

**The Journey of Recovery: Caregivers' Perspectives From a Hip Fracture
Telerehabilitation Clinical Trial**

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Title: The Journey of Recovery – Caregivers’ Perspectives from a Hip Fracture
Telerehabilitation Clinical Trial

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Ethics Approval

The study was approved by the Ethics Committee of the Research Center of Granada (cBI-cni.Nana 2015/09/28), all participants signed a consent form. The study was conducted according to guidelines established by the Helsinki Declaration and Law 14/2007 on Biomedical Research.

31 **The Journey of Recovery – Caregivers’ Perspectives from a Hip Fracture**

32 **Telerehabilitation Clinical Trial**

33 **ABSTRACT**

34 **Objective:** To explore family caregivers’ perspectives of the recovery process of older
35 adults with hip fracture, and describe experiences from caregivers who (i) used the online
36 intervention or (ii) received home-based care provided by the Andalusian Public Health
37 Care System.

38 **Methods:** This was an exploratory secondary study with informal family caregivers who
39 had an older adult family member with hip fracture enrolled in a novel telerehabilitation
40 (telerehab) clinical trial. Forty-four caregivers of older adults with hip fracture were
41 interviewed at 6-9 months after their family member’s hip fracture.

42 **Results:** Caregivers shared concerns of family members’ survival and recovery; they
43 recounted increased stress and anxiety due to the uncertainty of new tasks associated with
44 providing care and the impact on their lifestyle. Although most caregivers were satisfied
45 with the health care received, they made suggestions for better organization of hospital
46 discharge, and requests for home support. The main reasons why caregivers and their
47 family member chose the telerehab program were to, enhance recovery after fracture, gain
48 knowledge for managing at home, and the convenience of completing the exercises at
49 home. There were more family caregivers in the control group who expressed a high level of
50 stress and anxiety, and they also requested more social and health services compared with
51 caregivers whose family member received telerehab.

52 **Conclusions:** Family caregivers are an essential component of recovery after hip fracture
53 by providing emotional and physical support. However, future clinical interventions should

54 evaluate person-centered interventions to mitigate possible stress and anxiety experienced
55 by family caregivers.

56 **Impact statement:** Family caregivers' perspectives are necessary in the co-design of
57 management strategies for older adults after hip fracture.

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61

62 **INTRODUCTION**

63 Older adults' loss of function after hip fracture is consistently reported in the
64 literature¹. Much of the burden after hospital discharge is shouldered by informal
65 caregivers, such as family and friends, who support older adults to regain their ability to
66 complete activities of daily living. This is a global phenomenon that is observed, for
67 example, in southern Europe², Asia^{3,4}, South America⁵, and North America⁶. From the
68 caregivers' perspective, the unexpected and traumatic events associated with hip fracture,
69 and additional caregiving responsibilities, can lead to increased stress⁷ and burden², which
70 may negatively impact on caregivers' health⁸.

71 There is a priority to understand the lived experience of caregivers after hip fracture,
72 especially during the transition between hospital and home^{9,10} and after returning home¹¹.
73 Caregivers' identified care gaps such as the lack of shared information, confusion about
74 their role as caregivers, and disorganized discharge planning^{10,11}. There is a call for a
75 focused research agenda to explore caregivers' needs, including their knowledge of, and
76 attitude toward, hip fracture management and recovery¹².

77 Information and communication technologies (ICT) could be used as a tool to
78 improve shared information between health care professionals and caregivers⁶, and to
79 support caregivers and patients with hip fracture during the recovery process⁹ through
80 telerehab (care delivered remotely). Nevertheless, telerehab post-hip fracture has limited
81 published evidence, as highlighted in a recent systematic review¹³, and only a few
82 technology-inclusive interventions have been perceived as acceptable by patients with hip
83 fracture and or caregivers: Fracture Recovery for Seniors at Home (FReSH) Start toolkit for
84 older adults and their families¹⁴⁻¹⁶, hospital-based caregiver knowledge and skill
85 development workshops during the acute hospital phase², and an online hip fracture
86 resource center for caregivers¹⁷. Further to our knowledge few studies (if any) aimed to test
87 telerehab post-hip fracture with the older adult and caregiver dyad.

88 We designed @ctivehip to (i) address the recommendation to include technology as
89 part of health care management^{9,10}, and (ii) based on previous work^{14,16} where caregivers
90 stated they wanted to play an active role in the rehabilitation (rehab) process after hip
91 fracture². In the main clinical trial¹⁸, the primary goal was to compare the telerehab
92 program versus home-based in-person rehabilitation on functional recovery of older adults
93 with hip fracture. In addition, the program aimed to provide caregivers knowledge and skill
94 development to support recovery and falls prevention for older adults with hip fracture via
95 video-based information and exercises delivered through the online platform, and
96 individual video-conferencing. Included in the online platform there was a specific section
97 focused on promoting wellness for caregivers' health. Furthermore, caregivers of all
98 patients (intervention and control groups) were invited to participate in a workshop on hip
99 fracture management at home that took place at the hospital (during older adults' acute

100 hospitalization phase). We provide a detailed description of the main clinical trial testing
101 telerehab, elsewhere¹⁸.

102 Family caregivers play an important role in the lives of older adults, thus, we were
103 interested in caregivers' experience, perspectives, and suggestions for how best to enable
104 person-centered healthcare interventions. The objective for the present study was to explore
105 caregivers' perspectives, based on semi-structured interviews, of the recovery process and
106 describe experiences from (i) caregivers who used the online intervention, and (ii)
107 caregivers who received home-based care provided by the Andalusian Public Health Care
108 System.

109 METHODS

110 Family caregivers of older adults with hip fracture who previously participated in a non-
111 randomized clinical trial on telerehab (Clinical Trials Registration: NCT02968589NCT)
112 were included in this exploratory study **that was guided by the principles of Interpretive**
113 **Description**¹⁹.

114 As part of the study design older adult patients and their caregivers were given the choice
115 of enrolling in the telerehab intervention or a home-based rehab program. Inclusion criteria
116 into the main clinical trial were: (i) sustained a surgically repaired hip fracture; (ii) aged 65
117 years and older; (iii) high functional ability one week prior to the fracture; (iv) were able to
118 weight-bear on the fractured leg within 48 hours post-surgery; (v) community-dwelling
119 (own home or with relatives) post-hospital discharge; and (vi) have a family caregiver
120 willing to participate, and having access to the online intervention. Exclusion criteria were
121 older adults with severe cognitive impairment, not expected to live beyond six months, or
122 with post-surgery complications.

123 During the acute hospital phase, we invited older adults with hip fracture and
124 caregivers and offered them the choice of (i) participating in a home-based telerehab
125 program plus usual post-discharge care, or (ii) 5 - 15 home-based multi-disciplinary rehab
126 sessions and usual post-discharge care and. All family members were offered an
127 instructional workshop on hip fracture recovery during the acute hospital stay²⁰. Usual post-
128 operative home-based rehab was delivered by the Andalusian Public Health Care System.
129 The study was approved by the Ethics Committee of the Research Center of Granada (cBI-
130 cni.Nana 2015/09/28), all participants (older adults with hip fracture and caregivers) signed
131 consent forms (for the main study and interview study). The study was conducted according
132 to guidelines established by the Helsinki Declaration and Law 14/2007 on Biomedical
133 Research.

134 **Data collection**

135 Semi-structured interviews with family caregivers were conducted three to six
136 months after the end of their involvement in the main clinical trial (lasting 12 weeks),
137 between October 2017 and December 2018. **Most interviews took place at three months,**
138 **but we had some delays due to the limited availability of some caregivers over**
139 **summer. Nevertheless, their responses did not differ from caregivers who were**
140 **interviewed at 3 months.** The timing of the interviews was chosen to better understand (i)
141 caregivers' perceptions and experience with the recovery process, and (ii) the longer-term
142 experience participating in the telerehab program. The interviews were conducted by one
143 occupational therapist with clinical and graduate-level research experience in the
144 management of patients with hip fracture; the occupational therapist was not involved in
145 the main clinical trial.

146 We created an interview guide to explore caregivers' perceptions and experience
147 with hip fracture, including one question regarding why they decided to join or decline the
148 telerehab intervention arm of the study, and one final open question about anything else
149 that they would like to tell. During the interviews, participants were encouraged to talk
150 freely, and the interviewer used follow-up questions and prompts, such as "*Tell me more*
151 *about it*" to let participants provide more details of their experience. Each interview
152 typically lasted 20 minutes (range 12 - 25 minutes). Please see **Figure 1** for a list of the
153 questions guiding the interview.

154 Seventy-one participants were enrolled in the main clinical trial. At the final
155 assessment (i.e., at 12 weeks when formal health care and study ended), caregivers from
156 both the intervention and control groups were invited to participate in the semi-structured
157 interviews. Seventy family caregivers were invited to participate, representing 70 older
158 adults with hip fracture (one participant was lost to follow-up). Fifty-one caregivers agreed
159 to participate and signed the written informed consent for the interviews. Caregivers were
160 contacted via telephone three months later to confirm their participation in the study, and to
161 organize the interview. At the follow-up call, three caregivers did not answer the telephone
162 after several attempts, and four caregivers withdrew from the study. Thus, in total, 44
163 caregivers were interviewed representing 21 older adults with hip fracture from the
164 intervention group, and 23 older adults with hip fracture from the control group.

165 Interviews were conducted in Spanish, either in person or via telephone depending
166 on the preference of participants, or their physical location. Participants living within 30
167 kilometers of the hospital were offered either an in-person interview or a telephone
168 interview, while participants living beyond this radius were interviewed by telephone. Eight
169 interviews were conducted in-person, and 36 interviews were conducted by telephone. The

170 eight in-person interviews took place at the participants' preferred location (and not at a
171 hospital) in order to make the interview environment as comfortable as possible. We asked
172 about caregivers' basic sociodemographic information in the main clinical trial. All
173 interviews were recorded and transcribed verbatim, with some minor grammatical
174 corrections made to improve the understanding of quotes. The interviewer and one trained
175 assistant transcribed all recordings within the first two days following the session.

176 **Data analysis**

177 We conducted a content analysis following the recommendations described by
178 Graneheim and Lundman²¹ using a multi-step process to first determine the overall scope of
179 the findings, then examine data by creating meaning units, which are then condensed,
180 coded, and sorted into subcategories, categories, and themes. We chose this model of
181 content analysis because it originates from clinical research²¹, and has been used in studies
182 similar to our work²².

183 Data analysis was completed by the first two authors (Patrocinio Ariza-Vega and
184 Herminia Castillo-Pérez) and discussed during three meetings to reach consistency in
185 understanding and interpretation. First, a coding framework using a deductive analytic
186 approach for each interview question was created. Second, one cycle of coding and two re-
187 coding cycles were conducted, to increase the certainty of correctly classifying responses²³.
188 Both authors independently read each transcript in Spanish several times to understand the
189 meaning. Thereafter both authors independently identified meaning units related to the
190 study aims. Following this step, the two authors condensed, abstracted, and coded the
191 meaning units, with the aim to preserve the intended meaning. The coded meaning units
192 were compared and sorted into subcategories. In the final step, three categories emerged for
193 the recovery process and the telerehab program. The last author (Maureen C. Ashe)

194 reviewed the categories together with quotes (in English), and discussed them with the first
195 author.

196 We took several steps throughout this study to increase the trustworthiness of the
197 findings across the data collection and analysis phases²⁴. The interviews took place during a
198 period of 15 months, with caregivers of different ages, sex, and cultural contexts at
199 different locations (chosen by the caregivers). For data collection, the interviewer was an
200 occupational therapist (with graduate level research training) with experience working with
201 people with hip fracture. However, the interviewer did not know the study participants and
202 caregivers, and was not part of the main clinical trial. During the data collection phase, the
203 same interviewer conducted and transcribed (with one assistant) the interviews within two
204 days after each interview, and kept field notes to reference during the analysis phase.

205 Furthermore, the interviewer used prompts to clarify and extend participant responses; they
206 also confirmed the meaning and understanding of responses with participants during the
207 interview sessions. **The last member check with participants (from both groups) was
208 based on the Synthesized Member Checking method²⁵. A summary from emerging
209 themes and quotes were sent to a representative subgroup of participants after
210 completing the content analysis. We contacted participants a few weeks later via
211 telephone to comment on the summary, and invited them to change or add
212 information.** During data synthesis, the authors kept an audit trail to highlight the process
213 and analysis decisions. The investigator triangulation was carried out by two authors (both
214 graduate-level trained in research, and with related clinical experience) who worked
215 together during data analysis. A third author (with related clinical and graduate-level
216 research experience) reviewed the final themes and quotes, and discussed them with the
217 first author.

218 All interviews were conducted in Spanish (participants' native language). The same
219 person did the transcription and collaborated in the content analysis together with the first
220 author (both are native Spanish speakers). Translation of the content analysis and quotes
221 was conducted by the first two authors and reviewed by the last author (native English
222 speaker). They had continual and lengthy communication to ensure translation considered
223 the cultural context. Finally, the description of the caregivers (Table 1) and older adult
224 study participants (inclusion/exclusion criteria) provides contextual information to
225 highlight possible transferability of findings. We used NVivo 10 (QSR International,
226 Doncaster, Australia) **to assist with data management during analysis**. Descriptive data
227 were presented as numbers with percentages for categorical variables and as median
228 (interquartile range) for age.

229 **Role of the Funding Source**

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231 Andalusia, Spain, Grant number: PI-0372- 2014. The funder played no role in the design,
232 conduct, or reporting of this study.

233 **RESULTS**

234 In total, 44 caregivers with a median age of 52 years, 31 women and 13 men,
235 participated in the present study. More than half of the caregivers were employed, working
236 either part-time or full-time. An overall description of the sociodemographic variables of
237 the participants are presented in **Table 1**.

238 We identified three categories during data analysis of caregivers' responses to the
239 hip fracture and recovery process: (i) concern about survival and recovery; (ii) uncertainty,
240 anxiety and stress; and (iii) communication and resources: Looking for answers (please see

241 Figure 2). Below, we describe the main categories, and additional supporting quotes from
242 caregivers are presented in **Figure 3**, a visual summary of the main findings

243 **Concern about survival and recovery.** The most common experience reported by
244 caregivers was dealing with concerns about the health of their family member during the
245 first week after hip fracture. Caregivers' were concerned if their family member would
246 survive, dealing with post-op delirium, and questions related to the return of physical
247 function. "*...I thought my mother was dying. She was very sick, very bad...*" (Daughter, 54
248 years old, control group). "*...At the beginning he needed help getting up, going to the
249 bathroom, going to bed ... and we did not know if that would change or if it would be like
250 that forever*" (Daughter, 44 years old, intervention group).

251 Caregivers' reflected on their early expectations for their family members' recovery
252 potential. During the first weeks after the patients sustained the hip fracture, many
253 caregivers expected that the hip fracture would have worse consequences on their family
254 member's long term health. Some caregivers had expected that their family member would
255 recover to the level they had at the time of the interview (six to nine months' post-fracture),
256 while other caregivers expected that their family members would have a higher degree of
257 recovery at the time of the interview. "*...I expected her [to recover] faster and better, but
258 she still limps and [she] complains of pain some days...*" (Daughter, 44 years old,
259 intervention group).

260 Uneasiness about the risk of falls remained well after the study ended for the
261 majority of caregivers. Although many caregivers stated that they did not overprotect their
262 family members later in the recovery process, their comments sometimes were at odds. "*...
263 I was very afraid that she would fall when she was alone. Now I am afraid but I am not
264 obsessed... I do not overprotect her, but she is very determined and I do not want her to fall*

265 *again. I just tell her to be careful and not to climb on the ladder, to pick up things from the*
266 *closet, or not to go alone for shopping...*” (Son, 48 years old, control group).

267 **Uncertainty, anxiety, and stress.** The second most common experience expressed
268 by caregivers included uncertainty during the first few weeks after the hip fracture, and the
269 lifestyle changes required to adapt to the new and unexpected situation. “...*At the hospital,*
270 *staff told us that we should adapt the house but it was not just the house, we had to adapt*
271 *our lives to the new situation and we did not know how we were going to do it...*”
272 (Daughter, 51 years old, control group).

273 Following hip fracture, caregivers also reported anxiety and stress due to the new
274 situation; including temporary changes in residence for the first few weeks when they had
275 to stay with the family member, adjusting work schedule to be able to care for a family
276 member, and sleep disruptions. “...*It changes everything. I'm more uneasy thinking that*
277 *something bad [will] happen to her. I cannot leave her alone and I have less time to do my*
278 *things... It is stressful...*” (Daughter, 53 years old, control group).

279 Some caregivers reported additional stress related to the challenges of having
280 multiple family caregivers, sometimes with conflicting approaches to providing care. In
281 spite of this, most caregivers reported feeling capable of taking care of their family member
282 during the recovery process. A third of caregivers were concerned already during the
283 hospital stay how they could manage the “new” normal at home, after hospital discharge.
284 “...*I did not see myself capable of taking care of her, but I had no other choice. The world*
285 *came [crumbling down on] me...*” (Son 38 years old, intervention group).

286 **Communication and resources: Looking for answers.** Most caregivers were
287 satisfied with the health care services received in hospital and home. However, some
288 caregivers provided suggestions on how to improve the hospital care, such as more staff,

289 better coordination, and more rehab, while other caregivers requested better social services,
290 such as someone to help at home with everyday activities. The majority of caregivers
291 described communication with health professionals as “very good” or “good”. However,
292 almost a third of caregivers requested better communication with health professionals
293 during the acute hospital stay and after discharge. Furthermore, some caregivers requested
294 more involvement in discharge planning at the hospital. “...*We received very good*
295 *attention and the professionals were very kind... They clarified [our concerns], and told us*
296 *what exercises we could do. We bought a raised toilet seat before leaving the hospital*
297 *because they recommended it to us, and it was very useful...*” (Daughter, 58 years old,
298 control group); “...*nobody asked us if we had everything ready at home to take care [my*
299 *mother] but the doctor signed the hospital discharge [anyway]...It was much too fast... We*
300 *would have liked to talk with them [the health professionals] to [ask for] more time to*
301 *organize and prepare the house for her...*” (Daughter, 51 years old, control group).

302

303 **Choice of rehab intervention**

304 The main reasons why caregivers and their family member chose the telerehab program
305 were: (i) to enhance recovery after fracture; (ii) gain knowledge for managing at home; and
306 (iii) the convenience of doing exercises at home. “...*we would have lot of information*
307 *about the fracture and what we had to do to care her.... It would be a good help for us and,*
308 *of course, for her.... it would be easier for us not to have to go to the hospital for the*
309 *rehabilitation and be able to do it at home...*” (Son, 50 years, intervention group). The
310 reasons for declining the telerehab program were: (i) perceived challenges with technology;
311 (ii) lack of time to support family member (with hip fracture) with technology, e.g.,
312 navigating the website; (iii) caregivers’ perception that family members would not want to

313 complete exercises at home; (iv) preference of in-person rehab, even if it had associated
314 costs; or (v) no expected need for the program. "...Because it seemed like a lot of trouble to
315 do it online. We thought that she would not understand the program and we would not
316 know how to do it..." (Son, 56 years, control group). "...We work and did not have time to
317 do the exercises with her. Also my mother is not a person with much will and it would be
318 very difficult to pay attention to exercises on the computer..." (Daughter, 54 years, control
319 group).

320 Overall, caregivers experienced concern for their family member's survival and
321 recovery. There were more caregivers whose family member had received usual care who
322 expressed a high level of stress and anxiety than among caregivers whose family member
323 had received telerehab (15 and eight caregivers respectively) as the main change of their
324 lives after the hip fracture. Caregivers in the control group also requested more social and
325 health services (e.g., assistance with basic ADLs, and rehab visits) compared with
326 caregivers' whose family member received the intervention. Of note, prior to the hip
327 fracture, more patients in the control group lived with a caregiver. However, after the hip
328 fracture the groups were similar for living arrangements (**Table 1**).

329 DISCUSSION

330 In this study we present a detailed description of caregivers' perceptions and
331 experience of providing care for an older family member with a recent hip fracture who
332 were enrolled in a clinical trial. Caregivers provided rich contextual information on the
333 recovery process in general, and the impact on their lives. They shared concerns of their
334 family members' survival and recovery; as well as the uncertainty of how to manage care
335 following discharge. Collectively, these events may partly explain caregivers' reported
336 feelings of anxiety and stress, and their request to health care professionals for more

337 information and guidance on the recovery process. Overall, this study provided a valuable
338 description of hip fracture recovery from the caregiver lens that has implications for both
339 clinical management and practice-based research.

340 Caregivers in this study shared similar characteristics with participants from related
341 studies such as. they were children of older adults with hip fracture^{5,26}, were typically
342 women⁴ at middle age^{2,27}, and had additional caregiving support from family and friends²⁸.
343 The majority of the caregivers were working, in contrast to other studies where most
344 caregivers were unemployed^{2,26}. Furthermore, in this study, prior to the fracture many of
345 the older family members with hip fracture lived with the caregiver, and this proportion
346 increased following hospital discharge. Place of residence may be related to the social
347 norms of the geographic region, as other studies have not reported similar characteristics²⁹.

348 In our study, participants expressed concern for their family members' health status
349 and recovery. However, the underlying source of stress or uncertainty in the acute hospital
350 phase may have changed after discharge (e.g., at home) because of the different
351 environments and stage of recovery from hip fracture. A key motivator for caregivers to
352 enroll in the telerehab program was to optimize their family members' recovery, and to
353 gain knowledge and skills for caregiving. These reasons emphasize the recommendations to
354 use ICTs to support patients with hip fracture and their informal caregivers⁶, and are
355 consistent with other studies in which caregivers wanted to play a more active role in the
356 rehab process^{9,11}.

357 Another finding was that half of caregivers did not expect their family member to
358 recover from the fracture. The implications of these misperceptions are not fully elucidated,
359 but the **reason** may be related to frequently quoted statistics related to poor recovery after
360 hip fracture, such as high mortality within the first year³⁰, and half of older adults not

361 regaining their pre-fracture mobility¹. The results of this study generate future research
362 questions on ways to effectively communicate with older adults and their family caregivers
363 to maximize the recovery process.

364 Hip fracture is an unexpected event without an opportunity to plan, thus caregivers’
365 increased stress is understandable². For instance, it could result in a change in their already
366 busy daily routines⁵, or facing new responsibilities with limited time available for learning
367 and integration into their lives¹¹. Combined, these factors can increase feelings of stress and
368 anxiety, which can lead to negative health consequences^{7,10,11}. In the present study, the
369 caregivers of patients who received the usual home care expressed higher stress levels and
370 requested more social support resources compared with caregivers of patients who used the
371 telerehab program. However, caregivers of both groups identified similar concerns.

372 It is possible that caregivers who declined to participate in the telerehab program
373 felt overwhelmed at the prospect of additional “burden” into their already busy lives. Thus
374 we need to consult caregivers for how we deliver the program in the future, including the
375 timing and frequency of sessions, or the development of more user-friendly training
376 strategies for program delivery. It is also possible that the online program does not appeal
377 to everyone providing care after hip fracture.

378 Similar to other studies, caregivers in our study were confused about their role^{10,11},
379 and concerned with their capacity to manage the recovery process after hip fracture. They
380 expressed difficulties understanding how to support the older adult with hip fracture during
381 hospital stay, and during the transition back home, as previously reported in other studies²⁷.
382 Literature highlights that family caregivers of older adults with hip fracture want to be
383 involved in decision making at the hospital, but that they sometimes feel excluded from this
384 process^{9,27}. In this study, similar experiences were expressed by some caregivers, who had

385 not been involved in discharged planning, and consequently felt challenged to have
386 everything in place when their family member returned home. Despite these observations,
387 many of the caregivers expressed competence in providing care, a factor associated with
388 lower caregiving burden³¹. A difference between our study and other studies^{10,11} was the
389 inpatient workshops provided to all caregivers, which are described in detailed elsewhere¹⁹.

390

391 **Limitations**

392 We recognize several limitations with this study. First, the participants in this study do not
393 represent all people who fracture their hip, as we did not include older adults with cognitive
394 impairment. Thus, we cannot generalize the perceptions and experience to caregivers of all
395 patients with hip fracture. Nonetheless, our work gives valuable information to extend
396 previous research on online resources for caregivers of older community-dwelling adults
397 with hip fracture³². Second, the fact that most of the interviews were short and completed
398 via telephone could have affected the participants' descriptions. However, as telephone
399 interviews were preferred by the participants, we believe that using this mode did not
400 severely hamper the ability to explore the topic, rather we highlight new aspects of
401 caregivers' perceptions and experience with the recovery process after hip fracture.

402 Moreover, we conducted the interviews three to six months after the telerehab program had
403 finished, which could have influenced caregivers' memory. However, caregivers were
404 given an opportunity to choose where, when and how the interviews should be conducted,
405 to create a relaxing environment for the interviews.

406

CONCLUSION

407 This study provides insight into informal caregivers' concerns and expectations regarding
408 their family member's survival, health and mobility, including the uncertainty of the

409 outcome and possible required lifestyle changes after a hip fracture. Although they stated
410 confidence in their caregiving responsibilities, they wanted to be included in the care and
411 hospital discharge planning. Most caregivers were satisfied with the health care their family
412 members received, but they gave suggestions on care coordination in hospital. Furthermore,
413 they requested more rehab and hospital and home care staff to help older adults with
414 everyday activities after discharge from hospital. Finally, to our knowledge, this is the first
415 study to provide a detailed description of caregivers and older adults decisions for choosing
416 (or not) telerehab for hip fracture. Taken together, these findings provide rich insight into
417 recovery from the family caregivers' perspective to inform clinical practice and guide
418 future research for co-designing management strategies using ICTs for recovery after hip
419 fracture.

420

421 **Author Contributions and Acknowledgments**

422 All authors made a substantial contribution to the concept or design of the work; or
423 acquisition, analysis or interpretation of data. Patrocinio Ariza-Vega and Maureen Celeste
424 Ashe conceived the study, developed the content analysis, and drafted the manuscript.
425 Herminia Castillo-Pérez conducted the semi-structured interviews with caregivers and
426 participated in the transcription process and content analysis. Mariana Ortiz-Piña and
427 Jerónimo Palomino-Vidal recruited the caregivers and collaborated in the design and
428 transcription of interviews. Lena Ziden contributed to the design of the study and reviewed
429 the manuscript critically. All authors reviewed the manuscript critically for important
430 intellectual content, and approved the final version.

431

432 **Declaration of conflicting interests**

433 Conflict of Interest: none declared

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Table 1
Demographic characteristics of caregivers and patients

	All participants (n=44)	Tele- rehabilitation (n=21)	Usual care (n=23)
Age, years	52 (43.3-54.8);	50 (42.5-	54 (48-58);
Median (Q1-Q3); min-max	21- 85	53.5); 38-64	21-85
Gender (n, %)			
Women	31 (70.5)	16 (76.2)	15 (65.2)
Men	13 (29.5)	5 (23.8)	8 (34.8)
Relationship (n, %)			
Partner/ spouse	4 (9.1)	1 (4.8)	3 (13)
Son/Daughter	34 (77.3)	18 (85.8)	16 (69.6)
Other relatives/friends	6 (13.7)	2 (9.5)	4 (17.3)
Employment (n, %)			
Full- time	15 (34)	8 (38.1)	7 (30.4)
Part-time	13 (29.5)	6 (28.6)	7 (30.4)
Unemployed	16 (36.4)	7 (33.3)	9 (39.1)
Support of other caregivers (n, %)			
Yes	31 (70.5)	15 (71.4)	16 (69.6)
No	13 (29.5)	6 (28.6)	7 (30.4)
Living with the patients before fracture (n, %)			
Yes	25 (56.8)	9 (42.9)	16 (69.6)
No	19 (43.2)	12 (57.1)	7 (30.4)
Living with the patient after hip fracture (n, %)			
Yes	30 (68.2)	14 (66.7)	16 (69.6)
No	14 (31.8)	7 (33.3)	7 (30.4)
Age of patients, years	81 (75.3-83.8);	78 (72.5-82);	82 (79-86);
Median (Q1-Q3); min-max	67-89	67-87	67-89
Gender of patients (n, %)	32 (72.7)	16 (76.2)	16 (69.6)
Women			
Men	12 (27.3)	5 (23.8)	7 (30.4)

524 **Figure legends**

525

526 **Figure 1.** Interview guide

527 **Figure 2.** Caregivers' perceptions during hip fracture recovery

528 **Figure 3.** Selected quotes from caregivers

**Caregivers' role
and the impact of hip fracture**

What has been your greatest concern?

Did you feel capable of caring for your **family member** when the hip fracture occurred?

Throughout the recovery process, how difficult was **it** for you to provide care to your **family member**?

What changes have you perceived in your life after your **family member's** hip fracture?

Since the fracture occurred, do you think you overprotect your family member?

Are you afraid **he/she** will fall again?

Perceptions of patients' functional recovery

When your **family member** broke **his/her** hip, did you think he/she would recover to the level he/she is today? Did you think it would be better, worse, or the same?

Has your **family member** ever gone out alone **outside**, for example to go shopping or **for** a walk? Do they go **outside** with another **person**?

Experience with health care received

What would have improved the care **your family member** received at the hospital?

What would have improved the care **your family member** received at home?

How have you felt about **the** communication with **the healthcare** staff?

At the hospital, were you offered the use of a telerehabilitation program? Why did you decide to accept or decline the program?

Is there anything else I have not asked that you would like to tell me about taking care of your family member after hip fracture?

Figure 1. Interview guide

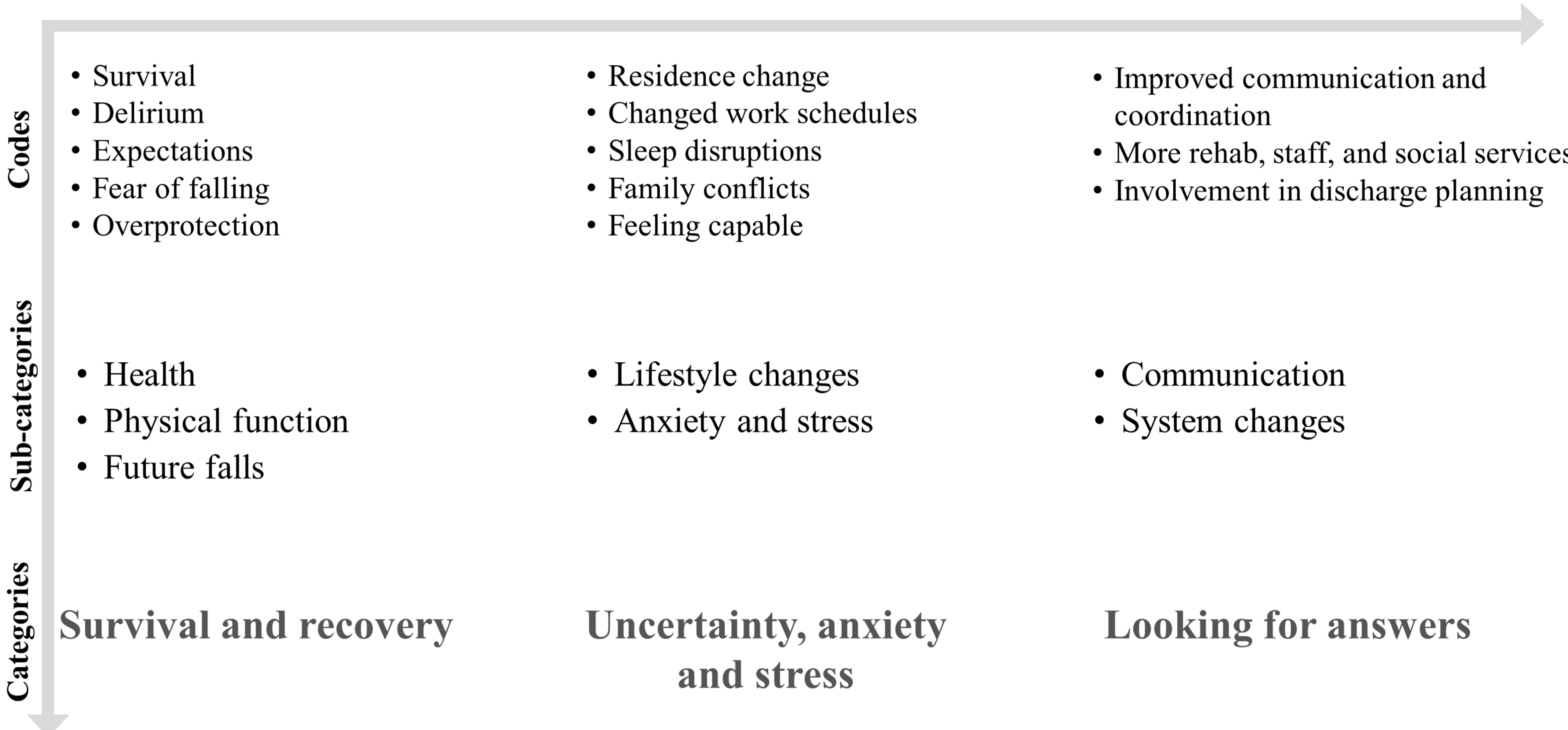


Figure 2. Caregivers' perceptions during hip fracture recovery

Concern about survival and recovery

“...In the hospital she was disoriented.... She behaved badly, she removed the [IV tubes] ... She insulted the nurses... We were afraid that she would not recover her common sense...” (Daughter, 65 years old, control group)

*“...I thought she could not walk again without [mobility] aids... I listened [to] other people who had suffered a hip fracture and everyone said it was very bad and very serious... But my mother is very strong and she is the caregiver of my father... She followed all the instructions we gave her... she said that she had to be independent **again to take care of my father...**”* (Daughter, 40 years old, intervention group)

Communication and resources: Looking for answers

“... In the hospital there was a bit of chaos... There [were few] staff and it took a long time [for them] to come when we called them... They were overwhelmed...” (Daughter, 40 years old, intervention group)

“When we got home, we contacted social services for a person to come home and help my mother with the bath and home tasks, but no one came... Only one nurse came [to her] home [once]...” (Daughter, 54 years old, control group)

Uncertainty, anxiety, and stress

“It was a great stress for me ...I live in another city and I took days off at work to be able to come to my parents’ place.” (Son, 43 years old, control group)

“...I was worried that he would not return to his normal life and need the help of his son and daughters for the rest of their live...” (Daughter, 44 years old, intervention group)

Choice of rehab intervention

“...It was my son who was in the hospital when they explained the program to him and he considered it a good thing for his father and we decided to [try] ... We had nothing to lose...” (Wife, 53 years, intervention group)

“...Because I had no idea how to handle the situation and I thought it could be the help I needed...” (Son, 38 years, intervention group)

“...It would be easier to hire someone to come home to do the rehabilitation without having to be with the computer, and the physiotherapist would know more than us...” (Daughter, 58 years, control group)

Figure 3. Selected quotes from caregivers