



To adjust and endure: a qualitative study of symptom burden in older people with multimorbidity



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ABSTRACT

Context: Older people with multimorbidity are vulnerable and often suffer from conditions that produce a multiplicity of symptoms and a reduced health-related quality of life.

Objectives: The aim of this study is to explore the experience of living with a high symptom burden from the perspective of older community-dwelling people with multi-morbidity.

Method: A qualitative descriptive design with semi-structured interviews, including 20 community-dwelling older people with multi-morbidity and a high symptom burden. The participants were 79–89 years old with a mean of 12 symptoms per person. Data were analyzed using content analyses.

Results: The experience of living with a high symptom burden revealed the overall theme, “To adjust and endure” and three sub-themes. The first sub-theme was “To feel inadequate and limited”. Participants reported that they no longer had the capacity or the ability to manage, and they felt limited and isolated from friends or family. The second sub-theme was “To feel dependent”. This was a new and inconvenient experience; the burden they put on others caused a feeling of guilt. The final sub-theme was “To feel dejected”. The strength to manage and control their conditions was gone; the only thing left to do was to sit or lie down and wait for it all to pass.

Conclusion: This study highlights the importance of a holistic approach when taking care of older people with multi-morbidity. This approach should employ a broad symptom assessment to reveal diseases and conditions that are possible to treat or improve.

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1. Introduction

Chronic diseases tend to increase with old age, and approximately 70% of people aged above 80 years have been reported to suffer from multi-morbidity (Boeckstaens & De Graaf, 2011). For community-dwelling older people with chronic diseases life is filled with challenges as they try to manage everyday life and cope with symptoms of different origins. Multi-morbidity is a condition that may cause loss of autonomy, disability, social isolation (Falk, Ekman, Anderson, Fu, & Granger, 2013) and frailty (Le Reste et al., 2013) if the diseases are not well managed. Even so, research has shown that older people tend to report fewer symptoms compared to younger people (Goldberg et al., 2010). It might be because it is more difficult for older people to detect and interpret symptoms (Riegel et al., 2010), or that older people might fail to recognize and report significance changes in health status as a result of the new signs or symptoms being covered by other chronic diseases (Bender, 1992). Older people with symptoms that are well managed

are more likely to feel safe, in control and to experience good health (Ebrahimi, Wilhelmson, Eklund, Moore, & Jakobsson, 2013). A challenge for the health care system is to organize and provide care that is individualized and that focuses on the whole person rather than on separate health issues (McEvoy & Duffy, 2008). A holistic approach could help researchers and clinicians to identify resources and barriers relevant to the management of similar and unique symptoms that cause problems in the everyday lives of older community-dwelling people with multi-morbidity.

Older people with advanced chronic diseases are known to suffer from symptoms such as pain, lack of energy/fatigue, shortness of breath and loss of appetite (Wajnberg, Ornstein, Zhang, Smith, & Soriano, 2013; Walke, Byers, McCorkle, & Fried, 2006). However, the way a symptom is perceived is a unique experience, and a lack of symptom control may result in significant deterioration of health-related quality of life (Newcomb, 2010). Symptom burden is defined as “the subjective, quantifiable prevalence, frequency, and severity of symptoms placing a physiologic burden on patients and producing multiple negative, physical, and emotional patient responses” (Gapstur, 2007). Symptom burden is often used to describe the sum of symptom scores or the mean number of symptoms per person (Gill, Chakraborty, & Selby,

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2012), and could serve as a sensitive target for intervention, particularly to improve outcomes related to quality of life in older people (Sheppard et al., 2013). However, there is no consensus on what level indicates a severe or a very severe symptom burden, nor on the experience and impact of symptom scores (Gill et al., 2012). The experiences of symptom burden in community-dwelling older people with chronic diseases have been reported by use of different symptom assessment scales (Eckerblad et al., 2015; Salanitro et al., 2012; Walke et al., 2006), but subjective descriptions of the older people's own experiences are scarce (Gill et al., 2012). Therefore, the aim of this study is to explore the experience of living with a high symptom burden from the perspective of older community-dwelling people with multi-morbidity.

2. Method

2.1. Design

A qualitative study based on semi-structured interviews with 20 older people with multi-morbidity, was performed by using content analysis. The participants in this study were recruited from a prospective single center randomized controlled trial with 382 older people (Mazya et al., 2013). The study followed the ethical guidelines given in the Declaration of Helsinki and was approved by the Linköping local ethical Committee (Dnr 2012/244-32).

2.2. Participants and procedure

We sought a purposive sample with participants that reported high scores on the Memorial Symptom Assessment Scale (MSAS) (Portenoy et al., 1994) after the second year follow-up in the Age-Fit study (Mazya et al., 2013). In this study, a high score on the MSAS equaled ≥ 3 on frequency, severity or distress in at least four prevalent symptoms. The total symptom burden score (TMSAS) was the average score of all 32 symptoms in the MSAS instrument (Zambroski, Moser, Bhat, & Ziegler, 2005). An information letter explaining the purpose of this study was sent to the participants who fulfilled the inclusion criteria. People who were willing were offered an appointment at their home for an interview. Sixteen women and four men were included in this study, and they had a mean age of 84 (± 2.9). The participants suffered from a high symptom load with a mean of 12 (± 5.3) prevalent symptoms per person as well as a high total symptom burden score median (range) 0.96 (0.31–2.27) (Table 1).

2.3. Interviews

The MSAS protocol from the second year follow-up was used to guide the interviews with additional open-ended questions. The first interview was performed by the first author (JE) as a pilot, and the transcription of this first interview was peer-reviewed by the last author (IH). No changes in the interview guide were made, and the first interview is therefore included in the analysis. The participants were asked the following questions: What does the symptom feel like? When does it bother you the most? What is it like living your life with many co-occurring symptoms? What consequences does it have? In what way does this affect your life? All interviews were performed by the first author (JE) between March and September 2013. The interviews were audio-recorded and transcribed, and confidentiality was provided by giving each interview transcript a code number. The interviews ranged between 20 and 55 minutes. In total, each visit lasted approximately 2 hours, including small talk.

2.4. Analysis

2.4.1. Content analysis

The transcribed interviews were analyzed using qualitative content analysis (Graneheim & Lundman, 2004). Content analysis is a suitable

method for analyzing sensitive phenomena and has come into wide use in health studies (Hsieh & Shannon, 2005). An advantage is that larger volumes of textual data and different textual sources can be dealt with at the same time (Elo & Kyngas, 2008). The analysis was inductive and resulted in themes (Graneheim & Lundman, 2004).

1. The transcribed interviews were read thoroughly several times to get a deeper understanding of the whole with a focus both on the surface structure of the text and the underlying meaning.
2. Significant text units (meaning units) were identified, marked, and labeled with open coding close to the participant's own statements (Table 2).
3. Codes were then sorted and grouped into sub-themes depending on the content.
4. During the analysis the sub-themes were grouped and re-grouped to identify significant similarities and differences, and two sub-themes were merged into one.
5. The final structure consisted of three sub-themes and one overall theme (Fig. 1).

2.5. Findings

2.5.1. To adjust or endure

To adjust or endure was interpreted as the overall theme in this study. Living your life with a high symptom burden was described by the participants as an endless struggle where you either had to adjust or endure to the current situation since they did not see any other option.

Participant (P); It takes time getting used to being old, and I believe that people who have always been physically active will face a more drastic change. It's like a sort of resignation. It is what it is, and I think you have to adjust to it. Interviewer (I); Do you have any strategies for dealing with this? P; No, this is how it is now and there is nothing I can do. Maybe I can choose one of the things I want to do and just push the other things aside. But that makes you feel bad about yourself. But you know there are so many ailments hindering me. (Participant 14. An 81-year-old woman who lived alone).

Living with a high symptom burden had an effect on their body and soul. One participant described it as "It is like my body and mind are not connected anymore and it is just awful". Their bodies were failing, and the life they were used to was gone forever. The majority of the participants also said that their fighting spirit or the will to take charge of their situation now was gone. The main theme of this study was composed of three sub-themes; to feel inadequate and limited, to feel dependent, and to feel dejected.

2.5.2. To feel inadequate and limited

The participants felt that they no longer had either the capacity or the ability to manage or control things. Things they had done with ease before were just not possible anymore since they described their bodies as "totally worn out," and they felt useless.

Interviewer (I); It says here (referring to MSAS score of the patients) that you do not recognize yourself anymore? Participant (P); Yes, I used to be a lot more active. Now I have a sort of a more vegetative life where I just try to make it through day by day. I; How would you say that you deal with all these issues? P; I think I have kind of survived myself. I am looking forward to and hope that I could get on my feet again and at least be able to help out a little bit. Then I would be better. But as it is, I alas find no great zest for life. (Participant 7; An 89-year-old man that lived with his wife).

Not only was the physical capacity failing; participants also said that their cognitive capacity was affected, e.g. before the high symptom burden developed one of the participants read four newspapers each

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