Title:

Actions Taken and Barriers Encountered by Professionals Working with Adults with Intellectual Disabilities who Experience Grief: A Qualitative Approach.

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Abstract

Experience of grief has increased among people with intellectual disability (ID) as a result of their longer life expectancy. Professionals supporting this population are often critical of the lack of adequate tools for dealing with this situation. The objective of this study was to identify the strategies and barriers that these professionals are confronted with when dealing people with ID who are going through the grieving process. A qualitative study was conducted involving 20 professionals working with people with ID. Four themes were extracted using thematic analysis: “Exclusion of clients from end-of-life and grief processes”, “Strategies to support the client’s grief process”, “Emotional and personal difficulties faced by the professionals”, and “Coping and regulation of the professional’s grief process”. Barriers identified by these professionals include not having the specific skills to support clients in their grief and the emotional impact of the death of a client.

Keywords: intellectual disability; grief; loss; bereavement; healthcare professionals; focus groups.

Introduction

Intellectual disability (ID) or Intellectual Developmental Disorder (IDD) is a neurodevelopmental disorder characterized by limitations in intellectual functioning and adaptive behavior that manifest as impairments in conceptual, social, and practical skills (American Psychiatric Association, 2022). The estimated worldwide prevalence of ID ranges from 0.05 to 1.55% (McKenzie et al., 2016), with more than 250,000 people in Spain having this diagnosis (Institute for Older Persons and Social Services, 2018).

Life expectancy for those diagnosed with ID has, in line with the general population, increased in recent decades (Coppus, 2013), and experiences of loss and grief are more likely as people with ID live longer (Blackman, 2013; Cristóbal et al., 2017). The emotional impact of grief in this population includes responses of sadness, worry, discomfort, loneliness, anger, anxiety, irritability, lethargy, and/or hyperactivity, among others (Brickell & Munir, 2008; McRitchie et al., 2014). In addition, there are specific characteristics of people diagnosed with ID, such as communication problems, difficulties in understanding the concept of death, and a strong attachment to caregivers, which can hinder preparation for grief and limit their adaptive coping capacity (Blackman, 2008; Brickell & Munir, 2008). Failure to adapt to a bereavement can lead to prolonged grief disorder (PGD), defined by a persistent longing for the deceased, excessive rumination, and difficulties in coming to terms with and telling others about the death. This is accompanied by intense emotional reactions, including sadness, guilt, anger, and even suicidal thoughts (Komischke-Konnerup et al., 2021).

It is important for professionals supporting people with ID to recognize feelings of grief in clients and to consider their coping strategies. However, the identification of grief indicators has been described as challenging and there is a lack of strategies and action protocols to support people with ID who are experiencing bereavement (McEvoy

et al., 2010; Morgan & McEvoy, 2014). People with ID have been found to be in need of greater emotional support and help from professionals following bereavements than those without ID (McRitchie et al., 2014). Furthermore, families often exclude or limit the involvement of people with ID in end-of-life processes, making it difficult for professionals to speak openly with their clients (Blackman, 2008; Handley & Hutchinson, 2013; McEvoy et al., 2010; McRitchie et al., 2014). It should be noted that both families and clients diagnosed with ID may also develop resilient responses to the reception of the diagnosis, as well as strategies for coping with the various environmental, individual, and family stressors (Grant et al., 2007).

Managing the emotions and feelings of professionals as they accompany people with ID in their grief is a further challenge. Emotional responses include pain, sadness, helplessness, concern for how the loss will affect the client's future, and stress caused by a lack of resources (Findlay et al., 2015; Morgan & McEvoy, 2014). Various studies have shown that providing support for clients in their grief can reactivate professionals' own experiences of bereavement (Handley & Hutchinson, 2013; Lord et al., 2017; McEvoy et al., 2010; Morgan & McEvoy, 2014). Research has also been carried out into the feelings of grief and loss experienced by professionals when faced with the loss of a client (Jonas-Simpson et al., 2013; Ravaldi et al., 2018).

A recent meta-synthesis identified only 11 qualitative studies reporting on the experiences of staff supporting adults with ID (Lord et al., 2017). Three main themes were identified: (1) difficulties in talking about death and bereavement due to uncertainty, (2) staff motivation to help and support clients to have a good death, and (3) the grieving process and the positive experiences of staff members (Lord et al., 2017). However, more research is needed in order to explore in greater depth the strategies used by professionals

supporting people with ID in this situation and to manage the different emotional responses that are generated.

The aim of this study was to identify the strategies and barriers that professionals working in centers for people with ID face when they have to support a client through the grieving process. The research questions were: *What strategies do professionals use to support people diagnosed with ID who are experiencing grief* and *what barriers do they face when intervening in this type of situation?*

Method

Design

A qualitative study was conducted using focus groups. The data were analyzed using thematic analysis as proposed by Braun and Clarke (2008). The focus groups were designed to capture the experiences of professionals working with people diagnosed with ID (Kroll et al., 2007).

Participants

Convenience sampling was used to recruit professionals supporting adults receiving care in an association for people with ID in the province of Granada, Spain. The association is a single organization providing (a) day-care services for people with ID and their families who need specialized support and (b) residential care for clients who have difficulties remaining in their own home. The study inclusion criteria for participants were: a) professionals working in the center for >1 year, b) working directly with clients diagnosed with ID according to DSM-5 TR criteria (American Psychiatric Association, 2022), and c) having ≥3 days/week direct contact with the center's clients.

Of the 36 professionals working at the center, 20 met the inclusion criteria and were assigned to one of four focus groups (n=5 in each group) by simple randomization to avoid selection bias. The final sample included 20 workers from different categories

representing the professional profile of those working in the center: one social worker (5%), three occupational therapists (15%), three psychologists (15%), and 13 caregivers or monitors (65%). Half of these professionals worked in the day center and half in the residential center, 70% were female, and the mean age was 40.55 years (SD= 9.32), ranging between 28 and 62 years. All participants worked with adults (aged 18-66) diagnosed with ID of varying severity (60% of adults had a moderate degree of disability, 30% mild, and 10% severe). The number of years' experience of these professionals in the field of ID ranged from 2 to 35 years, with a mean of 13.30 years (SD=8.99).

Instruments

A semi-structured script was prepared with open-ended questions based on the literature (Fernández-Alcántara et al., 2020; Jonas-Simpson et al., 2013; Lord et al., 2017; MacDermott & Keenan, 2014; McEvoy et al., 2010; Ravaldi et al., 2018) exploring professional's work or dealings with clients before and after the death of a loved one (Who informs the client about the illness and death of their loved one? How are you involved in the process? What do you focus on after the death of a client's loved one? What types of interventions do you make?), looked at how families behave (What do families usually do in these situations?), the barriers faced (What problems have you encountered in these situations? How did you solve them?), and their work and emotional experiences when a client from the center dies (Have you ever experienced the death of a client with whom you had worked for a long time or had ongoing contact? How did this loss affect you emotionally? How did it make you feel? How did you act/what did you do?).

Procedure

The study was approved by the Human Research Ethics Committee of the University of Granada (Ref: 445/CEIH/ 2017). First of all, three of the researchers (M.I.F.A., M.N.P.M., and F.C.Q.) held a meeting with professionals at the center to present the study and explain its objectives. The professionals who took part did so voluntarily and signed their written informed consent (both to participate in the study and for the group to be recorded) having been given a document describing the study. Participation was not remunerated in any way. Data confidentiality was ensured from the outset, with names replaced by alphanumeric codes.

Data were collected using focus groups moderated by the first author (M.I.F.A.), who has a Ph.D. in clinical psychology and is trained in qualitative techniques and analysis, and who had no previous relationship or contact with the association or participants. The focus group sessions took place between July and November 2019, with a duration of 90-120 minutes per session. During the focus groups the moderator invited all participants to share their experiences in the different areas assessed. The sessions were digitally recorded and later transcribed in Spanish by two researchers (M.I.F.A. and M.F.A.). After analysis, the selected quotations were translated into English through a process of reverse-translation by a native speaking expert who was supervised by the researchers to ensure that the original meaning was retained in English.

Data Analysis

Thematic analysis was conducted as proposed by Braun and Clarke (2008). This analytical approach was used because it made it possible to identify the different interventions, strategies and barriers faced by professionals (Braun & Clarke, 2021). In the first phase, three researchers (M.I.F.A., M.N.P.M., and M.F.A.) read the transcripts of each focus group in depth and familiarized themselves with their content. In the

second phase, these same researchers began line-by-line coding using an inductive approximation, which involved a data-led approach in which the participants' discourse was central to determining the codification (Howitt, 2013). The most relevant fragments and verbatim quotes were selected to construct the initial codes. In the third phase, codes showing similarities were grouped together into themes, which were then refined. In the fourth phase, the research team conducted a review of the codes and themes, recoding or creating new codes where appropriate. A triangulation process was used to compare and contrast the researchers' findings (Archibald, 2016) and the codes were then reviewed, analyzed, and approved by consensus between the three experts (M.I.F.A., M.N.P.M., and M.F.A.) following qualitative analysis to ensure rigor and reliability. In the final phase, the definitive themes and codes were identified and theoretical saturation was achieved (see Table 1). Atlas.ti software version 7.5.4 was used to organize, analyze, and interpret the qualitative data. As stated in the procedure section, the selected verbatim quotes were translated into English, followed by a back-translation process supervised by researchers to ensure the fidelity of the English version.

Results

Four main themes were extracted (see Table 1): 1) Exclusion of clients from end-of-life and grief processes, 2) Strategies to support the client's grief process, 3) Emotional and personal difficulties faced by the professionals, and 4) Coping and regulation of the professional's grief process.

----------Insert Table 1 here----------

Theme 1: Exclusion of clients from end-of-life and grief processes.

The professionals generally do not receive information from the family about the existence of an end-of-life situation, such as the diagnosis of a terminal illness. It is

usually the client with ID who mentions a sick relative or a loved one. In exceptional cases, the center is informed by the family or a coworker. In all cases, the professionals reported that clients are aware of changes in their family environment (see Table 2). The most common actions taken by family members in this situation were: a) to break the news; or b) to avoid breaking the news, thereby preventing the active involvement of the person with ID. Although some families tell people with ID that their loved ones are sick or dying, those with ID are frequently excluded from participating in family rituals of farewell. Many receive no information from their families at any point in the disease process, often on the assumption that they will not understand what is happening and/or will suffer less if they are kept in the dark. Professionals describe this situation as an injustice that leaves them with feelings of impotence and anger. In most of the cases analyzed, the families ask professionals who have closer affective ties to clients to tell them about their terminally ill loved ones (see Table 2).

----------Insert Table 2 here----------

Theme 2: Strategies to support the client´s grief process

Most professionals do not specifically analyze symptoms of grief. Instead they infer clients' feelings from overall observations of their behavior (see Table 3). The professionals focused on engaging clients in play and dynamic activities to distract them from their loss. They also stressed the importance of listening and providing emotional support through physical contact and displays of affection. Another key consideration was to allow clients to make decisions about what they wanted to do in the days following the death of a loved one. All the professionals tried to involve clients in death-related rituals, accompanying them to wakes, funerals, and/or religious ceremonies. However, this was only possible if they had family authorization or were themselves the legal guardian. Finally, professionals stated that it was important to

provide families with emotional support, guidance, and recommendations to help their family members with ID to cope with the grieving process.

----------Insert Table 3 here----------

Theme 3: Emotional and personal difficulties faced by the professionals

Nearly all the professionals had received information about illness and bereavement intervention. However, they indicated that were unsure how to apply this knowledge with clients with ID when they were going through a process of loss and grief. They highlighted the absence of clear guidance at their organization on the steps to follow in this type of situation, which made them feel insecure about their performance (see Table 4). The professionals reported a lack of skills and specific tools for breaking the news of the death of a loved one to clients. They also described the level of disability as an important factor, meaning that the approach must be tailored to the individual characteristics of each client. Half of the professionals acknowledged that their clients' grief experiences can reactivate their own memories of bereavement. Furthermore, a large majority of the professionals reported feeling very uncomfortable in this situation due to the sadness it brings and because they are unsure if they are responding well to the client's needs. All of the professionals expressed concerns about what happens next for clients in the aftermath of a bereavement. Most clients at the day center were described as unable to live independently and in need of a caregiver at home. The death of a client's main caregiver is particularly distressing for professionals, as it raises questions about where and how the client will live. A further difficulty identified by professionals was preparing for and acknowledging their own grief following the death of a client. The most common emotions generated by the loss of a client are sadness, anger, pain, and emotional exhaustion, which have a negative impact

on their work performance. The professionals described the difficulty of expressing their emotions openly in this situation, often preferring to hide their feelings to protect clients and avoid any negative impact on their work. Most of the professionals find it difficult to switch off and forget the deceased client, and some reported sleeping problems and increased conflict with their own loved ones at such times.

----------Insert Table 4 here----------

Theme 4: Coping and regulation of the professional's grief process

Finally, the professionals described a wide variability in the coping strategies (both loss- and restoration-oriented) used in the face of a client's death including: avoidance and distraction, which involved escaping from their feelings of sadness and pain and seeking refuge in their work routine to concentrate on other activities; expressing pent-up emotions through emotional release; engaging in enjoyable self-care and leisure activities; or seeking social support by talking about the experience with someone close in order to feel heard and comforted (see Table 5).

----------Insert Table 5 here----------

Discussion

This objective of the study was to identify the strategies and barriers that professionals working in centers for people with ID face when they have to support a client through the grieving process. The main barriers identified by professionals were a conspiracy of silence on the part of families, the lack of specific training and skills in loss and grief work with clients, and the emotional impact of clients' deaths. The most common strategies adopted in this situation include efforts to support clients' participation in farewell rituals, the provision of ongoing emotional support, and the active involvement of clients in daily routines.

We would highlight the large number of professionals who felt that it was difficult for people with ID to find out about the death or illness of loved ones and to actively participate in this process. The frequent avoidance of sharing bad news about the ill-health or death of family members with people with ID has been previously reported (Cristóbal et al., 2017), although they usually do become aware of the circumstances in which they are living (Handley & Hutchinson, 2013; McEvoy et al., 2010; McRitchie et al., 2014; Morgan & McEvoy, 2014). Lack of communication and involvement can have a negative impact on preparation for the grief process, not only for clients but also for professionals, who may feel anxious and frustrated about their inability to provide adequate care and emotional support (Manjón-Tortolero, 2018). Families often hide this type of news from people with ID or play down the severity of the situation to prevent their suffering (Blackman, 2008; Handley & Hutchinson, 2013; McEvoy et al., 2010; McRitchie et al., 2014). However, recent research suggests that adults with a diagnosis of ID can benefit from talking about death and end-of-life issues without experiencing emotional discomfort or distress (Stancliffe et al., 2021). Furthermore, their exclusion from farewell rituals denies them the social opportunity to share their emotions and may hinder their ability to come to terms with the reality of the loss and their preparation for grief, in line with previous research (Cristóbal et al., 2017; Morgan & McEvoy, 2014).

Professionals are aware of the different emotional and behavioral responses of the grieving client, especially in the days following the loss. However, they do not assess risk factors or the intensity of PGD, and there are no validated assessment instruments available in Spanish (Fernández-Ávalos et al., 2017). Previous research has found that healthcare professionals have difficulty implementing more dynamic grief

models, have received more training in stage-based models, and lack knowledge about the main factors associated with PGD (Dodd et al., 2020).

One of the grief models supported by a large body of scientific evidence that may help professionals to guide their interventions with people diagnosed with ID (Sheehan & Guerin, 2018) is the Dual Process Model of Coping with Bereavement (DPM: Stroebe & Schut, 2010). These authors identified two main approaches to coping with the loss of a loved one (loss-oriented and restoration-oriented) and suggested that oscillation between the two types of coping was an important predictor of grief resolution (Stroebe & Schut, 2010). Following this model's rationale, and in line with previous reports, we can see that the professionals in this study described a loss-oriented approach (Stroebe & Schut, 2010) as essential to support clients and encourage the expression of their emotions, especially in the immediate aftermath of bereavement (Handley & Hutchinson, 2013). The importance of actively participating in farewell rituals, always with the client's consent, was also mentioned, something which they considered to be highly beneficial for people with ID (McEvoy et al., 2010; McRitchie et al., 2014; Morgan & McEvoy, 2014). Professionals also provided numerous examples of the restoration-oriented approach (Stroebe & Schut, 2010), designing activities to distract the client and focusing on maintaining routines. Avoidance and distraction strategies, as well as rest periods, were recommended to avoid excessive death-related rumination (Eisma et al., 2014). Finally, in line with previous studies, professionals stressed the need to maintain ongoing communication with families throughout this process, offering support and advice to people with ID and their caregivers (Handley & Hutchinson, 2013; Watters et al., 2011).

Professionals identified the lack of specific training and action protocols as one of the main barriers, highlighting the difficulty of adapting general guidelines to people

with cognitive impairment, in line with previous studies (McEvoy et al., 2010; Morgan & McEvoy, 2014; Wiese et al., 2012). The most widely used recommendations relate to three types of intervention: a) preventive psychoeducational approaches in order to normalize death (Rodríguez-Herrero et al., 2013); b) group therapies to facilitate the expression of feelings with peers (Cristóbal et al., 2017); and c) individual therapies to support clients who have more difficulty with their grief process (Cristóbal et al., 2017). Tools to encourage emotional expression have been developed to compensate for communication limitations, such as the "memory box", which has been reported to help even people with severe ID to express their feelings (Young & Garrard, 2015).

The professionals spoke of reactivating feelings related to their own past bereavements (Handley & Hutchinson, 2013; Lord et al., 2017; McEvoy et al., 2010; Morgan & McEvoy, 2014), lending support to the need for tools to help them cope with loss-related emotions (Oñate & Calvete, 2017). They also expressed concern and anxiety about the future of bereaved clients, especially when the death is accompanied by changes in their economic or personal circumstances, among others, which could have a direct impact on their mental health (Brickell & Munir, 2008). These secondary losses should be taken into account. They are an additional source of emotional stress and pain for clients and should be addressed as part of a recovery-oriented approach to coping (Stroebe & Schut, 2010). For instance, clients may be advised of available sources of economic support or possible employment opportunities, where appropriate (Brickell & Munir, 2008; Cristóbal et al., 2017).

The death of a client has a strong impact on professionals, with major effects on their work and family life (Findlay et al., 2015; MacDermott & Keenan, 2014; Wiese et al., 2012), especially if they had a close emotional bond with the person. Many healthcare professionals in this situation experience "unauthorized or disenfranchised

grief", *i.e.*, grief that they do not seem to have the right to openly express or receive emotional support for (Lathrop, 2017; Tsui et al., 2019). The professionals in this study recognized that they do not always have the space and support to deal with the loss and usually keep busy working with other clients. They do not receive or seek help to cope with this situation, which is associated with negative physical effects and emotional exhaustion (Doka, 2020; Lathrop, 2017; Tsui et al., 2019).

The professionals use different strategies to cope with the death of a client. Emotional release and evoking positive memories help them to come to terms with the loss, and they also turn to self-care activities and social support (Oñate & Calvete, 2017; Plante & Cyr, 2011). However, the significant emotional impact of bereavement combined with heavy workloads can negatively affect their physical and emotional wellbeing (Kozak et al., 2013; MacDermott & Keenan, 2014), and there is a need to implement programs to support professionals in this situation (Gavín-Chocano, 2018; Veloso-Besio et al., 2013). Specific interventions that provide professionals with the skills to cope with these situations may be helpful. For example, Fernández-Ávalos et al. (2022) recently designed and tested the effectiveness of a brief online intervention for professionals in this context, finding improved post-traumatic growth scores after four sessions.

Study Limitations

Study limitations include the recruitment of participants using convenience sampling from a single center and the relatively small sample size compared to some other studies (Wark et al., 2018), which limits the extrapolation of results to other settings. In addition, the results of this exploratory study were not analyzed with regard to the severity of the clients' ID, their relationship to the deceased, the specific type of loss, or the professional category (clinicians or social care staff). The analysis also

failed to account for other potentially influential variables such as the clients' personality type or life experiences, or recent personal losses experienced by the professionals. For these reasons, further research is needed on the subjective experiences of professionals supporting clients with ID, controlling for these variables (Wark et al., 2018). It is important to explore further how the severity of ID may influence the interventions and feelings of professionals providing bereavement support.

Conclusions

In conclusion, the professionals identified a number of difficulties in supporting people with ID through end-of-life and grief processes. These include the exclusion of clients from the grieving process and the lack of guidance to follow in such circumstances. The professionals described the emotional impact of losing a client and the difficulty of coping with this situation. Specific training programs are needed to help professionals provide adequate emotional support and follow-up to clients, to equip them with strategies for coping with bereavement and thereby reduce the risk of clients developing PGD in the future, and to alleviate the emotional distress suffered by the professionals themselves after intervening in the grieving process of this population. There is also a need for prevention strategies and bereavement education interventions for families with young children diagnosed with ID. Finally, the findings of this research have important implications for the design of more appropriate grief interventions for adults diagnosed with ID and the establishment of self-care strategies for professionals working in this context.

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Table 1. Main Themes and Codes after Thematic Analysis.

Exclusion of clients from end-of-life and grief processes	**Strategies to support the client's grief process**	**Emotional and personal difficulties faced by the professionals**	**Coping and regulation of the professional's grief process**
Clients are aware of the end-of life process	Observing and identifying manifestations of grief	Absence of guidance	Avoidance and distraction
Exclusion from rituals	Distraction from the loss	Lack of skills for delivering "bad news"	Emotional release
Ignorance of information	Emotional Support	Reactivation of their previous loss	Self-care and leisure activities
Delivery of the bad news by the professional	Support decision making	Concerns about the future of clients	Social support
	Participation in death-related rituals	Negative feelings generated by the loss of a client	
	Recommendations to families regarding the grieving process	Difficulty of openly manifesting their emotions	
		Negative consequences in daily life	

Table 2. Verbatim Quotes Related to the Theme "Exclusion of clients from end-of-life and grief processes".

Codes	Verbatim Quotes
Clients are aware of the end-of-life process	"*Sometimes you find out directly when they're already dead, but that depends on the person, because some clients come in and say 'my dad's ill', or 'he's in hospital', or they say that they haven't been in because they went to the hospital with a family member." (I01-Male, Social Worker)*
	"They find out through comments from family members. When things get very complicated, some family members phone us and say 'Look, our relative is very ill', and they ask us for help in telling the client. Other times, the family members tell them about things themselves. But the truth is that they (the clients) know everything." (I02-Female, Psychologist)
Exclusion from rituals	*"I think that they try to hide it so as not to upset them; and to be honest, they cope much better the sooner they start to face it, but of course the family denies this, saying that they don't want them to suffer and that they feel sorry for them…but I think that makes it worse." (I13-Female, Psychologist)*
Ignorance of information	*"Sometimes, yes, the family does tell them, but if it's not a close relative but say an uncle or a distant cousin they may not even tell them about it or they just let it go, I think. […]For us it's also a tough and difficult situation, because you feel helpless …"(I03-Male, Occupational Therapist)*
	"The family does not usually tell us that someone close to the user has a terminal illness. We would like to know so we can handle it better." (I17-Female, Caregiver/Monitor)
Delivery of the bad news by the professional	*"Family members often call the person they're more familiar with or have more contact with. They might call the social worker, or caregivers, or the psychologist, but always the one they have most contact with …" (I02-Female, Psychologist)*
	"The families always believe that we'll explain it better than them, and that's not the case, I don't know why they think we've got a magic wand or that they'll pay more attention to us, I don't know, but in the end, well, most of the time we tell them the best way possible." (I19-Female, Caregiver/Monitor)

Table 3 Verbatim Quotes Related to the Theme "Strategies to support the client's grief process".

Codes	Verbatim Quotes
Observing and identifying manifestations of grief	*"It also varies from person to person, because you can go to the activity and see that they're sad even though they're taking part; but you notice things, like they're quieter, more withdrawn, and you can tell that they may not be feeling great."(I17-Female, Caregiver/Monitor)*
Distraction from the loss	*"I follow my intuition, and if I see that they're feeling down or sad, I give them a hug or pat, the slightest physical contact, and from then on I use any kind of distraction to lead them into something else, I think it's all good for them."(I06-Male, Caregiver/Monitor)*
Emotional support	*"Yes, I think the only other thing that you can do at these times is to be more present with them in that moment, or show a bit more interest in them, or talk to them more than usual. It also depends on the time we have here to carry out activities and whatnot, but I don't know, it's just letting the clients know I'm here to help them, right?"(I09-Male, Caregiver/Monitor)*
Support decision making	*"I don't know if I'd call it a leading role, but I think that they should be told you're the most important person right now and we have to be with you; act how you feel and do whatever you need to do at this time" (I05-Female, Occupational Therapist)*
Participation in death-related rituals	*"We think it's good for them to take part in the rituals, they all have a right to do so. I remember my colleague and I decided to take a client to a funeral, we took her in a wheelchair and did so because we thought it was right for her to be there. She loved her brother very much and he had been in a very bad way."(I10-Female, Caregiver/Monitor)*
Recommendations to families regarding the grieving process	*"When this happens, you talk to relatives to see how things are going, you call up with any excuse or, like I do, you ask about some paperwork and then, well, you ask about the situation and you tell them about all the rights they have, and you give them tools to help them through the process."(I01-Male, Social Worker)*

Table 4. Verbatim Quotes Related to the Theme "Emotional and personal difficulties faced by the professionals".

Codes	Verbatim Quotes
Absence of guidance	*"Speaking to them about death means explaining to them that they're never going to see their relative again and with a person who is very cognitively impaired, you don't know how to do that." (I17-Female, Caregiver/Monitor)*
Lack of skills for delivering "bad news"	*"It's true that sometimes you don't know what they are able to understand; then there's that fear of them misunderstanding things, and you find it more difficult to say it, more than anything because they might misinterpret it or you might not express yourself well…then, yes, it has an impact."(I18-Female, Caregiver/Monitor)*
Reactivation of their previous loss	*"[…] We're one big family here, and in some cases when a death occurs, at least for me, it brings back memories of my own past losses. I remember how awful a time I went through, and that makes it harder for me to help clients because I feel... I don't know … like weaker." (I14-Female, Caregiver/Monitor)*
Concern about the future of clients	*"At these times, they're left alone in the world, they begin to think about their future because, for example, one client's mother has died and she's already thinking that someday her father will go too, and this uncertainty and fear of being left alone and about what's going to happen, it really upsets them and it upsets us too"(I05-Female, Occupational Therapist)*
Negative feelings generated by the loss of a client	*"I felt very upset and angry about the death of a client we had, because she struggled a lot and in the end it was for nothing…it was unfair… Also, when she died, suddenly everything was removed from her room because another new client was coming in, and that made me feel that a death is being replaced by another person, as if it was something so normal and, honestly, that made me angry"(I12-Female, Caregiver/Monitor)*
Difficulty of openly manifesting their emotions	*"It affects your work on those days because everything is harder. I've had to shower clients and I really wanted to cry and I had to hold back, and it was extremely difficult for me, but I ended up doing my work anyway. I mean that those days I'm very overwhelmed and exhausted on all levels, but at the end of the day I do my work"(I10- Female, Caregiver/Monitor)*
Negative consequences in daily life	*"I think that most of us take problems from here home as well, especially when it's something like that, when someone from here is sick or dies; they're people you've known for a long time, and in the end they're a part of you, aren't they, part of your daily life? So it's inevitable, and sometimes I take it out on people when it's not their fault, like my loved ones, […]" (I16- Female, Caregiver/Monitor)*

Table 5 Verbatim Quotes Related to the Theme "Coping and regulation of the professional's grief process".

Codes	Verbatim Quotes
Avoidance and distraction	*"I try not to let it affect me and distract myself by going about my daily life at work; it's what helps me switch off from it. You often think, I don't feel like doing anything, I'd rather be at home, but in the end you start doing things and you're grateful for the escape."(I14- Female, Caregiver/Monitor)*
Emotional Release	*"I'm someone who has to hide away, because everyone tells you not to cry, don't cry; well, how can you not cry? When you finally find a space for yourself, you let it all out and say, well now I'll cry as much as I want, and, well, I don't think it's bad to take some time alone for yourself and let it all out."(I05- Female, Occupational Therapist)*
Self-care and leisure activities	*"I'm very active, so on days when I'm not feeling so great, I turn to sport to release all the tension I've built up. I think that finding activities that you enjoy, even though you don't feel like doing them, helps you feel better, and even more so in those situations…" (I15- Female, Caregiver/Monitor)*
Social support	*"I think that something as simple as talking about it with colleagues is good. It did help me going to the funeral, for example, and being with workmates; we cried for 15 minutes, and it's good for me to be with people who understand what I'm going through." (I11- Female, Occupational Therapist)*