascular diseases, including hypercholesterolemia, hypertriglyceridemia, myocardial infarction, valves disease, arrhythmia...	4
	Osteoporosis, arthritis, bone problems...	3.1
	Pain, chronic pain, headaches...	2
	Digestive system diseases, including irritable bowel syndrome, ulcerative colitis, gastroesophageal reflux disease, hiatal hernia...	2
	Depression	1.7
	Anxiety	1.5
	Respiratory problems, including asthma...	1.2
	Gynaecological problems, including ovarian cysts, endometriosis, miomas...	1
	Dermatologic diseases, including atopic dermatitis, eczema, psoriasis, acne...	1
Under any kind of therapy	No	75.6
	Yes, of which	24.4
Type of therapy (more frequently reported)	Oral contraceptives	5
	Drugs for thyroid problems	3.8
	Anxiolytics	2.2
	Vitamins (A, B group) and minerals (calcium, iron, iodine)	2
	Antidepressants	1.6
	Drugs for hypercholesterolemia	1.4
	Drugs for asthma	1
	Psychotherapy	1
	Corticoids	0.8
	Analgesics	0.4
	Non-steroidal anti-inflammatory drugs	0.4
	Anticoagulants	0.4
	Drugs for cardiovascular diseases	0.4
	Drugs for osteoarthritis	0.4

Measures

Participants completed the IPQ-R (N= 162, 36% of the total sample) or a brief version derived from the IPQ-R (N= 288, 64%) in order to report their cognitive and emotional representations on HT (Study 1). Participants also completed other self-reports that were specifically constructed for this research with the aim of exploring their perceptions about HT as a health risk factor as well as possible risks derived from HT, their perceived preventive behaviours for avoiding or reducing the risk of suffering from HT and their practiced preventive behaviours for avoiding or reducing the risk of suffering from HT (Study 2).

Illness perceptions:

Illness beliefs about HT were explored using a Spanish modified version of the Revised Illness Perception Questionnaire (IPQ-R) by Moss-Morris et al. (2002), which was adapted to assess illness perceptions on HT among healthy people (Del Castillo et al., 2013). A brief IPQ-R (BIPQR) was derived based on psychometric and content analyses (Godoy-Izquierdo et al., in preparation) in order to assess HT representations in a faster and easier way, given the extension of the assessment protocol for the aims of the Study 2. For equality purposes, only the items included in the BIPQR (i.e., completed by all the respondents) were used in the analyses in the present research.

Both the IPQ-R and the BIPQR evaluate nine dimensions from Leventhal and colleagues' SRM model and research findings: Identity (symptoms associated with the illness and label); Timeline (duration and chronicity); Evolution (course and temporal changeability or fluctuation of the illness and symptoms); Consequences (effects of the illness on an individual's lifestyle, health and well-being); (Lack of) Personal Control (personal influence on preventing and managing the disease); (Lack of) Treatment Control (availability and efficacy of treatments to manage or cure the disease and its symptoms); (Lack of) Illness Coherence (perceived personal understanding of the disease); Emotional Representations (emotional impact of the disease); and Aetiology or Causes (e.g., psychological, behavioural, biological, chance and external causes of the disease). For the aims of the present research, two items assessed each of the SRM dimensions and a total of 21 possible symptoms of HT (some of them not corresponding to high BP manifestations to identify possible tendency of response) and 19 possible causes of the disease were included (items in each subscale are indicated in Table 3).

For all of the dimensions except identity, the respondent must express his(her) level of agreement with a series of statements (e.g., “This illness has major consequences on patient's life”) or causal attributions (e.g., "One's own behaviour") on a Likert-type scale with five alternatives (from 1= “Strongly disagree” to 5= “Strongly agree”). In the causes dimension, a statement of "I don't know/I'm indecisive" was included. A blank question was also used for asking the participants to freely indicate the three more relevant causes of HT for them (info not used in this research). Partial scores were obtained as the mean of the scores for the items on each subscale (considering direct and reverse items, see Table 3), with higher scores indicating stronger beliefs about chronicity, cyclical course, impact and outcomes, causal factors' influence and emotional reactions to the disease, as well as poorer perceptions of personal influence and cure possibilities and perceived understanding of the disease. For the aims of calculating a global score, items belonging to the dimensions of personal control, treatment control and coherence were all reversed (e.g., Figueiras et al., 2010). For the identity dimension, answers to whether each in a series of symptoms was perceived as characteristic of the disease or not were examined. The higher the score, the more symptomatic the disease is perceived to be.

A global score in the BIPQR was calculated by summing the answers to all items excepting those from causes subscale, with higher scores reflecting stronger illness representations of the disease as a severe, symptomatic, uncontrollable, durable and unstable disease as well as un-understandable disease, with higher impact on the patient's health and life and higher power to generate emotional reactions.

Following previous suggestions (Moss-Morris et al., 2002; Weinman, Petrie, Moss-Morris & Horne,1996), we modified the IPQ-R to make it more complete, easier and better fitted to HT (see Del Castillo et al., 2013, for details). Furthermore, each reference to “my” illness was substituted by “the” illness or “hypertension”. The BIPQR used herein also included the following changes on the original, large IPQ-R. For the identity subscale, six new symptoms were added: heat, perspiration; flushing of face and neck; seeing problems; bleedings; confusion, disorientation; and ringing in the ears. The remaining dimensions except causes were summarized in two items per subscale, those considered as more representative of each dimension based on both content and psychometric analytical procedures (Godoy-Izquierdo et al., in preparation). Causes subscale was similar in both tools.

The psychometric properties of the IPQ-R have been previously demonstrated among English-speaking and Spanish populations (Del Castillo et al., 2011; Moss-Morris et al., 2002), as well as in the context of HT with Spanish populations (Beléndez, et al., 2005; Del Castillo et al., 2013; Pacheco-Huergo et al., 2012).

We decided to use our own brief IPQ-R instead of the Brief IPQ proposed by Broadbent et al. (2006) because of some psychometric limitations of the latter that have been pointed out. Concurrent validity with the IPQ-R regarding personal control and treatment control dimensions (Broabdent, Petrie, Main & Weinman, 2006; De Raaij, Schröder, Maissan, Pool & Wittink, 2012; French, Van Oort & Schröder, 2011) and convergent validity between the Brief IPQ and other measures (Bazzazian & Besharat, 2010; Lochting, Garrat, Storheim, Werner & Grotle, 2013) have been questioned. Moreover, there is no evidence of discriminant validity of the instrument (French et al., 2011) and it may lack of content validity (French et al., 2011; Van Oort, Schröder & French, 2011).

Perceptions of HT as a risk factor:

For the aims of the Study 2, the participants had to state whether they considered that untreated HT might be a risk factor for other diseases (0= No, 1= Yes, for non-severe diseases; 2= Yes, for both non-severe and severe diseases). Then, a list with nineteen diseases or health problems (see Table 5) which could be related to HT or not was presented to participants and they had to say whether those problems were related to HT or not (Yes/No). A blank question was added for the participants to indicate any other disease/s not mentioned in the list (not included in the analyses because nobody indicated an illness previously not mentioned). The information presented in this section was obtained from several medical bibliographic sources.

Perceptions of preventive behaviours and practice of preventive behaviours:

According to the aims of the Study 2, we also assessed participants' perceptions about preventive behaviours and their preventive actions in their daily life (with the specific aim of preventing HT). Two lists composed of the same fifteen behaviours (see Table 6) were presented. In the Perceived Preventive Behaviours Scale, participants must express his or her level of agreement on a Likert-type scale with eleven alternatives (0= “nothing at all”, from 1= "very little" to 10= “very much”) depending on their perception about the preventive character of each behaviour (i.e., perceived efficacy of the action for preventing HT). In the Practiced Preventive Behaviours Scale, they had to indicate their performance of each behaviour in their daily life on a Likert-type scale with eleven alternatives (0= “no practice”, from 1= "very little" to 10= “very much”). As in the HT as a Risk Factor section, information for these sections was obtained from several medical bibliographic sources.

Sociodemographic data:

Participants also indicated their age, gender, nationality, marital status, education level, work status and income level. They also reported current diseases and therapies undergone (of any nature), and whether they had ever suffered from HT. Participants were also asked to indicate whether any relative with whom they had ever lived was ever diagnosed with HT or was affected by HT at the moment of the study and their kinship, as well as whether (s)he was under any kind of treatment and his(her) adherence to prescriptions.

Procedure

For both Study 1 & Study 2, after the research was approved by the institutional research ethics committee, participants were asked to take part voluntarily and to sign an informed consent form. They had been informed previously that the general objective of the research was to learn their beliefs about HT and not to gauge their level of knowledge. Specific instructions for completing the questionnaires were given.

In both studies, a community-based convenience sample was constructed (i.e., people suffering or having suffered from HT were discarded). Three housing buildings and several community settings per district were selected at random with a local telephone directory. A person in one of every three possible households and one of every three people in the public settings were asked to participate and followed the above-mentioned procedure when they accepted.

Study design and statistical analyses

This is a cross-sectional, correlational study based on self-report data. After checking parametric assumptions, descriptive, univariate and multivariate analyses were conducted. Univariate Pearson correlations were used to explore associations among the variables of the study. Multivariate hierarchical multiple linear regression, using the method of stepwise selection, was applied to identify independent predictors.

Results

Non-specialised beliefs about HT

To establish the contents of illness models for HT in detail, descriptive data and the percentages of responses for each item were obtained (see Table 3).

Table 3: Percentages of agreement responses and descriptive results for each subscale.

Dimensions		%
Identity (0-21 [a]) (perceived symptoms of HT) *M*= 12.03, *SD*= 3.75; R= 0-21	Tachycardia [b]	92.4 [c]
	Headaches	86.9
	Fatigue, tiredness	81.1
	Heat, perspiration [b]	80.2
	Dizziness, vertigo [b]	76.4
	Emotional distress (sadness or anxiety) [b]	71.6
	Seeing problems (blurry vision, flashes...) [b]	70.0
	Flushing of face and neck [b]	69.1
	Pain anywhere [b]	67.8
	Sleep difficulties	65.8
	Breathlessness, respiratory problems [b]	62.7
	Bleedings [b]	58.2
	Weakness, loss of strength [b]	55.1
	Mobility difficulties [b], stiff joints, soreness	54.4
	Confusion, disorientation [b]	54.4
	Ringing in the ears [b]	43.1
	Nausea	33.8
	Stomach/intestine problems [b]	32.4
	Delirium and hallucinations [b]	16.9
	Weight loss	16.4
	Fever	14.4
Duration (acute/chronic) (1-5 [a]) *M*= 3.16, *SD*= 0.84; R= 1-5	1. Changes and symptoms of HT are likely to be long-lasting rather than temporary but they pass	47.8 [d]
	2. Symptoms of HT are for life (they are permanent, they don't pass)	44.8
Evolution (timeline-cyclical) (1-5 [a]) *M*= 3.12, *SD*= 0.95; R= 1-5	4. The symptoms of HT go through cycles in which they get better and worse	62.9 [d]
	3. The symptoms of HT change a great deal from day to day	29.6
Consequences (1-5 [a]) *M*= 3.15, *SD*= 0.83; R= 1-5	5.This illness has major consequences on patient's life or health	83.8 [d]
	6. This illness strongly affects the way others see and relate to patients	13.7
(Lack of) Personal Control (1-5 [a]) *M*= 1.73, *SD*= 0.74; R= 1-5	7.There is a lot which patients can do to control and manage their symptoms (REVERSE)	5.8 [d]
	8. What patients do determines whether their disease gets better or worse or has more or less impact in their life and health (REVERSE)	3.1
(Lack of) Treatment Control (1-5 [a]) *M*= 1.96, *SD*= 0.69; R= 1-5	9. There are treatments which effectively relieve or control the symptoms and changes of HT (REVERSE)	8.8 [d]
	10. Negative conditions and effects of HT can be prevented (avoided) by doing something or through a treatment or intervention (REVERSE)	3.6
(Lack of) Illness Coherence (1-5 [a]) *M*= 2.66,*SD*= 1.01; R= 1-5	12. I have a clear picture or understanding of this disease (REVERSE)	27.9 [d]
	11. The illness is difficult to understand for me	24.4
Emotional Representations (1-5 [a]) *M*= 2.14, *SD*= 1.05; R= 1-5	13.When I think on this disease I get upset	19.6 [d]
	14. I get depressed when I think I have or may have this disease	8.4

Table 3: (Continued).

Causes(1-5 [a])	Diet, eating habits	92 [d]
	Smoking	91.5
	Alcohol consumption	91.3
	Hereditary, genetic	87.2
	Stress or worry	84.4
	Ageing	78.9
	Overwork	76.3
	One’s own behaviour and habits	72.4
	One’s own emotions and moods	64.6
	Family problems or worries	63.9
	One’s own mental attitude and thoughts	49.9
	Poor medical care in the past	47.2
	One’s own personality	38.5
	Accident or injury	22.1
	Pollution, environmental contamination	21.5
	Immunity problems	17.9
	Chance, bad luck	12.3
	Other people	10.7
	Germs or viruses	2.5

Footnotes: Internal reliability of the BIPQR: Cronbach’s alfa=0.74. Range of possible responses: Identity subscale: 1=Yes, 0=No; Remaining subscales: 1=”Strongly Disagree”-5=”Strongly agree”. [a] Minimum and maximum possible score in the BIPQR subscales. [b] Symptoms added to the Spanish version of the IPQ-R and to the BIPQR. [c] Percentage of people answering “Yes”. [d] Percentage of people answering “Agree” plus “Strongly agree”.

Participants perceived HT as moderately symptomatic, with 1 in 2 participants indicating several symptoms. Some characteristic and bodily located signs such as tachycardia, headaches, fatigue/tiredness, heat and perspiration, dizziness/vertigo, seeing problems and flushing of face and neck were pointed out by 70% of participants or more. Seven in ten participants thought that HT generates emotional distress such as sadness or anxiety.

Moreover, HT is seeing as a moderately long lasting and cyclical disease with symptoms that get better and worse over time. HT is considered by participants as highly controllable by patients’ actions and behaviours, and they also showed high confidence in available therapeutic interventions to control the disease. Participants also perceived that HT affects patients’ daily life (84%) but not how the patient is viewed and treated by others, and reported to have a moderately meaningful understanding of what HT is, with 25% of participants indicating poor understanding. On the other hand, they didn’t show high emotional distress linked to the possibility of suffering from the disease. Causes more frequently chosen by the participants were those related to personal behaviour and lifestyle, like diet and eating habits, smoking or alcohol consumption. Indeed, one's own behaviours and habits was chosen by 72.4% of the participants as a causal factor for HT. Stress or worry and one's own emotions and moods were also perceived as important in the development of HT frequently. Uncontrollable causes such as heredity or ageing were also pointed out.

Predictors of HT perceptions

A hierarchical multiple linear regression analysis (stepwise) was conducted in order to explore the sociodemographic predictors of illness perceptions on HT. In a first step, total score in the BIPQR was regressed on sociodemographic variables; in a second step, family experience with the disease was introduced in the analysis. While age, gender and marital status did not predict the global score on the illness perceptions questionnaire, SES level emerged as a significant predictor in the first step, and remained as such along with family experience with the disease (marginally significant) in the second step. Table 4 shows the findings. The higher the SES level and the stronger the family experience with the disease, the weaker the perceptions of HT as a severe, durable, impacting and uncontrollable disease.

Table 4: Sociodemographic predictors of BIPQR global score.

Final model Adj. R^2= 0.021; *F*= 5.920, *p*= 0.003	Unstand. Coef. B	 St. Error	Stand. Coef. Beta	*t*	*p*
(Constant)	51.393	1.066		48.205	0.000
SES level	-1.156	0.405	-0.133	-2.852	0.005
Family experience with HT	-0.586	0.310	-0.088	-1.889	0.060

Note. SES level: 1= Low, 2= Medium, 3= High. Family experience: 1= No, 2= Yes, in the past; 3= Yes, currently.

Risk perceptions linked to HT

Only a small percentage of the participants considered that there is no health risk related to HT (0.9%) or that HT is a risk factor only for mild health problems (4.7%). Contrarily, the majority of the participants (94.4%) were aware about the severe problems that HT could generate. In average, participants perceived that HT was a risk factor for 8.39±3.50 problems (observed range: 0-19). Table 5 presents the percentages of agreement with the perception of HT as a risk factor for developing diverse health threats.

Table 5: Diseases related to HT.

Health problems	YES %
Cerebrovascular disease (ischemic attack, stroke, stenosis, embolism, aneurysms, etc.)	92.9
Myocardial infarction	92.2
Cardiac arrhythmia	79.8
Heart failure	75.8
Angina	74.0
Bleedings	56.7
Anxiety	54.7
Cholesterol	49.1
Blindness	39.3
Renal failure	37.8
Obesity	32.9
Depression	31.1
Respiratory diseases (asthma, bronchitis)	28.9
Diabetes	28.7
Bone and joints problems	21.8
Prostate problems	13.1
Fibromyalgia	12.9
Cancer	10.0
Hepatitis	7.1

Cardiovascular and cardio-coronary diseases were the most frequent perceived risks related to HT. Renal failure or visual impairment were referred by only 4 in ten participants. Many participants also linked suffering from emotional distress (anxiety, depression) to HT. Curiously, many participants considered that high BP may generate other risk factors such as high cholesterol blood levels, diabetes or obesity. Around 1 in 10 participants linked HT to non-related diseases, such as cancer, fibromyalgia or hepatitis.

Preventive perceptions and behaviours

We also explored perceived preventive behaviours and practiced preventive behaviours to face the risk of suffering from HT. Table 6 shows descriptive findings.

Although most of the participants thought that the listed behaviours help in avoiding high BP, the proportion of participants that practiced those actions was considerably lower, with up to 1 in 5 participants not executing them with the intention of preventing HT. Of the participants, 4.2% reported not conducting any of the listed preventive actions and 38% indicated to perform less than 5 preventive actions.

Table 6: Perceived and practiced preventive behaviours.

	Perceived preventive behaviours			Practiced preventive behaviours		
	NO (0)	YES (1-10)		NO (0)	YES (1-10)	
	(%)	*M*	*SD*	(%)	*M*	*SD*
1. Reducing the number of cigarettes/ stop smoking	2.2	8.56	1.77	23.8	8.35	2.74
2. Reducing alcohol intake	0.9	8.70	1.48	17.8	7.54	2.57
3. Reducing salt intake / low salt diet	0.2	9.38	1.04	14.7	6.48	2.76
4. Reducing saturated fat intake / low saturated fat diet	0.4	8.98	1.45	12.2	6.62	2.39
5. Reducing sugar consumption / low sugar diet	3.8	7.15	2.36	16.2	5.86	2.56
6. Reducing the consumption of stimulating beverages (coffee, tea...)	0.4	8.51	1.70	17.8	6.30	2.82
7. Increasing vitamins and minerals intake (fruits, vegetables, fish...)	3.3	7.69	2.31	13.8	6.76	2.43
8. Increasing calcium and potassium consumption	6.9	6.42	2.40	20.2	5.81	2.52
9. Increasing water consumption	3.1	7.42	2.35	13.6	7.04	2.41
10. Increasing physical activity in everyday life	0.7	8.71	1.55	10.2	6.74	2.57
11. Doing regular, moderate intensity exercise at least three times a week	0.9	8.61	1.63	17.8	6.25	2.85
12. Doing regular, high intensity exercise at least three times a week	9.8	5.93	2.60	41.6	5.15	2.95
13. Avoiding taking certain medications (anti-inflammatory treatments, contraceptives...)	6.4	6.20	2.48	28.7	6.64	2.89
14. Avoiding strong emotions and stress	0.9	8.04	1.89	22.0	5.84	2.52
15. Practicing strategies and activities to get relaxed	0.0	8.24	1.82	20.0	6.02	2.69

Concretely, nobody thought that none of the listed behaviours was successful in reducing the risk of suffering from HT and only 3.1% participants rated the perceived efficacy of the preventive behaviours as a whole as lower than 5 (moderate). The average perceived efficacy for the complete list of preventive actions was 7.72±1.27 (observed range: 2.73-10) in a 0-10 scale. The behaviours perceived by participants as more successful for preventing HT were reducing sodium and saturated fats intake, increasing physical activity levels and practicing regularly exercise at a moderate intensity, reducing alcohol, tobacco and stimulating beverages consumption, as well as controlling stress, negative emotions and arousal. The less frequently considered as successful preventive actions were doing high intensity exercise regularly, avoiding taking certain medicaments and increasing calcium and potassium consumption.

Participants reported to practice, in average for the complete list of preventive actions, 5.26±2.45 (observed range: 0-10) behaviours with the aim of preventing HT in a 0-10 scale. Participants pointed out different behaviours as (relatively) frequently conducted with the aim of preventing HT, but curiously most frequent practiced behaviours were not always those indicated as more successful for preventing HT. Those behaviours done in a highest proportion in order to prevent HT were reducing the number of cigarettes or stop smoking, reducing alcohol intake and increasing water consumption and daily physical activity, as well as conducting several modifications in diet, including increasing vitamins and minerals intake and reducing fat and salt intake, as well as avoiding taking certain medications. The behaviours conducted at a lower rate were doing regular high intensity exercise, increasing calcium and potassium consumption and avoiding strong emotions and stress.

Associations among illness perceptions for HT, perceptions of HT as a risk factor and perceived and practiced preventive behaviours

Table 7 shows the correlations between all the psychosocial variables of the study. In summary, results show that associations among BIPQR dimensions were as expected (exceptions were the inverse associations between identity and duration, and evolution and consequences dimensions). Furthermore, the perception of HT as a risk factor positively correlated with number of problems linked to HT and practiced preventive behaviours, as well as with the BIPQR dimensions of identity and consequences, and inversely with (lack of) personal and treatment control and (lack of) coherence dimensions. Number of health risks linked to HT positively correlated with perceptions of preventive behaviours, practice of preventive behaviours, the global score on the BIPQR and the scores on several dimensions of the BIPQR: identity, consequences, causes and emotional representations; it was inversely correlated with the (lack of) personal control dimension.

Perception of preventive behaviours positively correlated also with practice of preventive behaviours, the BIPQR global score and several dimensions of the BIPQR: identity, duration, consequences and causes; it was inversely correlated with evolution and (lack of) personal control dimensions.

Practice of preventive behaviours was further positively correlated with identity, consequences, (lack of) coherence and emotional representations dimensions of the BIPQR, and inversely correlated with evolution and (lack of) personal control dimensions.

Table 7: Correlations among the main psychosocial variables of the Study 2.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 HYPERTENSION RISK FACTORS	-	0.271**	0.071	0.145**	0.104*	-0.017	-0.039	0.100*	-0.245**	-0.100*	-0.164**	0.077	-0.053	-0.035
2 NUMBER OF HEALTH PROBLEMS		-	0.427**	0.162**	0.378**	-0.041	-0.089†	0.259**	-0.227**	0.039	-0.034	0.128**	0.304**	0.244**
3 PERCEIVED PREVENTIVE BEHAVIOURS			-	0.306**	0.255**	0.095*	-0.121**	0.259**	-0.201**	0.006	-0.031	0.050	0.344**	0.170**
4 PRACTICED PREVENTIVE BEHAVIOURS				-	0.119*	-0.005	-0.190**	0.258**	-0.285**	-0.038	0.098*	0.096*	0.079	0.068
5 IDENTITY					-									
6 DURATION					-0.097*	-								
7 EVOLUTION					0.015	0.071	-							
8 CONSEQUENCES					0.193**	-0.034	-0.157**	-						
9 PERSONAL CONTROL					-0.108*	0.016	0.157**	-0.266**	-					
10 TREATMENT CONTROL					0.053	0.051	-0.099*	-0.088†	0.368**	-				
11 COHERENCE					-0.019	-0.107*	-0.050	0.034	0.057	0.077	-			
12 EMOTIONAL REACTIONS					0.070	0.004	0.034	0.056	0.085†	0.068	0.047	-		
13 CAUSES					0.339**	0.017	0.072	0.195**	-0.049	-0.025	0.012	0.184**	-	
14 BIPQR_TOTAL					0.633**	0.205**	0.302**	0.270**	0.283**	0.350**	0.322**	0.453**	0.329**	-

† $p < 0.10$ * $p < 0.05$ ** $p < 0.01$

Upper panel: Associations among illness perceptions, perceptions of HT as a risk factor, perceived preventive behaviours and practiced preventive behaviours. Lower panel: Associations among BIPQR subtotal and total scores.

Predictors of risk perceptions, prevention perceptions and preventive behaviours

Influence of sociodemographic variables, i.e., gender, age, marital status, SES level and family experience with the disease, on HT risk perceptions, prevention perceptions and preventive behaviours was explored by a series of hierarchical multiple linear regression analyses (stepwise). Besides, perceptions on HT as a risk factor and on prevention options may influence each other and on behaviour, so they were also included among the predictors. In all of the analyses, in a first step, total scores in the measures of risk perceptions (HT as a risk factor and total number of problems associated to HT as a risk factor), prevention perceptions and preventive behaviours were regressed on all sociodemographic variables; in a second step, family experience with the disease was introduced in the analysis; BIPQR global score was introduced in a third step; the remaining variables were introduced in a fourth step as showed in Table 8.

When predictors of perceptions of HT as a risk factor were analyzed, only family experience emerged as significant predictor, so that people with a relative having HT were more likely to perceive the disease as a risk factor for further health problems. Number of problems related with HT was predicted by age: the younger the participant, the higher the number of future health risks linked to HT, and BIPQR global score: the stronger the beliefs on severity of the illness, the higher the number of problems associated to HT. Preventive perceptions were predicted by age and gender, illness beliefs as well as number of health risks linked to HT: women, younger participants and those perceiving HT as more serious and those who perceived a higher number of risks linked to HT were more likely to perceive HT as a preventable disease. Finally, preventive behaviours practiced were predicted by gender, perceiving HT as a risk factor and preventive perceptions: women, those who considered HT as a risk factor and those who perceived more preventive options were more likely to practice a higher number of preventive actions. Consequently, SES and marital status were not significant predictors of any of these variables. Global BIPQR score emerged as significant predictor of two of these outcome variables: Number of problems linked to HT and perceived preventive actions.

Table 8: Sociodemographic and psychosocial predictors of perceptions on HT as a risk factor and preventive perceptions and behaviours.

Final models	Unstand. Coef.		Stand. Coef.	*t*	*p*
	B	St. Error	Beta		
HT as a risk factor Cor. R^2= 0.015; F= 4.432, p= 0.012					
(Constant)	2.903	0.108			
Family experience	0.040	0.014	0.135	2.880	0.004**
BIPQR global score	-0.001	0.002	-0.023	-0.492	0.623
Number of problems linked to HT Cor. R^2= 0.148; F= 27.101, p= 0.000					
(Constant)	4.575	1.320			
Age	-0.074	0.010	-0.308	-7.062	0.000**
Family experience	-0.019	0.163	-0.005	-0.116	0.907
BIPQR global score	0.136	0.025	0.243	5.556	0.000**
Preventive perceptions Cor. R^2= 0.283; F= 30.504, p= 0.000					
(Constant)	6.704	0.720			
Age	-0.026	0.004	-0.302	-6.970	0.000**
Gender	0.262	0.118	0.092	2.224	0.027*
Family experience	0.044	0.055	0.033	0.802	0.423
BIPQR global score	0.018	0.009	0.088	2.112	0.035*
HT as a risk factor	-0.132	0.192	-0.029	-0.689	0.491
Number of problems linked to HT	0.114	0.016	0.314	6.897	0.000**
Preventive behaviours Cor. R^2= 0.135; F= 11.042, p= 0.000					
(Constant)	-2.997	1.667			
Gender	1.004	0.251	0.183	4.008	0.000**
Age	-0.012	0.008	-0.071	-1.426	0.155
Family experience	-0.070	0.117	-0.027	-0.601	0.548
BIPQR global score	0.008	0.018	0.128	0.461	0.645
HT as a risk factor	1.109	0.406	0.021	2.754	0.006**
Number of problems linked to HT	-0.011	0.037	-0.016	-0.301	0.763
Preventive perceptions	0.454	0.101	0.235	4.514	0.000**

Discussion

Although the SRM has been applied to different physical and mental illnesses, there are relatively few studies regarding the non-specialised beliefs that healthy people hold and how their beliefs influence health- and disease-related behaviours, and they have been conducted mainly with carers of patients (e.g., Anagnostopoulos & Spanea, 2005; Cabassa, 2007; Del Castillo et al., 2011; Dempster et al., 2011a,b; Figueiras & Weinman, 2003; Fortune, Smith & Garvey, 2005; Kaptein et al., 2007; Karademas, Zarogiannos & Karamvakalis, 2010; Lobban, Barrowclough & Jones, 2005; Searle, Norman, Thompson & Vedhara, 2007). That is particularly true for the Spanish population. Furthermore, research specific to HT is scarce, although this disease is one of the leading causes of morbidity worldwide and one of the main risk factors for serious pathologies such as heart attack, stroke or chronic renal failure. Moreover, most research to date on HT representations among non-hypertensive individuals is limited, with biased samples (e.g., small sample size, racial minorities, university students), methodological shortcomings (e.g., measurement of illness perceptions, dimensions considered in the analyses, influence of sociodemographic and experience with the disease factors) and out-of-date findings. This study sought to overcome many of these limitations in order to contribute to current knowledge related to the SRM. Furthermore, healthy people, risk populations, patients, relatives and carers of patients as well as health professionals are in need of tailored interventions focussed on their illness representations.

The present research encompassed two studies with different but related aims. The first study focused on establishing the representations of HT among Spanish normotensive adults of both genders with diverse SES and varied family experience with the disease. We also aimed to explore the impact of sociodemographic factors and family experience on illness representations specifically among healthy people. As we expected, Spanish normotensive population held HT representations that mixed both folk and biomedical knowledge. On the other hand, compared to sociodemographic conditions such as age or gender, SES level and family experience with the disease significantly contributed to cognitive and emotional constructions on HT.

Regarding illness representations, HT was considered by non-patients to be a symptomatic, cyclical and durable (i.e., chronic) disease that is highly controllable by both the patient and by treatments and that has a relevant impact on the patient’s life. The representation of HT as a symptomatic illness counteracts with the asymptomatic character of the disease, the so-called *silent killer*, at least until the disease becomes very advanced (Banegas et al., 2011). These results parallel those obtained in other studies conducted with non-patients (e.g., Del Castillo et al., 2013; Meyer et al., 1985;

Wilson et al., 2002) but notably contrast with those obtained with hypertensive patients, who perceive their disease as scarcely symptomatic (e.g., Bazán et al., 2013; Beléndez et al., 2005; Chen et al., 2009; Hsiao et al., 2012; Norfazilah et al., 2013), probably due to the lack of experience of clear manifestations of BP elevations. Nevertheless, other findings indicate that patients also perceive HT as a symptomatic disease with many manifestations of BP elevations (e.g., delaCruz & Galang, 2008; Figueiras et al., 2010; Fongwa et al., 2008; Heckler et al., 2008; Lukoschek, 2003; Meyer et al., 1985; Schlomann & Schmitke, 2007; Schoenberg & Drew, 2002). Compared to findings from the study conducted by Del Castillo et al. (2013) with a Spanish sample, in the present study the participants indicated, however, a higher number of symptoms. The participants considered that different bodily located symptoms and signs are characteristic of high BP, such as tachycardia, headaches, fatigue or heat and perspiration (identified by more than 8 out of 10 participants), which coincides with other research findings. A high percentage of the sample thought that HT generates also emotional symptoms, supporting previous findings (Del Castillo et al., 2013), probably misunderstanding and confounding causes and manifestations of high BP. Curiously, 1-2 in ten participants linked HT to deliriums and hallucinations or fever and many indicated other supposed symptoms of HT which have nothing to do with this disease, indicating folk beliefs on HT. These results may be indicating the necessity for non-specialised people of looking for possible indicators of the presence of signs and symptoms as a way to identify when they are ill.

HT was also seen as a moderately long-lasting and cyclical disease, with important, but not excessively severe, consequences in patients' daily life, supporting previous findings with Spanish data (Del Castillo et al., 2013; Godoy-Izquierdo et al., 2007). This perception may derive from the severe pathologies caused by HT and not from HT itself.

Furthermore, HT was perceived as a disease whose development, evolution and management are controllable by both the patient and the available treatments, supporting previous Spanish studies (Del Castillo et al., 2013; Godoy-Izquierdo et al., 2007). Strong perceptions of controllability may be due to the way how HT is treated in public health campaigns, which frequently emphasize the importance of individuals' actions and lifestyle for controlling this disease (Del Castillo et al., 2013).

Regarding coherence dimension, most of the participants reported to have a good understanding of the illness and its characteristics. This stands in contrast with findings obtained with a Spanish normotensive sample, that showed a poor understanding of the disease in a half of the participants (Del Castillo et al., 2013), but coincides with data obtained with Spanish patients (Beléndez et al., 2005). Supporting previous research with Spanish normotensive population (Del Castillo et al., 2013), the participants didn't demonstrate strong feelings of sad, anxiety or worry linked to the possibility of suffering from HT. This low perceived emotional impact stands in contrast with the fact that almost all of them believed that it has important consequences for patients and around 3 in 4 included emotional distress among its manifestations. These results could be explained by the fact that, although HT has a high incidence and prevalence in the population worldwide and it can be associated with serious or even lethal disorders, this is perceived to occur only in a relatively low proportion of (non-treated) hypertensive patients, given the high perceived controllability on the onset and evolution of the disease.

Finally, although factors related to personal behaviour and lifestyle such as diet, smoking or alcohol consumption, or psychosocial factors such as stress or worry were considered among the most important causes of HT by the participants, uncontrollable causes such as heredity or ageing were also pointed out. This results parallels findings from Del Castillo et al. (2013) study, although in the current study participants endorsed a higher relevance to behavioural causes, particularly to alcohol consumption, and are also in line with other studies with normotensive people and patients (e.g., Bazán et al., 2013; Beléndez et al., 2005; Chen et al., 2009, 2011; Godoy-Izquierdo et al., 2007; Heckler et al., 2008; Meyer et al.,1985; Meyers et al., 2014; Ross et al., 2004; Schlomann & Schmitke, 2007; Wilson et al., 2002). Again, these findings may be due to the way HT is treated in preventive interventions, where the management of controllable psychosocial risk factors is emphasised to decrease the impact of other uncontrollable risk factors.

In general, our findings are consistent in many respects with those from studies with normotensive individuals and also patients, including Spanish populations (e.g., Bazán et al., 2013; Chen et al., 2009, 2011; Del Castillo et al., 2013; Godoy-Izquierdo et al., 2007; Figueiras et al., 2010; Heckler et al., 2008; Hsiao et al., 2012; Norfazilah et al., 2013; Pickett et al., 2014; Ross et al., 2004; Schlomann & Schmitke, 2007). However, the participants in the present study reflected more negative illness perceptions, although similar perceived controllability, compared to Spanish patients (Beléndez et al., 2005). They also support previous findings regarding the fit of beliefs on HT to objective medical knowledge both in non-patients and patients (e.g., Del Castillo et al., 2013; Godoy-Izquierdo et al., 2007; Meyer et al.,1985; Schlomann & Schmitke, 2007; Wilson et al., 2002). As we predicted, HT representations were generally accurate but sometimes they differed from medical knowledge and were based on common sense, cultural beliefs and folk knowledge. Other researchers have stated that laypeople’s illness cognitions of diverse physical illness sharply diverge from current medical understanding (e.g., Anagnostopoulos & Spanea, 2005; Del Castillo et al., 2011; Godoy-Izquierdo et al., 2007; Karasz, Mc Knee & Roybal, 2003; Rees et al., 2004).

In Study 1, we also explored the influence of sociodemographic factors including age, gender, SES (composed by educational level, work status and monthly income) and family experience with the disease on lay illness models of HT. Contrary to previous research with patients (e.g., Beléndez et al., 2005; Chen et al., 2011, 2014; Heckler et al., 2008; Hsiao et al., 2012; Pérez, 2014; Pickett et al., 2014; Ross et al., 2004), we did not find any relevant influence of gender and age; however, such previous evidence indicated only a limited impact of sociodemographic conditions, and we also expected so. Contrary to previous findings with patients (e.g., Hsiao et al., 2012; Pickett et al., 2014; Ross et al., 2004) and our expectations, we found that SES predicted HT illness representations. Participants who had lower SES perceived HT as a more severe and durable disease, with stronger impact on patients' life and less possibilities of control by patients and treatments. In line with our findings, Pérez (2014) found that lower education level and lower annual income were related to weaker perceptions about timeline, personal control and coherence but stronger perceptions about identity and consequences, as well as higher overall negative perceptions on HT among patients.

We also found that family experience with the disease predicted more positive perceptions of HT, as we expected. The influence of family experience with the illness has been also shown by other studies with Spanish non-patients (Del Castillo et al., 2013; Godoy-Izquierdo et al., 2007) and with hypertensive patients (Norfazilah et al., 2013). However, whereas among non-patients, family experience has been associated to more benign representations of HT, it has been linked to more negative representations among individuals who also suffer from HT.

The second study aimed to explore possible associations between HT perceptions, perceptions of HT as a risk factor and perceived and practiced preventive behaviours in order to test the expected relationship illness perceptions-behaviour predicted by the SRM. Noticeably, almost 95% of the participants were aware about the serious problems that HT could be associated to. Health problems more frequently perceived by the participants as risks linked to high BP were cardiovascular diseases, which may be due to the fact that they are those people usually refer in their daily life and conversations because they are more common, more impacting or even because these illnesses have been traditionally considered health risks related to HT. Curiously, other important problems that could be provoked by HT such as renal failure or visual impairment were referred by only 4 in ten participants. Many participants also linked suffering from emotional distress to HT in a possible confusion of causes and consequences of HT. Another striking result is that many participants considered that this disease causes other cardio-metabolic risk factors such as high cholesterol blood levels, diabetes or obesity. Finally, a series of illnesses which are not related to HT was referred by around 1 to 3 in 10 participants. These results partially parallel those obtained in other studies exploring the awareness about HT risks in healthy people. For instance, Newell et al. (2009) found that Black people considered that HT could lead to severe health problems such as stroke and heart disease, but most of the participants failed in their perception of the seriousness of HT itself. Moreover, young African Americans with varied HT risk considered that HT has important consequences in patients' lives but many of the participants didn't know what are the potential health risks linked to HT and failed in estimating their own potential risk (Savoca et al., 2009). A sample of African American adults were knowledgeable of the serious, negative consequences such as cardiac problems, stroke, kidney disease and premature death that would result if BP is not controlled, but reported diverse important barriers for preventive behaviours (Peters et al., 2006). Aroian et al. (2012) with Hispanic population also found that participants were knowledgeable about potential risks linked to HT and how to prevent them, and had a positive attitude toward prevention, but they also reported diverse important barriers that strongly difficulted preventive efforts.

In Study 2, preventive perceptions and practices were also explored. We found that the vast majority of the participants thought that the proposed behaviours were useful for preventing HT. Furthermore, none of the participants showed a complete lack of confidence in lifestyle changes for the prevention of HT. Moreover, only a very small proportion of the participants (3.1%) rated the perceived efficacy of the preventive behaviours as a whole as lower than moderate. In general, participants showed a high perception of efficacy of the listed behaviours for HT prevention, resulting in a general average score of the complete list of almost 8 in a 0-10 scale. Concretely, the actions perceived by the sample as more successful for preventing HT were introducing modifications in diet, physical activity and substance use as well as controlling stress and negative emotions. These findings are in line with those obtained in studies with ethnic minorities (Aroian et al., 2012; Newell et al., 2009; Peters et al., 2006; Savoca et al., 2009).

Perceptions on the efficacy of actions for preventing HT are expected to be translated in the practice of such behaviours in daily life as a way to face HT risk. However, we observed that the number of people who practiced them was considerably low, with up to 1 in 5 participants in average not executing those actions with the intention of preventing HT. Whilst 4.2% of the participants reported not conducting any of the listed preventive actions, 38% of the participants indicated to perform less than 5 preventive actions. This incongruence between mental representations and actions has been also pointed out by other studies (Aroian et al., 2012; Newell et al., 2009; Peters at al., 2006; Savoca et al., 2009). The explanation of these dispiriting results could be related to that, even if healthy people know how to prevent HT, if they don't perceive a real likelihood of suffering from the disease they probably will not change their habits because of the effort these changes entail. Age of the participants might by also explaining our findings, given that HT is perceived to be related to ageing, and young adults, who probably do not perceive a high risk of suffering from HT in the short- or medium-term, are over-represented in our sample. In fact, participants might be conducting these behaviours for the overall derived health promoting and disease preventing effects, and not explicitly for preventing HT.

In regard to the associations among the psychosocial variables of our study, we found a clear relationship among the perception of health risks related to HT, the perception of preventive behaviours and the practice of them. The perception of HT as a risk factor correlated more robustly with the practice of preventive behaviour, while the perception of a higher number of health threats linked to HT correlated more robustly with the perception of preventive lifestyle changes. We also found that people who perceived more possibilities of HT prevention linked to different lifestyle changes also conducted these behaviours more likely.

Our findings also showed that illness beliefs about HT correlated with perceptions of risks, perception of preventive behaviours and practice of preventive actions. With the exception of duration and evolution dimensions, all the BIPQR dimensions correlated as expected with the perceptions of HT as a risk factor or the number of health threats linked to HT; and with the exception of treatment control dimension, all the BIPQR dimensions correlated as expected with the perception of prevention options or preventive behaviours. Specifically, we found that beliefs about the presence of more symptoms and of more serious consequences linked to HT were related to stronger perceptions of health risks of HT, higher confidence in the possibility of preventing HT using preventive behaviours and more frequent practice of these behaviours in daily life. Lack of personal control dimension was inversely related to all outcomes: The higher the perceived controllability on HT, the more serious and frequent risks linked to it but also the greater perceptions on preventability. Cyclic evolution beliefs were inversely related to perception and practice of HT preventive behaviours, so that people who perceived HT as a more stable disease considered preventive behaviours as more effective to control HT and consequently they practiced them more frequently. Emotional representations and coherence on the disease were related to the perceptions on HT risks and prevention actions, so that participants who doubt on that they have a meaningful understanding and have more negative emotional reactions usually put in practice more preventive behaviours. Causal attributions and BIPQR global score were directly related to risk perceptions and prevention perceived options. Duration and treatment control dimensions were the most weakly related to outcome variables. Our findings support the proposal by Cameron (2008) on the relationship between illness perceptions and illness risk perceptions, but add more illness representations to likelihood estimates.

Furthermore, supporting SRM proposals, illness beliefs revealed as significant predictors of some of the outcome variables included in this research. Concretely, stronger negative representations on HT were more likely to derive in perceptions of HT as linked to a higher number of health threats and stronger preventive perceptions. Family experience, besides affecting illness perceptions, predicted a stronger perception of HT as a risk factor for further health problems. Number of problems linked to HT and HT as a risk factor perception predicted higher likeliness of perceiving preventing options or conducting preventive actions, respectively. Practiced preventive behaviours was further predicted by perceiving preventive options. Moreover, age and gender revealed as important for outcomes variables. Women (e.g., Savoca et al., 2009) and younger people (e.g., Aroian et al., 2012) have demonstrated to be more aware about possible risks and prevention of HT. In our study, younger participants perceived more health risks linked to HT and both they and women perceived more possibilities of prevention. Furthermore, women were more likely to practice preventive behaviours in their daily life.

Our findings have important applied derivations, offering keys for HT prevention and control. They reveal the usefulness of knowing how a very extended but preventable disease such as HT is understood by healthy laypeople, how beliefs derive from an indirect experience with the disease and how non-patients perceive risks linked to the disease, possibilities of prevention and preventive efforts. This knowledge allows us to design interventions that can be targeted appropriately to different populations (i.e., non-patients vs. patients, carers, health professionals). As the SRM suggests, patients cope with their disease and its impact based on their beliefs and, for example, adhere to treatments, self-regulate emotional distress or adopt self-care activities or changes in lifestyles if they believe something can be done to manage the disease, its symptoms and its consequences (Petrie & Weinman, 2006). Based on SRM proposals (Cameron, 2008; Leventhal et al., 2011), it is expected that similarly healthy people avoid risks, seek medical care, undergo medical exams and adopt new healthy behaviours if they believe they can act against a disease and they believe they can suffer from it. Our research has established a positive relationship between perceptions about HT and attitudes, intentions and actions regarding protective and preventive behaviours, as other studies has shown for different physical illnesses (e.g., Andersson et al., 2009; Ali et al., 2013; Cameron, 2008; Chang et al., 2011; Claassen et al., 2010, 2012; Hevey et al., 2009; Raude & Setbon, 2005; Sullivan et al., 2010; Van Oostrom et al., 2007a, 2007b, 2007c). An individually focused revision and discussion of illness beliefs could modify misconceptions and biased, inappropriate and unrealistic expectations.

Our results also have shown a discrepancy between the perception of possibilities of preventing HT through changes in personal behaviours and the actual performance of these behaviours in daily life. This gap from knowledge, beliefs and attitudes to action should be studied more deeply, but it highlights the importance of introducing real changes in people's lifestyle to avoid HT. Understanding the illness beliefs and the perceptions of risks and possibilities of HT prevention held by healthy people also provides insights on how a particular illness or health-threatening condition is perceived prior to a possible direct experience with the disease. It also helps us to understand how these representations are changed by the illness experience; how they relate to specific coping behaviours, adjustment and health outcomes with and without personal or family experience; and how this information can be used to derive preventive and therapeutic interventions aimed at modifying illness beliefs in both patients and non-patients (Del Castillo et al., 2011, 2013). Furthermore, such knowledge would allow us to inform appropriate preventive and therapeutic interventions, so that the emotional and behavioural managing actions of non-patients (and patients) could be better adjusted to their respective condition and result in more positive outcomes in terms of health and well-being and management of risks. Our study also stresses the key role of health psychologists in primary and specialised care and, more broadly in community health policies and campaigns, for educating both laypeople (patients, non-patients, relatives and caregivers) and specialised staff.

However, some limitations of this study should be considered in future research. Given the scarcity of investigations on HT representations and preventive behaviours in Spanish and other populations, we encourage researchers to conduct new studies aimed at replicating our results and to include cross-cultural comparison purposes. It would be advisable to increase the number of participants and to include a more heterogeneous sample. The reliance on self-reported diagnoses of personal and family member HT has important limitations, as prevalence may be under- or overestimated. Nonetheless, this procedure has been found to show a moderate to excellent agreement with epidemiological, population-based prevalence in nationwide samples

(Lima-Costa, Peixoto & Firmo, 2004; Selem, Castro, Galvao, Lobo & Fisberg, 2013; Van Eenwyk, Bensley, Ossiander & Krueger, 2012). Thus, self-reports are considered valid and an appropriate indicator for the surveillance of HT prevalence in the absence of BP measurement. Researchers and health specialists are increasingly obtaining information on chronic illnesses from self-reports (e.g., Estoppey, Paccaud, Vollenweider & Marques-Vidal, 2011; Kaplan, Huguet & Feeney, 2010; Pereira et al., 2012; Pitsavos et al., 2006; Valderrama, Tong, Ayala & Keenan, 2008). However, medical data would complete self-reported information. Future research should also compare the beliefs of non-patients, caregivers and patients with controlled and uncontrolled HT. Further, neither the type and accuracy of knowledge the participants had nor the sources of their representations were considered herein, and it would be appropriate to know and compare the beliefs and behaviours of people who have significant medical knowledge with those held by people with no specialised knowledge. It would be also interesting to consider participant's current or future risk of having HT due to behavioural or genetic causes. Besides, it would be interesting to explore how illness perceptions and preventive representations and behaviours themselves change over time in response to new influences, such as an individual's personal and/or family experience with the illness or a tailored intervention. Finally, other analytical decisions (e.g., using IPQ-R dimensions) and strategies (e.g., indirect effects) might reveal different findings, and we encourage authors to conduct future research considering these recommendations.

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CAPÍTULO 11

ESTUDIO 5

Multidimensional psychosocial profiles clustering illness perceptions and preventive behaviours for hypertension among non-hypertensive individuals

Abstract

Personal representations about illnesses (i.e., illness schemata) have received increasing interest because they help in understanding health-related behaviours and health outcomes. The present research was conducted to explore the associations between hypertension (HT) cognitive and emotional constructions, perceptions of HT as a risk factor for further health threats and perceived and practiced preventive behaviours, with the aim of supporting the relationship illness perceptions-behaviour predicted by the Self-Regulation Model. A cross-sectional study was conducted with a community-based, convenience sample of normotensive adults who completed several self-reports on their illness perceptions, perceptions about HT as a health risk factor as well as possible risks derived from HT, perceived preventive behaviours for reducing the risk of suffering from HT and their practice of these preventive behaviours. To establish different psychosocial multidimensional profiles according to the variables of the study, a multivariate k-means cluster analysis was performed. Results showed that Spanish normotensive adults can be divided in three multidimensional profiles: Clusters 1 (48.8%) and 2 (5.4%) were composed of participants with low and very low, respectively, awareness of HT seriousness and linked risks who were poorly concerned about suffering from HT and derived consequences. They endorsed inaccurate, excessively optimistic cognitive and emotional representations about the disease, particularly participants in cluster 2; they also demonstrated low value conceded to preventive options. On the other hand**,** Cluster 3 (45.9%) was composed of participants with high awareness and concern of HT seriousness and linked risks as well as higher value conceded to preventive options. They had more realistic illness perceptions on HT which also were more adjusted to biomedical knowledge. These profiles were related with the practice of preventive behaviours, so participants of profile 3 demonstrated a relative higher investment in preventive efforts in comparison with the other two profiles, particularly with cluster 2, which showed dramatically lower preventative investment. Some differences related to family experience, sex and socioeconomic status were also found. Our findings are useful in designing interventions aimed at HT prevention considering multidimensional profiles of illness schemata and other related psychosocial variables.

Keywords: Illness representations, illness cognitions, illness schemata, k-means cluster analysis, self-regulation model, disease prevention.

Introduction

Hypertension (HT), systolic/diastolic blood pressure (BP) ≥140/90mmHg, is an important public-health challenge in both economically developed and developing nations (Kearney et al., 2005). The World Health Organization (WHO) in its report "General Information on HT in the World" states that the prevalence of HT has increased in a remarkable way worldwide, to the point that currently, 40% of 25-years-old or older population has an elevated BP (WHO, 2013). In Spain, HT affects to 47% of adult men and 39% of adult women, with slightly higher prevalence rates in the Southern region of the country (44%) compared to other regions (Grau et al., 2011; Valdés et al., 2014). Estimations for future rates of prevalence worldwide are alarming, pointing to an increase by about 60% for 2025 (Kearney et al., 2005). Unfortunately, a significant number of individuals with HT are unaware of their condition and, among those with a diagnosis, treatment is frequently inadequate (Kearney et al., 2004). Both in Spain and other nations, nearly 1/3 of patients does not know that they are affected by the disease, and only 50% is in treatment, with only 1 in 3 of men and 1 in 2 women well controlled by therapies (Banegas et al., 2011; Félix-Redondo et al., 2011; Ortiz et al., 2011).

Although HT is not a severe disease by itself, it is considered a “silent killer” because high BP is an important risk factor for other more serious disorders such as cardiovascular, kidney, eye or respiratory diseases. Thus, HT is a major source of morbidity and mortality, and it has been stated as the first risk factor for global disease burden, explaining 7% of deaths and disability-adjusted life years (Lim et al., 2012). An added problem is that a significant percentage of individuals, 30-50% of worldwide population (Banegas, 2005; Guo et al., 2011; Marta et al., 2013; Ostrowski, Artyszuk, Lewandowski & Gaciong, 2008; Zhang & Li, 2011), has BP levels considered as prehypertensive (a systolic BP of 120-139 mmHg or a diastolic BP of 80-89 mmHg), which arises the risk of, among others, cardiovascular events considering the continuity of the cardiovascular risk over the levels of BP (Huang et al., 2013).

Consequently, there is a need of interventions at a population level to improve awareness, treatment and control of HT in the community. But, given the figures of prevalence, unawareness and inadequate control among patients and the important health risks related to this *silent killer*, there is a need for interventions aimed at preventing the development of HT.

A number of controllable risk factors for HT have been well-established, including lifestyle and behaviour-related factors such as excessive body weight, suboptimal dietary pattern, high dietary sodium and low dietary potassium, reduced physical activity, smoking and excess alcohol intake (Forman, Stampfer & Curhan, 2009; Frisoli, Schmieder, Grodzicki & Messerli, 2011; Lloyd-Jones et al., 2010; Liu et al., 2012; Mozaffarian, Wilson & Kannel, 2008; Perk et al., 2012; WHO, 2013). Furthermore, emotional-distress risk factors have been also identified, including stress (Babu et al., 2014; Backé, Seidler, Latza, Rossnagel & Schumann, 2012; Chida & Steptoe, 2010; Gasperin, Netuveli, Soares & Pattussi, 2009; Landsbergis, Dobson, Koutsouras & Schnall, 2012; Nagele et al., 2014; Rainforth et al., 2007; Sparrenberger et al., 2009), anxiety (Olafiranye, Jean-Louis, Zing, Nunes & Vicent, 2011; Player & Peterson, 2011) and depression (Meng, Chen, Yang, Zheng & Hu, 2012; Nabi et al., 2011). Those risk factors are present not only at the adulthood but many years before (Kann et al., 2014; Moreno-Gómez et al., 2012).

The prevalence of these risk factors for HT in the general population is high. The WHO (2013) has stressed that the arise in the incidence and prevalence of HT worldwide may be explained by the higher incidence of these lifestyle risk factors, along with the population increase and their progressive higher longevity. In order to prevent BP levels from rising, primary and secondary prevention should be introduced to reduce or minimize these causal factors in the population, particularly in individuals with prehypertension (Guo et al., 2011). A community approach that decreases BP levels in the general population by even modest amounts has the potential to substantially reduce morbidity and mortality or at least delay the onset of HT and derived health threats (Chobanian et al., 2003). Dickinson et al. (2006), in a review of randomized controlled trials about lifestyle interventions to reduce raised BP, found that controlling diet, doing aerobic exercise, restricting alcohol and sodium consumption and taking fish oil supplements are effective ways to reduce BP in HT patients. Despite recommendations regarding lifestyle change for HT prevention coming from several institutions and professional associations, there is limited research focused on primary prevention of HT and factors associated to behavioural change.

Research about HT prevention in non-hypertensive population is lacking and has been conducted mainly with samples limited in their characteristics such as minorities (e.g., Aroian, Rosalind, Rudner & Waser, 2012; Gopinath et al., 2014; Newell, Modeste, Marshak & Wilson, 2009; Peters, Aroian & Flack, 2006; Savoca et al., 2009), and the findings show that family experience, culture, age and gender influences should be considered. It has pointed out that, in general, this population is moderately aware about risk factors for HT and health threats linked to HT and how to prevent the disease, but do not change their life-style in order to avoid HT due to several perceived barriers such as perceived difficulty and lack of resources, low self-efficacy or the negative influences of several factors such as family experience with the disease, culture or family and social support.

Nevertheless, none of these studies explored illness representations based on the Self-Regulation Model (SRM) and their possible influence on preventive perceptions and efforts. According to the SRM, also known as the Common Sense Illness Representations Model (Cameron & Moss-Morris, 2004; Diefenbach & Leventhal, 1996; Leventhal, Brissette & Leventhal, 2003; Leventhal & Diefenbach, 1991; Leventhal, Diefenbach & Leventhal, 1992; Leventhal, Leventhal & Cameron, 2001; Leventhal, Leventhal & Contrada, 1998; Leventhal et al., 1980, 1984, 1997), both healthy and ill people construct non-specialised models about illnesses which comprise a series of cognitive and emotional representations, in order to create an integrated, comprehensible and meaningful picture of a health-threatening condition. These illness representations directly influence individuals' illness-related problem- and emotion-focused coping actions (such as adherence to medical recommendations and management of sadness), conducted for facing perceived risks in order to protect their health, or to manage their condition when already ill for controlling disease-derived consequences and recovering well-being; and indirectly, by a mediation path of actions, illness representations also influence the adjustment to the disease and the consequences of illnesses (such as health status, well-being, quality of life or daily functioning) (see French, Cooper & Weinman, 2006; Hagger & Orbell, 2003; Kaptein et al., 2003; Kucukarslan, 2012; Lobban, Barroclough & Jones, 2003; Mc Sharry, Moss-Morris & Kendrich, 2011; Petrie & Weinman, 1997 for a review).

Based on the postulates of the SRM, illness representations are, thus, relevant for the prevention and management of diseases (Cameron & Leventhal, 2003; Cameron & Moss-Morris, 2004; Leventhal et al., 1980, 1998, 2003). Illness representations guide actions to promote health, detect risk and prevent illnesses; behaviours to manage acute and chronic illnesses; and the expression of preferences and treatment decisions during terminal illness (Leventhal et al., 2011). According to the SRM, it is expected that healthy people avoid risks, seek medical care, undergo medical exams or screening tests or adopt new healthy behaviours depending on the specific contents of their illness representations. Besides, it is expected that more accurate beliefs will lead non-patients to carry out more appropriate and beneficial behaviours to face health threats.

Illness representations schemata and efforts for lowering and controlling high blood pressure

Recently, there has been an increasing interest in identifying intra-individual configurations of perceptions that people may have on a specific disease, beyond concrete representations considered individually or separately. Following Clatworthy, Hankins, Buick, Weinman & Horne (2007), people do not hold illness representations in isolation; instead, these representations are part of a schema, so that when analyzing their influences on an outcome variable (for example, health-related behaviours, illness management actions or health outcomes) it seems more appropriate to take into account all aspects of a person's illness schema. Moreover, if different groups of people within a sample have profiles of illness perceptions that affect behavioural or health-related outcomes in different ways, it does not make sense to conduct nomothetic analysis using variables drawn from the entire sample, which may mask the real relationships between independent or predictor and dependent or predicted variables. The presentation of these profiles of beliefs and their prevalence may be more meaningful and easily interpreted than means and standard deviations of the entire sample, and allows for examining the utility of the SRM in predicting actions and outcomes derived from, or linked to, these beliefs (Clatworthy et al., 2007). Besides, groups of people with schemata associated with poor coping or outcome would be ideal targets for interventions (Clatworthy et al., 2007). The cluster analysis would not only identify these groups but would also provide information on the types of beliefs held by the groups that may need to be addressed in an intervention (p. 126).

Based on the seminal work by others demonstrating different schemata on illness perceptions and their influences on the reactions to diseases such as Addison disease, breast cancer, chronic fatigue syndrome and chronic pain, including coping efforts, quality of life and adjustment to the disease (Buick, 1997; Heijmans, 1999; Heijmans and De Ridder, 1998; Hobro, Weinman & Hankins, 2004; Moss-Morris, 1997), some research has been conducted recently with patients suffering from several diseases attempting to profile participants based on their cognitive and emotional representations on the disease they suffer from in order to predict or to compare behavioural or health-related outcomes (see Table 1). This research has revealed consistently the utility of clustering patients in order to explore the influence of illness representations on patient's coping and caring behaviours or well-being, based on the relationship between illness perceptions, management actions and health outcomes proposed by the SRM. Some research is focussed on health-related outcomes (e.g., Crawshaw, Rimington, Weinman & Chilcot, 2015; Dempster et al., 2010; Harrison, Kohlman & McCorry, 2014; Kaptein et al., 2010; Kohlman, Rimington & Weinman, 2012; McCorry et al., 2013; Miglioretti, Mazzini, Oggioni, Testa & Monaco, 2008; Skinner et al., 2011; Snell, Surgenor, Hay-Smith, Williman & Siergert, 2015). In general, the more positive the illness perceptions endorsed, the better the clinical outcomes linked to the disease. Other studies include any form of health-related managing behaviour (e.g., Charlier et al., 2012; Harrison et al., 2014; Kohlmann et al., 2012; Letelier, Nuñez & Rey, 2011; Lin & Hiedrich, 2012; Lowe, Porter, Snooks, Button & Evans, 2011; Medley, Powell, Worthington, Chohan & Jones, 2010). Contrary to health-related outcomes, for which findings clearly show a positive association between more positive illness perceptions and lower impairment, findings for the link between illness representations and managing behaviours are less conclusive or even contradictory, though in general a positive trend is demonstrated. Of all the studies reviewed, only those by Charlier et al. (2012) and Snell et al. (2015) clustered participants based on multidimensional psychosocial profiles (i.e., including other variables besides illness perceptions). Moreover, as far as we know only one study has been conducted with non-patients, concretely with carers of cancer survivors, and it focussed on changes in emotional distress and coping experienced by the participants as a consequence of diverse trajectories overtime of cancer-related illness representations (Graham, Dempster, McCorry, Donnelly & Johnston, 2015).

This study was designed to identify groups of people that share similar illness schemata on HT and to explore the relationship between different configurations or profiles of perceptions on HT and a behavioural outcome, preventive actions, among non-patients from the general population. To our knowledge, only two studies (Figueiras et al., 2010; Hsiao, Chang & Chen, 2012, see Table 1) were conducted with hypertensive patients in order to identify groups of patients that share a similar pattern of illness perceptions and whether these profiles influenced coping or caring actions. However, there is no research of this nature conducted with non-patients, and thus there is a lack of empirical evidence supporting the same effect among healthy people. Consequently, a core aspect of the present study is to investigate the relationship between overall schema of illness perceptions and behavioural outcomes among non-patients who have different experience with HT in terms of family experience, with the aim of testing the relationship illness perceptions-behaviour predicted by the SRM. Moreover, we were interested in exploring multidimensional trajectories that include not only cognitive and emotional representations of HT but also other perceptions related to the disease not included in the SRM, concretely perceptions of HT as a risk factor for further health threats and perceptions on preventive behaviours, in order to clarify the possible association of these complex schemata and preventive behaviour.

Table 1: Clusters identified in previous research and main characteristics of each cluster.

With HT Patients			
Study	Number of clusters (Method for clustering)	Characteristics of each cluster (illness perceptions)	Influences on behavioural or health-related outcomes
Figueiras et al. (2010) (Brief-IPQ was used. Causes dimension was excluded. Chronic and cyclical timeline were considered in one dimension. Emotional representations were separated in emotional impact and concern)	3 (AHCA with Ward's method)	"More negative" (36.2%): Highest identity, consequences, emotional impact and concern, higher chronic timeline and lower personal and treatment control. Lower coherence. "Moderately negative with low control and understanding" (40.1%): Lowest personal and treatment control, moderate identity, consequences and emotional impact, higher chronic timeline and concern. Lowest coherence. "More positive" (23.7%): Lowest identity, consequences, chronic timeline, emotional impact and concern and highest personal and treatment control and coherence. No differences for gender, age and education according to each illness schemata identified.	General schemata on HT: Moderate-to-high perceptions of symptoms, serious consequences, chronic timeline, high concern and negative emotional impact. High personal and treatment control. Good comprehensibility. Patients preferred brand medicines compared to generic medicines. Illness perceptions were associated with participants' beliefs about necessity and concerns about medication: A greater belief in the necessity and concern about treatment was associated with a more negative perception of HT in terms of symptoms, consequences, chronic timeline, emotional impact and concern. A greater belief in personal and treatment control was positively associated with perceived necessity of treatment and it was not associated with concern about taking medicines. Illness coherence was not related to perceived necessity or concern about medication. Outcome variables: C1 were more likely to choose a brand medicine, whereas C2 were more likely to choose a generic medicine. C3 chose equally brand and generic medicines. No effect of age, gender and education level as covariates.
Hsiao et al. (2012) (Causes dimension was excluded)	3 (AHCA with Ward's method)	"More positive but low controllability" (46.2%): Lower identity, lowest chronic and cyclical timeline, negative consequences and emotional representations. Higher treatment control but lowest personal control. Highest coherence. [More women] "More negative but high controllability" (12%): Highest identity, cyclical timeline, consequences and emotional representations, high chronic timeline. Highest personal and treatment control. Lowest coherence.[Oldest] "Mixed with high understanding" (41.9%): Lowest identity, highest chronic timeline, moderate-to-high cyclical timeline, consequences and emotional representations. Highest personal control but lowest treatment control. Highest coherence. No differences by gender, age, education and comorbidity among clusters.	General schemata on HT: Low level of symptoms, negative consequences, chronic but stable disease, relatively high emotional impact. High personal and treatment controllability. Good comprehensibility. Average adherence to drug treatments was moderately high (62.6%). Outcome variables: C1 had the best drug adherence, and C2 had the worst drug adherence.

With patients with other diseases			
Study	Number of clusters (Method for clustering)	Characteristics of each cluster (illness perceptions)	Influences on behavioural or health-related outcomes
Dempster et al. (2010)[a] With oesophageal cancer patients (Cluster analysis was used to identify groups of respondents who reported a similar profile of change in their illness perception over 1 year) (Emotional representations dimension was excluded. Causes dimension was factorized in emotional, behavioural and externalized causes)	4 (AHCA with Ward's method & k-means NHCA)	"More positive over time" (30.1%): Decreased identity, chronic and cyclical timeline and consequences, increased treatment control, decreased all perceived causes. Decreased personal control. Increased coherence. "Changing to more positive" (28%): Increased personal control and decreased treatment control over time. Decreased identity, increased chronic timeline, decreased cyclical timeline, decreased consequences, increased emotional and external causes. Increased coherence. "More negative over time" (23.3%): Decreased identity, increased chronic and cyclical timeline and consequences, decreased personal and treatment control. Decreased coherence. "Changing to more negative with increased control" (18.6%): Increased cyclical timeline and consequences, increased behavioural and external causes, decreased emotional causes. Increased personal and treatment control. Decreased coherence.	Changes in outcome variables over time were analysed. Anxiety and depression were stable or, more frequently, worse over time. Outcome variables: Anxiety and depression increased more over time in C3 than C1, as coping also changed. Cluster membership contributed to the prediction of changes in anxiety over time, but it was the less important predictor. Medical and sociodemographic conditions followed by coping explained the highest proportion. Cluster membership contributed to the prediction of changes in depression over time. Coping explained the highest proportion of change and medical and sociodemographic conditions the lowest proportion.
Charlier et al. (2012) With breast cancer patients (Identity and causes dimensions were excluded)	4 (AHCA with Ward's method & k-means NHCA)	MULTIDIMENSIONAL PSYCHOSOCIAL AND CLINICAL CLUSTERS (illness perceptions, emotional distress and coping) "Low distress-active approach group" (21.2%): Lowest chronic and cyclical timeline, consequences and emotional representations and highest personal and treatment control and coherence. Lower physical symptoms and fatigue and lowest psychological distress (anxiety and depression), best self-perceptions (future perspectives, self-esteem and body image), higher social support and highest problem-oriented coping, higher avoidance and lower emotional-oriented coping. "Low distress-resigned approach group" (32.3%): Very similar to C1, but lower personal and treatment control and higher chronic timeline, and poorer social support, lower problem-oriented coping and lowest avoidance and emotional coping. Lowest symptoms and fatigue. [Oldest] "High distress-active approach group" (24.2%): Higher chronic and cyclical timeline, consequences and emotional representations and lower personal and treatment control and coherence. Highest levels of physical symptoms, higher fatigue, lower psychological functioning, higher emotional distress, highest social support higher problem- and emotion-focused coping, and highest avoidance coping. [Most likely chemotherapy and participation in onco-revalidation program] "High distress-emotional approach group" (22.3%): Very similar to	Outcome variables: Physical activity levels were higher in C1 and C2 compared to C4. Women in C2 reported the lowest need for information and support for physical activity and women in C3 the highest one, whereas C1 and C4 were not different.

		C3 but with the worse levels in all the variables: Highest chronic and cyclical timeline, consequences and emotional representations, lowest personal and treatment control and coherence. Higher symptoms and highest fatigue, poorest psychological functioning and highest emotional distress, lowest social support, lowest use of problem-oriented coping, higher use of avoidance coping and highest use of emotional-focused coping. [Least likely to work]	
McCorry et al. (2013) With breast cancer patients (Clusters were established at baseline. Emotional representations dimension was excluded. Causes dimension was factorized in emotional, behavioural and externalized causes)	2 (AHCA with Ward's method & k-means NHCA)	"More negative perceptions" (63.2%): Greater symptoms, higher chronic and cyclical timeline, higher consequences and lower personal and treatment control. Lower coherence. Higher perceived causes of any type. "More positive perceptions" (36.8%): Lower symptoms, lower chronic and cyclical timeline, lower consequences and higher personal and treatment control. Higher coherence. Lower perceived causes of any type.	Outcome variables: C1 demonstrated higher levels of depression and anxiety. Anxiety and depression were predicted more importantly by illness perceptions clustering at the short time after diagnosis, and by coping at 6-month follow-up. Medical and sociodemographic conditions explained the lowest proportion at any time, and had lower contribution over time.
Medley et al. (2010) With brain injury patients (Emotional representations dimension was used as an outcome indicator of psychological distress. Causes dimension was excluded)	3 (AHCA with Ward's method)	“Low control/ambivalent” (23.6%): Lower symptoms, highest chronic timeline, lower cyclical timeline, lower consequences, lowest personal and treatment control. Lowest coherence. “High salience” (55.9%): Highest symptoms, higher chronic timeline, highest cyclical timeline, highest consequences, higher personal and treatment control. Lower coherence. “High optimism” (20.5%): Lowest symptoms, lowest chronic timeline and cyclical timeline, lowest consequences, highest personal and treatment control. Highest coherence. No differences by age, gender, education level or clinical indicators.	Outcome variables: C2 showed greater self-awareness of difficulties linked to their condition and range of coping strategies, including emotion-focused coping and wishful thinking, as well as the highest emotional impact. C1 & C3 showed lower levels of awareness, but differed in coping styles, with C1 showing a trend towards more avoidance coping. C3 showed the lowest emotional impact.
Snell et al. (2015) With brain injury patients (Clusters were established at baseline. Causes, personal control and treatment control dimensions were excluded)	3 (AHCA with Ward's method & k-means NHCA)	MULTIDIMENSIONAL PSYCHOSOCIAL AND CLINICAL CLUSTERS (illness perceptions and emotional distress) "High-adapters" (36.3%): Lowest identity, chronic and cyclic timeline, consequences and emotional representations, highest coherence. Lowest emotional distress (anxiety and depression). "Medium-adapters" (38.3%): Higher identity, chronic and cyclic timeline, consequences and emotional representations, lower coherence. Higher emotional distress (anxiety and depression). "Low-adapters" (25.4%): Highest identity, chronic and cyclic timeline, consequences and emotional representations, lowest coherence. Highest emotional distress (anxiety and depression). [Longest duration of symptoms, longest period post-injury, highest odds of post-injury intervention and of past or current psychiatric illness]. No differences by age, gender, education level, ethnicity, work status at time of injury or other clinical indicators.	Outcome variables: Baseline cluster-group membership was significantly associated with outcomes over time. High-adapters appeared recovered at recruitment and medium-adapters revealed almost similar improvements by 6-months. The low-adapters reported more symptoms, negative recovery expectations and distress at baseline and follow-up, being significantly at risk for poor outcome more than 6-months after injury.

Lin & Hiedrich (2012) With mild cognitive impairment (Causes dimension was excluded)	3 (AHCA with Ward's method & k-means NHCA)	"Few symptoms and positive beliefs " (28.6%): Lowest identity, consequences, cyclic evolution and emotional representations. "Moderate symptoms and positive beliefs " (42.9%): some symptoms but low consequences and emotional responses. "Many symptoms and negative beliefs " (28.6%): Highest identity, consequences, cyclic evolution and emotional representations. * Duration, personal control, treatment control and coherence: No differences. No differences by sociodemographic and clinical indicators, excepting C2 had higher family experience.	Outcome variables: C1 used fewer memory aids, problem-focused coping strategies, emotion-focused coping strategies, and dysfunctional coping strategies than C2 and C3. No differences for dementia preventive behaviours and use of supportive services.
Miglioretti et al. (2008) With amyotrophic lateral sclerosis (IPQ was used. Dimensions included were identity, consequences, chronic&cyclical timeline, personal&treatment control and causes)	2 (k-means NHCA)	"Adaptors" (52.7%): Lowest identity and consequences, highest controllability. Lowest attributions of the disease to external factors such as chance, or to poor medical care in the past. [Highest respiratory function] "Non-adaptors" (47.3%) * Timeline: No differences. No differences by age, gender and clinical indicators, excepting respiratory function (forced vital capacity).	Outcome variables: C1 demonstrated better mood status and physical and mental health-related quality of life.
Kaptein et al. (2010)[a] With osteoarthritis patients (Cluster analysis was used to identify groups of respondents who reported a similar profile of change in their illness perception over 6 years) (Causes dimension was excluded)	2 (AHCA with Ward's method & k-means NHCA)	"More negative illness perceptions over time" (47.5%) "More positive illness perceptions over time" (52.5%) No information on illness perception is offered for each cluster besides changes in patterns over time. Clusters differed according to changes in illness perceptions pattern over a six-year period: Those in C1 demonstrated increases in identity, chronic timeline and consequences, and decreases in personal and treatment control and emotional representations. Those in C2 demonstrated decreases in identity, chronic timeline, consequences and emotional representations, and increases in personal and treatment control. * Cyclical timeline and coherence: No differences.	Outcome variables: Physician reported pain intensity remained stable from baseline to 6-year follow-up and there were no differences between clusters in pain intensity over time. However, evolution in clinical status was significantly worse for C1 compared to C2, even when it was better at baseline for the first group; C2 remained stable or improved, depending on the indicator of functional impairment.
Skinner et al. (2011)[a] With type 2 diabetes patients (Clusters were established at first follow-up, 4 months after the intervention. Perceived seriousness, consequences and impact were measured with different measures than remaining dimensions. Treatment control, evolution and causes dimension were excluded)	4 (AHCA with Ward's & average linkage methods)	"Resisters" (31.5%) & "Resisters accepting consequences" (37.7%): In general, lower scores in duration, personal control, seriousness, impact and coherence. C1: Lowest scores in all the measures except perceived impact. "Accepters" (18.8%) & "Accepters resisting consequences" (12%): In general, higher scores in duration, personal control, seriousness and coherence, except C3: Lowest impact. [C4: Youngest]. No differences by gender or race.	64% of the participants remained within the same cluster group across assessments. Outcome variables: All groups improved in glycaemic control at the short-term (4 months) and maintained this control (8 and 12 months). C3 showed the better glycaemic control at the short-term. At medium- or long-term, no differences between cluster were found. All groups decreased BMI at the short-term and maintained this decline, but C3 also showed the lowest BMI at any time. Depression was very stable over time. There were differences for depression at baseline and in all follow-ups, with C1&2 being more depressed and C3 less depressed at any time. Glycaemic control was predicted by personal control dimension at 4

			months and by none illness perception dimension at 12 months. With those who remained in the same cluster over time, personal control and perceived impact predicted glycaemic control at 4 months. BMI was predicted by seriousness dimension at 4 months and by non illness perception dimension at 12 months. With those who remained in the same cluster over time, no illness perception predicted BMI at any time. Depression was predicted by cluster membership (C3 predicted lower levels of depression and C1 predicted higher levels of depression), perceived impact and coherence at 4 and 12 months. With those who remained in the same cluster over time, perceived impact predicted depression levels at 4 and 12 months, and C1 predicted being more depressed at 12 months.
Letelier et al. (2011) With type 2 diabetes patients (Coherence and causes dimensions were excluded. Emotional representations dimension was used as an outcome indicator of psychological distress)	3 (AHCA with Ward's method & k-means NHCA)	"Preoccupied" (39,8%): Highest identity, consequences, cyclic and chronic timeline and highest personal and treatment control. [Oldest, lowest educational level, urban area] "Hopeless" (36.9%): Higher identity, consequences, cyclic and chronic timeline and lowest personal and treatment control. [Longest time under treatment and time knowing about the disease]. "Denier" (23.3%): Lowest identity, consequences and cyclic and chronic timeline, higher personal control and highest treatment control. [Shortest time under treatment and time knowing about the disease, youngest, highest educational level, rural area]. No differences were found for gender and marital status.	Outcome variables: C1 demonstrated higher emotional representations than C2 and C3, whereas C2 demonstrated higher scores than C3. C1 demonstrated higher perceptions of medication necessity and concerns about medication effects than C2 and C3, whereas C2 and C3 were not found as different. C1 was found to report a higher intention to adhere to treatment than C2.
Kohlmann et al. (2012)[a] Crawshaw et al. (2015) With heart valve replacement patients (Clusters were established at baseline before the surgery and 12 months after the surgery. Causes dimension was excluded)	2 (AHCA with Ward's method & k-means NHCA)	"Negative perceptions" (41.2% at baseline; 42% at follow-up): Greater symptoms, higher chronic and cyclical timeline, higher consequences, lower personal and treatment control and higher emotional representations. Higher coherence. "Positive perceptions" (58.8%/ at baseline; 58% at follow-up): Fewer symptoms, less chronic and cyclical timeline, fewer consequences, higher personal and treatment control and lower emotional representations. Lower coherence. [Older, more males]	35.6% of participants changed their illness perceptions profile. According to their illness perceptions pattern over one year patients were grouped in four profiles: a) stable positive perceptions (N= 54), b) stable negative perceptions (N= 34), c) changing from positive to negative perceptions (N= 23, increased chronic timeline and decreased personal control), and d) changing from negative to positive perceptions (N= 25, increased personal and treatment control and decreased the remaining dimensions). Outcome variables: C2 and groups with positive perceptions one year after demonstrated better health status and quality of life and lower levels of emotional distress in the 12-month follow-up. No differences were found for rehab attendance after surgery. Cluster membership contributed to the prediction of health status and physical quality of life at 12 months, but it could not predict mental quality of life. All-cause mortality was recorded over a 10-year period. No differences in mortality risk between C1 and C2 were found for baseline and 1-year follow-up. After controlling for clinical covariates and sociodemographic

			factors, adjusted survival analyses revealed that patients who changed illness perceptions from positive to negative beliefs 1 year post-surgery had a x3 increased mortality risk compared to patients who held positive stable perceptions. (Not found for stable negative illness perceptions).
Grayson et al. (2013) With vasculitis patients (Causes dimension was excluded)	3 (k-means NHCA)	"Negative illness perceptions" (25%): Highest consequences and emotional representations and lowest personal control, treatment control and illness coherence dimensions. "Positive illness perceptions" (29%): Lowest consequences and emotional representations and highest personal control, treatment control and illness coherence. "Mixed illness perceptions" (46%): Lower consequences and emotional representations and higher personal control, treatment control and illness coherence. Gender, race, education, annual income, place of birth, disease duration, disease severity and remission duration were not predictors of illness perceptions.	Younger age, depression, active disease status and poor overall health were associated with negative illness perceptions. Illness perceptions were related to fatigue levels and, with the exception of chronic timeline, explained an equivalent proportion of variability in fatigue compared to measures of disease activity and other clinical indicators (remission duration, depression, sleep disturbances), and predicted it beyond these indicators and sociodemographic factors (age, race). Outcome variables: Influences of cluster membership on fatigue were not tested.
Harrison et al. (2014) With COPD patients (Causes dimension was excluded)	3 (AHCA with Ward's method & k-means NHCA)	"In control" (40,6%): Fewest symptoms, lower chronic timeline, lowest cyclical timeline, fewest consequences, highest personal control, lowest emotional representations. Lower coherence. [Oldest, more males and less disabled]. "Disengaged" (28.1%): Higher symptoms, lowest chronic timeline, lower cyclical timeline, lower consequences, lowest personal control, lesser emotional representations. Lowest coherence.[More disabled]. "Distressed" (31.3%): Highest symptoms, highest chronic and cyclical timeline, greatest consequences, lower personal control, highest emotional representations. Highest coherence.[Youngest]. * Treatment control: No differences.	Outcome variable: Anxiety and depression were lower in C1 and higher in C3. Health status was better in C1 and poorer in C3. Self-efficacy was higher in C1 and lower in C3. No differences in acceptance and adherence to pulmonary rehabilitation prior or following hospitalisation after acute exacerbation.
Lowe et al. (2011) With people using unscheduled urgent and emergency services for chronic and non-chronic diseases (Brief-IPQ was used. Causes dimension was excluded. Chronic and cyclical timeline were considered in one dimension. Emotional representations were separated in emotional impact and concern)	3 (AHCA with Ward's method & k-means NHCA)	"More negative & low control" (44.1%): Highest identity, consequences, emotional impact and concern, higher timeline and lowest personal control. High coherence. "More negative & high control" (30.4%): Higher consequences, emotional impact and concern, highest chronic timeline and personal control. Highest coherence. "More positive & low coherence" (25.5%): Lowest identity, consequences, chronic timeline, emotional impact and concern. Lowest coherence.	Outcome variables: C1 used secondary care in general more than C2 & 3, and used primary care more frequently with non-chronic conditions and more secondary and less community care with chronic conditions.

With non-patients			
Study	Number of clusters (Method for clustering)	Characteristics of each cluster (illness perceptions)	Influences on behavioural or health-related outcomes
Graham et al. (2014)[a] With carers of oesophageal cancer patients (Cluster analysis was used to identify groups of respondents who reported a similar profile of change in their illness perception over 1 year. Identity and emotional representations dimensions were excluded. Causes dimension was factorized in emotional, behavioural and externalized causes)	3 (AHCA with Ward's method & k-means NHCA)	"Moderately more negative over time" (46.2%): Marginal to moderate change in beliefs over time, with increased acute and cyclical timeline and consequences (for themselves and the survivor) and stronger causal beliefs, particularly emotional attributions. "More negative over time, lower consequences, higher coherence" (15.2%): Marked change over time of most illness beliefs, with increased chronic and cyclic timeline, patient and carer coherence and decreased personal (carer/survivor) and treatment control, consequences for carers and patients and causal attributions. "More positive over time, lower coherence" (38.6%): Marginal to moderate change, with decreased consequences for survivor and carer and causal attributions, and increased acute and cyclical timeline and personal and treatment controllability. Decreased coherence (patient and carer).	Changes in outcome variables over time were analysed. Anxiety and depression were stable or, more frequently, worse over time (1/3 of cases, approx.). Outcome variables: Anxiety and depression increased more over time in C1, while they decreased in C2 and C3; only C1 and C2 were significantly different. Fear/concern of recurrence was not different between clusters. No differences between clusters were found in coping. Cluster membership was the most important predictor of changes fear of recurrence over time: C3 vs. C1 exhibited decreased fear. Coping explained a limited proportion of change and medical and sociodemographic conditions were not significant predictors. Cluster membership contributed to the prediction of changes in depression over time: C2 and C3 vs. C1 exhibited decreased depression. Coping explained a limited proportion of change and medical and sociodemographic conditions were not significant predictors. Cluster membership marginally contributed to the prediction of changes in anxiety over time, but it was the less important predictor: C2 and C3 vs. C1 exhibited decreased anxiety. Coping explained the highest proportion.

Notes. [a] Illness perceptions change over time was used for clustering the cases. IQP-R: Revised Illness Perception Questionnaire (Moss-Morris et al., 2002) (Unless otherwise noted, IPQ-R was used); Brief-IPQ: Brief Revised Illness Perception Questionnaire (Broadbent et al., 2006). AHCA: Agglomerative Hierarchical Cluster Analysis; NHCA: Non-hierarchical (iterative) Cluster Analysis. Names of clusters were stated in the reports or assigned by the authors of the present study.

Aims of the present research

The present research was conducted to explore the associations between HT cognitive and emotional constructions, perceptions of HT as a risk factor for further health threats and perceived and practiced preventive behaviours with the aim of testing the relationship illness perceptions-behaviour predicted by the SRM.

Specifically, this study was conducted to explore three main objectives. First, we sought to know whether normotensive Spanish population could be divided in different profiles regarding their illness schemata on HT and other important related variables as risks perceptions and preventive options linked to HT using the SRM as a theoretical framework. In the case this division could be possible, we also wished to know the characteristics of each one of the different profiles identified. Although to our knowledge there is no study that investigates illness representations profiles in healthy people different from carers of cancer patients, based on previous findings conducted with HT patients (Figueiras et al., 2010; Hsiao et al., 2012) and other diseases using the SRM (Table 1), we expected to find different profiles about HT representations and other important variables for health outcomes. Given the lack of previous research, no hypothesis on their specific configuration was stated.

Our second aim was to explore the possible influence of different sociodemographic variables such as age, gender, and SES level and family experience with HT in the configuration of the illness schemata about HT (i.e., in the profiles identified previously). According to research in this arena, sociodemographic variables have no influence on illness schemata of HT and other illnesses (Figueiras et al., 2010; Grayson et al., 2013; Hsiao et al., 2012; Lin & Hiedrich, 2012; Medley et al., 2010; Miglioretti et al., 2008; Skinner et al., 2011; Snell et al., 2015). So, we expected that these variables exert little influence on the configuration of HT profiles. However, family experience might stand out as a relevant influence (e.g., Lin & Hiedrich, 2012), being related to more benevolent or optimistic schemata on HT.

Our last aim was to address the relationship between the different clusters of illness representations on HT, risks perceptions and preventive options and an important behavioural preventive strategy as is the practice of preventive behaviours in the daily life of healthy Spanish population. Different studies with HT patients (Figueiras et al., 2010; Hsiao et al.,2012) and other diseases (e.g., Charlier et al., 2012; Letelier et al., 2011; Lin & Hiedrich, 2012; Lowe et al., 2011; Medley et al., 2010) have shown the predictive value of different illness profiles in behavioural and coping strategies and health related outcomes, so we expected that different schemata about HT led to differences in the performance of preventive actions in order to avoid the development of HT. Contrary to some of the evidence not supporting a connexion between illness schemata and behaviour (e.g., Graham, Dempster, McCorry, Donnelly & Johnston, 2015; Harrison et al., 2014; Kohlman et al., 2012; Lin & Hiedrich, 2012), we expected to find that configurations including more negative illness illness-related factors which are more adjusted to biomedical knowledge accompanied by stronger perceptions of controllability will be associated to higher likeliness of conducting preventive behaviours (Figueiras et al., 2010).

Methods

Participants

A community-based, convenience sample was recruited at random from private households and community settings such as public transport stations, workplaces, parks, healthcare service delivery locations, academic centres and shopping centres. A total of 450 adults (72.7% women) 18 to 68 years old (M= 36.34, SD= 14.63) participated in this research. Table 2 displays their most relevant characteristics. Participants were mostly of a young age, with almost a half aged between 18-28 years old. We synthesised education level, occupational status and family income in an overall index and derived a composite socioeconomic index for socioeconomic status (SES)[1]. Participants were mainly medium SES level. At the time of the study, none of the participants had ever suffered from HT, although they reported to suffer from other chronic diseases (22.9%, see Table 2), and 58% (261 participants) had lived (11.8%) or were currently living (46.2%) with any relative who had HT.

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[1] Criteria for each SES level were as follows: 1) Low: a) no studies, primary or secondary school or vocational training, any work status (particularly domestic work, unemployment or retirement) and monthly family income up to 2000 euros, or b) unemployment with low income level, irrespective of educational level (this group contained mainly participants with low education level and low income level); 2) Medium: a) no studies, primary or secondary school or vocational training, any work status (particularly studying, employment or retirement) and monthly family income higher than 2000 euros, or b) university studies (any grade), any work status and monthly family income lower than 2000 euros (this group contained mainly participants with low-to-medium education level and high income level, or with high education level and low income level); 3) High: a) university studies (any grade), b) studying, employment or retirement, and c) monthly family income higher than 2000 euros (this group contained mainly participants with high education level and high income level who were studying, employed or retired). These criteria allowed to form three levels of SES which corresponded to SES levels in Spain derived from social indicators such as family income, occupation and education level according to data from the National Institute of Statistics (INE, 2012), and by which approximately 24.5-26.5% of Spanish citizens would have a low SES level, 45.5-52.5% would have a medium SES level, and 23-28% would have a high SES level. We decided to compute in indicator of SES because this measure of an individual's or family's economic and social position based on education, income, work status or occupation is considered a strong predictor of health-related factors, including health-related behaviours, risk factors and health outcomes (e.g., health problems, mortality, incapacity).

Table 2: Socio-demographic data.

Variable		%
Age ranges	18-28	47.8
	29-48	21.7
	49-68	30.5
Marital status	No current relationship, of which	30.2
	Single	20.9
	Separated/Divorced	6.7
	Widow	2.7
	Short-term relationship (< 1 year)	7.3
	Long-term relationship (> 1 year)	62.4
Socioeconomic status	Low	25.3
	Medium	48.4
	High	26.2
Educational level (highest completed level)	No formal education	1.1
	Primary school	11.1
	Secondary school and other formal education	11.1
	Vocational training	9.3
	University-Grade	63.6
	University-Postgrade	3.8
Occupational status	Housework	8.2
	Unemployed	8.7
	Student	46.9
	Retired	2.9
	Employed	33.3
Monthly family income	< 1000 euros	21.1
	1000-2000 euros	43.8
	2000-3000 euros	24.9
	>3000 euros	10.2
Relative with HT	Yes, currently	46.2
	Yes, in the past	11.8
	No	42
Relative patient kinship (more frequently reported)	Mother	20.6
	Father	20.5
	Grandfather/Grandmother	19.1
	Brother/Sister	5.4
	Uncle/Aunt	2.6
	Intimate partner/Spouse	1.8

Table 2: (Continued).

Physical or mental disease at the time of the study	No	77.1
	Yes, of which	22.9
Type of illness (Remaining illnesses were indicated by less than 1%)	Hypothyroidism, hyperthyroidism	4.5
	Cardiovascular diseases, including hypercholesterolemia, hypertriglyceridemia, myocardial infarction, valves disease, arrhythmia...	4
	Osteoporosis, arthritis, bone problems...	3.1
	Pain, chronic pain, headaches...	2
	Digestive system diseases, including irritable bowel syndrome, ulcerative colitis, gastroesophageal reflux disease, hiatal hernia...	2
	Depression	1.7
	Anxiety	1.5
	Respiratory problems, including asthma...	1.2
	Gynaecological problems, including ovarian cysts, endometriosis, miomas...	1
	Dermatologic diseases, including atopic dermatitis, eczema, psoriasis, acne...	1
Under any kind of therapy	No	75.6
	Yes, of which	24.4
Type of therapy (more frequently reported)	Oral contraceptives	5
	Drugs for thyroid problems	3.8
	Anxiolytics	2.2
	Vitamins (A, B group) and minerals (calcium, iron, iodine)	2
	Antidepressants	1.6
	Drugs for hypercholesterolemia	1.4
	Drugs for asthma	1
	Psychotherapy	1
	Corticoids	0.8
	Analgesics	0.4
	Non-steroidal anti-inflammatory drugs	0.4
	Anticoagulants	0.4
	Drugs for cardiovascular diseases	0.4
	Drugs for osteoarthritis	0.4

Measures

Illness perceptions:

Participants completed a Spanish modified version of the Revised Illness Perception Questionnaire (IPQ-R) by Moss-Morris et al. (2002) which was adapted to assess illness perceptions on HT among healthy people (Del Castillo, Godoy-Izquierdo, Vázquez & Godoy, 2013) (N= 162, 36% of the total sample) or a brief version derived from the above-mentioned tool which was obtained based on psychometric and content analyses (Godoy-Izquierdo et al., in preparation) (N= 288, 64%) in order to report their cognitive and emotional representations on HT. For equality purposes, only the items included in the brief IPQ-R (i.e., completed by all the respondents) were used in the analyses in the present research.

Both the IPQ-R and the brief IPQ-R evaluate nine dimensions from Leventhal and colleagues' SRM model and research findings: Identity (symptoms associated with the illness and label); Timeline (duration and chronicity); Evolution (course and temporal changeability or fluctuation of the illness and symptoms); Consequences (effects of the illness on an individual's lifestyle, health and well-being); (Lack of) Personal Control (personal influence on preventing and managing the disease); (Lack of) Treatment Control (availability and efficacy of treatments to manage or cure the disease and its symptoms); (Lack of) Illness Coherence (perceived personal understanding of the disease); Emotional Representations (emotional impact of the disease); and Aetiology or Causes (e.g., psychological, behavioural, biological, chance and external causes of the disease). For the aims of the present research, two items assessed each of the SRM dimensions and a total of 21 possible symptoms of HT (some of them not corresponding to high BP manifestations to identify possible tendency of response) and 19 possible causes of the disease were included, which were grouped in psychological, behavioural and external/uncontrollable causes.

For all of the dimensions except identity, the respondent must express his(her) level of agreement with a series of statements (e.g., "This illness has major consequences on patient's life") or causal attributions (e.g., One's own behaviour") on a Likert-type scale with five alternatives (from 1= "Strongly disagree" to 5= "Strongly agree"). In the causes dimension, a statement of "I don't know/I'm indecisive" was included. A blank question was also used for asking the participants to freely indicate the three more relevant causes of HT for them (info not used in this research). Partial scores were obtained as the mean of the scores for the items on each subscale (considering direct and reverse items), with higher scores indicating stronger beliefs about chronicity, cyclical course, impact and outcomes, causal factors' influence and emotional reactions to the disease, as well as poorer perceptions of personal influence and cure possibilities and perceived understanding of the disease. For the aims of calculating a global score, items belonging to the dimensions of personal control, treatment control and coherence were all reversed (e.g., Figueiras et al., 2010). For the identity dimension, answers to whether each in a series of symptoms was perceived as characteristic of the disease or not were examined. The higher the score, the more symptomatic the disease is perceived to be.

A global score in the brief IPQ-R was calculated by summing the answers to all items excepting those from causes subscale, with higher scores reflecting stronger illness representations of the disease as a severe, symptomatic, uncontrollable, durable and unstable disease as well as un-understandable disease, with higher impact on the patient's health and life and higher power to generate emotional reactions.

Following previous suggestions (Moss-Morris et al., 2002; Weinman, Petrie, Moss-Morris & Horne,1996), we modified the IPQ-R to make it more complete, easier and better fitted to HT (see Del Castillo et al., 2013, for details). Furthermore, each reference to “my” illness was substituted by “the” illness or “hypertension”. The brief IPQ-R used herein also included the following changes on the original, large IPQ-R. For the identity subscale, six new symptoms were added: heat, perspiration; flushing of face and neck; seeing problems; bleedings; confusion, disorientation; and ringing in the ears. The remaining dimensions except causes were summarized in two items per subscale, those considered as more representative of each dimension based on both content and psychometric analytical procedures (Godoy-Izquierdo et al., in preparation). Causes subscale was similar in both tools.

The psychometric properties of the IPQ-R have been previously demonstrated among English-speaking and Spanish populations (Del Castillo, Godoy-Izquierdo, Vázquez & Godoy, 2011; Moss-Morris et al., 2002), as well as in the context of HT with Spanish populations (Beléndez, Bermejo & García-Ayala, 2005; Del Castillo et al., 2013; Pacheco-Huergo et al., 2012).

We decided to use our own brief IPQ-R instead of the Brief IPQ proposed by Broadbent, Petrie, Main and Weinman (2006) because of some psychometric limitations of the latter that have been pointed out. Concurrent validity with the IPQ-R regarding personal control and treatment control dimensions (Broabdent et al., 2006; De Raaij, Schröder, Maissan, Pool & Wittink, 2012; French, Van Oort & Schröder, 2011) and convergent validity between the Brief IPQ and other measures (Bazzazian & Besharat, 2010; Lochting, Garrat, Storheim, Werner & Grotle, 2013) have been questioned. Moreover, there is no evidence of discriminant validity of the instrument (French et al., 2011) and it may lack of content validity (French et al., 2011; Van Oort, Schröder & French, 2011).

Participants also completed other self-reports that were specifically constructed for this study with the aim of exploring their perceptions about HT as a health risk factor as well as possible risks derived from HT, perceived preventive behaviours for avoiding or reducing the risk of suffering from HT and their practiced preventive behaviours for avoiding or reducing the risk of suffering from HT.

Perceptions of HT as a risk factor:

Participants had to state whether they considered that untreated HT might be a risk factor for other diseases (0= No, 1= Yes, for non-severe diseases; 2= Yes, for booth non-severe and severe diseases). Then, a list with nineteen diseases or health problems, which could be related or not to HT, was presented to participants and they had to say whether those problems were related to HT or not (Yes/No). A blank question was added for the participants to indicate any other disease/s not mentioned in the list (not included in the analyses because nobody indicated an illness previously not mentioned). The information presented in this section was obtained from several medical bibliographic sources.

Perceptions of preventive behaviours and practice of preventive behaviours:

With the aim of assessing participants' perceptions about preventive behaviours and their preventive actions in their daily life (with the specific aim of preventing HT), two lists composed of the same fifteen behaviours were presented. In the Perceived Preventive Behaviours Scale, participants must express his or her level of agreement on a Likert-type scale with eleven alternatives (0= “nothing at all”, from 1= "very little" to 10= “very much”) depending on their perception about the preventive character of each behaviour (i.e., perceived efficacy of the action for preventing HT). In the Practiced Preventive Behaviours Scale, they had to indicate their performance of each behaviour in their daily life on a Likert-type scale with eleven alternatives (0= “no practice”, from 1= "very little" to 10= “very much”). As in the HT as a Risk Factor section, information for these sections was obtained from several medical bibliographic sources.

Sociodemographic data:

Participants also indicated their age, gender, nationality, marital status, education level, work status and income level. They also reported current diseases and therapies undergone (of any nature), and whether they had ever suffered from HT. Participants were also asked to indicate whether any relative with whom they had ever lived was ever diagnosed with HT or was affected by HT at the moment of the study and their kinship, as well as whether (s)he was under any kind of treatment and his(her) adherence to prescriptions.

Procedure

The research was approved by the institutional research ethics committee. Participants were asked to take part voluntarily and to sign an informed consent form. They had been informed previously that the general objective of the research was to learn their beliefs about HT and not to gauge their level of knowledge. Specific instructions for completing the questionnaires were given.

A community-based convenience sample was constructed (i.e., people suffering or having suffered from HT were discarded). Three housing buildings and several community settings per district were selected at random with a local telephone directory. A person in one of every three possible households and one of every three people in the public settings were asked to participate and followed the above-mentioned procedure when they accepted.

Study design and statistical analyses

This is a cross-sectional, correlational study based on self-report data.

All the variables were re-coded, so high scores meant high levels of the respective feature (including all the brief IPQ-R dimensions). The scores were then transformed to Z scores. Standardised scores were used for metric variables to eliminate scaling differences among variables. Preliminary and exploratory analyses were conducted to check the data and parametric assumptions. Most of the variables were not normally distributed (Kolmogorov–Smirnov test, $p< 0.05$); however, Levene's tests confirmed homoscedasticity for the vast majority of the variables ($p> 0.05$). Thus, besides descriptive analyses, parametric tests were performed (with correction for non-homoscedasticity when appropriate). The analyses were conducted with version 19 of SPSS statistical package (IMB, 2010) and level of significance was set at $p< 0.05$.

To establish different multidimensional profiles according to the scores on the variables of the study, we performed multivariate non-hierarchical, iterative partitioning k-means cluster analyses with Euclidean distance as similarity measure (Clatworthy, Buick, Hankins, Weinman, & Horne, 2005; Jain, Murty, & Flynn, 1999). This analysis was utilised to maximise both the separation among clusters (low between-group homogeneity) and the homogeneity within clusters (high within-group homogeneity). Moreover, k-means cluster analysis has proven to be the most appropriate method in illness perceptions research designed to test the utility of the SRM in explaining health-related behaviours and outcomes (Clatworthy et al., 2007). The upper limit for iterations was set at 30 (Lowe et al., 2011). We followed criteria published by Clatworthy et al. (2005) for the use and reporting cluster analyses in Health Psychology. To decide the optimal number of clusters, we calculated the pseudo F (PSF) or variance ratio criterion (Calinski & Harabasz, 1974), as it has proven to be the most efficient statistic for determining the goodness of the clustering solution (Milligan & Cooper, 1985). The number of clusters corresponding with the highest PSF value is the optimal solution. We also considered Goodman and Kruskal's λ value (the closer to 0, the better the variables are working for clustering) and percentage of cases correctly classified (the higher the percentage, the better the solution). Furthermore, we took into account the suggestion by Clatworthy et al. (2007) of considering three groups as this number appeared relatively typical of the number of groups found both in illness perception research and Health Psychology research in general. In addition, a discriminant analysis was performed with all the variables introduced in cluster analyses in order to identify the best subset of variables for each cluster, that is, to corroborate the appropriateness of the groups and to establish the responsible variables for this grouping.

Then, once the clusters had been established, we performed univariate one-way analyses of variance (ANOVA) and multiple pairwise comparisons to explore significant differences among the multidimensional profiles and in relation to preventive behaviours practice. This behavioural indicator was used not only as criterion variable to cross-validate the cluster solution that was found (i.e., external validation; Clatworthy et al., 2005), but also as an outcome variable to explore expected different outcomes derived from different psychosocial configurations. Analyses of covariance (ANCOVA) were run to partial out the effect of sociodemographic conditions on behavioural indicators when cluster membership was considered.

Because cluster analytic techniques are particularly sensitive to outliers, univariate and multivariate outliers were checked before the analytic techniques. For univariate outliers, no Z score with an absolute value greater than 3 that could be considered as potential outlier was identified. For multivariate outliers, a case was considered an outlier if the probability associated with D2 in the Mahalanobis' distance test was 0.001 or less. Fourteen cases had combinations of values for the variables that were considered as potential outliers. An inspection of data revealed that they were unusual but possible cases, and those participants were retained for the analyses. Because outliers can be derived from a non-normal distribution of data, we also screened those values with boxplots and descriptive data. Based simultaneously on the univariate and multivariate tests, we did not exclude any participant from the analyses.

Further, multicollinearity may profoundly affect cluster analyses, with variables which are highly intercorrelated being over-represented in the outcomes. Moreover, as the degree of multicollinearity increases, the estimation of the coefficients become unstable and the standard errors can get inflated. We found no multicollinearity among the psychosocial and sociodemographic variables of this study, with variance inflation factor (VIF) being lower than 10 and the tolerance being greater than 0.1 for all variables. The condition index, which is considered to be the most robust test of multicollinearity, was very low for all variables. Consequently, no multicollinearity was detected and none of the variables were excluded from or combined for the cluster analysis.

Results

Table 3 shows descriptive findings for the psychosocial variables of the study.

Table 3: Descriptive findings.

	M	SD	MIN	MAX
HT as a risk factor	2.94	0.28	1	3
Number of health problems linked to HT	8.39	3.50	0	19
Perceived preventive behaviours	7.72	1.27	2.73	10
Practiced preventive behaviours	5.26	2.45	0	10
IPQ-R Identity	12.03	3.75	0	21
IPQ-R Duration	3.16	0.84	1	5
IPQ-R Evolution	3.12	0.95	1	5
IPQ-R Consequences	3.15	0.83	1	5
IPQ-R (Lack of) Personal control	1.73	0.74	1	5
IPQ-R (Lack of) Treatment control	1.96	0.69	1	5
IPQ-R (Lack of) Coherence	2.66	1.01	1	5
IPQ-R Emotional Representations	2.14	1.05	1	5
IPQ-R Causes, of which:	3.31	0.52	1.53	4.53
Behavioural	4.03	0.60	1	5
Psychosocial	3.56	0.86	1	5
Uncontrollable	2.68	0.53	1.38	4.13

HT is perceived as moderately symptomatic, with 3.6% of participants indicating less than 5 symptoms linked to HT, 22.4% indicating less than 10 symptoms, and the remaining 77.6% indicating 10 or more symptoms, with 26% of the total sample indicating 15 symptoms or more. More frequently indicated symptoms were tachycardia, headaches, fatigue/tiredness, heat/perspiration, dizziness/vertigo, emotional distress such as sadness or anxiety, vision problems and face/neck flushing (≥ 70% of participants). HT is also perceived as a moderately long lasting and cyclical disease, with negative consequences for patients. It is also considered by participants as highly controllable by patients' actions and behaviours and they also showed high confidence in available treatments and interventions to control the disease. Participants reported a perceived moderate-to-good comprehensibility of HT. On the other hand, they didn't show strong feelings of sad, anxiety or worry linked to the possibility of suffering from the disease. Participants linked HT mainly to behavioural and lifestyle causes, but other psychosocial factors such as stress and tension were also frequently reported. Uncontrollable causes were also indicated, but considerably less frequently.

Further, almost all of the participants considered HT as a risk factor for suffering from both non-severe and severe health problems, and, in a series of 19 possible health threats, participants reported risk for suffering from 8 problems, in average, among which cardiovascular diseases stood out (renal and visual problems were indicated only by 4 in 10 participants). Besides, they perceived that individuals can control the risk of suffering from HT itself by their behaviour, and their perception of the efficacy of behavioural preventive options was elevate (close to 8 in a ten-point scale, in average; no participant reported not perceiving any of the behaviours listed as a successful preventive option). Furthermore, they reported to practice a low number of preventive behaviours in order to prevent HT (5 preventive behaviours in average; 38% indicated practicing less than 5 behaviours, and 4.2% of the participants reported not practicing any of the behaviours listed with a preventive goal).

A k-means cluster analysis was conducted and, given the range of clusters reported in the Health Psychology and illness perceptions literature, two-cluster, three-cluster and four-cluster solutions were explored. The psychosocial variables considered in the analysis were illness representations of HT as measured by the brief IPQ-R, perceptions of HT as a risk factor for future health problems, number of health problems linked to HT as an indicator of the perceived seriousness of HT as a risk factor and perceived preventive options. After running the analyses, we chose the three-cluster solution because it was the solution with a greater percentage of participants in each cluster grouped correctly, it offered the biggest amount of information with the fewest number of clusters (i.e., had higher parsimony), it did not group a low number of atypical cases in a cluster (i.e., had higher replicability) and it had an easier and more meaningful interpretation. Missing data for each variable was very low (three cases -0.7% of cases- for brief IPQ-R dimension of perceived causes; hence, three participants were removed from the analysis). An initial ANOVA revealed significant differences among the clusters for all the included variables except brief IPQ-R dimension of duration ($p > 0.10$). Thus, we reran the cluster analysis with the significant variables, i.e., excluding only duration dimension of brief IPQ-R.

Consequently, three groups were identified, solution supported by PSF value, λ value and percentage of cases correctly clustered, all of which reached optimum values for a three-cluster solution. Each cluster was characterised by different psychosocial profiles (Figure 1). Based on these profiles, reflective of different levels of awareness of HT seriousness and control options, we labelled these groups as low-to-moderate awareness and concern, very low awareness and concern and high awareness and concern, respectively. Cluster 1 (48.8%) is composed of participants with low awareness of HT seriousness and linked risks as well as low value conceded to preventive options. Their perceptions related to HT form a profile with lower (standardised) levels of symptoms reported as being associated to HT (-0.5 SD), lower levels of negative consequences linked to the disease (-0.5 SD), average stability and perceived controllability and average-to-low perceived emotional impact and comprehensibility of HT. Causes are not clear for these participants, as they indicated behavioural, psychosocial and external-uncontrollable causes in levels -0.5 SD below the mean.

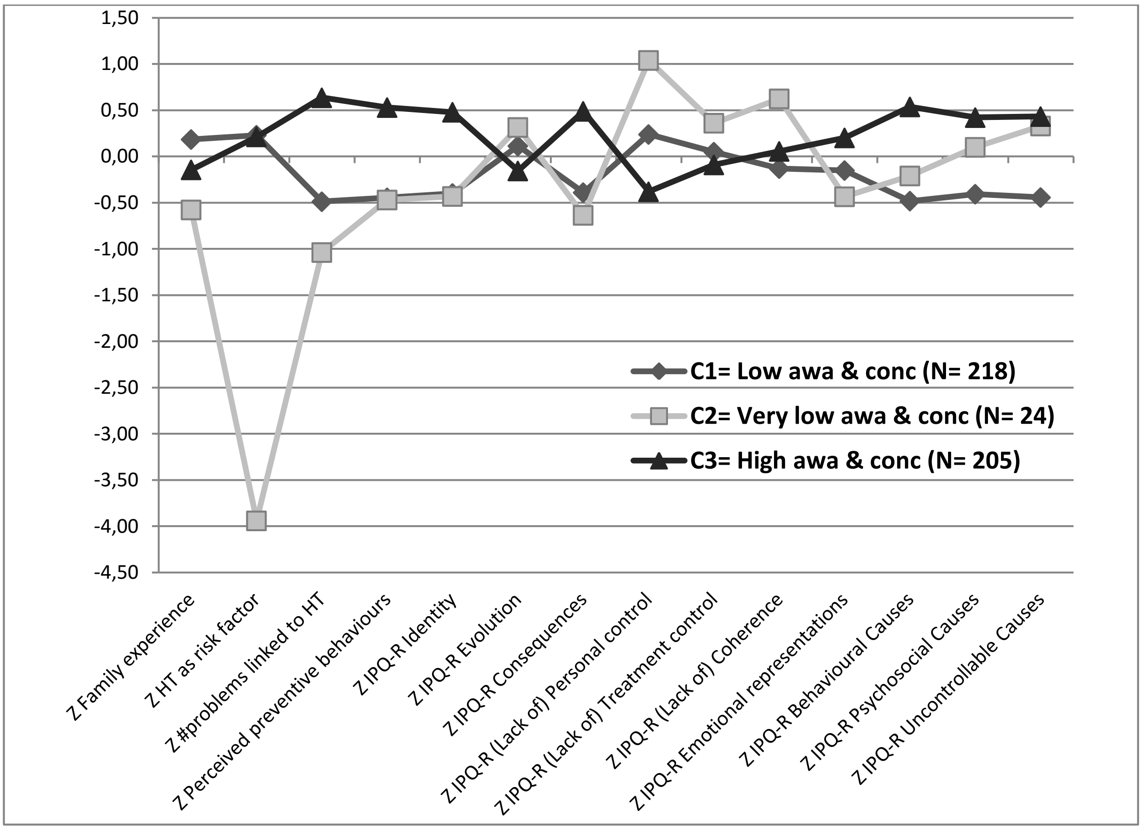

Figure 1. Graphical representation (final centroids) of the psychosocial profiles identified by the cluster analysis. Cluster 1 is composed of participants with low awareness of HT seriousness and linked risks as well as preventive options, so that they demonstrated to be poorly concerned about HT; Cluster 2 is composed of participants with even lower awareness of HT seriousness and linked risks as well as preventive options, with the most unrealistically positive picture of the disease; Cluster 3 is composed mainly of participants with high awareness of HT seriousness and linked risks as well as preventive options, so that they demonstrated to be highly concerned about HT.

Cluster 2 (5.4%) is composed of participants with, comparatively, lower awareness of HT seriousness and linked risks as well as of preventive options, so that they demonstrated to be poorly concerned about suffering from HT and derived consequences. They also self-reported to be poorly knowledgeable about HT (lack of coherence dimension, 0.5 SD above the mean) and they demonstrated generally the most unrealistically positive perceptions on the brief IPQ-R dimensions (i.e., lower levels of identity, stable, non-cyclical timeline, consequences and emotional impact, all rounding -0.5 SD below the mean). They also referred more uncontrollable causes for HT than behavioural or psychosocial causes. Notably, these cluster reported the lowest perceptions on personal and treatment controllability (0.5 to 1 SD above the mean). Compared to cluster 1, even when their perceptions on HT as illness were very similar, they demonstrated dramatically lower perceived health risks as a consequence of suffering from HT, as well as notably lower perceived personal and treatment control and higher perceptions on causality for psychosocial and uncontrollable etiological factors. Compared to cluster 1, they also had lower perceived comprehensibility on the disease. These participants had the lowest experience with the disease.

Cluster 3 (45.9%) is composed of participants with high awareness of HT seriousness and linked risks as well as higher value conceded to preventive options. They had the more realistic and adjusted to biomedical knowledge illness perceptions on HT, even when they weren't particularly confident in their global picture of HT. They perceived more symptoms linked to HT, more negative outcomes of HT for health and higher emotional impact, but also higher stability and more options for preventing HT from one's own behaviour and for controlling the disease, self-reporting the highest perceived personal control on the disease and treatment control (lowest brief IPQ-R scores on lack of personal and treatment control dimensions). They also indicated more frequently behavioural and psychosocial controllable causes, although they also indicated uncontrollable causes. Thus, they demonstrated to be highly concerned about suffering from HT and derived consequences. Compared to participants of cluster 2, participants in clusters 1 & 3 had higher family experience with the disease.

A discriminant analysis showed Wilks' lambda values of 0.043 and 0.377 (χ^2= 1379.819, χ^2= 426.215, *p*= 0.000) for the global model, indicating significant between-group differences and demonstrating a high discriminant power with a low proportion of the total variance in the discriminant scores not explained by differences among groups. Both discriminant functions explained on average 76% (89% and 62%) of the variability among groups (Pillai's η^2= 0.76). Using this clustering, 97.1% of the cases were correctly classified.

Clusters were then compared on the set of psychosocial measures using one-way ANOVAs and pairwise comparisons. The ANOVAs revealed significant differences for all variables among the clusters (Table 4). Bonferroni's or Games-Howell's pairwise comparisons were conducted upon Levene's *F* values. There were significant differences ($p < 0.01$) between clusters of low awareness and concern and very low awareness and concern for family experience with HT, perception of HT as a risk factor and number of problems derived from suffering from HT, perceived personal control, coherence and uncontrollable causes attributed, and marginally significant for psychosocial causes attributed ($p = 0.06$), and they were very similar in perceived preventive behaviours and almost all illness perceptions: identity, evolution, consequences, treatment control, emotional representations and behavioural causes ($p > 0.05$). Significant differences ($p < 0.01$) were found between clusters of low awareness and concern and high awareness and concern on all the variables with the exception of perceived risk linked to HT and the brief IPQ-R dimensions of treatment control and coherence ($p > 0.05$). Further, significant differences were found between clusters of very low and high awareness and concern for all variables ($p < 0.01$), except psychosocial and uncontrollable causes; for family experience with HT and the brief IPQ-R dimensions of evolution and treatment control, $p < 0.10$.

Besides, given that previous analyses indicated that age, gender and SES were significant predictors of the variables of the present study, possible differences in sociodemographic conditions due to cluster membership were analyzed. Clusters differed in terms of age ($F = 24.522$, $p = 0.000$), with participants in C3 being significantly younger than those in C1 ($p = 0.000$) and marginally younger than those in C2 ($p = 0.071$). There were also differences in terms of gender. All the clusters were composed of more women than men, according to the sample composition, but, across clusters, there were proportionally more men in C1, while women were equally frequent in C1 and C3 ($\chi^2 = 6.445$, $p = 0.04$). Clusters also differed in SES level of participants. Participants with lower SES were more likely to be in C1, participants with moderate SES were more likely in C3, whereas participants with higher SES where equally distributed in C1 and C3 ($\chi^2 = 24.818$, $p = 0.000$).

Table 4: Means (centroids), standard deviations and comparisons among the clusters for the clustering variables (Z scores) (N= 447).

Variables	LOW (C1) N= 218		VERY LOW (C2) N= 24		HIGH (C3) N= 205		*F*	*p*
	M	*SD*	*M*	*SD*	*M*	*SD*		
Family experience	0.18	0.97	-0.58	0.89	-0.14	1.00	10.224	0.000**
HT as a risk factor	0.23	0.00	-3.94	1.36	0.21	0.25	1579.179	0.000**
Number of health problems linked to HT	-0.49	0.65	-1.04	0.96	0.64	0.91	126.340	0.000**
Perceived preventive behaviours	-0.45	0.94	-0.47	1.21	0.53	0.72	70.631	0.000**
IPQ-R Identity	-0.40	0.86	-0.43	1.26	0.48	0.89	53.131	0.000**
IPQ-R Evolution	0.11	1.05	0.31	0.96	-0.16	0.93	5.158	0.006**
IPQ-R Consequences	-0.39	0.86	-0.64	1.06	0.49	0.91	57.369	0.000**
IPQ-R Personal control	0.24	1.03	1.04	1.14	-0.38	0.75	40.141	0.000**
IPQ-R Treatment control	0.05	0.98	0.36	1.22	-0.09	0.99	2.658	0.071
IPQ-R Coherence	-0.13	0.95	0.62	1.07	0.06	1.02	7.007	0.001**
IPQ-R Emotional Representations	-0.15	0.93	-0.43	0.88	0.20	1.04	9.353	0.000**
IPQ-R Causes_Behavioural	-0.48	0.98	-0.21	1.29	0.54	0.66	73.371	0.000**
IPQ-R Causes_Psychosocial	-0.41	0.96	0.10	0.99	0.42	0.86	43.299	0.000**
IPQ-R Causes_Uncontrollable	-0.44	0.91	0.33	0.75	0.43	0.92	51.378	0.000**

Note: LOW: Low awareness and concern; VERY LOW: Very low awareness and concern; HIGH: High awareness and concern. Standard Z scores were used for metric variables. Ordinal variables (family experience, perception of HT as a risk factor) were treated as metric variables. ** $p< 0.01$.

Further, ANOVAs were performed to explore differences among the participants in each cluster with respect to practiced preventive behaviours. Significant differences were found (Table 5). Post-hoc comparisons revealed that participants in clusters of low and very low awareness and concern practiced significantly less preventive behaviours than participants in cluster of high awareness and concern ($p< 0.01$). Differences between low and very low aware, concerned participants were also significant ($p< 0.05$), with very low aware people practicing the lowest level of preventive behaviours. Figure 2 displays these differences. Participants in the high awareness subgroup demonstrated a relative investment in preventive efforts, with levels that were 1/3 standard deviation above the average; participants in the low awareness subgroup demonstrated a poor investment in preventive efforts, with levels that were 1/4 standard deviation below the average, whereas participants in the very low awareness subgroup demonstrated a dramatically lower investment in preventive efforts, with levels that were close to one standard deviation below the average.

Table 5: Means, standard deviations and comparisons among the clusters for preventive behaviours practice (Z scores) (N= 447).

Variables	LOW (C1) N= 218		VERY LOW (C2) N= 24		HIGH (C3) N= 205		*F*	*P*
	M	*SD*	*M*	*SD*	*M*	*SD*		
Preventive behaviours	-0.22	0.99	-0.79	1.06	0.32	0.89	26.291	0.000**

Note: LOW: Low awareness and concern; VERY LOW: Very low awareness and concern; HIGH: High awareness and concern. Standard Z scores were used. ** p< 0.01.

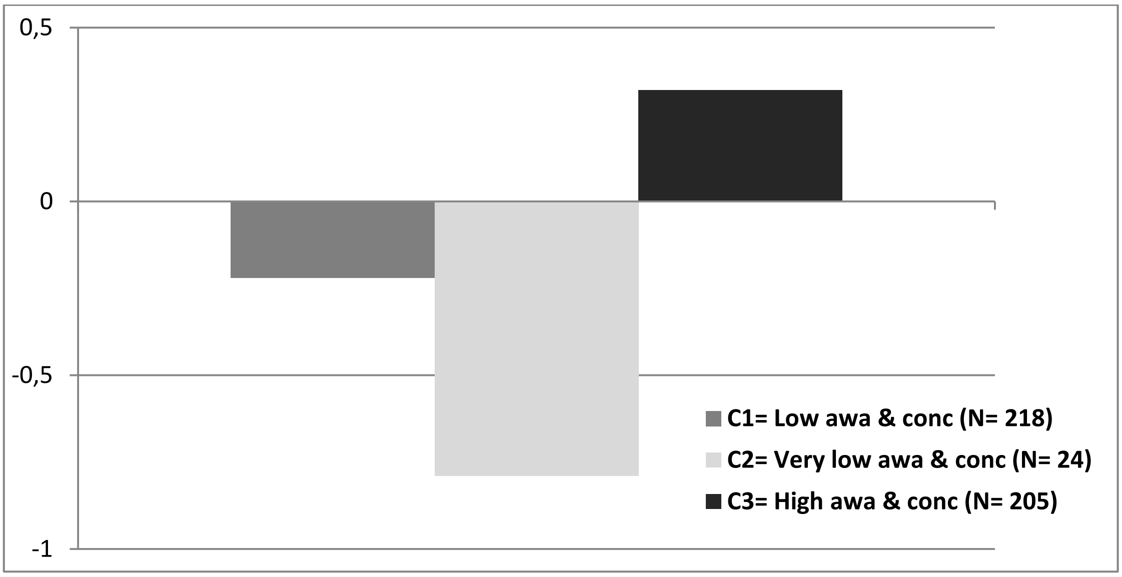

Figure 2. Graphical representation of preventive actions (Z scores) of each of the profiles identified in the cluster analysis. Cluster 1 (low awareness) and Cluster 2 (very low awareness) are characterized by a lower level of preventive effort; Cluster 3 (high awareness) is composed of people with higher level of preventive effort.

Sociodemographic variables are potential confounding variables in the previous analysis. Thus, to control for their effect, an ANCOVA was conducted to test whether age, gender or SES level were influencing preventive behaviours by clustering membership (in addition to ANOVAs assumptions, assumption of homogeneity of regression slopes was not violated, *F*= 1.627, *p*= 0.182). The covariate age was not significantly related to the outcome preventive behaviours (*F*= 1.876, *p*= 0.172), as was not SES level either (*F*= 1.573, *p*= 0.210). In contrast, gender was significantly related to preventive behaviours (*F*= 20.112, *p*= 0.000). After controlling for these effects, cluster membership demonstrated a significant effect on preventive behaviours (*F*= 18.192, *p*= 0.000). Bonferroni's post hoc pairwise comparisons revealed that being clustered in C2 was associated to a significant decrease in the practice of preventive practices compared to being clustered in C1, *p*= 0.035, 95% CI [-0.984, -0.026] and C3, *p*= 0.000, 95% CI [-1.442, -0.474], and that being clustered in C3 was associated to a significant increase in the practice of preventive practices compared to C1, *p*= 0.000, 95% CI [0.226, 0.680].

Discussion

Although the SRM has been applied to different physical and mental illnesses, there are relatively few studies regarding the non-specialised beliefs that healthy people hold and how their beliefs influence health- and disease-related behaviours (e.g., Anagnostopoulos & Spanea, 2005; Cabassa, 2007; Del Castillo et al., 2011; Dempster et al., 2011a,b; Figueiras & Weinman, 2003; Fortune, Smith & Garvey, 2005; Karademas, Zarogiannos & Karamvakalis, 2010; Kaptein et al., 2007; Lobban, Barrowclough & Jones, 2005; Searle, Norman, Thompson & Vedhara, 2007). This is particularly true for the Spanish population. Furthermore, research specific to HT is scarce, although this disease is one of the leading causes of morbidity worldwide and one of the main risk factors for serious pathologies such as heart attack, stroke or chronic renal failure. We have described in deep the cognitive and emotional representations that participants endorsed on HT elsewhere[2] and discussed how they parallel other findings (e.g., Bazán, Osorio, Miranda, Alcántara & Uribe, 2013; Beléndez et al., 2005; Chen, Tsai & Chou, 2011; Chen, Tsai & Lee, 2009; Del Castillo et al., 2013; Godoy-Izquierdo et al., 2007; Figueiras et al., 2010; Heckler et al., 2008; Hsiao et al., 2012; Meyer, Leventhal & Guttman, 1985; Norfazilah et al., 2013; Pickett, Allen, Franklin & Peter, 2014; Ross, Walker & McLeod, 2004; Schlomann & Schmitke, 2007; Wilson et al., 2002), as well as the associations between HT perceptions, perceptions

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of HT as a risk factor itself and perceived and practiced preventive behaviours. Healthy people, risk populations, patients, relatives and carers of patients as well as health professionals are in need of tailored interventions focussed on their illness representations. Thus, careful, individually focused revision and discussion of illness beliefs should modify misconceptions and biased, inappropriate and unrealistic expectations on the disease for a more successful health-related repertory of actions.

Some recent research on illness representations have moved away from looking at the predictive value of separate illness beliefs towards considering the overall pattern or schema of illness perceptions held by the individuals (French et al., 2006), which is closer to the original conception of Leventhal et al. (1984). Thus, the prediction of outcomes might be more effective if clusters or combinations of illness perceptions are used as predictors, instead of single illness perception constructs. As we argued in the introduction, exploring the whole profile of representations about a certain illness instead of different dimensions separately or individually is receiving increasing interest nowadays because of the important advantages of this research approximation in the field of illness representations. These advantages are related basically to the possibilities of interpretation of findings and also to their predictive value in important behavioural or emotional outcomes for health and illness. Further, identification of groups of individuals sharing common illness schemata also help to identify individuals that might benefit from targeted interventions or further research (Clatworthy et al., 2005).

Accordingly, the present study was conducted with a three-fold aim. Firstly, we sought to identify groups of people non-suffering from HT that share a similar profile regarding illness schemata on this disease and other important related variables such as risks perceptions and preventive options linked to HT, using the Self-Regulation Model as a theoretical framework. Thus, multidimensional psychosocial profiles were considered (e.g., Charlier et al., 2012; Snell et al., 2015). Our second aim was to explore the influence of different sociodemographic variables such as age, gender, SES level and family experience with HT in the configuration of the illness schemata about HT. Thirdly, we aimed to address the relationship between different profiles of illness representations on HT and an important behavioural outcome: the practice of preventive actions in their daily life as a way to avoid HT among non-patients from the general population. According to Clathworthy (2007), knowing this information give us important keys to classify the general population regarding their beliefs about HT with the final aim to design and implement preventive strategies tailored to specific groups with specific necessities and problems.

To achieve these aims, multivariate K-means clustering was used to form the psychosocial profiles, followed by an examination of illness beliefs about HT across clusters using analysis of variance approaches and multiple pairwise comparisons in order to explore significant divergences among the multidimensional profiles and in relation to preventive behaviours practice. The psychosocial variables considered in the multidimensional illness-related profiles were illness representations of HT as measured by the brief IPQ-R, perceptions of HT as a risk factor for future health problems, number of health problems linked to HT as a perception of the perceived seriousness of HT as a risk factor and perceived preventive options. The outcome variable was the practice of preventive behaviours with the aim of reducing the risk of suffering from HT in the future. In summary, we identified three different trajectories of illness representations. Two of the clusters included people who were not aware and concerned about the risks linked to HT and who had inaccurate beliefs about the illness, although one of them is more negative than the other one; consequently, but more markedly the latter, their behaviour was far from a preventive aim. The third one was composed of individuals who were aware of what is HT and how to prevent it, and consequently displayed a wide range of behavioural coping efforts to diminish the risk of suffering from HT in their life.

Concretely, two of the identified profiles, clusters 1 and 3, mirrored each other in their illness representations, with rather inverse illness representations. Cluster 1 involved nearly a half of the sample (48.8%) and was composed of participants with low awareness of HT seriousness and linked risks as well as lower rate of preventive options. In fact, many of their scores (7 out of 13) were rounding 0.5 SD below the mean. People in this cluster perceived HT as related to a lower number of symptoms and fewer serious consequences for patients. They also had average (moderate) confidence in the possibilities of control and cure of HT by the patients and the available treatments. Their understanding of the disease was from moderate to low, as well as their emotional representations, so compared to participants in cluster 3 they didn’t have a complete clear picture of HT and they experienced not very disturbing feelings of worry, anxiety and sadness because of the possibility of suffering from HT. Finally, regarding HT causality, participants included in this cluster didn’t hold clear ideas about factors that could generate HT and they indicated behavioural, psychosocial and external-uncontrollable causes at a lower rate. Participants clustered in this trajectory perceived HT as a risk factor for other important health problems, but they were unable to recognise the numerous health problems that HT can provoke. The perception of the potential efficacy of different behaviours in order to prevent HT is lower than average in this cluster, very similar to cluster 2 participants' perception. Consequently, their behavioural investment in preventing HT is low.

Cluster 3 involved 45.9% of the participants, those who had the global representation about HT being the most accurate and adjusted to biomedical knowledge. Many of their scores (7 out of 13) were rounding +0.5 SD above the mean, with more realistic perceptions on the disease and control opportunities and an adjusted global picture of HT. These normotensive people perceived that HT as linked with a higher number of symptoms and more negative consequences for patients’ life. Their perceptions on coherence and treatment control were average and did not differ too much from those of participants in cluster 1, but comparatively they demonstrated the highest perceptions of personal controllability. They also perceived the disease course as more stable and predictable. Although they perceived HT as an important health risk and thought that HT lead to many other important health problems, they had an optimistic perception about one's own role for preventing this disease and the possibilities of avoiding HT introducing changes in lifestyle. In connexion to that, they also stated more behavioural and psychosocial causes under the control of individuals, although they also considered that other uncontrollable causes are important in the genesis of this silent killer. When compared to participants in the other clusters, they exhibited the highest negative feelings of worry or sadness when they thought about the possibility of suffering from HT. Significant differences were found between this cluster and the remaining two for almost all of the variables included (notoriously excepting treatment control perceptions). As a consequence of their global perceptions, their behavioural investment in preventing HT is the highest.

Finally, cluster 2 is the smallest in size, with only a 5.4% of the sample. This cluster point out that a low but no negligible proportion of the community is *spaced out* about HT, its risk factors and risky outcomes, and are consequently in greater risk of severe morbidity and premature death, because their behavioural repertory is completely disconnected from a healthy lifestyle. In general, these participants had very inaccurate beliefs about HT that were far of objective medical knowledge. Comparatively, they reported a clear lack of understanding of the disease and certain confusion about the characteristics of HT. They were more likely to believe that HT is a unpredictable disease with a cyclical course with fewer symptoms and lower perceived impact on patients' health or life. Regarding their emotional reactions to the disease, these were the lowest among the three clusters, in line with the above-mentioned (excessively) optimistic perceptions on the disease. Compared to clusters 1 and 3, their perceptions of controllability of the disease by the patient and the available treatments were the lowest. Finally, in regard to the genesis of HT, they stated more uncontrollable causes for the illness than behavioural or psychological aetiological factors. Many of their scores (6 out of 13) were rounding 0.5 SD or more below the mean, with excessively pessimistic perceptions of controllability and unrealistic global picture of the disease (+0.5 SD to +1 SD). These unrealistic perceptions about HT are completed with a very low awareness of risks associated to suffering from HT. They also considered that the number and efficacy of preventive behavioural possibilities in HT avoiding is low. Consequently, their behavioural investment in preventing HT is dramatically lower.

Although clusters 1 and 2 could seem very similar, cluster 2 shows important and worrying differences. Participants of that profile had a problematic lower perception of the controllability of HT by the individuals and about health risks, and also a poorer comprehension of what this disease means as well as a higher perception of the weight of uncontrollable factors in the basis of HT. People clustered in this second profile are living rather unconcerned about the dangerousness of HT, its negative effects and the important problems that this disease could generate and they have a pessimistic perception about the possibilities of HT prevention. This conjunction of perceptions leads them to a lack of preventive cares or behaviours in their daily life and consequently had a huge increase of risk of suffering from HT and its severe consequences.

Taking participants of clusters 1 and 2 together, more than a half of the Spanish normotensive sample (54.2%) had a low awareness and concern about HT and specially about the possibilities of preventing this disease. This result is very worrying as it shows that 1 in 2 individuals in the general population in Spain is quite far from having an accurate and realistic view of the real dangers of this disease and especially of how to prevent this silent killer. Consequently, their behaviour is also far from a healthy lifestyle. These findings should alert health authorities to launch different actions tailored to the healthy population in order to develop realistic perceptions of this disease and to promote the adoption of preventive actions. The ultimate goal would be to minimize the risk of HT conducting an adequate primary prevention through active health policies and campaigns.

As we explained in the introduction, few studies have tried to identify different profiles regarding illness models in HT and no one of these studies have been conducted with normotensive population. As far as we know, only two studies conducted with hypertensive patients have identified different profiles about the representations that patients had about this disease. Figueiras et al. (2010) and Hsiao et al. (2012), with samples of Portuguese and Taiwanese patients respectively, found that their illness beliefs could be included in three different profiles (see Table 1) that were similar in some aspects to those of our study but differed noticeably in others. However, the authors did not labelled them based on beliefs' accuracy and proximity to biomedical knowledge, but on the valence of the contents of the representations. Clusters of "more negative", "moderately negative" and "more positive" illness configurations in the study by Figueiras et al. (2010) correspond to C3 (highest awareness and concern), C2 and C1 (lowest awareness and concern) in our study, but they show a contrary pattern of beliefs regarding controllability and coherence. Clusters of "more negative", "mixed" and "more positive" illness configurations in the study by Hsiao et al. (2012) correspond to C3 (highest awareness and concern), C2 and C1 (lowest awareness and concern) in our study, but they show a contrary pattern of beliefs regarding timeline-course and coherence. Furthermore, as in our case, they also found that these profiles were related with different outcomes and behaviours regarding HT care. In the first study, the authors found a relationship between illness schemata of HT (more negative beliefs but higher perceptions of controllability) and the beliefs about the necessity and concern about medication as well as the election of brand or generic medicines. In the second one, the authors found that participants with more positive illness perceptions but lowest sense of control had better drug adherence, and patients with a mixed model demonstrated the worst adherence.

Regarding sociodemographic differences in cluster membership, there were proportionally more men and individuals with lower SES (i.e., lower education level and income) in C1, so it could be said that individuals with these conditions are likely to be less aware about this health-threat and to have a more optimistic perception about the disease and its impact, which could lead them to a less active role in HT prevention. Moreover, participants in C3 were younger than in C1 and C2, and we also found proportionally more women and people with moderate SES in C3, the cluster with the highest awareness and concern and preventive actions. These findings are contrary to main evidence (see Table 1), but support that sociodemographic conditions might have an influence on how people perceive illnesses (Harrison et al., 2014; Kolhman et al., 2012; Letelier et al., 2011). However, literature is inconclusive on this point. Our findings are similar to those obtained by Harrison et al. (2014) and Kolhman et al. (2012) in that more benevolent illness schemata are more likely among males and older people.

Besides, we found that individuals in C2 (i.e., lowest awareness and concern as well as preventive efforts) were characterised by lower family experience compared to C1 and C3. However, family experience has been related previously to more benevolent or optimistic illness schemata for cognitive impairment (Lin & Hiedrich, 2012). Based on our findings, it seems that having lived with HT at home leads to a higher level of realistic perceptions on this disease and probably some level of fear from having it, motivating people to avoid it and guiding behaviour; however, the particular configurations of C1 and C3 point out that other variables besides family experience with the disease are of relevance for the schemata on an illness and their influences on behaviour. These findings help us in tailoring interventions to modify illness perceptions based on what seems to be more likely given a particular configuration of sociodemographic conditions.

We also explored the relationship between the different schemata about HT identified and a behavioural outcome as is the practice of preventive actions. Other research conducted with hypertensive patients found that being clustered in an specific profile of HT perceptions was related with behavioural outcomes such as the election of the type of medication (Figueiras et al., 2010) or adherence to drug treatment (Hsiao et al., 2012). The influence of the illness schemata on different behaviour-related outcomes has been also demonstrated for other illnesses: coping strategies in brain injury patients (Medley et al., 2010) and mild cognitive impairment patients (Lin & Hiedrich, 2012), intention to adhere to treatment in type 2 diabetes (Letelier et al., 2011), physical activity levels in breast cancer (Charlier et al., 2012) and use of primary, secondary or community care services in different chronic and non-chronic disease (Lowe et al., 2011). We found that, when the effects of possible confounders were controlled for, the effect of cluster membership on preventive behaviours was significant. Participants in the high awareness and concern subgroup, i.e., those with the most negative perceptions on HT but highest sense of controllability, demonstrated a relative higher investment in preventive efforts, with levels that were 1/3 standard deviation above the average; participants in the low awareness and concern subgroup demonstrated a poor investment in preventive efforts, with levels that were 1/4 standard deviation below the average, whereas participants in the very low awareness and concern subgroup, i.e., those with the most benevolent perceptions on HT but lowest sense of controllability, demonstrated dramatically lower investment in preventive efforts, with levels that were close to one standard deviation below the average. These results manifest, as we expected, that normotensive people in clusters C1 and C2 are less motivated to introducing changes in their lifestyle in comparison with participants of C3, with more accurate and realistic (i.e., more negative) representation of this disease and the important consequences and problems that may derive from it as well as on the success of some behaviours for diminishing the risk of suffering from HT in the future, along with stronger perceptions of personal controllability. Our findings support those from Figueiras et al. (2010) regarding the perceptions of necessity of treatment among hypertensive patients, but run counter those by Hsiao et al. (2012) regarding the adherence to medication. It is difficult to compare our findings with those obtained with other populations and diseases due to dissimilarities of clusters' configurations, but our results support some of them (e.g., Lin & Hiedrich, 2012 for coping styles) and contradict some others (e.g., Charlier et al., 2012 for physical activity). Perhaps the type of population and behaviour is a key factor on this relationship, something that future research should clarify.

The important differences between the three configurations obtained in the present study, especially between clusters of low and very low awareness and concern (C1 and C2) and cluster of high awareness and concern (C3) give us important and valuable information in order to increase the accuracy of illness representations, the perception of dangerousness of the disease and the possibility of prevention of HT with the final aim of reducing the prevalence of this disease due to an adequate, tailored primary prevention.

This study suffers from many limitations to be addressed by future research. Extracting descriptive attributes for a group of individuals can be performed with different group-profiling statistical strategies to construct descriptions of a group focussing on extracting cohesive groups based on some defined characteristics. These procedures can yield different groupings both in terms of the number of groups and group membership and it may be problematic in interpreting the results, because each methodology could lead to potentially different interpretations of the underlying structure of the data (Eshgi, Haughton, Legrand, Skaletsky & Woolford, 2011). Thus, different clustering methodologies may result in different results which may make any interpretation of the results dependent upon the methodology used (Eshghi et al., 2011; Gelbard, Goldman & Spiegler, 2007). This suggests that it is necessary to ensure that the assumptions underlying the various methods are indeed appropriate for the data. Some of these procedures, which have been used in illness perceptions and SRM research, are the model-based clustering by latent class analysis and latent profile analysis (for categorical and continuous observed variables, respectively) or derived more refined hierarchical methods, or the spatial map-based multidimensional scaling method. In these analyses it is assumed that the variables used for grouping are independent and, consequently, only the latent variable causes the observed variables to be related to each other.

Some comparisons of different methods seem to indicate that non-hierarchical methods typically perform better than hierarchical ones (Gelbard et al., 2007) and that, compared to, for example, latent class analysis, traditional cluster analysis provides the most homogeneous clusters while most effectively differentiating between clusters (Eshghi et al., 2011). Nevertheless, the best method depends on different factors, including type of data and their properties (e.g., covariances), aims of the researcher or knowledge on number of clusters, and others have indicated that other techniques such as latent class analysis or latent profile analysis may perform better under some circumstances (Steinley & Brusco, 2011). We decided to run k-means analysis because the major part of the research on illness perceptions uses this method for clustering participants and it has proved to be stable and valid for grouping cases.

Moreover, many of such studies involve a previous hierarchical clustering (e.g., Ward's method) to obtain a suitable initial number of clusters and a posterior non-hierarchical clustering (e.g., k-means cluster analysis) for refining grouping and profiling, and this has been also recommended (Clatworthy et al., 2005). Nevertheless, as presented in Table 1 and as stressed by Clatworthy et al. (2007), two to four clusters merged in the research regarded with clustering based on illness perceptions. Given this, we eliminated the first step and used k-means for exploring solutions with two, three and four factors in order to select that with higher statistical support and theoretical meaningfulness. We also based our decision on several indexes such as PSF and Goodman and Kruskal’s λ, considered efficient statistic for determining the goodness of the clustering solution.

Furthermore, given the scarcity of investigations on HT representations and preventive behaviours in Spanish and other populations, we encourage researchers to conduct new studies aimed at replicating our results and to include cross-cultural comparison purposes. It would be advisable to increase the number of participants and to include a more heterogeneous sample. The reliance on self-reported diagnoses of personal and family member HT has important limitations, as prevalence may be under- or overestimated. Nonetheless, this procedure has been found to show a moderate to excellent agreement with epidemiological, population-based prevalence in nationwide samples (Lima-Costa, Peixoto & Firmo, 2004; Selem, Castro, Galvao, Lobo & Fisberg, 2013; Van Eenwyk, Bensley, Ossiander & Krueger, 2012). Thus, self-reports are considered valid and an appropriate indicator for the surveillance of HT prevalence in the absence of BP measurement. Researchers and health specialists are increasingly obtaining information on chronic illnesses from self-reports (e.g., Estoppey, Paccaud, Vollenweider & Marques-Vidal, 2011; Kaplan, Huguet & Feeney, 2010; Pereira et al., 2012; Pitsavos et al., 2006; Valderrama, Valderrama, Tong, Ayala & Keenan, 2008). However, medical data would complete self-reported information. Future research should also compare the beliefs of non-patients, caregivers and patients with controlled and uncontrolled HT. Further, neither the type and accuracy of knowledge the participants had nor the sources of their representations were considered herein, and it would be appropriate to know and compare the beliefs and behaviours of people who have significant medical knowledge with those held by people with no specialised knowledge. It would be also interesting to consider participant's current or future risk of having HT due to behavioural or genetic causes. Finally, it would be interesting to explore how illness perceptions and preventive representations and behaviours themselves change over time in response to new influences, such as an individual’s personal and/or family experience with the illness or a tailored intervention.

Despite these limitations, our results are novel and interesting. To date, there are no precedents about the identification of HT illness models profiles in healthy general population and the relationship between these configurations and behavioural outcomes such as the practice of preventive actions. Thus, our findings allow us to better understand the relationship between different profiles of illness schemata, perceptions of health risks and prevention possibilities in a very common and high incidence disease such as HT, and the efforts in preventing this silent killer that the normotensive population makes. Furthermore, as far as we know, our research is pioneer in clustering illness representations about HT in the general population. Definitely, our findings could be very helpful in order to design and implement strategies in a practical way. On one hand, our findings highlight the problem of the lack of awareness about what this illness means and the health problems that can be provoked by a high BP in the general population. On the other hand, knowing in which profile is involved a person instead his(her) isolated HT representations helps us to easily modify groups of inaccurate beliefs about HT and linked health risks in people of the two profiles identified as more dangerous, especially in one of them. This could be an effective way for incrementing preventive behaviours in these collectives.

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PARTE IV:
DISCUSIÓN

CAPÍTULO 12

Discusión general, limitaciones y perspectivas futuras

12.1. Discusión general

El objetivo general de esta Tesis Doctoral ha sido explorar los postulados centrales del Modelo de Autorregulación (SRM, *Self-Regulation Model*) de Leventhal y colaboradores (Cameron y Leventhal, 2003; Diefenbach y Leventhal, 1996; Leventhal y Diefenbach, 1991; Leventhal et al., 1980, 1984, 1992, 1997, 1998, 2001, 2003). Modelo teórico ampliamente aceptado acerca de las representaciones tanto cognitivas como emocionales de la enfermedad que las personas construimos, y que en los últimos años se ha convertido en objeto de importante interés en el ámbito de la Psicología de la Salud, dando lugar a gran cantidad de investigaciones y estudios. Sin embargo, como se ha señalado en más de una ocasión a lo largo de esta Tesis Doctoral, aunque el SRM ha sido aplicado a un amplio número de enfermedades tanto físicas, como psicológicas (aunque en menor medida en estas últimas), la mayor parte de la investigación se ha orientado a conocer las creencias de enfermedad y su relación con otras variables (e.g., afrontamiento, adherencia a regímenes terapéuticos, reacciones emocionales…), así como, su influencia en el bienestar y calidad de vida de la población enferma, o con alto riesgo de padecer la enfermedad. En mucha menor medida, se ha orientado a estudiar estas mismas variables en población sana, cuidadores de esos enfermos, o familiares, quedando relegada a un segundo plano la población general, que no padece ni ha padecido la alteración.

A pesar de ello, el SRM establece que también en población no enferma las representaciones cognitivas y emocionales sobre la enfermedad en general, así como sobre cada alteración en particular, juegan un papel nuclear en la percepción de la enfermedad, incluyendo el posible riesgo de padecer una alteración, y en las conductas de manejo de dicho riesgo, incluyendo la prevención de la misma, a través de la elicitación de una serie de estrategias y actuaciones (e.g., búsqueda de información, cambios en el estilo de vida, someterse a exámenes médicos periódicos...) que permitan proteger y conservar la salud y el bienestar. En este sentido, es importante subrayar que las creencias sobre la enfermedad son representaciones de la misma que pueden estar o no, basadas en conocimientos adecuados, pero que de igual manera van a guiar la conducta del individuo que las tiene. Por ello, se espera que representaciones cognitivas más ajustadas al conocimiento biomédico y reacciones emocionales más funcionales y adaptativas motivarán conductas más eficaces de manejo de las amenazas a la salud.

Por ello, esta Tesis Doctoral ha perseguido el objetivo de estudiar las representaciones de enfermedad en población española sana, así como la relación entre esas representaciones y variables de afrontamiento y prevención de la misma, en dos enfermedades concretas, el cáncer y la hipertensión. La elección de estas dos enfermedades, que en un principio puedan parecer tan dispares, no ha sido al azar, sino que ha sido determinada por diversos motivos, uno de ellos, es su enorme impacto e incidencia a nivel mundial y al devastador efecto que pueden tener para la salud y el bienestar si no se actúa a tiempo sobre ellas.

De un modo general, los estudios 1 y 2 se han centrado en estudiar las representaciones cognitivas y emocionales sobre el cáncer que tiene la población sana con diferentes grados de relación con la enfermedad, y los estudios 3, 4 y 5 han estudiado las representaciones no especializadas sobre la hipertensión.

Con respecto al **estudio 1**, se han planteado como objetivos la exploración de las representaciones cognitivas y emocionales que sobre el cáncer posee la población que no ha padecido esta enfermedad, y con diferente experiencia familiar con la misma, así como la posible influencia de variables sociodemográficas en esas representaciones tales como la edad, el sexo o el nivel educativo, así como de la experiencia familiar derivada de haber convivido o no, con un enfermo de cáncer.

Los hallazgos de este estudio confirman la propuesta del SRM avalada por diferentes estudios realizados con enfermos de cáncer, poblaciones en riesgo y supervivientes (e.g., Anagnostopoulos y Spanea, 2008; Buick, 1997; Buick y Petrie, 2002; Constanzo et al., 2010; Hevey et al., 2009; Hopman y Rijken, 2015; Hoogerwerf et al., 2012; Gercovich et al., 2012; Llewelyn et al., 2007; Lancastle et al., 2011; Orbell et al, 2008; Rees et al., 2004; Scharloo et al., 2005; Trask et al., 2008) respecto a que las personas construimos diferentes esquemas de la enfermedad, en función de diferentes fuentes de información, incluyendo creencias, conocimientos y experiencias personales, informaciones recibidas de otros, y el cuerpo de conocimiento popular y las creencias y normas socio-culturales (Diefenbach y Leventhal, 1996; Leventhal et al., 1980, 1984, 1992; Leventhal y Diefenbach, 1991). También confirman nuestra hipótesis de partida, que establecía que las representaciones de enfermedad, en este caso sobre el cáncer, podrían considerarse como una combinación de aspectos ajustados y cercanos al conocimiento biomédico objetivo y de otros aspectos más alejados del mismo como creencias laicas, populares y culturales, aunque los hallazgos de los estudios con población sana (incluidos familiares y cuidadores y supervivientes al cáncer) son variados e inconclusos (e.g., Anagnostopoulos y Spanea, 2005; Buick y Petrie, 2002; Cameron, 2008; De Castro et al., 2013, 2015; Del Castillo et al., 2011; Dempster et al., 2011a,b; Figueiras y Alves, 2007; Godoy-Izquierdo et al., 2007; Graham et al., 2015; Johansson et al., 2004; Juth et al., 2005; Lykins et al., 2008; Orbell et al., 2008; Rees et al., 2004; Wang et al., 2010).

En general, los resultados del estudio 1 indican que el cáncer era percibido por los participantes como una alteración de larga duración, aunque no necesariamente crónica, que es sintomática y dolorosa y en la que la pérdida de peso y de fuerza o debilidad, las náuseas y los problemas emocionales se encuentran entre los síntomas más destacados. La población española sana también consideraba la enfermedad como cambiante y cíclica con periodos en los que mejora y empeora, así como asociada a importantes posibilidades de curación a través de los tratamientos médicos existentes, aunque la confianza en la influencia de las acciones del propio paciente sobre su enfermedad fue mucho menor. El cáncer fue asimismo considerado como una alteración con un fuerte impacto en la vida de los pacientes y sus familiares. La mitad de los participantes consideró poseer una buena comprensión de lo que esta enfermedad significa. En cuanto a las representaciones de causas, el cáncer es considerado como prevenible, ya que los factores más frecuentemente señalados por los participantes fueron aspectos controlables como fumar, el consumo de alcohol o los hábitos de alimentación, aunque también destacaron otros aspectos de carácter no controlable como son la contaminación, la herencia, la edad o la suerte. Finalmente, los participantes mostraron sentimientos fuertes de miedo, ansiedad, preocupación o tristeza ante la posibilidad de sufrir la enfermedad en el futuro.

Estos resultados serían muy similares a los hallados en el único estudio que ha explorado las representaciones sobre el cáncer en población sana española, aunque en este último la confianza en las posibilidades de controlar la enfermedad a través de las acciones del propio enfermo era mayor que a través de los tratamientos disponibles y la percepción de las posibilidades de prevenir la enfermedad fue menor que en nuestro estudio (Godoy-Izquierdo, López-Chicheri et al., 2007). También están en la línea de otros estudios realizados con muestras no españolas (e.g., Anagnostopoulos y Spanea, 2005; De Castro et al., 2013, 2015; Dempster et al., 2011a,b; Figueiras y Alves, 2007; Juth et al., 2005; Orbell et al., 2008; Rees et al., 2004; Wang et al., 2010).

El conocimiento de las representaciones tanto cognitivas como emocionales que la población sana construye acerca del cáncer puede ser de gran utilidad de cara a desarrollar programas dirigidos a prevenir la aparición de la enfermedad por un lado, y a desmitificar su letalidad favoreciendo expectativas más positivas y realistas sobre las posibilidades reales de curación y control y destacando el carácter preventivo de la misma a través del desarrollo de adecuados hábitos de vida. En este sentido, las representaciones emocionales y cognitivas halladas en este estudio 1 podrían ser indicativas de algún modo de la influencia de determinadas campañas desarrolladas por las administraciones públicas en nuestro país; en concreto, las representaciones de alta curabilidad, factores causales controlables y no necesaria cronicidad podrían estar relacionadas con el modo en que el cáncer es mostrado por parte de las administraciones y organismos sanitarios y de sus esfuerzos por generar en la población general una concepción de la enfermedad más optimista y relacionada con aspectos prevenibles.

Con respecto a la influencia de variables de carácter sociodemográfico en las representaciones emocionales y cognitivas sobre el cáncer, diferentes estudios han mostrado que estas variables ejercen una escasa, pero existente, influencia (e.g., Anagnostopoulos y Spanea, 2005; Lehto, 2007; Wang et al., 2010). En consonancia, en nuestro estudio sólo se hallaron algunas diferencias significativas de acuerdo con el nivel educativo para las dimensiones de coherencia y evolución, lo que parece apoyar la idea, por otro lado lógica, de que a mayor nivel de educación formal las representaciones son más ajustadas y correctas.

Por otro lado, los resultados de este estudio han apoyado el importante papel que la experiencia con la enfermedad, en este caso derivada de convivir o haber convivido con un enfermo de cáncer, ejerce en las representaciones sobre la enfermedad en población sana y que ha sido demostrada por diferentes investigaciones (e.g., Anagnostopoulos y Spanea, 2005; Buick y Petrie, 2002; Dempster et al., 2001b; Godoy-Izquierdo et al., 2007; Juth et al., 2015; Lykins et al., 2008; Orbell et al., 2008). En el estudio 1 de esta Tesis Doctoral se ha encontrado que los familiares, amigos o cuidadores de enfermos de cáncer perciben la enfermedad como más sintomática y muestran representaciones emocionales más fuertes ligadas a la posibilidad de enfermar ellos mismos de cáncer. Estos resultados parecen mostrar unas percepciones más negativas del cáncer relacionadas con la experiencia con la enfermedad que podrían relacionarse con la percepción de manera directa de los efectos y consecuencias que la enfermedad implica para las personas que la padecen. Además, confirman parcialmente nuestra hipótesis de partida, ya que hubiera sido esperable, en la línea de una percepción de la enfermedad como más severa y con mayor impacto, que se hubieran encontrado también diferencias significativas para la dimensión de consecuencias. Godoy-Izquierdo, López-Chicheri et al. (2007) hallaron, sin embargo, una influencia de la experiencia familiar con la enfermedad diferente a la encontrada en nuestro estudio, que mostró que los participantes que convivían o habían convivido con un enfermo poseían creencias más positivas en identidad, duración, evolución, consecuencias, control personal y por tratamiento. No obstante, ese estudio incluía un amplio número de enfermedades tanto físicas como mentales y la experiencia familiar con la enfermedad fue valorada de forma global para el conjunto de alteraciones, lo que podría explicar las diferencias con nuestros resultados. En el caso concreto del cáncer, Wang et al. (2010) hallaron también diferencias en población sana relacionadas con la experiencia para la dimensión de causas, aspecto que no se ha confirmado en nuestro estudio.

Si nos centramos en el **estudio 2** de esta Tesis Doctoral, éste se ha desarrollado con el objetivo de explorar el componente emocional de las representaciones del cáncer en población sana, dada la escasez de estudios en ese ámbito y la importancia de las reacciones emocionales en las conductas de afrontamiento de riesgos y prevención de la enfermedad. En segundo lugar, este estudio ha ido dirigido a confirmar la relación postulada por el SRM entre las diferentes dimensiones que conforman las representaciones acerca de la enfermedad, en este caso del cáncer, y especialmente la existente entre representaciones emocionales y cognitivas.

Con respecto a estos objetivos, nuestros hallazgos han puesto de manifiesto que las personas que no padecen ni han padecido cáncer muestran reacciones emocionales de miedo, tristeza o preocupación entre moderadas y altas cuando consideran la posibilidad de sufrir esta enfermedad en cualquiera de sus variantes. Estos resultados pueden ser considerados como similares, aunque un poco más altos, a los obtenidos en otros estudios con población sana que incluían todos los tipos de cáncer (Figueiras y Alves, 2007), cáncer de cuello de útero (De Castro et al., 2015) y colorrectal (Orbell et al., 2008). Sin embargo, los resultados de otros estudios con enfermos de cáncer (e.g., Cameron, 2005; Hoogerwert et al., 2012; Hopman y Rikjen, 2015; Trask et al., 2008) y su comparación con las representaciones emocionales de la población sana han puesto de manifiesto que padecer la enfermedad lleva a una disminución o atenuación de las reacciones emocionales negativas. Por otro lado, los estudios realizados con población de riesgo (De Castro et al., 2015; Hevey et al., 2007; Lancastle et al., 2011; Van Oostrom et al., 2007c) han mostrado representaciones emocionales más fuertes que las de los pacientes y muy similares a las de la población general, lo que parece indicar que el malestar emocional puede ir evolucionando a lo largo de todo el proceso de la enfermedad, siendo más intenso cuando aún no se padece o se percibe un riesgo real de sufrir cáncer y atenuándose después del diagnóstico y durante el tratamiento (e.g., Bárez, Blasco, Fernández-Catro y Viladrich, 2009; Lam et al., 2013) debido probablemente a una mayor adaptación a la situación y a que los esfuerzos de la persona se concentran en el proceso de reinterpretación de su situación, afrontamiento de la enfermedad y recuperación de la salud.

En cuanto al segundo de los objetivos, es decir, comprobar si, tal y como propone el SRM y nuestra hipótesis de partida, existe una estrecha relación entre los componentes cognitivos y emocionales de las representaciones de enfermedad, de modo que los aspectos cognitivos posean capacidad predictiva sobre los emocionales, los resultados de este estudio avalan dicha propuesta. En concreto, nuestros hallazgos han puesto de manifiesto una relación directa entre las dimensiones de identidad, consecuencias y etiología y el malestar emocional asociado al cáncer en población sana, e inversa entre la dimensión de duración y esas representaciones emocionales. Es importante destacar como otro hallazgo de este estudio que la relación entre aspectos cognitivos y malestar emocional se vio moderada por el efecto de la edad y la experiencia familiar con la enfermedad. En este sentido, se ha hallado que las representaciones cognitivas son el factor que explica en mayor medida el malestar emocional relacionado con el cáncer, mientras que el efecto de la edad y la experiencia familiar es más modesto. De este modo, la población sana que posee una percepción del cáncer en general como de menor duración, asociado a un mayor número de síntomas y consecuencias más graves para pacientes y cuidadores y que considera que es provocado por factores incontrolables como la edad o la herencia y que además posee una mayor edad y experiencia familiar con la enfermedad experimentará reacciones emocionales más fuertes y negativas. Este papel moderador de la edad y la experiencia familiar en el papel predictivo de las representaciones cognitivas acerca del cáncer sobre las representaciones emocionales no ha sido mostrado por ningún otro estudio, lo que convierte al estudio 2 de esta Tesis Doctoral en pionero en ese sentido.

Nuestros resultados apoyan parcialmente los de otros estudios que muestran la influencia de las representaciones cognitivas en el malestar emocional en cáncer. En el estudio de Figueiras y Alves (2007), desarrollado con población sana acerca del cáncer de piel (entre otras enfermedades), las representaciones emocionales de los participantes correlacionaban de manera positiva con las dimensiones de identidad, duración, evolución, consecuencias y coherencia, mientras que lo hacían de forma negativa con las de control personal y por tratamiento, no encontrándose correlación alguna con las atribuciones de factores causales psicosociales y de riesgo. Con respecto a los estudios realizados con pacientes (e.g., Lancastle et al., 2011; Gercovich et al., 2012) se ha comprobado, que al igual que en el nuestro, las representaciones emocionales correlacionaban de manera directa con las dimensiones de consecuencias y causas de carácter no controlable (Lancastle et al., 2011) y con estas dimensiones y también la de identidad (Gercovich et al., 2012). Sin embargo, estos estudios han hallado una mayor influencia de las representaciones cognitivas en el malestar emocional, especialmente el de Gercovich et al. (2012), mientras que Hagger y Orbell (2005) encontraron en mujeres con cáncer de cabeza y cuello que su malestar emocional correlacionaba con todas las dimensiones excepto la de control personal: de manera directa con identidad, duración, consecuencias y causas e indirecta con las de control por tratamiento y coherencia.

Un aspecto que podría ir en contra de la lógica es la relación inversa entre las dimensiones de duración y representaciones emocionales halladas en nuestro estudio, aunque algunos estudios con enfermos de cáncer han encontrado resultados similares (Millar et al., 2005). Esta relación podría ser explicada por la percepción de que una duración excesivamente corta de una enfermedad como el cáncer podría ser asociada con un fatal desenlace, lo que llevaría un malestar emocional más intenso.

Los resultados de este estudio apoyan de forma clara la relación propuesta por el SRM entre las dimensiones que conforman las representaciones de enfermedad, en este caso en cáncer, en concreto la interdependencia entre las representaciones emocionales y cognitivas, y subrayan el valor predictivo de estas últimas sobre el malestar emocional.

Por otro lado, de acuerdo con el SRM, las representaciones sobre la enfermedad en general, y específicamente las de carácter emocional, van a ejercer una notable influencia en la adopción de comportamientos preventivos (Leventhal et al., 2001) y en el caso del cáncer diferentes estudios con población sana y en riesgo han mostrado que las creencias que construimos sobre esta enfermedad van a determinar nuestros esfuerzos por prevenir su aparición (e.g., Cameron, 2008; Constanzo et al., 2010; Figueiras y Alves, 2007; Orbell, Hagger, Brown y Tidy, 2006; Orbell et al., 2008; Trask et al, 2008), aunque otros estudios parecen señalar resultados contradictorios (De Castro et al., 2015; Hevey et al., 2007). En este sentido, distintos estudios en el ámbito de la prevención de la enfermedad han destacado el papel que los aspectos emocionales, por encima de otros de carácter cognitivo, van a jugar para la puesta en marcha de acciones de evitación de riesgos y prevención del desarrollo de enfermedades (e.g., Cameron et al., 2005; Decruyenaere et al., 2000; Orbell et al., 2008), aunque dicha influencia parece estar mediada por otras dimensiones como la de control personal y puede depender del tipo de comportamiento preventivo (Decruyenaere et al., 2000). En cualquier caso, parece claro que conocer y actuar sobre el malestar emocional relacionado con una enfermedad, en este caso el cáncer, va a jugar un papel clave en las posibilidades de prevención primaria de la misma con población sana. Nuevamente y dado que se ha demostrado que la experiencia con la enfermedad modera esta interdependencia entre representaciones cognitivas y emocionales, podría ser adecuado contar con la visión de familiares y cuidadores de enfermos de cáncer a la hora de diseñar e implementar acciones en prevención primaria.

Como conclusión, en relación a los dos estudios desarrollados con respecto a las representaciones del cáncer en población que no padece ni ha padecido la enfermedad, nuestros hallazgos parecen confirmar los postulados básicos del SRM que han sido explorados, así como en general nuestras hipótesis de partida, aunque alguna de ellas tan sólo parcialmente.

El resto de estudios que forman parte de esta Tesis Doctoral han estudiado las representaciones laicas o no especializadas de la hipertensión. El **estudio 3**, que puede ser considerado, junto con el estudio 1 sobre cáncer, como la base sobre la que se asientan y desarrollan el resto de investigaciones, ha ido dirigido a conocer y comparar las representaciones cognitivas y emocionales sobre la hipertensión en población española sana y la posible influencia en esas representaciones, de variables como el género, la edad, el nivel educativo y la experiencia familiar derivada del hecho de convivir o haber convivido con un enfermo de hipertensión. Los resultados han puesto de manifiesto que las representaciones que la población sana construye acerca de la hipertensión son una combinación de conocimiento médico-biológico, y por tanto correctas y ajustadas, y de otras creencias más alejadas de este conocimiento y de tipo popular y cultural. Estos resultados serían similares a los obtenidos en otros estudios sobre hipertensión con población sana (Meyer et al., 1985; Wilson et al., 2002) y en el único que a nuestro conocimiento se ha realizado con población española sana (Godoy-Izquierdo, López-Chicheri et al., 2007). También coinciden en gran medida con los resultados de otros estudios realizados con pacientes (e.g., Bazán et al., 2013; Beléndez et al., 2005; Chen et al., 2009, 2011; Figueiras et al., 2010; Heckler et al., 2008; Hsiao et al., 2012; Norfazilah et al., 2013; Pickett et al., 2014; Ross et al., 2004).

En relación a los contenidos de esas representaciones en nuestro estudio, encontramos que, en general, la enfermedad era percibida como sintomática, lo que contradice la ausencia de síntomas en esta alteración al menos hasta que se encuentra muy avanzada. Los participantes indicaron en este sentido una media de cinco síntomas como manifestaciones de la alteración, entre los que destacaban la presencia de fatiga, cansancio, taquicardia, mareos o vértigo. Resulta llamativo, por ejemplo, que casi la mitad de los participantes consideraran las alteraciones del estado de ánimo como síntomas de la hipertensión, lo que podría indicar una confusión entre posibles causas y consecuencias o manifestaciones de la misma. La hipertensión fue considerada también como una enfermedad estable en su evolución, duradera en el tiempo y asociada a un impacto moderado para la vida de los pacientes, pero no para sus cuidadores o familiares. En cuanto a las posibilidades de control de su desarrollo y evolución, los participantes mostraron una elevada confianza tanto en la capacidad para ello del propio paciente como en la eficacia de los tratamientos actualmente disponibles. Las representaciones de coherencia de la enfermedad indicaron que la mitad de los participantes tenía dudas acerca de las características de este problema. En relación a las representaciones de carácter emocional, encontramos que los participantes no mostraban fuertes sentimientos de preocupación, miedo, tristeza o ansiedad cuando afrontaban la posibilidad de sufrir hipertensión, pese a ser una de las principales causas de morbi- y mortalidad en la actualidad. Finalmente, los participantes señalaron como factores etiológicos fundamentales aspectos comportamentales (e.g., hábitos de alimentación o consumo de alcohol o tabaco) y psicológicos (e.g., estrés) pero también de carácter incontrolables (e.g., herencia o edad). Aunque estos resultados son similares en muchos aspectos a los obtenidos en el otro estudio que, a nuestro conocimiento, ha sido realizado con población española sana (Godoy-Izquierdo, López-Chicheri et al., 2007), existen algunas diferencias, como que los participantes de nuestro estudio percibían la enfermedad como sintomática, cosa que en el caso del citado estudio no ocurrió, quizás por la composición de la muestra o la medida utilizada. Del mismo modo, la hipertensión era percibida como más impredecible y cambiante en dicho estudio.

En este tercer estudio, se ha puesto también de manifiesto, tal y como habíamos hipotetizado, que variables como el sexo, la edad o el nivel educativo ejercen una influencia modesta en las representaciones cognitivas y emocionales sobre la hipertensión, al igual que ocurrió con los resultados del estudio 1 de esta Tesis Doctoral realizado con cáncer. Aún así, hemos hallado algunas diferencias relacionadas con estas variables, en concreto con el sexo y el nivel educativo. Específicamente, nuestros resultados indican que los hombres perciben consecuencias más graves asociadas a padecer hipertensión y, tal y como cabría esperar, mayores niveles de educación formal se van a relacionar de algún modo con representaciones más ajustadas y correctas, aunque sólo se han hallado diferencias significativas para las dimensiones de duración y control por tratamiento.

Sin embargo, la experiencia familiar con la enfermedad, entendida en términos de convivir o haber convivido con una persona hipertensa, se ha revelado como una importante influencia en las representaciones cognitivas y emocionales de la hipertensión, al igual que ha ocurrido en el caso del cáncer en el estudio 1 de esta Tesis Doctoral, de modo que encontramos que aquellos adultos normotensos españoles con experiencia familiar perciben la hipertensión como más controlable tanto por el paciente como a través del tratamiento, más impredecible y cambiante en su curso y muestran menores niveles de emociones negativas cuando se enfrentan a la posibilidad de padecerla. Es decir, la experiencia indirecta parece en este caso relacionarse con representaciones más positivas, en contra de lo que habíamos hipotetizado. No obstante, la experiencia familiar predijo de forma directa las puntuaciones globales en el IPQ-R. Sin embargo, de nuevo hubiera sido esperable que otras dimensiones como consecuencias o identidad, que determinan las percepciones de impacto y severidad de una alteración, hubiesen mostrado diferencias significativas derivadas de esa experiencia. Esta influencia de la experiencia con la enfermedad apoyaría la propuesta del SRM de que la experiencia jugaría un papel clave en la construcción o modificación de nuestras representaciones cognitivas y emocionales sobre una enfermedad, tal y como argumentamos en el capítulo 3 de la Introducción general. Este papel relevante de la experiencia ha sido demostrado en numerosos estudios (e.g., Anagnostopoulos y Spanea, 2005; Buick y Petrie, 2002; Dempster et al., 2001b; Juth et al., 2015; Lykins et al., 2008; Orbell et al., 2008), así como en el estudio de Godoy-Izquierdo, López-Chicheri et al. (2014) realizado con población española sana, aunque, como ya hemos comentado anteriormente, la influencia de la experiencia en dicho estudio fue valorada para un conjunto amplio de enfermedades, lo que limita la posibilidad de hacer comparaciones con nuestros resultados.

El **estudio 4** de esta Tesis Doctoral está formado a su vez por dos estudios. Los objetivos del primero de ellos han ido dirigidos a confirmar los resultados del estudio 3, pero superando algunas de las limitaciones del anterior con una muestra más amplia y heterogénea. Los hallazgos de este primer estudio han puesto de manifiesto que, tal y como muestra la investigación sobre modelos de enfermedad en diversas alteraciones físicas (e.g., Anagnostopoulos y Spanea, 2005; Karasz, McKee y Roybal, 2003; Meyer et al.,1985; Rees et al.,2004; Ross et al., 2004; Wilson et al.,2007), así como los estudios realizados en población hipertensa (e.g., Bazán et al., 2013; Beléndez et al., 2005; Chen et al., 2009, 2011; Figueiras et al., 2010; Heckler et al., 2008; Hsiao et al., 2012; Norfazilah et al., 2013; Pickett et al., 2014; Ross et al., 2004) y sana en hipertensión (Meyer et al., 1985; Wilson et al., 2002), entre los que se incluyen los escasos estudios realizados en población española (Del Castillo et al., 2013; Godoy-Izquierdo, López-Chicheri et al., 2007), las representaciones construidas por la población normotensa española acerca de la hipertensión son una mezcla de aspectos biomédicos objetivos, y otros laicos de tipo cultural o popular.

En este sentido y a grandes rasgos, la hipertensión es percibida como sintomática, cíclica y de larga duración, con un impacto significativo para la vida de las personas que la sufren. Además, la población sana española considera esta enfermedad como asociada a importantes posibilidades de control tanto por parte de la persona enferma como a través de los tratamientos disponibles y manifiestan tener una buena comprensión de la hipertensión por su parte. En cuanto a la etiología de este “asesino silente”, los participantes en el estudio señalaron como las causas más importantes factores relacionados con aspectos personales, de comportamiento o estilo de vida (e.g., dieta, tabaco, alcohol) así como factores de tipo psicosocial (e.g., estrés y preocupaciones), pero también consideraron que en la génesis de esta enfermedad influyen otros factores incontrolables como la herencia o la edad. Finalmente, si dirigimos nuestra atención a las representaciones emocionales es necesario destacar que éstas no son especialmente altas, ya que la posibilidad de sufrir hipertensión no provoca en la población española normotensa importantes sentimientos de tristeza, ansiedad o preocupación. Estos hallazgos son similares a los obtenidos por Godoy-Izquierdo, López-Chicheri et al. (2007) con población española, aunque como diferencia más importante se podría subrayar que en nuestro estudio la hipertensión es considerada como sintomática, cosa que no ocurre ese estudio realizado con población española y que contradice el carácter asintomático de esta alteración, al menos hasta estadíos muy avanzados. Esta percepción de la presencia de sintomatología en la enfermedad mostraría de algún modo la necesidad que tenemos de experimentar señales o signos que nos indiquen la presencia de una enfermedad. Con respecto a las posibles diferencias con el estudio 3 de esta Tesis Doctoral, en el estudio 4 se ha hallado que la hipertensión es percibida como más duradera y asociada a mayores y más graves consecuencias así como más cíclica y cambiante. Por otro lado, los participantes de este cuarto estudio otorgan mayor importancia a factores de tipo comportamental en la génesis del problema y manifiestan poseer una mejor comprensión de la enfermedad.

En cuanto a la influencia de variables sociodemográficas en esas representaciones, nuestros hallazgos han mostrado que variables como el género o la edad ejercen escasa influencia en las creencias de la población española sana acerca de la hipertensión, mientras que el estatus socioeconómico y, sobre todo, la experiencia con la enfermedad determinan de algún modo la construcción o modificación de esas representaciones. En este sentido, los hallazgos de este estudio muestran que los participantes con un mayor estatus socioeconómico (entendido como la combinación de nivel educativo, situación laboral y nivel de ingresos) y mayor experiencia familiar con la enfermedad mostraban percepciones más positivas sobre la hipertensión, contradiciendo nuestra hipótesis de partida, señalando de algún modo que estos factores llevan a la población sana a tener percepciones de menor severidad de la enfermedad y a ser más optimista sobre esta alteración. Así, ésta era considerada como menos grave y duradera, con consecuencias poco severas para la vida de los pacientes y mayores posibilidades de control tanto personal como por tratamiento. En este sentido, habría sido deseable haber explorado la influencia del estatus socioeconómico en el caso del cáncer, aunque por motivos de organización de esta Tesis Doctoral y orden en la realización de los estudios no ha sido posible. Por ello, sería recomendable realizar investigaciones en el futuro que traten de replicar este resultado considerando estas variables sociodemográficas de forma conjunta, puesto que además la literatura tiende a explorarlas de manera separada, si bien se trata de variables que se relacionan estrechamente y tienen un impacto importante en otras variables relacionadas con la salud. Los resultados del estudio 3 de esta Tesis Doctoral también muestran una influencia de la experiencia en el sentido de relacionarse con percepciones más positivas sobre la hipertensión. Otros estudios con población no española han mostrado la influencia de factores económicos o de ingresos en las representaciones acerca de la hipertensión (Pérez, 2014) y especialmente de la experiencia familiar tanto con pacientes hipertensos (Norfazilah et al., 2013) como con población normotensa (Godoy-Izquierdo, López-Chicheri et al., 2007; Lin y Hiedrich, 2012).

La influencia demostrada que la experiencia con la enfermedad posee en la construcción y modificación de las representaciones cognitivas y emocionales así como el papel moderador de la misma en la interdependencia entre ambos tipos de representaciones podría poseer un carácter aplicado para la Psicología de la Salud y las administraciones públicas en el ámbito de la promoción de la salud y la prevención de la enfermedad es la posible colaboración de personas con experiencia familiar, y su conocimiento sobre la enfermedad con la que han convivido a la hora de diseñar e implementar actuaciones preventivas dirigidas a la población general. Su experiencia podría ser de gran ayuda para mostrar a las personas sanas que no han convivido nunca con un enfermo que padezca dicha alteración en qué consiste la enfermedad desde la perspectiva de un cuidador o familiar, ayudándoles de forma cercana y directa a una mejor comprensión de cada trastorno y a modificar concepciones erróneas.

En relación al segundo de los estudios que conforman el estudio 4, éste tenía como objetivos los de explorar las asociaciones entre las representaciones cognitivas y emocionales que sobre la hipertensión construye la población sana y las percepciones de los riesgos asociados a padecer hipertensión, así como la percepción de la eficacia de llevar a cabo cambios en el estilo de vida para evitar esos riesgos y prevenir el desarrollo de esta enfermedad y la introducción real de modificaciones en el estilo de vida a través de la práctica de conductas concretas de prevención de la hipertensión. Se trataba, por tanto, de explorar la relación existente entre las representaciones de enfermedad y las respuestas de afrontamiento que el SRM postula.

Los hallazgos de este estudio muestran de forma clara que la población sana española es consciente de los serios problemas para la salud relacionados con una elevada presión arterial, ya que casi el 95% de los participantes la considera un factor de riesgo para el desarrollo de otras alteraciones y problemas. En este sentido, los problemas de salud señalados por los participantes con mayor frecuencia son las alteraciones cardiovasculares, pudiéndose considerar éstas como el conjunto de enfermedades “prototipo” de las provocadas por una elevada presión arterial. Sin embargo, otros problemas como la insuficiencia renal o problemas visuales son percibidos como originados por la hipertensión por tan sólo una cuarta parte de los participantes, lo que muestra que en la conciencia colectiva hay un grupo de enfermedades, las cardiovasculares, que son las que tradicionalmente se han asociado a la hipertensión y que continúan formando parte de manera clara de las percepciones de riesgo elicitadas por la población sana. En el otro extremo, nuestros hallazgos también destacan representaciones del riesgo para la salud relacionado con la hipertensión muy alejadas del conocimiento médico-biológico, como la consideración de que el estrés puede ser provocado por esta enfermedad, en una posible confusión de causas y consecuencias de la enfermedad, o la percepción de que la hipertensión puede conducir a otras enfermedades de tipo cardio-metabólico como hipercolesterolemia, diabetes u obesidad, problemas con los que se asocia frecuentemente la hipertensión pero que no son causados por ésta. Finalmente, entre 1 y 3 participantes de cada 10 también han considerado otras enfermedades que no tienen relación alguna con la hipertensión como provocadas por ésta. Estos hallazgos muestran, por tanto, un desconocimiento parcial por parte de la población sana de cuáles son los riesgos para la salud asociados a una elevada presión arterial y deberían llevar a las administraciones públicas y organismos relacionados con la salud a plantearse la necesidad de una adecuada educación a la población no paciente dentro de las políticas de promoción de la salud y prevención de la enfermedad. Estos resultados vuelven, por tanto, a mostrar cómo en las representaciones acerca de los riesgos relacionados con la hipertensión existe una combinación de conocimiento objetivo de tipo biomédico y aspectos culturales y populares. Nuestros hallazgos apoyan parcialmente los de otros estudios que han explorado las percepciones sobre los riesgos asociados a una elevada presión arterial en población sana en minorías étnicas y que mostrarían la influencia de aspectos culturales y sociales (Aroian et al., 2012; Newell et al., 2009; Savoca et al., 2009).

Una vez conocidas las representaciones la enfermedad y las percepciones de riesgo, el siguiente objetivo fue explorar las posibilidades de prevención de la enfermedad y el desarrollo de conductas para evitar su aparición en esta población. En relación a ello, nuestros hallazgos han mostrado que los participantes en este estudio consideran la enfermedad como prevenible en una altísima proporción, y que los comportamientos preventivos propuestos eran de utilidad, de moderada a alta en la mayor parte de los casos, para reducir eficazmente la probabilidad de desarrollar hipertensión. En este sentido, es significativo que ninguno de los participantes mostraran una total falta de confianza en las posibilidades de prevenir la enfermedad introduciendo cambios en su estilo de vida.

De acuerdo con otros estudios realizados con minorías étnicas (Aroian et al., 2012; Newell et al., 2009; Peters et al., 2006), las acciones percibidas por los participantes como más exitosas en la prevención de la hipertensión fueron introducir cambios en la dieta, realizar actividad física, reducir el consumo de alcohol y tabaco y controlar el estrés y las emociones negativas. Teniendo en cuenta estos resultados, por un lado la alta conciencia de los riesgos asociados a la hipertensión y por otro la elevada estimación de la posibilidad de prevención de esta enfermedad a través de la realización de cambios concretos en el estilo de vida, podríamos suponer que la población sana va a realizar acciones en su vida diaria dirigidas a minimizar la posible aparición de la hipertensión como un modo de evitar toda una serie de importantes riesgos asociados. Sin embargo, los resultados no pueden ser más desconcertantes. En este sentido, era esperable que estas percepciones se tradujeran en un alto porcentaje de los participantes en una elevada práctica de conductas preventivas, pero los resultados han mostrado que el número de adultos españoles sanos que llevaba a cabo esas acciones para reducir la probabilidad de desarrollar la enfermedad era considerablemente bajo. Así por ejemplo, más del 4% no realizaban ninguna de las 15 conductas propuestas y un 38% habían introducido menos de 5 de esos cambios en su vida diaria, mostrando por tanto una falta de coherencia entre sus representaciones mentales y sus conductas. Aunque hubiera sido deseable hallar otros resultados acerca de esta importante cuestión, esta incongruencia entre representaciones y conductas preventivas en hipertensión ha sido señalada anteriormente por otros estudios (Aroian et al., 2012; Newell et al., 2009; Peters at al., 2006; Savoca et al., 2009). Quizás la percepción de escasas posibilidades reales de desarrollar la enfermedad unida a la baja edad media de los participantes, ya que el envejecimiento es considerado como una de las principales causas de la hipertensión, explique de algún modo estos resultados. En cualquier caso, estos hallazgos ponen de manifiesto la necesidad de emprender acciones que incidiendo sobre las representaciones que la población sana construye sobre los riesgos asociados a esta enfermedad y las posibilidades de prevención incrementen la puesta en marcha de cambios reales en su estilo de vida. Se trataría, por tanto, de lograr movilizar a la población sana para que sean capaces de avanzar de representaciones relacionadas con la eficacia de las conductas preventivas a otras de necesidad de esas conductas. Por ello, consideramos que este estudio es muy revelador y arroja luz sobre la importante cuestión de la prevención primaria de la hipertensión, de los aspectos que pueden contribuir a la misma y de cómo intervenir para reducir el impacto de esta enfermedad.

Este estudio también ha puesto de manifiesto la presencia de numerosas e importantes asociaciones entre las variables psicosociales que forman parte del mismo. En primer lugar, se ha hallado que las representaciones acerca de la hipertensión se relacionan tanto con la percepción de riesgos como con la percepción y práctica de conductas preventivas, revelándose como predictores significativos de algunas de las variables comportamentales incluidas en este estudio, lo cual apoyaría de forma clara la propuesta del SRM en ese sentido y, en concreto, la relación entre representaciones de enfermedad y desarrollo de conductas de prevención, puesta de manifiesto por diferentes estudios (e.g., Cameron, 2008; Constanzo et al., 2010; Figueiras y Alves, 2007; Orbell, Hagger, Brown y Tidy, 2006; Orbell et al., 2008; Trask et al, 2008), aunque otros hayan encontrado resultados contradictorios (De Castro et al., 2015; Hevey et al., 2007). Así, nuestros hallazgos han mostrado que todas las dimensiones que conforman, de acuerdo con el SRM, las representaciones emocionales y cognitivas de enfermedad, con la excepción de duración y evolución, se relacionaban con las percepciones de riesgos asociados a la hipertensión y el número de problemas de salud que podrían derivarse de la misma; y, con la excepción de las percepciones de control por tratamiento, el resto de dimensiones correlacionan con la percepción y práctica de conductas preventivas. Es necesario destacar que la percepción de la hipertensión como más sintomática y con mayor impacto en la vida diaria de los pacientes se relacionaba con una mayor conciencia sobre los riesgos que una elevada presión arterial conlleva para la salud, mayor confianza en la posibilidad de prevenir la hipertensión introduciendo cambios en el estilo de vida y una puesta en práctica de esas conductas con mayor frecuencia para prevenir la enfermedad. Las percepciones de control personal mostraron también una importante relación con estas variables, ya que una mayor percepción de control por parte del propio individuo sobre la hipertensión se relacionaba con una mayor conciencia de los riesgos así como de las posibilidades de prevención. Por otro lado, la percepción de la hipertensión como menos cíclica lleva a considerar los comportamientos preventivos como más efectivos y, como sería de esperar, a una mayor práctica de los mismos en la vida diaria para evitar el desarrollo de la enfermedad. En relación a la coherencia, los adultos españoles sanos que creen poseer una comprensión de lo que esta enfermedad significa menos clara ponen en práctica en su vida diaria un mayor número de conductas para prevenir la hipertensión. En cuanto a los componentes emocionales de las representaciones sobre la hipertensión, los participantes que mostraban mayores sentimientos de preocupación, tristeza o ansiedad ante la posibilidad de sufrir hipertensión percibían mayor número de amenazas para la salud asociadas a la hipertensión, mayores posibilidades de prevenirla y ponían en práctica comportamientos preventivos en mayor medida.

Por otro lado, también se ha encontrado una relación entre las percepciones de riesgo y la percepción y práctica de conductas preventivas, de modo que aquellos participantes que consideran la hipertensión como un factor de riesgo en sí misma llevan a cabo una mayor práctica de conductas preventivas, mientras que la percepción de un mayor número de amenazas para la salud asociadas a una elevada presión arterial se relaciona con una mayor percepción de la posibilidad de prevenir la enfermedad introduciendo cambios en el estilo de vida y una mayor práctica de las mismos. Además, los participantes que percibían mayores posibilidades de prevenir la hipertensión a través de determinados comportamientos también los realizaban en mayor medida. En este sentido, los resultados de este estudio confirman nuestra hipótesis de partida de que representaciones más negativas van a estar relacionadas con una mayor percepción de riesgos y una mayor eficacia percibida de los comportamientos preventivos, así como con una mayor introducción de cambios en el estilo de vida como un modo de prevenir la enfermedad. Sin embargo, otras representaciones de carácter positivo como una elevada percepción de controlabilidad, una buena comprensión de lo que la enfermedad significa así como la percepción de la alteración como más estable van a ejercer una influencia en esos aspectos, mostrando que las representaciones relacionadas con la prevención de la hipertensión requieren de una combinación de creencias que enfaticen la severidad y el impacto de la enfermedad pero también las posibilidades de hacerle frente y obtener resultados positivos.

Finalmente, nuestros hallazgos han mostrado también una influencia de variables sociodemográficas. Así la edad, el sexo y la experiencia familiar con la enfermedad parecen ejercer una influencia en estas variables comportamentales. En este sentido, las mujeres y los participantes más jóvenes se han mostrado más conscientes de los riesgos ligados a la hipertensión y de la prevención de la misma. Los más jóvenes consideraban un mayor número de riesgos ligados a la hipertensión, y tanto las mujeres como estos últimos perciben mayores posibilidades de prevenirla, aunque son las primeras las que más conductas preventivas introducen en su vida cotidiana. En cuanto al papel de la experiencia familiar, nuestros hallazgos han mostrado que los adultos españoles sanos que conviven o han convivido con un/a paciente hipertenso/a poseen también una mayor percepción de la enfermedad como un factor de riesgo para importantes problemas de salud. De nuevo, la experiencia indirecta con la enfermedad vuelve a mostrarse como un factor importante, en este caso relacionado con aspectos comportamentales de evitación de riesgos y prevención, y, de nuevo, estos participantes con experiencia familiar muestran representaciones más negativas acerca del riesgo asociado a la misma, tal y como habíamos hipotetizado.

Estos resultados, apoyan de forma clara el postulado del SRM que señala la existencia de una relación entre representaciones cognitivas y emocionales de enfermedad y conductas de afrontamiento, en este caso conductas preventivas. Al mismo tiempo, poseen un importante carácter aplicado, ya que ponen de manifiesto la necesidad de llevar a cabo intervenciones psicoeducativas, que teniendo en cuenta las representaciones acerca de la hipertensión y su influencia en las percepciones de riesgo y las posibilidades de prevención, pero sobre todo el papel que éstas juegan en la prevención real de la enfermedad por parte de la población general, maximicen la realización de cambios en el estilo de vida que favorezcan una prevención primaria y disminuyan la incidencia de la enfermedad.

El **estudio 5**, el último de los que componen esta Tesis Doctoral, tenía como objetivo principal explorar la posibilidad de agrupar a la población sana española en diferentes perfiles psicosociales multidimensionales de acuerdo con sus representaciones emocionales y cognitivas acerca de la hipertensión y de otras variables relevantes como la percepción de riesgos asociados a esta alteración o la eficacia percibida de los cambios en el estilo de vida para prevenir dicha enfermedad. En relación a este primer objetivo, en torno al cual se articula el quinto estudio, nuestros hallazgos han puesto de manifiesto que la población sana puede ser dividida de forma clara en tres perfiles o *clusters* de acuerdo con las variables anteriormente comentadas. Esta posibilidad de separar en perfiles globales las representaciones de enfermedad que permitan estudiar las creencias como un todo (i.e., esquemas de enfermedad) y no de forma aislada e independiente, ya había sido demostrada anteriormente con otras alteraciones utilizando el SRM (Charlier et al., 2012; Crawshaw, Rimington, Weinman y Chilcot, 2015; Dempster et al., 2010; Harrison, Kohlman y McCorry, 2014; Kaptein et al., 2010; Kohlman, Rimington y Weinman, 2012; Letelier, Nuñez y Rey, 2011; Lin y Hiedrich, 2012; Lowe et al., 2012; McCorry et al., 2013; Miglioretti, Mazzini, Oggioni, Testa y Monaco, 2008; Medley, Powell, Worthington, Chohan y Jones, 2010; Skinner et al., 2011; Snell, Surgenor, Hay-Smith, Williman y Siergert, 2015), así como con pacientes hipertensos (Figueiras et al., 2010; Hsiao et al., 2012), pero no se había explorado esa posibilidad con población sana en hipertensión, por lo que nuestro estudio resulta pionero en ese campo.

Con respecto a los perfiles identificados, dos de ellos incluyen a población sana con bajos niveles de conciencia y preocupación sobre los riesgos asociados a la hipertensión y con unas representaciones poco ajustadas y correctas, aunque en el segundo de ellos estos problemas en el ajuste de las representaciones y en las percepciones cognitivas y emocionales asociadas a los riesgos de padecer hipertensión adquieren tintes casi dramáticos. En general, los participantes incluidos en los perfiles de baja conciencia y preocupación (48.8% de la muestra) y muy baja conciencia y preocupación (5.4% de la muestra) perciben la hipertensión como escasamente sintomática, con poco impacto en la vida de los pacientes, muestran moderada confianza en las posibilidades de control por parte del enfermo y los tratamientos y exhiben un comprensión percibida de la enfermedad que va de moderada a baja. Con respecto a las causas, incluyen tanto aspectos comportamentales, como psicológicos e incontrolables, mostrando importantes dudas acerca de su etiología. Ante la posibilidad de padecer hipertensión no manifiestan sentimientos especialmente negativos y, aunque creen que puede provocar problemas serios de salud, muestran dudas sobre cuáles pueden ser esos riesgos. Además, manifiestan baja confianza en las posibilidades de prevenir la enfermedad a través de cambios en el estilo de vida. El perfil de muy baja conciencia y preocupación se diferenciaría básicamente del otro en la existencia de percepciones más bajas de controlabilidad por parte del paciente y de los tratamientos y menor percepción de riesgos asociados, así como en una comprensión más pobre de lo que la enfermedad significa y mayor atribución de la misma a factores psicosociales e incontrolables.

En el otro extremo se situaría el tercer perfil, que incluiría al 45.9% de los participantes y que mostrarían una elevada conciencia y preocupación sobre la hipertensión. Estos adultos sanos mantendrían creencias más ajustadas y correctas sobre este problema, sus riesgos asociados y la probabilidad de evitar su desarrollo a través de comportamientos de prevención. En general, consideran la enfermedad como sintomática, de larga duración, con un importante impacto para la vida de los pacientes, muestran elevada confianza en las posibilidades de control por parte del propio paciente hipertenso, sentimientos de preocupación, ansiedad, tristeza o miedo ante la posibilidad de padecerla y atribuyen su génesis a factores de tipo comportamental o psicosocial y, por tanto, controlables. Aunque poseen una percepción de la peligrosidad de la hipertensión más fuerte que los miembros de los otros dos perfiles, los participantes incluidos en este *cluster* se muestran al mismo tiempo más optimistas sobre la posibilidad de controlarla mediante cambios en su estilo de vida.

Este estudio 5 ha ido dirigido también a explorar la posible relación entre los perfiles globales de representaciones acerca de la hipertensión, los riesgos asociados a ella y las posibilidades percibidas de prevención a través de la introducción de cambios en el estilo de vida y una variable fundamental en el caso de esta enfermedad y la población sana, como es la práctica de conductas preventivas en la vida cotidiana de los participantes. Esta cuestión tampoco ha sido previamente estudiada en población sana, aunque en pacientes hipertensos dos estudios (Figueiras et al., 2010; Hsiao et al., 2010) han mostrado la posibilidad de establecer relaciones entre diferentes perfiles y variables conductuales como la elección de un determinado tipo de fármaco o la adherencia a los tratamientos farmacológicos. En este sentido, los hallazgos de este estudio han puesto de manifiesto que, tal y como hipotetizamos, de acuerdo con sus representaciones sobre la enfermedad, sus riesgos para la salud y la eficacia de los comportamientos preventivos, los participantes que formaban parte del perfil de alta conciencia y preocupación (*cluster* 3) mostraban una práctica de comportamientos preventivos elevada, con niveles 1/3 por encima de la desviación típica media, en comparación con los perfiles de baja y muy baja conciencia y preocupación (*clusters* 1 y 2, respectivamente), mostrando este último unos niveles que podrían considerarse casi dramáticos, casi 1 punto por debajo de la desviación típica media, en la modificación de sus hábitos de vida para prevenir la aparición de la hipertensión.

Es importante subrayar que los perfiles de baja y muy baja conciencia y preocupación representarían a más de la mitad de los participantes (54.2%), aunque afortunadamente el perfil de muy baja conciencia y preocupación sobre la hipertensión y sus riesgos solo abarcaría a un 5% de la población española sana. Estas cifras muestran de forma muy clara que una parte muy importante de las personas sanas mantienen creencias poco ajustadas y realistas sobre la hipertensión, sobre los riesgos que ésta implica y también sobre las posibilidades de prevención de la misma, y en consecuencia no introducen cambios en su propio estilo de vida destinados a prevenir la enfermedad, lo que podría suponer a todas luces un importante problema a la hora de reducir la incidencia y el impacto de este problema en nuestro país y requeriría de un importante esfuerzo por parte de las administraciones de salud encaminado a la modificación de dichas representaciones disfuncionales si se desea realmente que se produzca una adecuada prevención primaria.

Finalmente, el último objetivo del estudio 5 ha ido dirigido a explorar la existencia de diferencias en los diferentes perfiles identificados relacionadas con variables sociodemográficas como el sexo, la edad, el estatus socioeconómico así como de la experiencia familiar con la enfermedad. En este sentido, nuestros hallazgos han mostrado diferencias con respecto al sexo, en concreto una mayor presencia de hombres en el perfil 1, de baja conciencia y preocupación sobre la hipertensión, lo que podría indicar que la población sana masculina tiene percepciones menos ajustadas de la enfermedad y sus riesgos y una menor ejecución de comportamientos preventivos. Por otro lado, se han hallado también diferencias relacionadas con el estatus socioeconómico que, a grandes rasgos, irían en la línea de mostrar una menor conciencia y preocupación sobre la hipertensión y sus riesgos, así como menos confianza en las posibilidades de prevención de ésta, en personas sanas de estatus socioeconómico más bajo, y una mayor preocupación sobre la enfermedad y sus riesgos y representaciones más ajustadas y realistas en niveles medios de estatus socioeconómico.

Por último, una vez controlado el efecto de las variables sociodemográficas, los perfiles identificados han mostrado asimismo diferencias relacionadas con la experiencia familiar con la hipertensión. Específicamente, los resultados señalan que el perfil 2 (muy baja conciencia y preocupación) es aquel que incluye un menor número de participantes con experiencia familiar con la enfermedad, lo que podría indicar que la ausencia de experiencia en este caso ejerce un efecto inmunizador contra la hipertensión que lleva a percibir la enfermedad y sus riesgos como menos graves y preocupantes. Dicho de otra forma, parece que tener experiencia con la enfermedad ayuda a construir percepciones de ésta más positivas y realistas, aunque no necesariamente más ilusoriamente benignas.

Esta división de la población sana en diferentes perfiles psicosociales multidimensionales de representaciones cognitivas y emocionales, así como también de percepciones de riesgo y posibilidades de prevención, y la asociación demostrada entre esos esquemas globales y la puesta en marcha de conductas preventivas nos ofrece información muy valiosa de cara al desarrollo de intervenciones con población general que favorezcan la prevención primaria de la hipertensión. Nuestros hallazgos facilitan y maximizan las posibilidades de intervención al trabajar con esquemas globales y no con dimensiones y variables independientes, lo que supone un importante hallazgo dada la ausencia de estudios en esta dirección con población sana en esta alteración.

A la luz de los resultados obtenidos en los diferentes estudios que forman parte de esta Tesis Doctoral se podría decir que nuestras hipótesis de partida se verían apoyadas casi en su totalidad, aunque parcialmente en algunos casos. No obstante, de forma general se podría señalar que los postulados básicos del SRM se cumplen también en población sana y, por tanto, se puede afirmar de forma clara la aplicabilidad del modelo en población no paciente con todas las consecuencias tanto teóricas como prácticas que ello conllevaría.

12.2. Limitaciones y perspectivas futuras

Los estudios que conforman esta Tesis Doctoral presentan en conjunto algunas limitaciones que deben ser comentadas y resueltas de manera conveniente en el futuro.

Una de las principales limitaciones ha sido el reducido tamaño de las muestras utilizadas, haciendo necesario de cara al futuro confirmar los resultados encontrados con muestras de mayor tamaño, ya que el tamaño de la muestra en nuestros estudios podría de algún modo limitar la potencia estadística de los análisis realizados. Otra limitación, derivada de la anterior sería la posible falta de heterogeneidad y representatividad de la muestra, ya que no se llevó a cabo un proceso de selección previo de la misma y nuestros participantes fueron españoles adultos voluntarios pertenecientes a las provincias de Granada y Jaén, y el único aspecto que se consideró como criterio de exclusión fue el padecer o haber padecido en el pasado alguna de las alteraciones objeto de estudio. Además existe una sobrerrepresentación de población de adultos jóvenes, especialmente en algunos de los estudios. Por ello, en el futuro sería recomendable tanto incrementar el número de participantes como utilizar una muestra que sea representativa de la población general española.

En segundo lugar, y en relación aún con la muestra utilizada en estos estudios, es necesario destacar que todos los participantes eran de nacionalidad española y, dado que la literatura señala que los aspectos culturales podrían jugar un papel clave en la construcción de las representaciones cognitivas y emocionales sobre la enfermedad (Jonnalaggada et al., 2012; Norfazilah et al., 2013), esas posibles influencias deberían ser exploradas realizando en el futuro investigaciones con ciudadanos de otros países y culturas así como de otras razas o etnias que permitan generalizar los resultados obtenidos en nuestros estudios más allá de nuestras fronteras.

En tercer lugar, las medidas utilizadas en esta investigación son todas autoinformes, y aunque diferentes estudios realizados fundamentalmente con encuestas nacionales sobre aspectos de salud han puesto de manifiesto que este tipo de medidas son adecuadas (Lima-Costa, Peixoto y Firmo, 2004; Selem, Castro, Galvao, Lobo y Fisberg, 2013; Van Eenwyk, Bensley, Ossiander y Krueger, 2012) y el uso de medidas de autoinforme por parte de investigadores y especialistas en salud se está viendo incrementado en los últimos tiempos (e.g., Estoppey, Paccaud, Vollenweider y Marques-Vidal, 2011; Kaplan, Huguet y Feeney, 2010; Pereira et al., 2012; Pitsavos et al., 2006; Valderrama, Tong, Ayala y Keenan, 2008), sería adecuado poder contar con otro tipo de medidas objetivas como pruebas médicas e informes clínicos u observación conductual.

Por otro lado, los estudios que forman parte de esta Tesis Doctoral han sido realizados con población sana aunque con distinto grado de experiencia familiar con el cáncer y la hipertensión. Sin embargo, de cara al futuro sería recomendable desarrollar estudios que incluyan a enfermos en diferentes estadíos, variantes de la enfermedad (especialmente en cáncer) o aspectos clínicos así como a supervivientes para valorar sus representaciones cognitivas y emocionales y conocer cómo esas creencias cambian de acuerdo con la experiencia directa con la enfermedad y a lo largo del curso de la misma.

En quinto lugar, y en relación con lo anterior, en nuestros estudios no se ha tenido en cuenta el posible riesgo de desarrollar cáncer o hipertensión de los participantes ni su percepción sobre ese riesgo. Por ello, en el futuro sería deseable al estudiar las representaciones cognitivas y emocionales de enfermedad en población sana prestar especial atención al riesgo de padecer una determinada enfermedad relacionado con aspectos familiares, genéticos o comportamentales para comparar las representaciones de población sana pero en riesgo con la de población sana que no lo está.

En sexto lugar, otra posible limitación de nuestra investigación estaría relacionada con el hecho de que no se ha estudiado la fuente de la que proceden las representaciones sobre el cáncer y la hipertensión, ni tampoco ningún indicador objetivo de su grado de corrección y ajuste. En este sentido, sería recomendable que los estudios futuros sobre esta cuestión se desarrollasen también con profesionales de la salud y especialistas para comparar sus representaciones cognitivas y emocionales con las de la población sana, en riesgo y enferma.

Un aspecto muy importante, especialmente en el caso del cáncer es el apoyo social y familiar. En nuestros estudios, dado que se han llevado a cabo con población no enferma, no se han valorado las percepciones y creencias sobre la enfermedad de cuidadores directos para compararlas con las de los propios enfermos, y por ello en el futuro la investigación debería incluir a personas enfermas y sus cuidadores.

En séptimo lugar, la relación entre representaciones cognitivas y emocionales de enfermedad y aspectos comportamentales como el afrontamiento de riesgos y el desarrollo de conductas preventivas sólo ha sido explorada para el caso de la hipertensión pero no en el del cáncer, por lo que de cara al futuro la investigación debería explorar el papel de las representaciones sobre el cáncer en aspectos clave para la prevención como la percepción de las posibilidades de prevención, las intenciones para realizar cambios conductuales y adoptar comportamientos saludables, así como tratar de replicar nuestros resultados en hipertensión en población sana española superando las limitaciones en la muestra ya comentadas al inicio de este epígrafe.

Otra posible línea futura de investigación consistiría en establecer comparaciones, y analizar las diferencias y similitudes, entre las representaciones cognitivas y emocionales que tiene la población sana sobre dos enfermedades *a priori* tan dispares, pero a la vez con consecuencias tan graves, como son la hipertensión y el cáncer, en la línea de tener una comprensión y explicación más globalizadora de estas dos enfermedades y de entender un poco mejor cómo se produce el proceso de construcción de los modelos mentales de ambas y, por tanto, como consecuencia, del ajuste a las mismas.

Finalmente, existen otras limitaciones de carácter metodológico y de diseño. En primer lugar, el diseño transversal de esta investigación no permite establecer vías causales direccionales, incluso cuando algunas estrategias de análisis estadístico permiten explorar relaciones teóricas de causalidad. Un diseño longitudinal prospectivo correlacional o un diseño experimental con una intervención dirigida a modificar representaciones inadecuadas y a favorecer creencias más ajustadas sobre la enfermedad así como sobre los riesgos asociados y las posibilidades de prevención que incremente el desarrollo de comportamientos preventivos reales permitiría observar posibles cambios en las variables y sus relaciones a lo largo del tiempo, o entre los grupos del estudio que reciben dicha intervención frente a los que no la reciben y en comparación con los niveles de partida. Otra cuestión importante de cara a futuras investigaciones es la necesidad de explorar la presencia de relaciones indirectas (i.e., efectos de mediación y moderación) entre las variables que se han revelado como relevantes en la investigación de las representaciones cognitivas y emocionales sobre la enfermedad en general y en los estudios que conforman esta Tesis Doctoral en particular.

La investigación futura debe, además de corregir las deficiencias comentadas, diseñar e implementar intervenciones que vayan dirigidas a construir representaciones tanto cognitivas como emocionales del cáncer y la hipertensión adecuadas, ajustadas y realistas, así como representaciones correctas del riesgo y la prevención y que enfaticen la puesta en práctica de manera real en la vida cotidiana de cambios conductuales, así como explorar la eficacia de dichas intervenciones, siendo necesario seguir investigando, con los instrumentos adecuados, los múltiples beneficios derivados de la aplicación de un programa de intervención dirigido a la población sana que tenga en cuenta todas las dimensiones que nuestros estudios han revelado como relevantes.

Adicionalmente, es necesario seguir investigando los principales aspectos psicosociales que determinan el afrontamiento de la enfermedad en personas que aún no la padecen, especialmente los factores que influyen en la puesta en marcha de modificaciones reales en el estilo de vida dirigidas a prevenir el desarrollo de una determinada alteración. Ese aspecto se perfila como nuclear de cara a reducir el impacto de enfermedades tan importantes como son el cáncer y la hipertensión, ya que sólo conociendo esos factores, sus relaciones y el modo en que determinan los esfuerzos de la población sana para protegerse contra una determinada enfermedad podremos diseñar protocolos que ayuden a estas personas a iniciar y mantener cambios en su conducta que permitan afrontar las posibles amenazas para su salud, favoreciendo en última instancia su bienestar y calidad de vida.

A pesar de las limitaciones de nuestra investigación, nuestros resultados pueden considerarse interesantes y novedosos, algunos de ellos incluso pioneros, y resaltan la importancia y aplicabilidad del Modelo de Autorregulación y sus postulados básicos en población sana.

CAPÍTULO 13

Conclusiones generales

De acuerdo con los objetivos tanto de carácter general como específicos de cada uno de los estudios que conforman esta Tesis Doctoral, y a la vista de los resultados obtenidos, podemos extraer las siguientes conclusiones generales.

En primer lugar, y si centramos nuestra atención en los estudios 1, 3 y 4, el primero de ellos realizado con cáncer y los otros con hipertensión, parece claro que los postulados del SRM que establecen que a) construimos representaciones de la enfermedad, las cuales recogen una amplia variedad de características percibidas de ésta, para dotar a dicha condición de un sentido completo y con significado para nosotros, y que b) dichas representaciones incluyen una combinación de aspectos tanto ajustados y objetivos cercanos al conocimiento biomédico así como otros populares y culturales y, por tanto, más alejados de ese conocimiento, quedan avalados por los hallazgos de estos estudios. Para el caso de ambas enfermedades se cumplen ambos postulados y los estudios referidos muestran cómo la población sana posee en general creencias que son apropiadas y correctas sobre estas enfermedades, sus características, evolución, impacto y posibilidades de control y curación así como de los aspectos emocionales ligados a las mismas, pero también otras percepciones que son erróneas, fruto de ideas que perviven en nuestra cultura y nuestra sociedad, confusiones entre causas y consecuencias o errores ligados a una mala interpretación o comprensión de lo que cada enfermedad significa.

Esta información sobre cómo la población sana percibe dos enfermedades muy comunes y con importantes consecuencias para la salud y el bienestar, de manera previa el desarrollo de las mismas, tiene una gran utilidad de carácter aplicado para el desarrollo de estrategias de intervención dirigidas a la educación de los no pacientes que tengan en consideración en qué dimensiones existen representaciones más y menos ajustadas y correctas, de cara a lograr que los esquemas de enfermedad, que engloban creencias cognitivas y representaciones emocionales, sean lo más ajustados posible al conocimiento biomédico objetivo.

En segundo lugar, los hallazgos de estos tres estudios han puesto de manifiesto que la influencia de variables de carácter sociodemográfico es limitada, y sólo en casos muy puntuales y específicos la edad, el sexo o el nivel educativo conducen a cambios en las representaciones cognitivas o emocionales. Sin embargo, el estudio 4 ha mostrado que si consideramos el estatus socioeconómico, entendido como una combinación de nivel de ingresos, nivel educativo y posición laboral, en lugar de valorar estas variables de forma separada, la influencia sobre las representaciones acerca de la hipertensión parece ser más evidente.

De acuerdo con los resultados de nuestros estudios, la variable que incide de manera más importante en las representaciones cognitivas y emocionales sobre el cáncer y la hipertensión es la experiencia con la enfermedad, derivada del hecho de convivir o haber convivido con una persona que padece o ha padecido alguna de estas alteraciones (i.e., experiencia familiar). Esta influencia clara de la experiencia indirecta con una enfermedad, en este caso ejemplificada en el cáncer y la hipertensión, vendría a apoyar otra de las propuestas del SRM demostrada en una amplia variedad de estudios con distintas enfermedades y poblaciones.

En este sentido, de cara tanto a cuestiones de investigación como de intervención (e.g., prevención) con población general, pero muy especialmente en este segundo caso, sería recomendable considerar a la población sana con experiencia familiar con una alteración concreta como un subgrupo específico y diferenciado dentro la población sana. No obstante, nuestros hallazgos también señalan una influencia diferente de la experiencia con la enfermedad para enfermedades como la hipertensión y el cáncer. Mientras que en la segunda haber convivido con una persona enferma se asocia a crear representaciones cognitivas más severas o graves del cáncer y a experimentar reacciones emocionales más negativas, en el caso de la hipertensión sucede al contrario, y ayuda a crear percepciones más positivas y probablemente más ajustadas o realistas de la enfermedad, y no peligrosamente benignas (i.e., conciencia de la gravedad y preocupación por el riesgo, asociado a mayor inversión conductual preventiva). Por ello, las intervenciones con ambos grupos de personas deben tener en cuenta este efecto diferencial. La razón por la que esto sucede (por ejemplo, si la experiencia familiar se asocia en un caso a construir percepciones más dramáticas del cáncer en términos de bienestar y funcionamiento personal y familiar, mientras que en el otro ayuda a percibir como más manejable personalmente el impacto de la hipertensión sobre la salud y el riesgo de futuras complicaciones) es algo que la investigación futura debe explorar para ser considerado en el diseño de intervenciones aplicadas.

Por otro lado, los resultados del estudio 2 de esta Tesis Doctoral han puesto de manifiesto de forma indiscutible, por un lado, el importante impacto emocional que el cáncer provoca en la población sana y, por otro, la interrelación entre las diferentes dimensiones del SRM, postulada por el modelo, y específicamente el valor predictivo de las dimensiones de carácter cognitivo, en nuestro caso identidad, duración, consecuencias y causas, sobre el malestar emocional o representaciones emocionales de la enfermedad.

En este sentido, teniendo en cuenta el primero de los hallazgos, en población sana la posibilidad de sufrir cáncer genera un importante impacto emocional relacionado con sentimientos de ansiedad, preocupación, miedo y tristeza. Esta reacción emocional además se va a ver determinada por las representaciones cognitivas que las personas sanas construyen sobre el cáncer, siendo éstas el principal elemento de influencia en el malestar emocional. Pero además, la experiencia familiar con la enfermedad parece tener un papel moderador en esa interdependencia entre aspectos cognitivos y emocionales en cáncer.

Estos hallazgos poseen importantes implicaciones relacionadas, entre otros aspectos, con las posibilidades de prevención de la enfermedad. En este sentido, de acuerdo con los resultados de las investigaciones al respecto, parece claro que los aspectos emocionales ejercen un importante papel en la evitación de riesgos y el desarrollo de conductas de protección y prevención de la enfermedad. De acuerdo con nuestros resultados, las intervenciones en prevención primaria del cáncer deberían incluir no sólo aspectos emocionales de carácter persuasivo que generen un impacto en la población sana, sino que deberían incidir también en los aspectos cognitivos que predicen ese malestar emocional, es decir en la severidad percibida del cáncer debido a su sintomatología, las consecuencias y el impacto que la enfermedad puede tener para pacientes y familiares, o la duración percibida del proceso de enfermedad. Lógicamente, las intervenciones no pueden centrarse únicamente en generar malestar emocional, no podemos quedarnos únicamente en un mensaje de miedo, sino que deben complementarse con aspectos formativos y que enfaticen la importancia y el modo de prevenir el cáncer y los beneficios del cambio de conducta hacia hábitos de vida más saludables, así como la necesidad de llevar a cabo revisiones periódicas y exámenes médicos, generando también esperanza. En definitiva, las reacciones emocionales podrían ser un buen punto de partida para promover actitudes y motivaciones más proclives hacia la prevención.

La importancia de introducir cambios en el estilo de vida por parte de la población sana para prevenir la aparición de enfermedades, en concreto la hipertensión, con todos los riesgos que esta enfermedad conlleva para la salud parece estar fuera de toda duda, y en este sentido los resultados del estudio 3 de esta Tesis doctoral han puesto de manifiesto la relación entre representaciones cognitivas y emocionales sobre la hipertensión, percepciones del riesgo asociado a la enfermedad y la eficacia de los comportamientos preventivos y la práctica de conductas de prevención destinadas a evitar la aparición de la hipertensión. Esta relación entre representaciones cognitivas y emocionales sobre una enfermedad y variables conductuales, como las conductas de afrontamiento y prevención, constituye uno de los postulados nucleares del SRM y también se ha visto avalado por los resultados de este estudio.

En este sentido, nuestros hallazgos han mostrado que existe una influencia clara de las creencias acerca de la hipertensión en la percepción de los riesgos para la salud asociados a una elevada presión arterial, en la confianza en la eficacia de los comportamientos de prevención y en la puesta en marcha de dichas conductas en la vida cotidiana de las personas sanas. Si se tiene en cuenta esa influencia y el sentido de la misma, consideramos que actuando sobre esas representaciones podremos lograr modificar en parte esas variables que van a incidir de forma clara en el afrontamiento de los riesgos y que van a determinar finalmente el bienestar y calidad de vida de la población sana.

Los resultados de este estudio han mostrado también que las variables sociodemográficas van a ejercer algún tipo de influencia en las percepciones de riesgos y en la percepción y práctica de conductas preventivas, pero que la experiencia familiar con la enfermedad emerge como un aspecto a tener en cuenta.

Un aspecto muy revelador puesto de manifiesto en este estudio es que, a pesar de que la población sana es totalmente consciente de los importantes riesgos que para la salud supone padecer hipertensión así como del modo en que la enfermedad se puede prevenir y el alto grado de eficacia de esos comportamientos de prevención, esas creencias no se traducen en conductas específicas en su estilo de vida para evitar desarrollar este “asesino silente”. Este descorazonador hallazgo debe considerarse un elemento clave y constituir el punto de partida para desarrollar actuaciones de prevención primaria que no sólo enfaticen los riesgos de una elevada presión arterial y ofrezcan modos de evitarlos, sino que además pongan el énfasis en la necesidad de modificar el estilo de vida, la facilidad de esos cambios, la forma de hacerlo y los enormes beneficios que supondrán para nuestra salud.

Además, y dado el conocimiento que se deriva de este estudio sobre la influencia de las representaciones cognitivas y emocionales que la población sana posee sobre la hipertensión en las conductas de prevención de la enfermedad, sería adecuado considerar esas representaciones también como objeto de intervención, de modo que la modificación de las mismas en el sentido indicado contribuya a actitudes y motivaciones más positivas hacia una introducción real de cambios conductuales.

Finalmente, los resultados del último de los estudios que constituyen esta Tesis Doctoral han puesto de manifiesto la posibilidad de considerar las representaciones cognitivas y emocionales sobre la enfermedad de manera global, es decir formando esquemas que incluyen representaciones emocionales y cognitivas específicas y diferenciales, en lugar de dimensiones aisladas e independientes. Éste es otro postulado básico del SRM apoyado por nuestros resultados.

Además, al considerar perfiles psicosociales multidimensionales en este estudio, se ha demostrado que dichos esquemas además van a mostrar características propias y distintas a las del resto de perfiles con respecto a otras importantes cuestiones como las percepciones de riesgos, la confianza en las posibilidades de prevención a través de cambios en el estilo de vida y la práctica de esas conductas de prevención primaria en la vida diaria.

En este sentido, se han encontrado tres perfiles diferentes, dos de los cuales muestran unos niveles bajos o muy bajos de conciencia y preocupación sobre la hipertensión y sus riesgos, y sólo en otro de ellos la población sana es realmente consciente de los riesgos asociados a la enfermedad y muestra una preocupación real por la posibilidad de padecerla. La pertenencia a uno u otro de los perfiles no sólo se relaciona con aspectos cognitivos o representacionales, sino que se va a traducir también en cuestiones comportamentales como son la introducción de cambios reales en las conductas de la vida cotidiana para prevenir la enfermedad.

Nuevamente nos encontramos con que las representaciones emocionales y cognitivas, en este caso consideradas de manera conjunta e interrelacionada, van a determinar aspectos claves para la prevención de la hipertensión, lo que no sólo apoya los postulados nucleares del SRM sino que es de gran utilidad a la hora de intervenir en este ámbito. Una cuestión que no puede ser pasada por alto es la del importantísimo porcentaje de la población sana, más de la mitad de acuerdo con nuestros resultados, que se vería incluido en un perfil de representaciones cognitivas y emocionales y percepciones de riesgo y prevención de baja o muy baja conciencia y preocupación, lo que lleva inevitablemente a una escasa predisposición a la prevención de la hipertensión.

De nuevo, la experiencia con la enfermedad se revela como una variable que debe ser tenida en cuenta, ya que nuestros resultados señalan que la población sana que no convive o ha convivido con un/a hipertenso/a se incluye en mayor medida en el perfil más peligroso que posee unas representaciones cognitivas y emocionales y de riesgos que los conducen a valorar de manera menos acertada las posibilidades de prevenir la enfermedad e introducir cambios en sus conductas cotidianas en ese sentido.

Todo estos hallazgos poseen importantes implicaciones prácticas de cara a la intervención en prevención primaria, ya que conocer, por un lado, que las representaciones sobre la hipertensión y otras variables fundamentales para la prevención como la percepción de riesgos y la confianza en las posibilidades preventivas se agrupan formando perfiles globales o esquemas, y que además esos perfiles también se relacionan con las conductas reales de afrontamiento, debe facilitar el desarrollo de actuaciones tendentes a crear esquemas globales más positivos en la línea del *cluster* de alta conciencia y preocupación por la enfermedad. Por otro lado, el preocupante porcentaje de la población sana que no es consciente de lo que esta enfermedad implica y, en consonancia, no llevan a cabo ningún tipo de actuación dirigida a evitar su aparición debe apremiarnos a trabajar en el desarrollo de intervenciones y estrategias que, teniendo en cuenta el papel de la experiencia familiar, actúen sobre las representaciones cognitivas y emocionales y permitan a la población sana generar niveles adecuados de conciencia y preocupación, pero también de confianza en las posibilidades de prevención, que se traduzcan en cambios reales en sus vidas.

De forma general, si revisamos los hallazgos de los diferentes estudios que conforman esta Tesis Doctoral, podemos afirmar que los postulados básicos del SRM que han sido explorados en población sana se cumplen, mostrando, por tanto, las posibilidades de aplicación de este modelo teórico en personas que no padecen ni han padecido una determinada enfermedad y la utilidad y valor del mismo en esta población. Por otro lado, es importante destacar que en población sana la experiencia con la enfermedad derivada de convivir o haber convivido con alguien enfermo es un factor de especial relevancia en la configuración de las representaciones emocionales y cognitivas de la enfermedad que debe ser considerado en la investigación al respecto o a nivel aplicado. Finalmente, también queda demostrado de forma clara el importante carácter aplicado del SRM en población general sana y las posibilidades que este modelo ofrece para una adecuada intervención en prevención primaria, favoreciendo la eficacia de los programas preventivos dirigidos a la reducción del impacto que enfermedades tan graves como el cáncer o la hipertensión pueden provocar a nivel mundial. En este sentido, no podemos olvidarnos de la importancia y el valor de las actuaciones preventivas en términos de costes sanitarios futuros y de que ese valor se ve multiplicado si tenemos en cuenta los costes personales, familiares y sociales.

De acuerdo con todo ello, la relevancia que las representaciones cognitivas y emocionales acerca del cáncer y la hipertensión poseen en relación a las posibilidades de prevención de estas epidemias mundiales subraya también el papel de las actuaciones psicológicas y de los psicólogos como agentes de prevención de la morbi-mortalidad, incidiendo en definitiva en la salud, calidad de vida y cantidad de vida sana de los ciudadanos.

En definitiva, nuestros hallazgos confirman, con una población que había sido relegada a un segundo plano en los estudios sobre representaciones cognitivas y emocionales de enfermedad desarrollados con el SRM como marco conceptual, que este modelo es aplicable y posee gran utilidad también en población sana, de modo que las representaciones emocionales y cognitivas que esta población construye sobre la enfermedad van a determinar su afrontamiento de los riesgos y su puesta en marcha de conductas de protección y prevención, incidiendo así en su salud, bienestar y calidad de vida.

PARTE V:
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