


# Experienced Loneliness in Home-Based Rehabilitation: Perspectives of Older Adults With Disabilities and Their Health Care Professionals

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## Abstract

This study aimed to describe and interpret perspectives of older adults with disabilities and their health care professionals (HCPs) on experienced loneliness during home-based rehabilitation. The interpretive description methodology guided the study. Data included semistructured individual interviews with seven older adults and a focus group interview with three HCPs. The analysis revealed four main findings that symbolized experienced loneliness. “Unspoken pain” and “gatekeeping emotions” concerning experienced loneliness as a taboo and stigma during rehabilitation were closely connected. “Resignation” and “awaiting company” signified the consequences of experienced loneliness when not addressed. Unspoken pain, gatekeeping emotions, resignation, and awaiting company were dominating experiences in the lives of the older adults during a home-based rehabilitation program following disability. This had restrained them from verbalizing and coping with loneliness during rehabilitation and life in general. The HCPs’ attempt to provide support for the older adults in coping with loneliness appeared to be characterized by gatekeeping emotions and keeping hidden agendas.

## Keywords

rehabilitation, loneliness, older adults, disability, interpretive description

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## Introduction

Studies have shown that 45% of older adults experience loneliness (Dykstra, 2009; Hansen & Slagsvold, 2016; Nyqvist, Cattan, Andersson, Forsman, & Gustafson, 2013; Routasalo & Pitkala, 2003; Routasalo, Tilvis, & Strandberg, 2006). The prevalence of loneliness rises with age (Luanaigh & Lawlor, 2008; Normann, 2010). A growing body of evidence indicates that loneliness may have a profound negative impact on health, behavior, cognition, and emotions of older adults, with serious consequences if left unattended (Hagan, Manktelow, Taylor, & Mallett, 2014; Hawkey & Cacioppo, 2010). Furthermore, it has been argued that risks associated with loneliness as well as social isolation are equivalent to the harmful effects of obesity, smoking, and physical inactivity (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). Loneliness can be described as a subjective, complex emotion experienced by an individual as an unpleasant feeling of lack of connectedness or communality with others (Beaumont, 2013; Peplau & Perlman, 1982) due to a discrepancy between the desired and actual social relations (Peplau & Perlman, 1982). Experienced loneliness may lead to cognitive decline (Fratiglioni, Wang, Ericsson, Maytan, &

Winblad, 2000; Tilvis, Ka, Jolkkonen, & Valvanne, 2004), increased use of health services (Ellaway, Wood, & Macintyre, 1999; Geller, Janson, McGovern, & Valdini, 1999), and early institutionalization (Tijhuis, De Jong-Gierveld, Feskens, & Daan, 1999; Tilvis et al., 2004). Older adults are liable to feel lonely when reduced social and economic resources, death of relatives, retirement, and disability lead to reduced social affairs (Dykstra, 2009; Jylhä & Jokela, 2008; Pinquart & Sörensen, 2001; Routasalo & Pitkala, 2003). Targeting social isolation among older adults has, worldwide, shown to be a growing public health challenge and concern, due to the detrimental effect that loneliness can have on health and well-being (Dickens, Richards, Greaves, & Campbell, 2011). It is argued that this is an understudied area where more, well-conducted studies of the effectiveness of such interventions for alleviating social isolation are

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needed (Dickens et al., 2011). Research suggests that older adults' experiences of loneliness may be alleviated through rehabilitation (Ollonqvist et al., 2008; Savikko, Routasalo, Tilvis, & Pitkala, 2010).

The group of older adults is often frail, subsequent to disability, and in need of help and support (Kjellberg, Hauge-Helgestad, Madsen, & Rasmussen, 2013). To meet the needs of the older adults' home care or a change in home care, services are applied in the shape of home-based rehabilitation (Kjellberg et al., 2013). In Denmark, home-based rehabilitation was launched to help people live independently, reduce hospital admissions, and adjust health services to a rapidly aging population (Danish Health and Medicines Authority, 2016). Among the new rehabilitation initiatives, the health care professionals (HCPs) were encouraged to deal with loneliness among older adults. Danish primary care rehabilitation is based on the white paper framework (Johansen, Rahbek, Møller, & Jensen, 2004) that defines rehabilitation as

A goal-oriented, cooperative process involving a member of the public, his/her relatives, and professionals over a certain period of time. The aim of this process is to ensure that the person in question, who has, or is at risk of having seriously diminished physical, mental and social functions, can achieve independence and a meaningful life. Rehabilitation takes account of the person's situation as a whole and the decisions he or she must make, and knowledge-based measures (p.16).

In addition, a holistic biopsychosocial approach of the International Classification of Functioning, Disability and Health (World Health Organization, 2001) is used as a framework for rehabilitation in Danish primary care (MarselisborgCentret, 2011). According to Wade, the biopsychosocial model may serve as an essential part of rehabilitation (Wade, 2015). The biopsychosocial model ensures that both health care systems and patients look beyond disease and symptoms, and take parameters such as social function and participation into account (Wade, 2015). Overall, there is evidence that rehabilitation can improve health-related quality of life and functional status, along with reducing the costs associated with home care (Ryburn, Wells, & Foreman, 2009; Whitehead, Worthington, Parry, Walker, & Drummond, 2015). The Danish Health Authority emphasizes that older adults' ability to cope with disability through rehabilitation has a tremendous significance for their quality of life (Danish Health and Medicines Authority, 2016). Hence, it is recommended that rehabilitation in primary care is based on the older adults' perception of their own resources to strengthen their ability to manage and cope with daily activities and experience a meaningful everyday life (Danish Health and Medicines Authority, 2016; Johansen et al., 2004). Home-based rehabilitation is defined as

Home-based or domiciliary rehabilitation is an alternative to hospital-based therapy that aims to increase independence and quality of life, on the basis that the home is the ideal setting for

rehabilitation because that is where skills it establishes are to be used. ("<https://informme.org.au/Learning-and-resources/Home-based-rehabilitation>," n.d.)

Rehabilitation at home is of interest because it differs from an institutional setting, and the older adults can participate in rehabilitation as a part of their everyday life in known domestic surroundings, hence have better possibilities to transfer learned competences directly to their lived lives (Danish Health and Medicines Authority, 2016). Home-based rehabilitation is also an area of interest due to the tendency of shorter hospitalizations, causing increased intake and a demand of greater efficiency in primary care (Danish Health and Medicines Authority, 2016). It is recommended that HCPs focus on ways to support coping and motivation, including interventions directed toward loneliness (Danish Health and Medicines Authority, 2016). During rehabilitation, the importance of the HCPs' efforts in motivating the older adults is tremendous regarding the outcome of rehabilitation (Danish Health and Medicines Authority, 2016). The HCPs aim to provide a central role in guiding the older adults, both in finding ways to cope with and in accepting loneliness (Danish Health and Medicines Authority, 2016). A growing number of studies published during the past decades have focused on older adults and loneliness, often consisting of cross-sectional and longitudinal prognostic studies (Honigh-de Vlaming, Haveman-Nies, Heinrich, Van't Veer, & CPGM de Groot, 2013; Kirchhoff, Grøndahl, & Andersen, 2015; Lasgaard, Friis, & Shevlin, 2016; Masi, Chen, Hawkey, & Cacioppo, 2011; Nyqvist et al., 2013). However, none of them explores a home-based rehabilitation setting.

We find that there is a gap in literature concerning older adults' experience of loneliness during home-based rehabilitation. The purpose of this study was, therefore, to describe and interpret the perspectives of older adults with disabilities, and their HCPs on experienced loneliness during home-based rehabilitation.

## Materials and Method

### *Study Design and Participants*

The qualitative inductive methodology, interpretive description, formed the study design (Thorne, 2016). Through answering research questions arising from clinical practice, interpretive description aims at generating new insights to inform practice-oriented research (Handberg, 2016; Thorne, 2016). To obtain practice improvement, interpretive description seeks a conceptual description regarding patterns and relationships in the phenomenon being researched (Handberg, 2016; Thorne, 2016). The study and data construction was conducted in the primary care setting of Syddjurs (the southern part of Djursland, Denmark) that offers a rehabilitation program for older adults seeking home care following disability (Primary Care of Syddjurs, 2017). Rehabilitation is offered to persons who, due to physical, social, or

**Table 1.** Characteristics of the Older Adults With Disabilities, Participating in the Individual Interviews.

	ID 1	ID 2	ID 3	ID 4	ID 5	ID 6	ID 7
Gender	F	F	F	F	F	F	M
Age group	80–89	80–89	80–89	70–79	70–79	80–89	70–79
Occupational status	Retired	Retired	Retired	Retired	Retired	Retired	Retired
Cohabitation	Lives alone	Lives with others	Lives alone	Lives alone	Lives alone	Lives alone	Lives alone
Area of residence	Rural (<40,000 citizens)	Rural (<40,000 citizens)	Rural (<40,000 citizens)	Rural (<40,000 citizens)	Rural (<40,000 citizens)	Rural (<40,000 citizens)	Rural (<40,000 citizens)
Participated in a 10-week rehabilitation program	X	X	X	X	X	X	X
Functional level	Walking distance about 100 m Walks with zimmer frame	Walking distance about 500 m Walks with zimmer frame	Walking distance about 1 km Walks with zimmer frame	Walking distance about 2 km Walks with zimmer frame	Walking distance about 200 m Walks with zimmer frame	Walking distance about 500 m Walks with a cane	Walking distance about 50 m Walks with zimmer frame

psychological disability, experience challenges in managing and coping their everyday life. There are about 350 individual home care rehabilitation programs in the primary care of Syddjurs every year (Primary Care of Syddjurs, 2017). The average rehabilitation program lasts for 10 weeks, and an interdisciplinary team consisting of nurses, home care workers, and therapists collaborates on supporting the older adults in regaining prior functioning and in alleviating social problems (Danish Health and Medicines Authority, 2016). The service is free of charge as part of the National Health System in Denmark (Danish Health and Medicines Authority, 2016).

The interviews were conducted by the first author from February to March 2017 in the primary care setting of Syddjurs. The first author, who conducted all interviews, is a physiotherapist with prior knowledge of home-based rehabilitation of older adults in primary care. The first author used to work in the rehabilitation team 2 years prior to the interviews; so, she had knowledge of the HCPs, but not the participants.

Consecutive sampling in relation to the inclusion criteria was planned for the group of older adults and the HCPs (Thorne, 2016) and the perspectives of both groups on the experience of loneliness were included in the study. Inclusion criteria for the older adults were age of 65 years or more, physically and mentally capable of participating in a 1-hour interview, and participation in the rehabilitation program. The HCPs assisted with the recruitment by referring any eligible older adults to the study. All seven participants meeting the inclusion criteria agreed to participate in the study (Table 1). All five HCPs (all female), who conducted rehabilitation within Syddjurs primary care, were invited (by oral and written information) to participate in the focus group interview, but two fell ill on the day of the interview. Hence, three HCPs (occupational therapists and physiotherapists), aged between 25 and 45 years, participated in the focus group interview. Interview guides were created for both groups of participants and focused on experiences with loneliness in relation to rehabilitation (Thorne, 2016).

### Procedure

Data consisted of seven individual, semistructured, recorded interviews with older adults with disabilities in the rehabilitation program and a semistructured, recorded focus group interview with three HCPs.

*Individual interviews.* The individual interview guide was focused on experiences with loneliness during rehabilitation. Examples of key questions from the interview guide are as follows: “How would you describe the word loneliness?” “In what way do you think that older adults experience loneliness?” “How would you describe the way that you experience loneliness?” “What are your experiences of speaking about loneliness?” and “Have you discussed what might be done to ease the loneliness with the HCPs?” Because the rehabilitation program took place in the homes of the older adults, it seemed appropriate to conduct the interviews in this setting. The first author made appointments with the respondent per telephone. The interviews were conducted during daytime, and, in all cases, the interviewer was alone with the respondent. During two of the interviews, there were interruptions in terms of relatives visiting and a cleaning lady using a vacuum cleaner. One of the interviews was postponed halfway through the interview, and one of the respondents called off the interview after 20 minutes because she found the questions too intrusive. The other six interviews lasted approximately 1 hour. See Table 1 containing the main characteristics of the respondents in the individual interviews.

*Focus group interview.* The focus group interview guide was focused on the HCPs’ perspectives on the older adults’ experiences with loneliness during rehabilitation. Examples of key questions from the focus group interview guide are as follows: “What is important to you when working with rehabilitation?” “What is meaningful to the older adults experiencing loneliness?” and “How do you verbalize loneliness towards the older adults?” The focus group interview was

conducted in a primary care conference room in the primary setting of Syddjurs.

Interview guides, interviews, and transcriptions were collected in Danish. All interviews were recorded. In addition to the interviews, field notes were made on general reflections during the data construction and ongoing analysis. The field notes served as a means of reflection and analysis for the subsequent interview sessions (Thorne, 2016).

### Data Analysis

The design for data analysis was provided by the interpretive description methodology (Thorne, 2016) to generate knowledge leading to a fuller understanding of the older adults' experiences of loneliness, and to better professional, informed decisions about the individual older adult in rehabilitation (Handberg, 2016; Thorne, 2016). The analytical process was conducted in four iterative phases. First, all data were transcribed from the recorded interviews and uploaded to the qualitative software NVivo™ (Handberg, 2016; Thorne, 2016), after which an initial reading and preliminary coding took place. Second, a phase of discernment, where particular circumstances and patterns related to the study aim were identified. Third, a critical appraisal of relationships within data and with relevance of thematic options led to a primary categorization and interpretation. Fourth, an extraction of main messages arising from key insights formed a final interpretation and categorization structure concerning the participants' perspectives on experienced loneliness during rehabilitation (Handberg, 2016; Thorne, 2016).

Throughout the analysis, the authors worked together to ensure validity in an iterative and thoughtful analysis with repeated considerations and discussions on the relationships and interpretations of the data set. The findings were guided by "constant comparative analysis" by shifting attention from the whole data set to the individual case (Handberg, 2016; Thorne, 2016). The final findings were representative for all participants, and moreover, nuances within data were described and elaborated on to ensure envisioning the variability. The interviews were conducted in Danish and quotes were translated to English. An English linguist proofread the entire article.

### Ethics Statement

Ethical approval for the study was obtained at the Danish Data Protection Agency. Potential participants were informed about the study, verbally and in writing, and an informed written consent was obtained from all participants for the collection and registration of personal data. All information regarding informants was anonymized, and the data were stored by law and will be deleted after project completion.

## Results

The findings represent an understanding of older adults' and HCPs' perspectives on experienced loneliness during rehabilitation. Analysis revealed "unspoken pain" and "gatekeeping emotions," which represented loneliness as subject to taboo and stigmatizing during rehabilitation, along with "resignation" and "awaiting company," which described the consequences of loneliness when not addressed.

### Unspoken Pain

According to the older adults, loneliness was one of the hardest issues to talk about, which is why they failed to address their experiences of loneliness with the HCPs during rehabilitation. The older adults referred to the experience of loneliness as a sad and powerless state where nothing happened. They expressed the feeling of loneliness as closely related to a certain kind of longing such as longing for the ones they loved, longing for company, longing for physical contact, and longing for their lost functions. Hence, the older adults blamed themselves and described loneliness as their own personal problem, and they could not share these experiences with others. One of the older women revealed that her experience of loneliness was much too painful for her to talk about, which was why she considered ending the interview.

ID 2: Being lonely is something I would never say out loud anywhere. Which I have told you. It's here and now and that's it.

Several of the older adults told that they would never ask anyone for help to cope with their loneliness.

Interviewer: Do you find it difficult to talk about loneliness?

ID 1: Yes, it actually is. It's probably the hardest thing . . . for me . . . to talk about, I guess. Because there's nothing I can do about it. I feel sort of alone with my loneliness.

Interviewer: What impact do you think this rehabilitation program had on your loneliness?

ID 1: It . . . it . . . nothing, I guess. I'll continue being just as lonely as before. No matter what . . . there's nothing to do about it.

They emphasized that they did not reveal any details or thoughts about their loneliness, to not risk being rejected by their friends or relatives.

Interviewer: Who do you talk to when feeling lonely?

ID2: I don't talk to anyone about it . . . cause it's annoying for my family and friends to listen to. People don't get happier talking about loneliness, so I avoid bringing up the subject.

The experience of loneliness in some ways became self-reinforcing when the older adults were intimidated by how their friends or relatives would react.

ID 4: I'm a bit disappointed that no one comes around to visit, I used to have so many visitors . . . you know? But I understand why they don't want to come around. I'm not interesting anymore. I used to create stuff with my hands. I used to paint beautiful pictures . . . now my hands don't work any longer.

According to the HCPs, articulating psychosocial problems as a part of the rehabilitation program could be hard for the older adults; hence, the HCPs themselves rarely talked directly about loneliness with the older adults in the rehabilitation program. Instead, the HCPs "beat around the bush" and mainly approached the subject of loneliness indirectly. One of the HCPs described how the tough conversations on loneliness often felt like "turning a knife in the wound," because she could tell how painful it was for the older adult. According to the HCPs, speaking openly about loneliness as part of the rehabilitation program could potentially create an uncomfortable situation for both the HCPs and the older adults, especially if there was no intervention to properly meet the older adults' challenges after having opened and shared the experiences of loneliness.

If I'm aware that I'm 'stirring up a hornet's nest' and there's nothing at all I can do about it . . . I know she's extremely lonely, and there is nothing in the world I can do about it. That's a tough situation, because I feel like I expose the citizen and leave her hanging. (C, HCP)

Overall, loneliness remained unaddressed during rehabilitation and, therefore, became a taboo subject for both the older adults and the HCPs. The unspoken pain that accompanied verbalizing loneliness was essentially the reason why the older adults found it safer to cover up the experiences of loneliness and refrain from asking for the support they needed. The older adults were intimidated by how they would appear toward their friends and relatives and by how these would react to their feeling of loneliness. They were afraid that they might appear as socially-not-attractive, which caused a feeling of stigmatization. Hence, their feeling of loneliness became subject to taboo, out of a fear that it would cause an even greater feeling of loneliness if they shared their true feelings.

### *Gatekeeping Emotions*

The older adults stated that they were not quite certain about what the rehabilitation program involved, and they expressed how it had never crossed their minds to articulate their experience of loneliness as part of the program. Furthermore, they explained being uncertain about the agenda of the interventions during rehabilitation, and in addition, the older adults sensed that the HCPs had hidden agendas, for instance, in the shape of social interventions disguised as walks.

ID 3: I don't know why the therapist came here. Well, I honestly don't know what purpose she had. But, you know, there's a lot of people coming here. Some of them came to go for a walk with me. Then we went for a walk. But usually I walk on my own, so I really don't need them.

According to the HCPs, their intentions during rehabilitation were to cover all aspects of the older adults' needs, including their need for company, even though they acknowledged that it was quite challenging to live up to these intentions. When designing the rehabilitation program, the HCPs described how they cooperated with the older adults on setting goals for the program. According to the HCPs, both parties tended to focus on physical needs and goals, which inevitably led to the rehabilitation program focusing on gaining functional independence.

We usually focus on the physical rehabilitation goals. When trying to discuss depression or loneliness . . . the older generation is simply not schooled for discussing those subjects, so we actually don't talk about it. (C, HCP)

Professionally, the HCPs explained that they found a physical approach gentler and more useful with the older adults, to avoid overstepping their boundaries. Hereby, the HCPs revealed how they disguised their approach to make it feel more appropriate. In some cases, the HCPs expressed that loneliness was addressed later in the rehabilitation program, subsequent to the physical issues, when they felt better acquainted with the older adults. At this point in the program, the HCPs said it would be less complicated using a direct approach to address loneliness.

Regarding an issue like loneliness, you might offend someone if you are too direct. In some situations, you must be direct, but it's all about reading the older adult's thoughts, otherwise it serves no one. Because, if you do ask someone who isn't ready for it too directly, they would just clam up and then you might make it even worse. (C, HCP)

By focusing on the older adults' physical needs, instead of psychosocial needs, the HCPs' intentions were to protect the older adults from stigmatization. Intentionally or unintentionally, the HCPs decided whether to bring up sensitive subjects, such as loneliness, and hereby, they served as gatekeepers of the older adults' emotions. Because the HCPs did not encourage the older adults to address their experiences of loneliness as part of rehabilitation, ultimately, the HCPs contributed to treating loneliness as a subject of taboo and stigmatization.

By having hidden agendas, it seemed that the HCPs may have mislead or confused the older adults in their attempt to comprehend the aim and content of rehabilitation as coherent, structured, and predictable. Moreover, the lack of comprehension caused the older adults to believe that they were not actually able to receive help with dealing with loneliness. Thus, it appeared that the HCPs' gatekeeping of emotions

and keeping hidden agendas may have reduced the older adults' motivation and ability to cope with loneliness as part of the rehabilitation program.

### Resignation

The older adults described everyday life after rehabilitation as passive, unsatisfying, and as leading to feelings of despair. Finding a way out of loneliness seemed difficult, and was, in some cases, explained as almost impossible. Several of the older adults experienced loneliness as a condition of life they were not able to cope with.

ID 5: So it [everyday life] has completely changed. I don't usually just sit here staring like this, but I can't see how it could be much different.

The older adults outlined that the feeling of loneliness was constantly present, no matter what, as if there was no way out of it. Since loneliness had "crept" up on them, the older adults described a feeling of inability, as if loneliness had become a part of their personality without them even noticing it. According to the older adults, their behavior had changed, and they were somewhat powerless and hesitant about contacting other people, experiencing the monotony of passing time watching TV.

ID 4: Well, it [everyday life] feels more or less ordinary, right. You get up in the morning, eat your breakfast and then . . . that's it . . . then there is nothing.

Interviewer: What do you mean by nothing?

ID 4: Well, it means I'm doing nothing. Just sitting on the couch watching television or a movie. I watch a lot of television. You get to do that when you are all alone. That's inevitable.

The HCPs recognized the passivity in the older adults during rehabilitation with reference to lack of motivation. According to the HCPs, the reason why the older adults turned down participating in a primary care activity during rehabilitation was that loneliness caused uncertainty and made them unable to relate to new situations. According to the HCPs, it was essential to acknowledge that not all people felt like going to the community center to "hold hands." The HCPs were afraid that the older adults who experienced loneliness might feel like all options were lost when turning down an offer. The HCPs emphasized that they needed interventions that could support the older adults when dealing with loneliness, both during and after rehabilitation, to overcome the older adults' resignation and the consequences hereof.

Finding appropriate intervention methods is challenging. I've seen citizens who cried, because they felt lonely. When talking about it, they say it's because they've lost their husband. But the

longing is unbearable, and who are they supposed to discuss it with? In a situation like this, they don't feel like going to the Centre and make new friends . . . they feel like . . . like staying at home. (B, HCP)

The older adults' experiences of loneliness subsequent to rehabilitation were characterized by resignation and neither the older adults nor the HCPs felt that loneliness issues were handled properly during rehabilitation. Resigning from social activities and staying at home was a mechanism used by the older adults to cope with loneliness. This behavior, they explained, kept them from committing to their friends and relatives and from emerging as socially-not-attractive, which potentially could reinforce the feeling of loneliness. Overall, the older adults could not find meaning in any aspect of their state of loneliness, and they expressed that they did not find it worth dealing with the situation. Hereby, the older adults chose to give up, based on their own interpretation of the situation.

### Awaiting Company

Closely related to the resignation subsequent to rehabilitation, several of the older adults described feeling homebound and socially restricted. Multiple barriers for not being able to attend social contexts were emphasized by the older adults. They mentioned challenges regarding personality, disability, and physical surroundings, which interfered with their ability to socialize. For instance, most of the older adults explained that their walking frame was a barrier for them to get out of their homes. Feeling isolated, the older adults described spending most days sitting at home waiting for somebody to drop by.

ID 1: Right now, everyday life is sort of boring I would say. Obviously, nothing is happening, nothing except from when the care worker comes around to give me a bit to eat. It's a boring day, because nobody visits me voluntarily. If somebody finally shows up, it's great, you know . . . but nobody shows up . . . at least very few do.

In general, the older adults described their relatives to be of the greatest importance to them and they explained that they felt at their best when spending time with their relatives. They described how the feeling of loneliness could change, depending on whether they expected a visitor or not. Yet, several older adults could not tell how often their relatives came to visit. Some relatives came for 1 hour every Saturday and, in some cases, the older adults were in a constant waiting position for their relatives to come and visit. According to the older adults, they experienced the waiting time as a void, afraid of demanding too much of their relatives. The older adults described being hesitant about reaching out to their relatives, because they had their own family to take care of or because they lived far away. Some explained that having close relatives led them to not consider new social

relations. An older woman explained how talking to her son on the phone every day and getting visits from him every weekend covered her need for company. During the interviews, the older adults explained how the care workers were of great importance to them as well. To some older adults, the only social contact during the day would be with the care workers, and to some, the care workers were a close relation and a safety net. This meant that the older adults were waiting for the care worker to visit, and they all expressed that it would mean the world to them if the care worker had the time to sit down and talk.

According to the HCPs, rehabilitation was often strenuous for the older adults because a disability kept them from having the strength to meet new people. They emphasized that the older generation was used to meeting people face to face. The older adults experienced a dependency on their relatives and the care workers to fill a social gap subsequent to rehabilitation. Because of this dependency, the older adults described being careful not to complain or to interrupt the care workers during their visit. The conduct of the older adults indicated that the rehabilitation program failed to provide them with strategies for regaining their independence, which was why the constant awaiting company seemed to take up a major part of the older adults' everyday lives.

## Discussion

This study had several important findings regarding loneliness during a rehabilitation program, from the perspectives of both older adults and their HCPs. According to the findings, unspoken pain, gatekeeping emotions, resignation, and awaiting company were dominating experiences in the lives of the older adults, keeping them from expressing and coping with loneliness during rehabilitation, and in life in general. The HCPs' attempts at helping the older adults cope with loneliness were characterized by the HCPs gatekeeping emotions and having hidden agendas.

Loneliness was perceived by the older adults as subject to taboo because they avoided expressing their feelings of loneliness during rehabilitation. Research on loneliness shows, corresponding to the older adults' experiences, that loneliness is indeed subject to taboo, making it difficult for people who experience loneliness to cope with it (Cacioppo & Patrick, 2008; Gierveld & Van Tilburg, 2011; Killeen, 1998). A reason why the older adults did not speak openly about loneliness during rehabilitation could be related to the fear of being rejected by others; thus, the older adults in this study described how they felt stigmatized, a feeling that may have led to their experiences of passivity and resignation (Cattan, Newell, Bond, & White, 2003). The social stigma related to loneliness is characterized as being very significant because the lack of social bonds and friendships is perceived as socially unfavorable (Rokach, 2012). This pattern is also found among the older adults in this study who were leading solitary lives without involving anyone in their pain. They

found it difficult to establish new relationships and to find the support they needed for handling loneliness, for instance, during rehabilitation.

The unspoken pain that the older adults referred to can be seen as similar to the social pain induced by loneliness, which has a protective function equivalent to physical pain (Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006). Social pain may appear when the individual experiences disconnection from the group that he or she belongs to. This may explain the intensity of the older adults' experiences of pain caused by loneliness (Cacioppo et al., 2006). It is a paradox that the older adults went through the rehabilitation program experiencing this social pain, considering the holistic approach of the rehabilitation program as well as the intended social interventions that should reduce loneliness (Danish Health and Medicines Authority, 2016). It would require both acknowledgment and acceptance from the older adults of their own situation to help each individual verbalize loneliness and, hence, to plan a rehabilitation program that contains concrete objective aims for targeting loneliness (Moustakas, 1972; Rokach, 2014).

By gatekeeping the emotions of the older adults, the HCPs made it almost impossible to speak openly about loneliness, and the HCPs explained that they rarely introduced interventions to reduce loneliness in the rehabilitation program. Literature argues that in rehabilitation, all HCPs hold a significant power in gatekeeping emotions, resources, and services (Hammell, 2006; Handberg, Midtgaard, Nielsen, Thorne, & Lomborg, 2016; Levack, 2009). Thus, it is considered that gatekeeping has an impact on activities in rehabilitation (e.g., goal planning) that raises both ethical and practical questions (Hammell, 2006; Levack, 2009). Accordingly, studies found that home-based rehabilitation is not organized according to the wishes and needs of the older adults (Cattan et al., 2003), partly because the HCPs act as gatekeepers (Lindquist & Tamm, 1999). Hence, it is suggested that HCPs in rehabilitation, to a greater extent, base their approach on the holistic needs of older adults (Chana, Marshall, & Harley, 2016; Lindquist & Tamm, 1999). The HCPs in this study emphasized that they used the holistic approach, but found it challenging to be precise in their description of the possibilities of rehabilitation as well as in involving the older adults in goal setting. Therefore, the HCPs intentionally or unintentionally kept hidden agendas and initiated mainly physical interventions, to meet psychosocial goals and without addressing the underlying causes. This appeared to cause confusion about the purpose of rehabilitation as well as reinforcing the loneliness stigma at the older adults.

Overall, it appears that our findings on unspoken pain and gatekeeping emotions formed a double barrier concerning the prospects of addressing the implications of loneliness during rehabilitation. Addressing loneliness as a part of a more systematic strategy on rehabilitation may prove effective on reducing loneliness. Studies have shown

positive effects and importance of sharing and verbalizing negative emotional experiences (Nils & Rimé, 2012; Rimé, 2009). The HCPs' socioaffective responses may imply reinforced social integration, reduced loneliness, and reduced distress (Nils & Rimé, 2012). Furthermore, it is argued that therapy and support may benefit and relieve the older adults by enabling them to share painful and strong experiences uncensored, without worrying that it might influence their relationships (Rokach, 2014). Overall, this shows that verbalizing loneliness can play a role in breaking the taboo of loneliness and in avoiding its consequences, and that the HCPs play an important role in supporting the older adults to address their feelings of loneliness (Chana et al., 2016) during rehabilitation.

Regarding the finding resignation, the HCPs explained that they tried to oblige to the older adults' resignation, for instance, by offering them activities at the community center. Often these activities turned out to be inadequate for the older adult, and the HCPs did not offer alternative approaches. For the older adults, this led to a reduced manageability of loneliness subsequent to rehabilitation. Therefore, it got even more difficult for the older adults to cope with loneliness in addition to finishing the rehabilitation program along with relating to a different home care service. Evidence shows that interventions developed on a theoretical basis and including group-based interventions to alleviate loneliness seem more likely to be effective (Dickens et al., 2011; Masi et al., 2011; Savikko et al., 2010). Yet, it is suggested that older adults who are not able to attend group-based interventions, for example, at the community center, should be offered similar interventions in their own homes (Cattan et al., 2003). Related to the finding awaiting company, the HCPs emphasized the lack of social interventions both during and after rehabilitation, with a focus on the individual needs, for instance, life after the loss of a relative. The older adults in this study showed a strong need for someone to talk to and said that their care workers were of great importance to them. Hence, it is suggested that because care workers are already familiar with the rehabilitative approach, they would be able to play an important role in supporting the older adults when coping with loneliness (Danish Health and Medicines Authority, 2016; Meldgaard Hansen, 2016).

Barriers for addressing loneliness in rehabilitation were uncovered and identified, and made it possible to guide or advise HCPs to focus on ways to support the older adults better in coping with loneliness. Thus, the HCPs play a central role in changing the present culture and norms on loneliness, in being able to speak openly about loneliness, and in prioritizing loneliness in rehabilitation agendas. Rehabilitation programs, therefore, ought to ensure that all HCPs support older adults in coping with loneliness by breaking the taboo of loneliness, understanding the purpose of rehabilitation, and by gaining positive social relations.

### *Methodological Considerations*

Concerning trustworthiness and credibility, a clear specification of the analytical process was accomplished through stringency and triangulation. With regard to internal validity, this study was framed using semistructured individual interviews and focus group interviews as data sources, which proved to be suitable for an extensive analysis.

This enabled the production of meaningful insights into both the older adults' and the HCPs' perspectives. All participants were highly motivated and committed to sharing their experiences and perspectives on loneliness. Individual interviews were useful for obtaining an in-depth view of the reflections and perspectives of the individual, as well as for gaining focused knowledge on the older adults' experienced loneliness, which may be used to inform the rehabilitation practice. The dynamic group interaction between the HCPs in the focus group interview made it suitable for a collective capitalizing of perspectives on the phenomenon (Thorne, 2016).

Interviews with the older adults were conducted subsequent to rehabilitation, and it should be considered that additional interviews with the older adults during rehabilitation might have added new angles to the study. The experience of the author may have been beneficial to her interaction with both the older adults and the HCPs. The first author was a former colleague with two of the interviewed HCPs in the rehabilitation program, which could potentially affect the HCPs answers. It can potentially be an impediment in case the older adults or the HCPs saw the first author as an insider of the primary care setting, which could lead them to avoid addressing issues that could compromise their own or the researcher's position (Thorne, 2016). In relation to studying in a well-known field, we realize that the first author might have been influenced by her preunderstanding, like leading her to, for instance, overhear important comments or not touch on questions she did not think were relevant. However, the first author got the impression that the participants acted openly and honestly toward her, and did not seem reluctant to share thoughts, feelings, reflections, and perspectives (Thorne, 2016). We realize the likelihood of existing "blind spots" and the importance of continuously taking on the challenge and probing data to look further for elements that might be overlooked because they appear "obvious" (Thorne, 2016).

Purposive sampling was used for recruitment, allowing us to target, respectively, older adults experiencing loneliness and HCPs working in the rehabilitation unit for inclusion (Thorne, 2016). In relation to the focus group interview, a greater variation, and, hereby, multiple angles of perspectives, might have been obtained by including a more diverse group of HCPs, adding both nurses and care workers as well (Thorne, 2016). In addition our study could have been enriched and unfolded by observational research, which might have added to an even deeper insight (Thorne, 2016).



Our sample size was influenced by the length of the inclusion period (2 months), in which all older adults and HCPs who met the inclusion criteria in the period were included. We acknowledge that the sample size is rather small, and acknowledged that, with a longer period, we might have been able to include more participants and, thereby, broaden our perspective with new possible aspects to the inquiry (Thorne, 2016).

Therefore, to obtain more diversity, more participants should have been included. For instance, although it is suggested that rehabilitation services are offered to older adults with physical and mental disabilities, our sample description only represents individuals with physical disabilities, which is considered a limitation. In addition, more participants might have provided the possibility to add diversity with respect to marital status and gender, which are factors that can influence experiences of loneliness (Dahlberg, Andersson, McKee, & Lennartsson, 2015; Franklin et al., 2018).

In addition, it can be argued that focus groups interviews and interviews per se never should be taken entirely at face value, but always regarded as construct in a specific setting and context, designed to achieve particular social actions (Potter & Hepburn, 2005). However interviewing as a strategy for generating data provided knowledge of both the older adults' and the HCPs' perspectives; yet, applying participant observation to the study would have made it possible to observe social interactions between HCPs and the older adults, which might have led to further insights and strengthening the validity (Handberg, 2016; Thorne, 2016). The sample of older adults became more homogeneous than predetermined, because they represented some variety in age, but only little variety in sex and cohabitation. For instance, if more men and younger adults and more cohabitant or married adults had been included, it would have given the study a broader perspective. Women are more likely to admit negative emotions, and it is less socially acceptable for men to reveal experiences of loneliness than for women (Lasgaard & Friis, 2015; Pinquart & Sörensen, 2001), which is why more men in the study might have added a different perspective to what we found. It is acknowledged that the results of this study are limited in terms of what they may suggest about men and about cohabitant or married older adults.

We knew that the HCPs' perspectives on older adults' experiences of loneliness would all come from females (no men were employed in the rehabilitation team). We, therefore, acknowledge that the interview reflects a female perspective, which may have caused the findings to take a different direction than they had if there had been men participating.

Based on international research, there is reason to suppose that loneliness is as widespread and has the same consequences worldwide as in this sample, even though there may be national societal matters that differentiate (Cacioppo

et al., 2006; Jylhä & Jokela, 2008; Killeen, 1998; Luanaigh & Lawlor, 2008; Nyqvist et al., 2013; Ollonqvist et al., 2008; Rokach, 2014; Routasalo & Pitkala, 2003). Important to mention is that the experience of loneliness may be very different in other cultures, where older adults with disabilities still live with extended family (multigenerational and not living alone) and role expectations are intact, or older adults are revered. Regarding external validity, it is estimated that the findings of this study may be considered transferable to other similar home-based rehabilitation contexts.

### *Practice Implications*

The findings of this study suggest areas for further elaboration in future home-based rehabilitation programs for older adults in a primary care setting.

Clinical practice can be guided by the following issues:

- Loneliness in older adults living alone needs to be of high concern in primary care.
- HCPs need to be specifically trained in ways to address and treat loneliness to be able to offer adequate interventions both during and after rehabilitation.
- Developing a research-based, systematic strategy on targeting loneliness, considering the importance of providing information on loneliness and verbalizing it.
- Developing social home-based interventions to support the older adults who are not able to attend group-based interventions in coping with loneliness.
- Make sure that there is follow-up of the older adult participants after the rehabilitation intervention.

### **Conclusion**

As described in this study, the findings illustrate that home-based rehabilitation does not have the right culture for addressing and speaking about loneliness. The perspectives of older adults and their HCPs on experienced loneliness document why loneliness is not addressed in home-based rehabilitation in primary care. According to the findings, unspoken pain, gatekeeping emotions, resignation, and awaiting company were dominating experiences in the lives of the older adults, restraining them from verbalizing and coping with loneliness during rehabilitation, and in life in general. The HCPs' attempts at providing support for the older adults in coping with loneliness appeared to be characterized by the HCPs gatekeeping emotions and keeping hidden agendas. Further research is needed to explore the conduct of HCPs with regard to supporting older adults in addressing loneliness in a rehabilitation setting, as well as the possibilities of social interventions in primary care, to develop systematic approaches for reducing loneliness.

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