




RESEARCH ARTICLE

New insights and access to resources change the perspective on life among persons with long-term illness—An interview study

Åsa Hedlund¹  | Tina Nordström¹ | Marja-Leena Kristofferzon^{1,2}  |
Annika Nilsson^{1,2} 

¹Department of Health and Caring Sciences, University of Gävle, Gävle, Sweden

²Department of Public Health and Caring Sciences, Section of Caring Sciences, Uppsala University, Uppsala, Sweden

Correspondence

Åsa Hedlund, Department of Health and Caring Sciences, University of Gävle, Kungsbäcksvägen 47, SE-801 76 Gävle, Sweden.
Email: asa.hedlund@hig.se

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Abstract

Aim: The aim was to describe individuals' experiences of living with long-term illness.

Methods: A qualitative approach with a descriptive design was used. Semi-structured interviews were conducted with 16 persons (50–80 years). They were also asked to self-rate their perceptions of their current health status and confidence in their ability to cope with everyday life.

Results: One main theme was identified: new insights and access to resources change the perspective on life. Personal characteristics and support from others were advantageous in finding ways to deal with limitations related to the illness. Most of the persons experienced a changed approach to life, in that they now valued life more than they had before. However, some persons also experienced lost values and found it difficult to accept medications. The persons rated their current health status as slightly above average, but their confidence in their ability to cope with everyday life as high.

KEYWORDS

long-term illness, nurses, nursing, patient experience, qualitative research, Sweden

1 | INTRODUCTION

Living with long-term illness is a part of life for many persons today (WHO, 2014). Experiencing physical and psychological limitations and having feelings of reduced capacity are common among this group (Harkness, Spaling, Currie, Strachan, & Clark, 2015; Lou, Carstensen, Jørgensen, & Nielsen, 2017). Several of these people mobilize resources to maintain normally activities or to reorganize activities (Ambrosio et al., 2015; Lowe & McBride-Henry, 2012; Olano-Lizarraga, Oroviogicoechea, Errasti-Ibarrondo, & Saracibar-Razquin, 2016). Previous research has found that persons living with long-term illness attempt to understand their symptoms; they make

efforts to stay well through self-care as well as to accept their physical limitations (Ambrosio et al., 2015; Olano-Lizarraga et al., 2016). They also overcome life obstacles by keeping to their life values (Ambrosio et al., 2015).

2 | BACKGROUND

Long-term illnesses such as heart failure (WHO, 2014) and neurological conditions (Dowrik, Dixon-Woods, Holman, & Weinman, 2005) are prolonged illnesses that do not resolve spontaneously and can almost never be cured (Dowrik et al., 2005). They are the leading cause of

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death in many countries (WHO, 2014) and place an economic burden on society (Bielemann, Silva, Coll Cde, Xavier, & Silva, 2015). Longevity has increased since 1970 in developed countries all over the world (Timonin et al., 2016), and the prevalence of long-term illness increases with age (Formiga et al., 2013). Treatments are often both prolonged and complex (Dowrik et al., 2005).

People living with long-term illness experience different physical symptoms (Bratzke et al., 2015; Olano-Lizarraga et al., 2016) that may affect the ability to perform activities in daily life (Hopp, Thornton, Martin, & Zalenski, 2012; Min & Min, 2015; Olano-Lizarraga et al., 2016). They may also experience decreased socializing, less engagement in leisure-time activities and financial stress (Lou et al., 2017; Martin, 2016; Olano-Lizarraga et al., 2016) due to medical costs and not being able to work (Martin, 2016). In a partner relationship, dealing with long-term illness may bring the person and his/her collaborate closer or push those farther apart (Martin, 2016). Furthermore, persons living with long-term illness may experience feelings of shame due to the lack of control over their bodies (García-Sanjuán, Lillo-Crespo, Sanjuán-Quiles, Gil-González, & Richart-Martínez, 2016). Other feelings are fear (Hopp et al., 2012; Vahedparast, Mohammadi, & Ahmadi, 2017) and uncertainty because of the illness unpredictable nature (Olano-Lizarraga et al., 2016; Wilkinson & das Nair, 2013). All of these experiences may lead to lower quality of life (Fotos et al., 2013). A person's ability to cope with illness depends on the resources he/she possesses, such as physical strength, cognitive and emotional skills, family, friends (Antonovsky, 2005; Olano-Lizarraga et al., 2016) and acceptance (Mei & Turale, 2017; Olano-Lizarraga et al., 2016). With help from their own resources, the persons can develop strategies to cope with their limitations (Olano-Lizarraga et al., 2016; Lou et al.). In this context, coping refers to a person's cognitive and behavioural efforts to manage perceived stress, where stress can be understood as internal and external demands (Lazarus & Folkman, 1984). Coping can be categorized into two major strategies: problem- and emotion-focused coping. The efficiency of different coping strategies varies across situations, but often a problem-focused strategy is more effective than an emotion-focused one (Lazarus, 2006). A successful coping strategy can give a feeling of meaning in a demanding life, which is important to the person's well-being (Folkman, 1997).

Research has shown that self-efficacy concerning the ability to cope with symptoms increases over time, after repeated attempts at symptom management (Spaling, Currie, Strachan, Harkness, & Clark, 2015). The process of finding new solutions to problems related to the illness can be long and tough (Mei & Turale, 2017; Roy & Giddings, 2012), and the strategies developed are not always beneficial (Harkness et al., 2015; Kaasalainen et al., 2013; Spaling et al., 2015). For instance, some people with long-term illness tire of the necessary lifestyle changes and stop making them even when they know they are risking their health (Harkness et al., 2015). Healthcare professionals can provide important support for this patient group by, for example, providing person-centred care (i.e. adapt the communication and information to the patient's need), involving patients in their own care (Zizzo, Bell, Lafontaine,

& Racine, 2017) and offering home health care (Jones, Harris-Kojetin, & Valverde, 2012). Home health care together with family support can enable persons to remain in their own home (Lowe & McBride-Henry, 2012).

Research on persons living with long-term illness has focused on, for example, their quality of life (Fotos et al., 2013), personal economy (Sav et al., 2013) and partner relationship (Martin, 2016). Nonetheless, long-term illness is a growing problem worldwide, with negative consequences for the persons, their family and society. Nurses play an important role in caring for and supporting patients with long-term illness, not least in the context of home health care. To meet the challenge of providing person-centred care, we need to take a holistic approach to understand what the illness entails for individuals and learn more about their experiences of living with long-term illness. Therefore, the aim of the present study was to describe persons' experiences of living with long-term illness.

3 | METHODS

3.1 | Sample and settings

A qualitative study with a descriptive design was conducted in central Sweden from June 2015 to January 2016. The persons were selected from a previous study (Nilsson, Carlsson, Lindqvist, & Kristofferzon, 2017) conducted in 2012, where inclusion of persons was based on the 2011 International Statistical Classification of Diseases and Related Health Problems, 10th Revision. Persons were recruited from two hospitals in central Sweden and met the following inclusion criteria: 18–85 years of age, a long-term illness of more than three months' duration and mastery of the Swedish language. In the present study, one inclusion criterion and one exclusion criterion were added: living in a relationship and having cognitive impairments, respectively. Purposive sampling (Polit & Beck, 2016) was used to achieve variation in persons' age, illnesses, illness duration and gender.

Twenty-six persons were contacted by telephone, and of them, 10 declined to participate in the study: two had recovered, one was too ill, and seven were not interested. Of the 16 persons who participated, nine were men and seven were women between 50 and 80 years of age (mean 71.4). The medical diagnoses were chronic heart failure ($N = 5$), multiple sclerosis (MS) ($N = 5$), Parkinson ($N = 3$) and stroke ($N = 3$); persons had received their diagnoses between four and 40 years ago. Most persons lived with a partner, either in their own house or in an apartment. One person had a partner, though they lived separately.

3.2 | Data collection

The persons were contacted by the first (ÅH) and second author (TN) via telephone, and information about the study was given during the phone call. Data were collected using semi-structured interviews, and the persons decided the location and time of the interview.

TABLE 1 The interview questions

1	Background questions	Family and children, social networks, housing, occupation, work, sick leave, retirement, medical history, (including duration of symptoms, cause of problems)
2	Tell me about how you feel	What it is that feels good? What feels less good? What difficulties are there?
3	Tell about a typical day	How is it when it is good? What difficulties are there?
4	Tell about a day at work (If the person is working)	How is it when it is good? What difficulties are there?
5	Tell about your leisure	What do you engage in What limits you in your spare time?
6	Tell about what you do to manage stress in your everyday life	Natural Mental Social Existential (values, meaningfulness)
7	Describe the resources you feel you have to manage everyday life	Abilities Experiences Knowledge Ways of coping Personality (opportunities, barriers) Interests and leisure activities that you have/had
8	Describe who gives you support in managing your everyday life	Work (employer, colleagues, etc.) Rehab (physiotherapist, occupational therapist, doctor, nurse, curator, psychologist, etc.) Social insurance, Patient association, Union Informal networks (family, friends, associations, blogs, etc.)
9	Tell about what makes life meaningful for you	Spirituality (faith, nature etc.)
10	Tell about what connection you experience with others in your everyday life	Leisure, friends and colleagues Friends and relatives Close relationships and cohabitation

Demographic data, including medical history, perceptions of current health status and confidence in one's ability to cope with everyday life, were also collected. ÅH and TN carried out the interviews in the persons' home. The persons were also asked to self-rate two items: their confidence in their ability to cope with everyday life and their perception of their current health status. The responses were made on a Likert scale and on a EuroQol-visual analogue scale (EQ-VAS) (The EuroQol Group, 2015, 2015). An interview guide was used including open-ended questions (Table 1). The interviews lasted from 24 to 132 minutes and were audio-recorded and transcribed verbatim. Two pilot interviews were conducted to determine whether the questions were relevant to the study aim. Data from the pilot interviews were included in the study, as they were judged relevant to the aim.

Written informed consent was obtained from all persons prior to the interview. The persons were informed that their participation was voluntary and that the interview would be audio-recorded. They were also informed that they could not be identified from the results and that the material would be stored so that no one unauthorized could access it. The study conformed to the ethical principles defined in the World Medical Association Declaration of Helsinki

(WHO, 2001) and was approved by the regional ethics review board (reg. no. 2010/346).

3.3 | Data analysis

A qualitative approach was used to analyse the interview data. The transcribed interviews were entered into Open Code 4.0 (Umeå University, 2015) for coding and analysed using qualitative content analysis (Graneheim & Lundman, 2003). The interviews were listened to and the transcriptions read through several times by ÅH. Three researchers (ÅH, TN and AN) reviewed some of the interviews together. Meaning units were identified from the data, and these units were condensed to make the texts shorter without losing their essence and then abstracted and labelled with codes. After being compared for their differences and similarities, the codes were sorted into sub-themes and then discussed among the four authors. By the time consensus was reached, six sub-themes and one theme had emerged. Descriptive statistics such as mean, standard deviation (SD), minimum, maximum and mode were used to describe the participations self-rated confidence concerning the ability to cope with everyday life and perception of their current state of their health.

and good verbal skills was necessary if one was to get help from healthcare providers: *'I have an easy time expressing myself verbally, otherwise I wouldn't have gotten any help (1)'*. Also experienced as helpful was being the kind of person who speaks up to influence healthcare decisions. However, a few persons felt they lacked advantageous personal characteristics: *'I like to be there when someone else fixes something, but I don't have any ideas to add (9)'*. One person had a desire to be able to question the physicians' decisions, and another wanted to be the kind of person who takes the initiative in making new friends.

4.4 | Experiencing support from stakeholders, family and other people

The persons described that different stakeholders, family and other people were often supportive. Healthcare providers were supportive when they, for example, were easy to contact, let the person be involved in his/her own care and made sure the person saw the same doctor or nurse over a long period: *'By having long-term contact with me (doctor's name) didn't need to... to read about... my situation... he knows me... and what my concerns are (5)'*. When healthcare professionals used humour in their communication with patients, patients felt better about following their medical advice. Other stakeholders such as authorities and companies, for example, could assist with personal finances, supply an electric wheelchair and deliver food. Children, friends and the partner were important sources of support in everyday life for all of the persons: *'She (his wife) makes sure I get food and that I'm comfortable, I get hugs and all kinds of things like that, that you want (9)'*. Patient associations, social media and thoughtful strangers on trips or in the physician's waiting room were also experienced as supportive, as were patient groups: *'I experience it (the patient group) as a kind of feedback... if you have concerns of some kind (5)'*. Several of the persons experienced lack of support from healthcare professionals. This could cause them to avoid contact even when they needed it, or avoid asking the physician about things related to the illness: *'It's been a long time since I dared say anything (to the doctor), I don't know, I feel I get snubbed all the time (14)'*. If the partner was ailing as well, it was easy for the two of them to drag each other down instead of supporting each other: *'It's like two people out at sea who are drowning. They can easily pull each other down (6)'*.

4.5 | Redefining life values and feeling confident about the future

All persons described that life included several valuable things and several said that values had been redefined with time. For most of them, the family was now the most valuable part of life: *'What is definitely most important to me now, it's my grandchildren... I love them... Sometimes we get to take care of them, and I rejoice every time (12)'*. Other valuable things were, for example, having dreams for the future, faith in God and belonging to a social context: *'We always go to the concert hall here on Fridays – that's something we really like to do (13)'*. Maintaining one's own identity felt important, and this meant

having a life outside the partnership—having one's own friends and interests. Several of the persons mentioned their sense of gratitude. They were grateful for others who supported them and for their remaining bodily functions, because these things made other values more attainable. Having an illness that was not fatal was also something to be thankful for. Some persons also experienced hope, for example, that they would live happily for a long time or die quickly when that day came: *'I hope that the day something happens that either it will be quick and give me life again, or that I'll just pop off, thanks and goodbye (9)'*. However, lost values were mentioned by some of the persons, such as being out in the woods, exercising, walking like before, having the ability to run and work in the garden like before: *'Not being able to run and to ... to walk about and shovel earth or dig in my garden like I did before... they... are... negative things... in my view (5)'*.

4.6 | Gradually accepting the illness and limitations

For several of the persons, accepting the illness and getting used to the negative consequences had become easier over time. This was, according to some of the persons, essential to having a good life: *'I've accepted... accepted it. Before if I said absolutely not... I would not accept it. But you have to do it in order to live a good life (2)'*. Some of the persons mentioned that their acceptance could also be reluctant, such as when they followed the physician's advice even when they did not like it or when they took medications despite their distaste for them. Not accepting medications also occurred: *'I don't like taking medications... I try to stop... I try to slowly phase them out (10)'*. One reason for being sceptical about medications was the fear of becoming addicted or the experience that they did not help. Some used alcohol instead.

4.7 | Feeling life itself is more valuable than before

Living with a long-term illness also gave most of the person's new insights into life, which they now saw as a gift. Life was experienced as more valuable than before and they strived to make every day as good as possible, because life felt fragile and could change or end at any moment. Despite that, some persons described that their fear of death was gone: *'Before I was afraid of dying, but now I can see eternity, even though the situation is actually the opposite (8)'*. The pursuit of new gadgets, status and accomplishments was no longer important. Only being alive mattered: *'What's most important is that I'm alive... Not what I accomplish (11)'*. Another insight from one person was that you do not have to hurry things. You might as well do it tomorrow. Some persons described that many things no longer seemed worth fighting for and battles were therefore chosen carefully. If something failed to go as planned, it was best to accept it instead of getting upset. According to some of the persons, it was important to learn to deal with adversities. One person said you realize you can manage more than you think: *'And I've started sorting things a bit... cleaning closets... started in the attic and took out the fall, winter stuff... It felt good to get it done, but I never thought I'd have the strength (14)'*. Despite their own illnesses, several of the persons desired good health and joy

TABLE 3 Confidence and current health status using means, standard deviations (SD), minima, maxima and modes (N = 16)

	Self-rated confidence in their ability to cope with everyday life	Perception of their current health status
Mean	7.7	62.0
SD	1.0	15.8
Minimum	6	40
Maximum	10	100
Mode	8	50

Note: Self-confidence scale: 1 = no faith and 10 = greatest possible confidence.

Perception of their current health status: 0 = worst imaginable state of health and 100 = best imaginable state of health.

for others. Some years after diagnosis, they had gained perspective: there were other people who were worse off. Some persons said that the days went too fast; they needed more hours. In some cases, role reversal had taken place in the relationship, which led to admiration of the healthier partner's strength and empathy for him/her. Several of the persons also experienced no longer caring what others thought about them: *'I know my body and well I know... what needs to happen for me to... move on... That might seem conventional, but I don't care (5)'*.

4.8 | Self-confidence and health status

The interviews revealed that the persons experienced several limitations in everyday life but had developed strategies to cope with them. The quantitative data support these results, showing that patients rated their current health status as just above average, but their confidence in their ability to cope with everyday life as high (Table 3).

5 | DISCUSSION

The main results were that persons with long-term illness experience that *new insights and access to resources change the perspective on life*. Personal characteristics such as optimism and mental strength were helpful in finding ways to deal with limitations, as was receiving support from stakeholders and one's partner. Most of the persons experienced a changed approach to life, including redefinition of life values, acceptance of the illness and a changed perspective on life, from which life is seen as more valuable and fragile than before. However, persons also experienced lost values and found it difficult to accept medications. The quantitative data support the information above by showing that persons rated their current health status as just above average, but their confidence in their ability to cope with everyday life as high.

Our results are in line with previous findings showing that persons living with long-term illness experience a variety of limitations in daily life (Hopp et al., 2012; Lou et al., 2017; Wilkinson & das Nair, 2013) and that both problem-focused and emotion-focused strategies (Lazarus & Folkman, 1984) for coping with these symptoms must be developed (Ambrosio et al., 2015; Harkness et al., 2015) with the support

of different resources (Bratzke et al., 2015). Surprisingly, the present study showed that limitations could be used as advantages. One person—a teacher—used his inability to walk to find new successful ways of dealing with unruly children. According to Lazarus and Folkman's theory of coping (Lazarus & Folkman, 1984), physical health is one of the most important coping resources. Persons in the present study, whose physical health was impaired, nonetheless had found effective ways of coping with limitations. This means that other resources can compensate for impaired physical health as regards managing the limitations associated with long-term illness. Optimism was used, but also personal characteristics that are not obviously constructive, such as anger. This can be seen in light of Antonovsky's (Antonovsky, 2005) theory of salutogenesis, according to which all internal resources, including advantageous personal characteristics, can contribute to give people the strength needed to cope with stressful experiences and to maintain health throughout life.

The persons in the present study said that healthcare providers who involved patients in their own care were supportive, which confirms previous findings (Zizzo et al., 2017). This reveals the need for healthcare providers to focus on taking into account patients' participation. Another important source of support in life was the persons' partner. However, it seems to be difficult to balance being dependent on one's partner and maintaining a feeling of identity and independence. Earlier research has shown similar results (Lowe & McBride-Henry, 2012; Martin, 2016). In addition, the present study showed that when both partners were ailing, they could drag each other down instead of supporting each other. This speaks to the need for better support from different stakeholders in society to relieve the partner's burden.

Several of the persons experienced a redefinition of life values, such as being grateful for remaining bodily functions instead of lamenting the lost ones. According to Folkman (Folkman, 1997), creating values from losses is associated with positive psychological states and experiencing meaning in life. Similar results have been seen among persons with other severe diagnoses (Kristofferzon, Löfmark, & Carlsson, 2008; Strang & Strang, 2001), implying that, regardless type of illness, persons can find meaning in life. Nonetheless, some persons in the present study experienced lost values due to the limitations caused by the illness. It is known that long-term illness increases the risk of depression (Bratzke et al., 2015; Riedel, Bitters, Amann, Garbe, & Langner, 2016), and it is reasonable to assume that

lost values contribute to this risk. Healthcare professionals play an important role in helping patients with long-term illness find and maintain a feeling of meaning in life. This should be an important part of care.

Acceptance of the illness was seen as essential to living a good life, and existing research has shown that acceptance is a necessary element of achieving a positive approach to living with long-term illness (Ambrosio et al., 2015; Mei & Turale, 2017). It was, however, difficult for some persons to accept the medical treatment, something also found in earlier research (Bratzke et al., 2015; Mei & Turale, 2017; Sav et al., 2013). This could be due to fear of becoming addicted or the experience that drugs did not help, leading to non-adherence to medication regimens. Lack of detailed knowledge of the medicines' purpose and of how they help in treating the illness is seen in persons with chronic heart failure (Spaling et al., 2015). Taken together, the above-discussed findings speak to the need for better medical treatment information and support from healthcare professionals for patients with long-term illness.

Persons also experienced having gained new insights and a changed perspective on life. Life felt more valuable now than before and they tried to make every day as good as possible because they knew how quickly life could change or end. In the light of this and the above findings, the persons seem to experience what Lazarus and Folkman (Folkman, 1997), in their theory of coping, called positive reappraisal. This means reassessing a situation to see it in a more positive light, which is one way to find the positive meanings of a demanding life (Folkman, 1997).

The quantitative data (Table 3) showed—not surprisingly given the qualitative findings—that persons rated their current health status as just above average, but their confidence in their ability to cope with everyday life as high. Spaling et al. (Spaling et al., 2015) found that self-efficacy in managing symptoms in everyday life increased over time among persons with long-term illness. The persons in the present study have had their illness for several years, sometimes decades, and may therefore have developed greater self-confidence than they had at the outset. Perhaps it will continue to increase. Still, they rated their own health status as just above average, which is in line with earlier research (Brettschneider et al., 2013) showing that persons between 65 and 85 years with long-term illness gave similar rating of their current health status. This can be seen in relation to a general population sample that rated their current health status as high (McCaffrey, Kaambwa, Currow, & Ratcliffe, 2016).

5.1 | Strengths and limitations of the study

One limitation of the study was that two researchers were involved in conducting the interviews. There is a risk that differences between the interviewers may underlie differences in the interview data. To decrease that risk, it is important to establish the interview questions in advance (Patton, 2015). ÅH and TN therefore used pre-determined open-ended questions and conducted pilot interviews evaluated by AN and MLK. Another limitations were that several potential participants chose not to participate in the study. One

declined participation because he/she was too ill. The study may therefore not capture the experience of the least healthy persons and might have turned out different if these persons had been included. Moreover, the results could have been different if persons without partners or if only single persons had been included. However, the study was conducted in Sweden and the findings may thus not be valid in other countries, especially in countries with a different social and healthcare system.

6 | CONCLUSION

The results show that persons with long-term illness can cope with their limitations and find meaning in life if resources, such as advantageous personal characteristics and support from stakeholders and other people, are available. Healthcare professionals need to take a holistic approach to individualizing care for these patients, that is care that helps patients find or use their own resources in the most effective way. The present results highlight the need for further studies exploring what kind of support healthcare professionals must provide if they are to help persons with long-term illness find and maintain meaning in life. There is also a need for studies on how persons with long-term illness can be supported to feel satisfied and comfortable with their medical treatment and on how stakeholders can help to relieve the burden placed on the partners.

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CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

AN and MLK constructed the study design. ÅH and TN conducted the interviews. ÅH initially analysed the data and ÅH, TN and AN met to discuss the findings. All authors were responsible for critical revisions and for finalizing the manuscript.

ETHICAL APPROVAL

This study was approved by the regional ethics review board (reg. no. 2010/346).

ORCID

Åsa Hedlund  <https://orcid.org/0000-0003-4676-9010>

Marja-Leena Kristofferzon  <https://orcid.org/0000-0002-1864-5777>

Annika Nilsson  <https://orcid.org/0000-0003-1969-0163>

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