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Research Article

“I Feel Worn Out, as if I Neglected Myself”: Older Patients’ Perspectives on Post-hospital Symptoms After Acute Hospitalization

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Abstract

Background: The transition between hospital and home is a vulnerable period for acutely hospitalized older patients during which they are at increased risk for adverse health outcomes. Yet, studies describing experiences of a geriatric patient population postdischarge from a patient perspective are missing.

Objective: To characterize patient experiences with recovering at home after acute hospitalization.

Design and Methods: Qualitative semi-structured interviews, involving 20 recently discharged patients (age ≥ 70), were conducted. A thematic analysis of the content was performed.

Results: Ten categories were identified as recurring topics, which were grouped into 3 major themes. The first theme describes the effect of hospitalization on daily life. Participants described that the problems they encountered were mostly caused by symptoms they experienced since discharge, which were grouped into 2 themes: (a) physical consequences of hospitalization and (b) motivational and psychological problems after hospitalization. Among most frequently presented symptoms were fatigue, apathy, unsteadiness while standing, and fear of falling.

Implications: Impairment in mobility and instrumental activities of daily living was the dominant experience for interviewed patients. This disability was mainly attributed to four main symptoms: fatigue, apathy, unsteadiness while standing, and fear of falling. We propose a tentative model that summarizes the role of posthospital symptoms in the recovery process and the potential syndromes (frailty, posthospital syndrome, palliative symptoms, and sickness behavior) that could underlie these shared symptoms which may act as a conceptual framework for future research. Our study points at the relevance of symptom experiences in functional recovery postdischarge.

Keywords: Acute hospitalization, Older patients, Posthospitalization, Symptoms, Activities of daily living

For acutely hospitalized older patients, the transition from hospital care to home reflects a vulnerable period during which patients are at a high risk for adverse health outcomes. More than 30% of patients aged 65 or older experience hospitalization-associated disability (HAD), defined as a loss of one or more activities of daily living (ADL), compared to 2 weeks before hospitalization (Buurman et al., 2011; Gill, Allore, Gahbauer, & Murphy, 2010; Zisberg, Shadmi, Gur-Yaish, Tonkikh, & Sinoff, 2015). Postdischarge mortality can be as high as 25% (Boyd et al., 2008; Clark et al., 2014; Walter et al., 2001), and 20% of patients require a second hospital stay within 30 days postdischarge (Kansagara et al., 2011).

The harmful consequences of hospitalization come as an unpleasant surprise to many older patients: they expect to leave the hospital in a better condition (Boltz, Capezuti, Shabbat, & Hall, 2010), but instead encounter unforeseen problems with mobility and self-care (Greysen et al., 2014; Neiterman, Wodchis, & Bourgeault, 2015). The 30-day postdischarge period, in particular, has been marked as a crucial window for recovery from the disabilities developed during hospitalization, and absent of recovery from HAD by 1 month predicts persistent disability and even mortality (Boyd et al., 2008). Importantly, during this period the patient has an increased vulnerability to develop new acute conditions, resulting in a high rate of readmissions (Dharmarajan et al., 2015).

Recent efforts to improve discharge and transitional care have resulted in decreased readmission rates and addressed challenges such as medication reconciliation and medical management (Hesslink et al., 2012; Prvu Bettger et al., 2012). Moreover, Naylor and colleagues (2013) underscore the importance of symptom assessment and management in transitional care interventions, which evidently provides an important contribution to their positive effect (Verhaegh et al., 2014). However, interventions that specifically support recovery from HAD postdischarge are still sparse (Bray-Hall, 2012), and a lack of proper patient engagement and preparation after hospitalization underscores the need for transitional care interventions with a focus on patients' vulnerable health status postdischarge (Krumholz, 2013; Naylor et al., 2017).

Earlier studies have mostly identified generic risk factors for HAD, such as age and the severity of the index admission (Covinsky, Pierluissi, & Johnston, 2011), and much research has limited its focus to health outcomes and other medical aspects after hospital discharge, including functional decline, readmission, and mortality. Research further shows that geriatric syndromes such as mobility impairment, lack of appetite, incontinence, and depressive symptoms, present at hospitalization or which may develop or deteriorate during hospitalization, are important risk factors for poor posthospitalization outcomes (Anpalahan & Gibson, 2008; Bell et al., 2016; Buurman et al., 2011; Hoogerduijn, Schuurmans, Duijnste, de Rooij, & Grypdonck, 2007; Lakhan et al., 2011; Simmons

et al., 2016; Wang, Sheu, Shyu, Chang, & Li, 2014). Scant attention has, however, been paid to the patient's perspective on recovery and the symptoms they experience postdischarge. Available research focused on select patient population and have, for example, identified fatigue as a frequent patient-reported outcome among surgical patients (DeCherney, Bachmann, Isaacson, & Gall, 2002; Zargar-Shoshtari & Hill, 2009) and stroke patients (Glader, Stegmayr, & Asplund, 2002; Morley, Jackson, & Mead, 2005). Also, among older patients with co-morbid mental health problems symptoms such as apathy, anxiety, and difficulty sleeping have been described for posthospitalization (Bradshaw et al., 2013). However, currently missing are studies characterizing experiences of a general geriatric patient population in the wake of being discharged after an acute hospitalization.

To provide a rich understanding of participants' experiences after acute hospitalization, a qualitative research approach was applied, as it allows for a detailed exploration of individual experiences (Curry, Nembhard, & Bradley, 2009; Malterud, 2001). To summarize, the objective of this qualitative study was to characterize patient experiences regarding recovery at home during the first month after an acute hospitalization. Specifically, during semi-structured interviews patients were invited to describe which posthospitalization symptoms they experienced in the first 2–3 weeks after discharge, their experience of posthospitalization symptoms, and how they perceived those symptoms to impact their daily life. A secondary aim was to utilize this information to formulate a conceptual framework that may guide future research in this area.

Methods

Study Setting and Sample

The study was conducted between February and May 2015 in the Netherlands. Community-dwelling older individuals aged ≥ 70 , who had been acutely hospitalized were recruited from the cardiology and internal medicine wards in a 1024-bed tertiary teaching hospital, the Academic Medical Center in Amsterdam, and from a geriatric medicine ward in a 708-bed regional teaching hospital, the Gelre hospital in Apeldoorn. Exclusion criteria were: (a) being cognitive impaired (Minimal Mental State Examination < 20 ; Folstein, Folstein, & McHugh, 1975); (b) inability to speak or understand Dutch; (c) being terminally ill; (d) admission to another inpatient care setting after discharge.

Procedures

To gain a comprehensive insight into the patient's perspective on recovery at home after acute hospitalization and posthospitalization symptoms, it was decided to conduct semi-structured interviews. This method is particularly effective for gathering data when the research objective

concerns the perspective of people as it allows for a detailed and in-depth exploration of patient experiences (Barriball & While, 1994; Curry et al., 2009; Malterud, 2001). In light of the fact that the first month after discharge represents a critical period for recovery (Boyd et al., 2008), the semi-structured interviews were conducted in the second or third week after discharge. As part of recruitment at the Academic Medical Center (AMC), a daily discharge list was checked and one of the authors (R. v. S.), who is employed as a researcher at the department of geriatrics at the AMC, contacted eligible participants by telephone. At the Gelre hospital, a geriatrician (B. C. v. M.) asked eligible patients 1 or 2 days before discharge permission for R. v. S. to approach them for possible participation. After permission was given by the participants, R. v. S. contacted these patients by telephone after discharge. If patients confirmed willingness to participate an appointment for an interview was made.

We aimed to characterize the patient perspective on recovery and to understand patient experiences of symptoms in the first weeks after discharge. For this purpose, an interview guide was developed to specifically assess these aspects. First, R. v. S. and B. M. B. developed a draft of the interview guide. The interview guide was then discussed with the research team, which generated complementary ideas on questions, upon which the interview guide was adjusted again. Thereafter, the interview guide was pilot tested. After two interviews the interview guide was critically reviewed by R. v. S. and L. A. R. and adjusted again. Over the course of data collection the interview questions underwent minor modifications.

The interviews began with a short introduction by the researcher and clarification of the study aim, and participants were invited to introduce themselves. Then, several questions were asked with regards to experiences with recovery and ADL since hospital discharge. Some example questions are: "Since leaving the hospital, were there difficulties with performing your daily activities?"; and "Since leaving the hospital, did you experience any complaints?" We note that the interview guide also allowed probing for more information and allowed participants to reflect and share their experiences freely (Barriball & While, 1994). As we aimed to gain an understanding of patient experiences of symptoms, probes were used to evoke a more detailed response when participants stated which symptoms they experienced. Some examples of probing questions were: "How do you experience this particular symptom?"; "Is this particular symptom affecting your daily life?" Also, probing questions were asked when participants shared their experiences with difficulties in performing their daily activities by, for example, asking what was causing these difficulties. Most participants shared their experiences of symptoms after being asked these questions, but when the interviewee had difficulties describing which exact symptoms he or she experienced, a list of 24 prespecified symptoms leading to restricting in daily activities was used to

ask about specific symptoms (Chaudhry et al., 2013; Gill, Desai, Gahbauer, Holford, & Williams, 2001). When participants stated they experienced particular symptoms of this list since discharge, similar probes as described above were used to evoke a more detailed response.

One of the authors (R. v. S.) conducted all interviews. The interviews took place at participants' homes and took between 1.5 and 3 h. Written informed consent was obtained before the interview. Although family members were not actively recruited for participation, occasional family members indicated they preferred to stay present, and it was decided to not ignore them during the interviews. Verbal informed consent was obtained from these family members for using their input for data analysis and using anonymized quotes for scientific publication. Such quotes were occasionally used to add context to the statements of the patients (e.g., to indicate that a statement was not a direct response to the interviewer). Notes with initial interpretive comments were made during the interviews, which were used to verbally summarize the interviews. The notes were discussed with the participants immediately after the interview for comments and/or corrections. Also, notes were made on the setting and circumstances of the interview for recall of the context of each interview. Interviews were held until saturation was achieved on the content, that is, no new information emerged from the data on the topic of interest (Guest, Bunce, & Johnson, 2006), namely the effect of hospitalization on daily life and the posthospitalization symptoms patients experienced.

Data Analysis

To identify, analyze, and report patterns in the data a thematic analysis of the content was performed (Braun & Clarke, 2006). As we aimed to report patient experiences with recovery at home, an essentialist analysis method was used and an inductive thematic coding approach was performed for data analysis, without the use of a pre-existing coding frame. Furthermore, we aimed to provide a rich thematic description of the entire data set to get a sense of all predominant and important concepts rather than a detailed description of some themes.

A coding structure was developed iteratively. R. v. S. and L. A. R. read each transcript to become familiar with the data. Initial categories were identified using an open coding approach—R.v.S. and L.R. coded all relevant topics while reading through the transcripts. The identified categories were grouped into themes based on similarities, and connections were made between the different categories and themes that derived through open coding. By re-coding the data iteratively, it was decided whether the identified themes and categories had enough data to support them and which of the themes had to be removed. For example, first it appeared that categories emerged on symptoms such as pain and anxiety. However, there was not enough data to support these categories, upon which they were removed.

It also occurred that categories were merged together. For example, fatigue and sleepiness during the day were initially two separate codes, but as these symptoms were often mentioned together it was decided to merge them into one category. Data analysis was thoroughly discussed within the research team and the team agreed on the final coding structure and the included themes and categories. Upon deciding on a final coding structure, R. v. S. and L. A. R. re-coded all interviews independently. Quotes were labeled with relevant codes and translated into English. Examples of codes are symptoms such as fatigue and apathy, and codes pertaining to the effect of hospitalization on daily life. Discrepancies between R. v. S. and L. A. R. were resolved through discussion and consensus within the research team. The study leader (B. M. B.) provided supervision during data analysis to ensure reliability and integrity of data. For the data coding process, the computer program MAXQDA 11 was used.

A secondary aim of this study was to develop a conceptual framework by integrating the present analyses with the existent literature. This model was developed on the basis of reflection on the data, the relevant literature, and their integration through in-depth discussions within our research team. The existing literature was consulted with the perspective to identify information on possible mechanisms that may underlie our findings. Through this synthesis, we aimed to provide a tentative framework for further

research and adaption of transitional care interventions that include symptom management postdischarge.

Ethical Considerations

The Medical Ethics Research Committee of the Academic Medical Center confirmed that the Medical Research Involving Human Subjects Act did not apply to the research project. Official approval by the committee was hence not required.

Results

Twenty participants, mean age of 82.7 (SD = 7.82) (13 female), were included (Table 1). After 18 interviews saturation of the data emerged as no new themes or categories were observed in the data with regard to the effect of hospitalization on daily life and posthospitalization symptoms patients experienced. Sixteen participants were recruited from the Academic Medical Center. All participants were community dwelling, of which 10 were living with their partner. A participant's partner or child was present during nine interviews, and for two of those interviews only part of the time.

On the basis of the iterative analyses, in line with the methods described above, 10 categories were identified as recurring topics in most interviews. These were grouped into three major themes (Table 2). The first theme describes

Table 1. Patient Characteristics

Participant	Gender	Age	Marital status	Diagnose	Length of hospital stay (days)	Family member present during interview?
1.	Male	96	Widow—living alone	Pneumonia	19	Yes, daughter (partly present)
2.	Female	86	Living with partner	Dyspnoea	4	Yes, partner
3.	Male	71	Living with partner	Sepsis	9	Yes, partner
4.	Male	81	Living with partner	Dyspnoea	4	Yes, partner
5.	Male	84	Living with partner	Dyspnoea	4	Yes, partner
6.	Female	90	Widow—living alone	Pneumonia, urinary infection	9	No
7.	Female	71	Widow—living alone	Pneumonia	6	No
8.	Female	91	Single	Heart failure	7	No
9.	Female	78	Living with partner	Urinary infection	19	Yes, partner
10.	Female	98	Widow—living alone	Heart failure	6	No
11.	Male	77	Living with partner	Dyspnoea	4	Yes, partner
12.	Female	81	Widow—living alone	Dyspnoea	12	No
13.	Female	86	Living with partner	Bacterial infection	7	Yes, partner (partly present)
14.	Male	72	Widower—living alone	Pneumonia	9	No
15.	Female	72	Living with partner	CMV-infection	19	No
16.	Female	86	Widow—living alone	Heart failure	4	No
17.	Female	83	Living with partner	Pulmonary embolism	7	Yes, partner
18.	Female	81	Widow—living alone	Dyspnoea	10	No
19.	Male	82	Living with partner	Bacterial infection	22	No
20.	Female	88	Widow—living alone	Dysregulated diabetes	14	No

Table 2. Categories and Themes

Categories	Themes
1. Transition to home	The effect of hospitalization on daily life
2. Impairment in daily functioning	
3. Increased need of help	
5. Stiffness and muscle weakness	Physical consequences of hospitalization
6. Unsteadiness/dizziness while standing	
7. Weight loss and poor appetite	
8. Fatigue	
9. Apathy	Motivational and psychological problems after hospitalization
10. Fear of falling	

the effect of hospitalization on daily life (transition from hospital to home, impairment in daily functioning, and increased need of help). Participants described that the problems they encountered with activities were mostly caused by the symptoms they experienced since hospital discharge, which were grouped into two themes: (a) physical consequences of hospitalization (stiffness and muscle weakness, unsteadiness/dizziness while standing, weight loss and poor appetite, and fatigue); (b) motivational and psychological problems after hospitalization (apathy and fear of falling). In the following paragraphs, we describe the themes and categories derived from the interviews, illustrating them by quotations from the interviews.

Theme 1—The Effect of Hospitalization on Daily Life

All patients were looking forward to go home and stated they were happy to be discharged from the hospital. However, although glad to be home, being on their own again presented some challenges as well. Many participants encountered difficulties in daily life after they were acutely hospitalized and they were not able to perform all activities as they were used to before hospitalization due to their hospital stay. Subsequently, they were more dependent and experienced an increased need for help, which, according to the participants, could be frustrating. Hence, three categories emerged under the theme “the effect of hospitalization on daily life”: transition from hospital to home; impairment in daily functioning; and increased need of help.

Transition From Hospital to Home

The majority of participants indicated that they did not worry about their hospitalization, stayed calm during their hospital stay, and were all satisfied with the quality of care. Nevertheless, most participants indicated they were happy to return back home and felt that the transition from the hospital to their homes went well. However, returning home created insecurity among some of the participants and they had to get used to being home as they felt like they were suddenly on their own again. It appeared that

being hospitalized felt convenient, as help was available. Also, several participants indicated that hospitalization was pleasant due to the company they had there. Particularly patients who were living on their own, had to get used to being alone after hospital discharge..

It's a major transition, in the hospital everything is being done for you. But then you get home. (...) Well, you'd just have to take care. And on top I also had a bladder infection. (...) My daughter does a lot for me but she only pays short visits. (...) For the remainder of the day you're alone, you know? And I'm used to that but actually, at the hospital, it was cozy with roommates. I missed that when I came home, you know? P10 (F) 98

Impairment in Daily Functioning

The majority of participants felt that they declined in function since hospitalization. Subsequently, some participants had difficulties with their basic ADL, such as bathing and dressing and the vast majority of participants encountered difficulties in instrumental activities of daily living (IADL), such as cooking and grocery shopping.

I went grocery shopping with my son last Saturday and I felt so weird. Like where am I ... I wasn't ready for it and I was happy my son was there. (...) I wasn't ready for it, while I was perfectly able to go grocery shopping alone before. P7 (F) 71

Also, many participants indicated they had not taken up their usual leisure activities after discharge. For example, one participant had not started with art painting after she returned home, and another had stopped playing billiards and other activities:

Participant's daughter: Your activities, like playing billiards, playing cards and visiting the navy are currently on hold. Participant: Yes no, with billiards, I'm not running around the pool table anymore, no way! I write these days! (...) Writing down scores you know. P1 (M) 96

Two others had not attended their seniors gym classes since they returned home. For some of the participants going for walks became problematic, and others indicated they had problems working in their garden since discharge. Furthermore, it was often mentioned that participants were not visiting neighbors or friends. All participants indicated they hoped they would pick up their old habits again soon.

I always visited another old lady at the end of the street to play board games. (...) I hope we can do that again because I enjoyed doing that (...). When I'm ready for it I will go again but I am not able to sit at the table for that long and to walk that far. But I hope I can visit her again because she likes it as well. P10 (F) 98

Increased Need of Help

As a consequence of their impairment in daily functioning, many of the participants became increasingly dependent and in need of help. Therefore, some participants received home care since discharge, but mainly informal caregivers were providing the care that participants needed. It was often mentioned that it was frustrating to be dependent on the help of others as they rather performed their daily activities independently. One participant explained that he felt so helpless, waiting for others to take him outside. Although participants indicated they appreciated the help they received, being dependent also made them feel as though they were a burden, because they had to ask their loved ones for help.

My children, they do so much for me. And I feel like they are stuck with me. I don't like that. You're getting so dependent, you know. I hate that so much. (...) You have to accept it, but it's so hard. I hate it to ask my children to do things for me. (...) But last week my son spontaneously started cleaning my doorstep—and I was so happy I hadn't asked. P10 (F) 98

Theme 2—Physical Consequences of Hospitalization

The vast majority of the participants indicated they felt that hospitalization had a negative impact on their physical health. Participants were not able to perform the activities they were used to do, mainly due to the physical consequences of hospitalization. Four categories were classified under the theme “physical consequences of hospitalization”: stiffness and muscle weakness; unsteadiness/dizziness while standing; weight loss and poor appetite; and fatigue.

Stiffness and Muscle Weakness

As many participants were bedridden or inactive for quite some time, they felt the negative consequences of bed rest on their body. In particular, the physical impact of hospitalization was reflected in the stiffness and muscle weakness participants felt after hospitalization.

How things are going? Well, I was bedridden for almost one month of course. Because of that I'm still feeling so stiff now. In the hospital I wasn't able to get out of bed. Well, now at least I can get out of bed. (...) I came, so to speak, as a dead body out of bed the first time. (...) You can't even start to compare how I feel now with how I felt before hospitalization. It's incomparable! P19 (M) 82

Some participants felt that their arm strength declined, resulting in, for example, difficulties cooking. Many participants indicated loss of strength in their legs, resulting

in walking problems—hampering participants in their mobility. It came up that this was quite bothersome in certain situations. For example, one participant was forced to stop shopping as she was no longer able to walk due to a loss of muscle strength in her legs:

This week I went to drugstore, which is really small. So I left my mobility scooter outside. I was half way through it and I thought by myself; aah damn it I have to get out! (...) My legs became so tired. P15 (V) 72

Unsteadiness/Dizziness While Standing

The vast majority of participants indicated they felt uncertain/unconfident while standing or walking since hospital discharge. It appeared it was hard to explain this feeling and most participants described it as a combination of feeling shaky, unsteady, and sometimes dizzy. Unsteadiness and/or dizziness were restricting many participants in their mobility and activities. Also, a lot of participants mentioned they currently use a walking aid.

Every now and then it feels like I'm going to lose my balance. I mean it's rather like losing my balance than I feel I will stumble. Like I'm swaying back and forth. (...) That's actually why, when I walk outside, I use a walking stick. Well I camouflage it by using an umbrella, but it is a walking stick. (Laughter) I'm still a vain man! P19 (M) 82

Weight Loss and Poor Appetite

More than half of the participants indicated they experienced weight loss since hospitalization. Evidently, the vast majority of these participants experienced a decreased appetite during their hospital stay. It was frequently mentioned that the food in the hospital was not tasteful and the portions are too big for an older person. Many of these participants felt their decreased appetite was still an issue since hospital discharge. Although they knew it was important to eat well, it appeared to be hard for many participants to do so.

Yes, I only ate small portions last month. My friend said: you eat like a bird. (...) But I had no desire to eat. (...) At the hospital it was a real disaster and it is finally starting to get a little bit better now.... P6 (F) 90

Fatigue

Many participants indicated that since they were discharged from the hospital, they felt extremely tired during the day. Although most participants stated that this feeling of fatigue was new to them, they were not surprised and

some participants mentioned that their doctor had warned them about it.

Previously, I didn't even know what it was like to feel tired. (...) And now, I feel so tired! I don't know what it is, like if it was some kind of special flu or so, but I feel worn out, as if I neglected myself.... P2 (F) 86

Fatigue caused restriction in daily activities for many participants and disrupted their daily routines. Many participants described feelings of exhaustion and tiredness while performing an activity, either preventing them from performing any activities at all, or making activities less pleasant.

From time to time I'm exhausted. My arms, my legs ... sometimes it's like I can't move them (...) And I always did everything by myself (...) I still iron my clothes but I mean polishing silver is impossible now (...) So, I take it more easy currently. (...) I was busy housekeeping this week and then suddenly I became tired. And that happens to me a few times a day. P16 (F) 86

In addition to a feeling of fatigue, approximately half of the participants adapted their daily routine after discharge by sleeping during the day.

Yes, I'm tired, in the morning I'm already tired. (...) Like this morning, when I got out of bed, I wished it were noon already so I can get back to bed (Laughter). But I mean I don't know how I am supposed to feel at this age. I've never been 91 before. P8 (F) 91

Although it came up that some participants avoided daytime napping because it would affect their nightly sleep quality, other participants indicated they felt they needed to sleep during the day due to the sleep problems they encountered since hospitalization.

I was never sleepy before but currently I feel sleepy during the day. Well, it's also because I can't sleep at night at the moment. I often fall asleep at 3 AM and wake-up at 8, and that's not that much. (...) After lunch when I take a rest, I sleep an hour or so. P19 (M) 82

Theme 3—Motivational and Psychological Problems After Hospitalization

The majority of participants expressed that they stayed calm during their hospitalization and accepted the situation they were in. However, it appeared that hospitalization also had a psychological effect on participants; they experienced certain motivational and psychological problems after hospitalization. These problems were hampering participants in their daily functioning or made them feel uncertain. Two categories emerged under this theme: apathy and fear of falling.

Apathy

Most participants indicated they felt apathetic since hospital discharge. In most cases, they used other words to describe this feeling but explained it as a feeling of being less active and having a lack of initiative or motivation, since discharge.

I'm tired (...) and subsequently I feel apathetic. I mean I don't feel like doing anything. So I sit in my chair most of the time, reading and I do crossword puzzles a lot. (...) (Sighs) Tiredness and feeling lifeless, well lifeless ... I don't know what it is ... Anyway, I wish I did more. P12 (F) 81

Throughout the day, many participants did not feel like doing anything. They indicated they had no interest in activities such as strolling, painting, and knitting, and they lacked any motivation to do something.

Currently, I'm not going outside that often. I have to put myself to going outside (...). Yes, I really have to ... (snaps her fingers) (...) I don't feel like doing anything lately. I always tried to walk half an hour a day. But now I often think I will do it later and at the end of the day I didn't walk. (...) Then I get slow, playing Wordfeud or reading a stupid magazine ... just completely lifeless. (...) I need to be pushed in order to do something. P8 (F) 81

When asked specifically what caused this feeling of being apathetic, it appeared it was hard to explain but it came up that it was frustrating.

I hope I will feel like doing things again, you know? (...) Because it annoys me I don't do that much. I often think damn it woman, start doing something already. (...) Then I think I just wasted another day, doing nothing. I was always active before. Therefore, I hate myself for doing nothing lately. P12 (F) 81

Although confidence and hope to become better was present, many of the older individuals were passively recovering and waiting for their daily functioning status to improve. Many participants were making excuses for the fact they had not been outside yet, of which blaming the weather was most frequently used.

Well, now I'm not even thinking about going outside. But soon, when the weather is better, I plan on walking again. His wife: well, the weather has been lovely this week! P3 (M) 71

Fear of Falling

Fear of falling was highly prevalent among the participants, which was, besides unsteadiness while standing, further affecting mobility. Fear of falling was accompanied by a feeling of being more uncertain while walking.

I would like to walk outside again but I feel so uncertain. I'm not standing on my feet properly. It's hard to explain, but it's awful. (...) I'm afraid I may fall. (...) Like this morning, I had to go to the bathroom and though I was not, I felt like I was shaking. (...) I often think don't act so stupid! Just go already! But that's really tough, just as tough as not smoking. P13 (F) 86

A few participants indicated that their doctor warned them to prevent falling. However, it was mentioned they were solely told to be careful and not how they actually could prevent falling. This warning appeared to be counterproductive for some of the participants as they became afraid to fall after the warning.

I never really thought of it before (...) but I feel much more uncertain while walking now. But that's because of the doctor, he warned me and I wish he hadn't told me I should look out. (...) If he hadn't warned me perhaps I wouldn't have that fear. Like it has become some sort of obsession now, because my GP and cardiologist both said to me be careful that you don't fall! (Laughter). P16 (F) 86

Apathy and fear of falling were, along with fatigue and unsteadiness/dizziness while standing, most frequently present among the participants. The participants stated that it was a combination of these symptoms that affected their daily life.

Discussion

This qualitative study involved community-dwelling older adults who were acutely hospitalized and subsequently discharged to home. Patients were mainly affected in their mobility, IADLs and leisure activities, and they experienced difficulties resuming their daily routines. This disability was almost without exception attributed to four main symptoms, that is, fatigue, apathy, unsteadiness while standing, and fear of falling. Also, muscle weakness and decreased appetite and weight loss were often reported. Hence, it seems that a combination of symptoms hampers older patients to get back to their daily routine. Furthermore, patients appeared to be passively waiting to recover, while early recovery after hospital discharge is crucial to prevent other adverse outcomes (Boyd et al., 2008).

It was recently proposed to use the term posthospital syndrome to denote the vulnerable 30-days postdischarge period in which patients are at elevated risk for adverse outcomes and readmission (Krumholz, 2013). In line with this proposition, the participants attributed the symptoms they experienced to their recent hospitalization. For example, many patients encountered difficulties sleeping since hospitalization, which is also common among hospitalized geriatric patients (Isaia et al., 2011) and may account for fatigue experienced postdischarge. Also, unsteadiness while standing and a concomitant fear of falling experienced by

the patients in the current study may be secondary to the loss of muscle mass and strength that is due to malnutrition (Kagansky et al., 2005) and bed rest during hospitalization (Kortebein et al., 2008; Zisberg et al., 2011).

An additional hospitalization-associated explanation could be that patients experience sickness behavior postdischarge: which is a biologically driven constellation of behavioral and psychological symptoms caused by inflammatory activity and homeostatic dysregulation. Characteristic symptoms include fatigue, apathy, psychomotor slowing (i.e., activity becomes slowed and increasingly effortful), disturbed sleep, and lack of appetite (Dantzer, O'Connor, Freund, Johnson, & Kelley, 2008). This constellation shows a striking overlap with the symptoms reported by the current participants, and presents a psychobiological mechanism that warrants further examination.

There are, however, other, nonmutually exclusive, possible explanations for the symptoms experienced by the patients in our study. First, it is conceivable that acute hospitalization evoked a health status change resulting in the onset, or worsening of frailty symptoms. At least three of the frailty criteria (Fried et al., 2001) were frequently reported postdischarge by many patients: that is, weight loss, perceived weakness, and fatigue. Additionally, many patients were affected in their mobility and felt unsteady while standing, which could indicate two remaining frailty-criteria: slow walking speed and low physical activity. A characteristic feature of frailty is the impaired ability to recover homeostasis and functioning after stressors such as illness and hospitalization (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013). Besides, frail older persons are at great risk for acute hospitalization (Fried et al., 2001); all of which are defining characteristics of the posthospital syndrome.

Another explanation for the constellation of symptoms reported by the interviewees, (e.g., fatigue, unsteadiness while standing, weight loss, and loss of appetite) is that these represent the symptoms observed during a palliative phase (Alley et al., 2010; Chaudhry et al., 2013). Acute hospitalization is more common in the last year of life, which in turn plays an important role in further decline during this last phase (Gill, Gahbauer, Han, & Allore, 2015). Considering the high mortality rates postdischarge (Boyd et al., 2008; Buurman et al., 2011; Walter et al., 2001), the posthospital symptoms could therefore also reflect the fact that the older patients in our study are at the end-of-life.

Together Figure 1A and B present a tentative framework that was developed after data collection and analyses were completed, and which represents a synthesis of the present findings and the extant of literature. In Figure 1A, we attempted to integrate the present patient-reported findings with existing knowledge about possible mechanisms that may underlie these current findings. This integration resulted in the Venn-diagram that illustrates the strong phenotypical overlap between the posthospitalization symptoms and, respectively, sickness behavior, frailty,

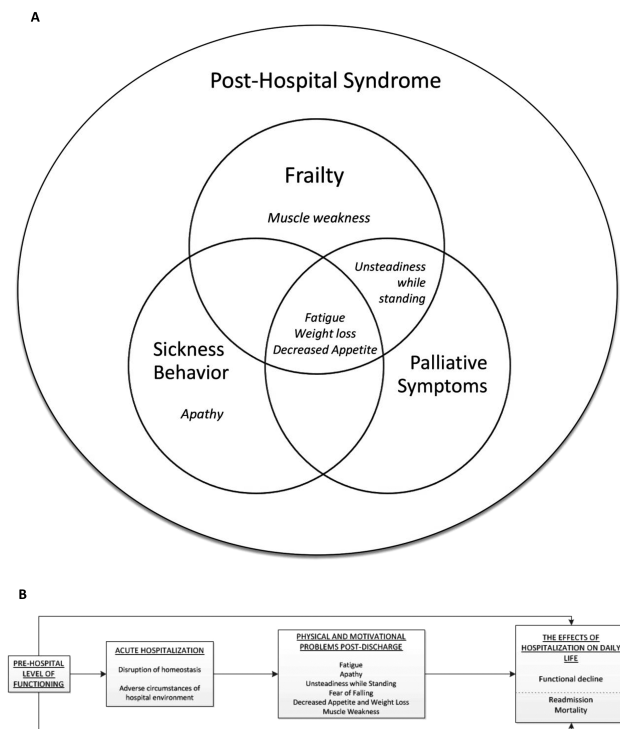


Figure 1. Based on a synthesis of the extant literature and the patient experiences reported here, panel A illustrates the potential pathways underlying posthospital symptoms. Central herein is the observation that symptoms experienced post hospitalization show a notable phenotypical overlap with well-characterized syndromes not previously linked to hospitalization; and the term posthospital syndrome may compass all these experiences. For example, sickness behavior, characterized by symptoms like fatigue and apathy, might ensue because patients still experience elevated inflammatory activity and homeostatic disruption postdischarge. Likewise, acute hospitalization may evoke a health status change resulting in the onset or worsening of frailty symptoms, such as muscle weakness, fatigue, weight loss. Lastly, given the similarity with symptoms in the palliative phase, the posthospital symptoms may also mark patients’ last phase of life. Panel B presents a summarizing framework demonstrating that following hospitalization, that is, an adverse event that involves significant disruption of homeostasis, older patients may experience a constellation of physical and motivational problems postdischarge that hamper daily functioning. These symptoms might hinder optimal recovery from functional decline, which also could place patients at elevated risk for readmissions and mortality.

and symptoms that characterize end of life. The model tentatively proposes these syndromes as potential underlying mechanisms of the posthospital symptoms. In line with, and as an extension of the preceding discussion, **Figure 1B** presents a framework that may guide contextualization of posthospitalization symptoms. The symptoms shown in **Figure 1B**, are those symptoms explicitly highlighted by the interviewees as relevant to them, described under the theme “physical and motivational problems” postdischarge. Likewise, “functional decline” in **Figure 1B** derived from analyses that were subsumed under the theme “the effects of hospitalization on daily life.” Other elements in the model are based on the existing literature, that is, the

role of the patient’s prehospital level of functioning and the adverse factors during hospitalization.

Many of the symptoms reported in our study are common manifestations of physical recovery, and may be characterized as normal and transient. However, in light of research showing that such symptoms are also associated with progressive functional decline (Avlund, Rantanen, & Schroll, 2006; Clarke, Ko, Lyketsos, Rebok, & Eaton, 2010; Delbaere, Crombez, Vanderstraeten, Willems, & Cambier, 2004), the postdischarge symptoms may also form a hindrance to optimal recovery postdischarge. For example, symptoms like fatigue or fear of falling may foster a passive behavior during recovery, when an active rehabilitation effort would be more conducive or essential even. Such detrimental effects may become amplified even in frail patients that are characterized by a lower physical resilience (Clegg et al., 2013). This, in turn, could place these patients at higher risk for readmissions and mortality (Boyd et al., 2008; Kansagara et al., 2011). Finally, the symptoms experienced as a consequence of hospitalization may reflect a continuation of an already, and now possibly accelerated, palliative phase (Alley et al., 2010; Chaudhry et al., 2013). More research is urgently required in order to further specify the role of posthospital symptoms in the recovery process and to unravel their underlying mechanisms as a basis for targeted interventions.

Strengths and Limitations

The findings should be considered carefully, as the results are subject to certain limitations. First, the small sample size may provoke questions regarding generalizability to a bigger population. However, the number of participants was adequate for the purpose of this qualitative study as saturation of the data emerged. Besides, a heterogeneous patient-group was included, recruited from hospitals in two different regions in the Netherlands. Second, due to the qualitative nature of the study correlations between symptoms and, for example, functional decline or readmissions cannot be made. Third, all patients were interviewed in the second or third week postdischarge, and were asked to describe their experiences with recovery since discharge. There is a possibility that the issues mentioned at the time of the interviews may not entirely reflect experiences at other time points, for example, the first days postdischarge or at a later time point. Fourth, patients living at a nursing home or admitted to another care setting, for example, skilled nursing facility, were excluded, while they may experience other or more pronounced symptoms. Finally, as the study protocol did not include a medical assessment it cannot be ruled out that a single-disease process or comorbidity caused different symptoms. Besides, although participants stated that the symptoms were new to them, it is unknown whether they experienced symptoms prior

to hospitalization. Despite these limitations, this study provides valuable insight into the impact of acute hospitalization on older individual's daily functioning.

Implications for Daily Practice

In the current study, the impact of hospitalization on daily life was according to the patients, mainly caused by fatigue, apathy, unsteadiness while standing, and fear of falling. In light of previous studies showing that such symptoms correlate well with functional decline (Avlund et al., 2006; Clarke et al., 2010; Delbaere et al., 2004), symptom-assessment in the postdischarge period could improve the identification of patients at risk and help prevent further functional deterioration. Also, in light of research demonstrating the effectiveness of patient education for patient empowerment/independence and management of expectations (Carroll & Dowling, 2007; Henderson & Zernike, 2001), more realistic and detailed information on posthospital symptoms might help patients to more adequately interpret these symptoms and could stimulate active and anticipatory coping instead of a passive response.

Conclusion

In the first weeks after hospital discharge, patients were mainly affected in their mobility and IADLs, which was almost without exception attributed to a combination of fatigue, apathy, unsteadiness while standing, and fear of falling. Muscle weakness, decreased appetite, and weight loss were also reported. Our study provides information on the possible nature and attributions of posthospitalization symptoms older patients experience after acute hospitalization. This information can help improve transitional care interventions aimed at successful recovery after an acute hospitalization. Further research is required in order to quantify posthospital symptoms among older patients and to investigate their underlying mechanisms.

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