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“Longing to be independent again” – A qualitative study on older adults’ experiences of life after hospitalization

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ABSTRACT

It is important to support older adults’ independence after hospitalization and, thus, to increase their perceived quality of life. The present descriptive study took a qualitative approach and aimed to describe older adults’ experiences of their life situation after hospital discharge. Fifteen individuals (≥ 65 years) from two regional hospitals in central Sweden were interviewed between October 2015 and January 2016 in their own home following hospital discharge. The interview data were analyzed using manifest and latent qualitative content analysis. The analysis revealed one theme: “Longing to be independent again” based on four categories: ‘Dependent on other people and aids’, ‘Obstacles, impediments and limitations in daily life’, ‘Adapt to the situation’ and ‘Psychological and physical values’. Understanding older adults’ experiences of life after hospitalization is also a prerequisite for being able to provide person-centered care.

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Introduction

The most common causes of hospitalization in people over 65 years are fall accidents, where hip fractures are most common, followed by other kinds of fractures, stroke and heart failure.¹ The need for rehabilitation and care after hospitalization is often extensive among these patients and may be provided in the home by formal and/or informal caregivers.^{2–4} In Sweden, the county councils and municipalities are required to offer all residents in the county council these services.⁵ How these efforts can be coordinated is regulated in Sweden by the National Board of Health and Welfare,⁶ which emphasizes establishment of a healthcare plan and clearly states what rehabilitation efforts, specific care, support and services are needed if the person is to experience good quality of life and feel independent. When patients are about to be discharged from hospital to their own home, but are still in need of rehabilitation and/or care, a care planning meeting⁷ may be necessary. Participants in this kind of meeting are typically the patient, informal caregivers (family and/or other relatives) and a multidisciplinary team consisting of a nurse. This effort is called transitional care⁸ and involves, according to Coleman and Boulton,⁹ a number of essential elements, e.g., communication between providers about the discharge assessment, a care plan, preparation of the patient and caregiver for the care transition, a follow-up plan,

and patient education. Older patients run an increased risk of poor outcomes in the transition from hospital to home, including failures in communication between providers across healthcare agencies, poor continuity of care and limited access to services.^{10,11} In Sweden, this primarily involves cooperation between the hospital and the receiving municipality. It is important that, before the patient is to return home, municipal nurses receive timely information concerning, e.g., future care needs, rehabilitation needs and other assistance from the hospital.¹² However, it has been shown that transferring this information across professional boundaries can be difficult.¹³ To avoid misunderstandings or mistakes, such as home-help staff who fail to appear or lack of aid equipment needed for activities of daily living (ADL),¹⁴ healthcare professionals must cooperate in a satisfactory manner. Andreassen, Lund, Aadahl and Sørensen¹⁵ interviewed fourteen older adults two to five days after they had been discharged from an acute admission. They showed that the participants’ feelings varied between well-being and lack of well-being. The frailer participants experienced the transition to home to be unsafe and troublesome, whereas the less frail experienced this to a lesser extent. Patients’ transition from hospital to post-discharge healthcare, residential care or the home setting¹⁶ has the potential to disrupt continuity of care and may increase the risk of an adverse event due to inadequate planning of the discharge.¹⁷ After discharge, the person may return home directly with assistance, return home following short-term residential care if more care is needed than can be provided at home or move to a permanent accommodation. One

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principle goal of care of older adults is to maintain their ability to perform basic self-care activities such as bathing, dressing, using the toilet, transferring out of a bed or chair, and eating without assistance. These activities, known as activities of daily living (ADLs), are fundamental to maintaining older people's independence and quality of life. Loss of independence in ADLs is strongly associated with a feeling of lower quality of life.^{18,19} A recently published study by Bruun-Olsen et al.²⁰ revealed that, after having been discharged from hospital, older adults recovering from a hip fracture reported feeling vulnerable and that the fracture disrupted normal life. When older adults, irrespective of previous activity level, cannot be as active as before, the result may be physical deterioration beyond what is expected due to natural aging,²¹ which may lead to poorer quality of life and increased mortality. Providing good quality care of older adults has also been shown to reduce the risk of complications and, consequently, the cost of end-of-life care and municipal care.²² Previous research has shown how important the communication between different caregivers is with regard to avoiding misunderstandings and mistakes when the older adults are cared for after hospital discharge. For this reason, to provide older adults with adequate, timely and sufficient care and support, it is important to examine their experience of their situation at home after having been discharged. Therefore, in the present work, the aim is to describe older adults' experiences of their situation at home after hospital discharge.

Methods

Design

The study was descriptive in design and had a qualitative approach.

Participants

The present study was part of a larger research project, where the inclusion criteria were: 65 years or older prior to hospital discharge and already registered for care planning, including various rehabilitation and/or care activities at home. The exclusion criteria were: needing to be permanently relocated to a nursing home after discharge, needing palliative care or being unable to answer questions due to cognitive impairment. A purposive sample of 15 older, recently hospitalized people was recruited for the present study. Shortly before discharge, they were informed about the present study and invited to participate. Participants were asked about participating in the present study during a previous study they had also participated in, making participation in the previous study an inclusion criterion for the present study. No participants dropped out during the study. A research assistant tied to the project (AB) conducted all of the interviews. The present study included participants from two regional hospitals in central Sweden. Researchers responsible for the research project (AO & B-M S) provided information on people who had given their oral consent to participate in the interview to the assistant, who thereafter contacted them by phone about three weeks after they had been discharged. By that time, the participants had time to think about possible participation, and written consent was then obtained at the time of the interview.

Data collection

Data were collected using individual face-to-face semi-structured interviews²³ in the participants' own home, using an interview guide. The interviews started with a question about their experience of their life situation after discharge from hospital; this was followed by questions about what a normal day could look like and how they experienced the various care activities. To

clarify and develop the participants' answers, follow-up questions²⁴ were posed. The interviews were conducted between October 2015 and January 2016, lasted between 17 and 90 minutes (average 39 minutes) and were recorded on an Mp3 audio recorder. Field notes were taken after each interview,²⁴ documenting where the interview took place, information about the physical environment and non-verbal communication, e.g., crying and facial expressions. The field notes were used in the analysis phase to bring the author back to the specific interview situation and to gain a clearer, deeper understanding of the participant's story. The present study is part of a larger research project; additional findings will be published elsewhere.

Data analysis

The interview data were analyzed using manifest and latent qualitative content analysis as described by Patton²⁴ in accordance with the following steps: 1) all interviews were transcribed verbatim, 2) the transcribed texts were listened through once and read through repeatedly to get an overview of the material and to ensure that the text was consistent with the recorded interviews, 3) using an inductive approach, meaning units were identified that corresponded to the study aim, 4) the meaning units were then condensed and labeled with a code representing the content of the condensed sentence, and 5) the codes expressing similar meaning were grouped into sub-categories and categories. This concluded the manifest part of the analysis. An underlying theme emerged that characterized all of the interviews, concluding the latent analysis. Illustrative quotations from the informants are presented in the findings. Examples from the analysis is presented in [Table 1](#).

Ethical considerations

Ethical approval was granted by the Regional Ethical Review Board (2014/489). The participants were informed orally and in writing about the study aim and procedures. Another aspect of research ethics taken into consideration was the fact that all of the interviews were conducted in the participants' own homes, based on their own preferences. By allowing the participants themselves to choose the time and place of the interviews, their integrity and self-determination were promoted, which became the focus of the entire interview process. The interviewer conducted the interviews in a sensitive manner and would have interrupted them if emotionally difficult situations had occurred or if the participants had seemed uncomfortable with the situation, though this was not discussed during any interview. The interviewer also set aside plenty of time for the interviews, thus giving participants time to talk about any feelings that might arise.

Trustworthiness

In order to strengthen the trustworthiness of the study,^{24,25} credibility and dependability have been considered. All interviews were conducted by one of the authors using the interview guide. Furthermore, the interviewer had also spent sufficient time in the field to establish good communication with the informants, thus displaying prolonged engagement. The data analysis, however, was performed jointly by the first and second authors, and the results were then discussed by all members of the research group. The data analysis process is clearly described in the methodology section of the present study to ensure credibility. Illustrative quotes linked to the theme and each category in the results also enhance the study's credibility.²⁴ Use of the COREQ checklist²⁶ has helped in reporting on the study in a comprehensive and transparent manner.

Table 1
Examples from the data analysis.

Meaning unit	Condensed meaning unit	Code	Sub-category	Category	Theme
But you know, home-help service is... well it's good it exists, but anyway I thought it was a bit... how should I explain...? It was a little forced on me...	Home-help service was forced on me.	Forced assistance	Formal support	Dependent on other persons and aids	"Longing to be independent again"
Because it [my hip fracture] put me in a horrible dilemma of having to call people [family/friends] and ask for help with everything. I couldn't help myself.	I had to call people to get help, I couldn't help myself.	Need the help of others	Informal support	Dependent on other persons and aids	
A motorized tricycle I used to ride around on, but that's over now, because I can't get up on it.	Can't get up on tricycle and can't get out and ride around.	Difficulty getting up on a vehicle	Physical	Obstacles, impediments and limitations in daily life	
I have to get used to walking with it [a prosthesis] all the time.	Have to get used to constantly using a prosthesis.	Continuously using a prosthesis	Physical	Obstacles, impediments and limitations in daily life	
But I try anyway. I walk backwards down the stairs and clean them. I can do it.	But I try, walk backwards down and clean the stairs. I manage it.	Able to clean things my own way	Strategy	Adapt to the situation	
I mean that there are limitations after surgery and then you just have to adapt to it.	Limitations after surgery that you have to adapt to.	Accepting limitations after surgery	Accept	Adapt to the situation	
Yes, you feel like a different person when you're out around other people... happier.	Feel like a happier person when around others.	Happier when around other people	Social interactions	Psychological and Physical values	

Findings

The sociodemographic characteristics of the 15 participants are presented in Table 2. The participants had been hospitalized due to planned hip surgery, hip fracture, arm fracture or severe infection. The length of hospitalization varied between 4–20 days (median 9 days). All participants lived alone, with the exception of one man. The latent analysis revealed a theme: **"Longing to be independent again"** based on four categories: *Dependent on other people and aids*, *Obstacles, impediments and limitations in daily life*, *Adapt to the situation* and *Psychological and physical values* (Table 3).

Longing to be independent again

The overall theme showed that, to manage in daily life, the informants became dependent on other people and aids after hospitalization. Their own physical impediments, as well as environmental obstacles in their own homes, made life complicated. The informants expressed how they tried to adapt to and accept their new situation, and also communicated values that were psychological and physical in nature.

Table 2
Sociodemographic characteristics.

	All	Women	Men
Sex	15	9	6
Age (Md years)(range)	84(70–93)	84(70–93)	85(74–91)
Living in a city	8	6	2
Living in a rural area	7	3	4
Living in an apartment	8	6	2
Living in a terrace house	7	3	4
Living alone	14	9	5
Reason for needing care	3	2	1
- Planned hip surgery	9	5	4
- Hip fracture	1	1	
- Arm fracture	2	1	1
- Severe infection			
Length of hospitalization (Md days) (range)	9(4–20)		

I want to manage on my own... not be a burden on others... but... now I'm thankful for every day I can get up [out of bed] and manage fairly well by myself" (5).

Dependent on other people and aids

After hospitalization, the informants needed support to achieve a manageable, sustainable living situation. The support was provided in the form of *formal support*, staff from the home-help service and/or physiotherapists, but also by their relatives: *informal support*. Many of the informants also needed different kinds of aids to manage their daily life. There was variation in informants' descriptions of their perceptions of the home-help service as well as the kind of assistance they received, from, e.g., weekly cleaning to care several times a day. The informants who had home-help service prior to hospitalization said it was the home-help service staff who enabled them to live in their own homes after discharge. In contrast, the informants with first-time support from home-help service found it intrusive, because they no longer had *"control over their own days"* (3). As one informant said: *"I don't intend to have people around me all the time helping, it doesn't feel natural"* (6). Some informants reported wanting to get to know the staff who came. There were two reasons for this: 1) New staff who had not been in their home previously did not know where to find things, e.g., cleaning supplies. 2) It felt safer and more comfortable when you knew the staff helping with, e.g., showering. One woman said: *"I'd rather switch to a better shower day than to switch a person from home-help service"* (8). Several informants also mentioned that the some decisions, especially when they were supposed to shower, were made by others: *"What bothers me is that they (the home-help service) have decided I should shower twice a week, but that happens when they want it to"* (9). *"It's pretty limiting and I guess everybody feels like that, because everything is planned in a way, it's not normal"* (2). The formal support also included visits from physiotherapists, who were responsible for rehabilitation programs and/or various aids. Several informants reported having a portable toilet next to the bed temporarily, until their walking ability improved, thus facilitating use of the toilet at night. Other informants described the value of having a motorized bed and a raised toilet

Table 3
Theme, categories and sub-categories revealed from the analysis.

Theme	<i>"Longing to be independent again"</i>			
Categories	Dependent on other persons and aids	Obstacles in daily life	Adapt to the situation	Psychological and Physical values
Sub-categories	Formal support Informal support	Physical Environmental	Strategy Acceptens	Being outdoors Social interactions

seat, both of which facilitated the period after hip surgery. All informants had a safety alarm. Some could not see *"anything positive at all"* about the safety alarm, just the feeling it was *"only in the way,"* while others saw it as a great source of security: *"... this (points at safety alarm) is a real source of security, it's like having someone beside you all the time. You feel safe"* (5). The informants felt that the physiotherapists both increased their faith in their own abilities and encouraged them to *"dare more."* The informants also felt that the physiotherapists were highly engaged in helping them achieve goals such as *"dancing again in the senior dance group"* (12), *"walking the stairs up to my daughter's house"* (7) and *"driving my car again"* (15). Several of the informants also received informal support. This mainly came from relatives, especially children, but also from siblings, close friends or neighbors. The informants talked about the great support these people gave them, both emotionally and practically. Practically, they helped with cleaning, shopping, cooking, contact with home-help care and accompanying informants to doctor's appointments or hospital visits. One informant mentioned that she asked her children for practical help, but preferred turning to a friend of her own age for emotional support, meaning that it felt as though the friend was *"on the same level"* (1).

Obstacles, impediments and limitations in daily life

The limitations the participants experienced in daily life were described as *physical impediments and/or environmental obstacles* and were perceived as entailing a loss of independence. This adverse situation created feelings of sadness, and as one informant said: *"the life that existed before hospitalization is now no longer possible due to my house and home, and body and soul ..."* (11).

The informants described bodily impediments that had emerged during and after hospitalization, thus impacting their daily life. These impediments could involve different kinds of pain situations (e.g., due to the injury or disease), reduced strength, and hospitalization complications, such as infections, side effects from medicines, etc. They made several activities they could do by themselves before being hospitalized difficult, e.g., going to the grocery store, library or doing chores like the laundry, without any help in the form of formal and/or informal support. The impediments also meant no longer being able to drive a car, visit friends spontaneously, help babysit the grandchildren or walk the dog. Due to the informants' injury or disease, environmental obstacles also emerged. Some of the informants' homes needed to be rebuilt to make room for the aids they needed to manage in daily life. In a number of cases, rebuilding meant having to move out of their home for several weeks. After getting a walker and/or wheelchair, some informants could no longer reach or go out onto their balcony or into the garden independently, due to, e.g., high thresholds or narrow doorways (narrower than their wheelchair): *"I can't get out of my wheelchair any more ... before (the operation) I could walk and move around and go wherever I wanted"* (1).

Adapt to the situation

The informants described ways to deal with their new or changed life situation, either by developing different kinds of strategies to motivate them to keep going and/or just accepting the situation as it is.

"That's what my life looks like now. But you might as well accept it and hang in there as long as you can" (12).

The informants described accepting their life situation *"as it is"* (11) and actively taking measures to deal with it. They mentioned that acceptance concerned their changed life situation after hospitalization, but also changes associated with getting older. Acceptance of aging meant accepting that physical functions deteriorate as part of a natural process. Many informants reported accepting the bodily limitations that arose after injury, surgery or illness. Acceptance involved understanding that: *"after a hospital stay, the body may not be like it was before"* (12), but also that rehabilitation takes longer when you get older. Moreover, acceptance involved understanding that there will be different needs and new people – home-help staff – in their daily lives. Some, however, saw the presence of such services as a *"transitional period"* (15) that would not last forever because their physical abilities would improve. The informants said they found it easier to accept the home-help service if they kept possible improvement in mind. Several informants also mentioned accepting *"that life is coming to its end"* (3) and that there is no need to be depressed over their current situation. There was an acceptance characterized by *"being ready for life and living it according to existing conditions"* (7). All informants reported that they, in one way or another, had needed to change something in their daily life after hospitalization. Adjustments were needed owing to their decreased physical ability after an accident or planned operation. One informant said: *"You can't live the way you used to anymore, and when that became obvious then the adjustments started"* (10). The adjustments sometimes involved giving up activities they had previously been engaged in, e.g., leaving the board for the condominium one lived in. Another participant had talked to her daughter about no longer being able to take care of her dog. Still another said she could only help her daughter with the grandchildren when she had enough energy to do so, whereas before hospitalization she was always ready to help. The informants also mentioned having adapted to decreased physical functioning by taking shorter walks, walking on asphalt instead of in the forest or sitting at the kitchen table looking at the birds outside the window instead of going outdoors. One informant reported using the television as *"a way to travel"* (2) to different countries, now that this was no longer possible in real life. Other ways to adapt to the new life situation included eating more food to build muscle mass, eating ready-made food and using a shower chair to allow independent showering. The informants also mentioned that motivation was needed to do rehabilitation exercises, household chores or activities adapted to their current functional abilities and to achieve established goals. One informant said: *"you always need a carrot, everyone needs them"* (5), referring to having a strategy for finding motivation.

Psychological and physical values

The informants mentioned various values in life, both values that had been important to them prior to hospitalization and values for their present situation. However, some values made it clear that their life situation had changed in both positive and negative ways. What the informants' experiences of hospitalization meant for their current life situation varied. For those who had been hospitalized for a

planned operation, e.g., hip surgery, the new life circumstances created new opportunities because the surgery meant pain relief and being able to engage in activities they previously could not manage. Some informants said that being able to cancel some home-help services was evidence that they were on the path to recovery and independence, perhaps even returning to their pre-hospitalization health status. The informants also described the value of maintaining the everyday activities and routines they engaged in prior to hospitalization. Another value the informants mentioned was the importance of being and going outdoors – for some just going out onto the balcony, for others being in the forest: “*It’s so wonderful what the fresh air outdoors does for my well-being*” (1). Being outdoors even allowed them to stop thinking about their own physical impediments, and instead focus on experiencing nature. One informant talked about how, prior to hospitalization, she valued being out in the forest picking berries, something she could no longer do by herself due to bodily obstacles. Several of the informants also reported how important social activities were to them. Interacting with neighbors, friends, former colleagues, children or grandchildren increased the informants’ perceived “*quality of the life*” (6) and independence. One informant mentioned that social interaction was also of great value in maintaining necessary activities: “*It’s easier to make food when a neighbor’s going to come over*” (8). Some informants reported that being without social interaction had been much easier to deal with prior to hospitalization, but now when they absolutely not could go out and see their friends, they felt very sad.

Discussion

In the present study, older adults described their experiences of life after hospital discharge. They longed for an independent life, hence the limitations that prevented them from being independent were both physical and environmental. To manage obstacles in daily life, the older adults used different kinds of strategies and described the support they needed. The participants also described psychological and physical values of importance to them, both prior to and after their hospitalization. Several previous studies have found that older adults desire to be independent after hospitalization (cf.^{27,28}); studies also have shown the positive effects of independence on quality of life.^{29,30} The participants talked about the various limitations that reduced their ability to be independent. The physical impediments included pain or trouble walking, and the environmental obstacles could be, e.g., high thresholds. Such limitations had led to reduced ability to participate in social activities, and the informants could no longer visit family members or friends as before. This has also been demonstrated in other studies showing the long-lasting consequences for people with a hip fracture.^{29,31} It is therefore important that older people be given the opportunity to receive exercise-based rehabilitation at home after hospitalization. Studies have shown that exercised-based rehabilitation at home can improve functional ability and increase independence.^{32,33} In the present study, the formal support provided by physical therapists was of great importance to the participants. Some participants wished they could perform the chores the home-help staff did by themselves, even though they understood it was this help that had allowed them to go home after hospitalization. Some older adults also described the help provided by the home-help staff as violating their privacy, because they no longer had control over their own daily schedule. Instead it was the staff who decided, e.g., when it was time to shower (cf.³⁴). A systematic review by Gregory et al.³⁵ revealed that older adults found it important to defend their privacy and to be able to make choices about their own care. This shows the significance of person-centered care in increasing older people’s satisfaction with care. Other studies have also shown the importance of staff adopting a person-centered approach, which improves older people’s ability to influence their

care,^{36–38} as well as the importance of care being designed to maintain older adults’ autonomy and participation.³⁹ Discharge coordination and planning plays an increasingly important role in making the transition from hospital to home more effective.^{9–11} Naylor and Keating⁴⁰ described several problems that commonly occur when older adults are transferred from hospital to home, revealing that nurse-led interdisciplinary interventions improved the quality of life for older adults during this process. It might be difficult to see the whole situation for every authority/organization, because healthcare is run by several (hospitals/municipalities), and thus it is only the older adult who experiences the whole. This is why it’s important for professionals to gain more knowledge from older adults about how they experience transitional care, as this will help the healthcare system design person-centered care and, thereby, enable improved quality of life. When the discharge planning process fails to identify and/or address a patient’s care needs, the risk of hospital readmission is elevated and the length of the hospital stay may be longer. Previous studies have revealed factors that might cause readmission to hospital among older adults (cf.⁴¹). In another systematic review, Pascale Blakey et al.⁴¹ found that older adults perceived readmission to hospital to be challenging and associated with negative emotions and decreased well-being. They felt they were not part of the decision-making process.⁴¹ A recently published study by Forsman and Svensson⁴² also found that the noisy surroundings at hospitals made it difficult for older adults to participate in the decision-making process in a satisfactory manner. The discharge process therefore requires multidisciplinary collaboration, and the patients themselves as well as relatives should have the option to play an active role in the process. Participants in the present study also talked about the importance of the informal care provided by relatives or friends, some indicating this care was the only reason they could still live at home. Such informal care is common and places great demands on informal caregivers.^{43,44} It has also been shown that the amount of informal care is typically greater than the amount of formal care, and that care needs decrease with increased independence.^{45,46} For this reason, is it important both for the older adult and for the informal caregiver to be given professional support, the goal being to decrease the older adults’ level of dependency. Furthermore, the participants developed different strategies to adapt to their new life situation, a finding also described in previous studies.^{47–49} Nurses and other healthcare professionals may need to help older adults find a coping strategy that gives them motivation, because negative thoughts can lead to deterioration in physical functioning.⁵⁰ The participants in the present study described different values in life that were important to them, e.g., being outdoors or doing activities with others, and such values have also been described as important by older adults in earlier studies.^{51–53}

Conclusion

The present study provides some empirical evidence concerning older adults’ experiences of their life situation following hospitalization. It is important to gain in-depth knowledge about how older adults experience their life situation as well as different forms of care and care initiatives after hospitalization. Such knowledge could help health professionals enhance older adults’ independence and participation in decisions concerning their own care and possible rehabilitation programs. The present findings are of clinical significance for both the design and type of support offered to older adults after hospitalization. This is because understanding older adults’ experiences after hospitalization is a prerequisite for offering person-centered care, for meeting society’s increasing needs for well-designed older adult care as well as for avoiding re-hospitalization among the older population.

Limitations

The study's limitations include, but are not confined to, the transferability of the findings. Thus, detailed and thick data description was applied to give other researchers full insight into the steps of the research process. One weakness of the study might be that the verbatim transcripts were not returned to the informants for confirmation (member-check/ confirmability). Regarding design, a descriptive study and a qualitative approach were chosen. This choice was based on the study aim and the desire to obtain a meaningful overview of the investigated phenomena, thus a small sample of participants.

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