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Author(s): Tiilikainen, Elisa; Hujala, Anneli; Kannasoja, Sirpa; Rissanen, Sari; Närhi, Kati

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“They’re always in a hurry” – older people’s perceptions of access and recognition in health and social care services

Elisa Tiilikainen, Anneli Hujala, Sirpa Kannasoja, Sari Rissanen ja Kati Närhi

Abstract (max 300 words)

The article examines older people’s perceptions of quality of life from the perspective of access and use of health and social care services. The data includes focus group discussions with older people living alone. The data was analysed using thematic analysis focusing on the older people’s collective views on health and social care services as supportive or restrictive factors for their quality of life. Two central themes were present in all the focus group discussions: the importance of accessing services and information regarding the services, and need for recognition within the services/by the professionals. Both themes were connected to the older people’s desire to maintain autonomy in their everyday life despite increasing functional disabilities, which was seen as an important factor of quality of life. The older people felt that accessing and finding information about the services was difficult, and dependent on the professional’s good will and the older person’s own financial resources. Within the services, older people experienced a lack of recognition of their own personhood and individual needs. The participants felt that they were easily bypassed and left out of negotiations regarding their own care. The article highlights the importance of developing

health and social care services and practices towards a more holistic approach recognizing older people's individual needs.

Key words: older people, quality of life, access to services, access to information, recognition

What is known about the topic?

- As the population ages, the number of people using health and social care services increases
- Access to services and quality of care are known to have a strong relationship with older people's quality of life
- Previous qualitative studies on the topic have concentrated in long-term care and informal carers

What this paper adds?

- Highlights the importance of developing health and social care services and practices towards a holistic approach, in which the older person's personhood and individual needs are recognized and supported
- Promoting quality of life of older people does not only need financial resources and structural changes, but also changes in attitudes and in the care culture of professionals

Introduction

This article explores older people's perceptions of quality of life from the perspective of access and use of health and social care services, using focus group discussions with older people living alone. The number of people in old age is growing rapidly, and the use of health

and social care services is increasing (Forma et al. 2017). This highlights the importance of analysing the influence of social and health care services on the quality of life (QoL) in old age and how these services can be developed further. Although different existing measurements offer indicators of how QoL may be affected by access and use of health and social care services, it is important to gain understanding of the lived experiences behind them.

Quality of life is widely understood as a dynamic, multi-dimensional concept. An often used conceptualization of quality of life is the World Health Organization's definition (2002), which emphasises the subjective evaluation and the cultural, social and environmental context of QoL. The multidimensional measure WHOQOL-BREF assesses four dimensions of QoL: physical health, psychological functioning, social relationships and the environment (The WHOQOL Group, 1998), taking into account both subjective and objective domains of quality of life. However, QoL of people receiving help and care, for example, call for more differentiated analyses (Vaarama, 2009; Vaarama & Pieper 2004).

Environmental factors, such as access to services, are taken into account in most multidimensional models used to measure quality of life in old age. The model of care-related QoL (crQoL) integrates the ways in which QoL is influenced by social and health care, typically under conditions of long-term care (Vaarama, 2009). This conceptual framework recognizes the interaction between the dimensions of quality of life and quality of care. The assumption is that "good" care aims to maximise quality of life of the client by responding to the client's individual needs.

According to Vaarama (2009), home care is not just about giving older people the instrumental help they need to perform their daily activities. It is about giving responsive care that reflects older persons personal preferences or their view of a "good life", and treats

them with dignity and respect. In addition, a good life requires adequate goods, services and environments. For people in need of care, services and the care setting become an essential environmental factor in the provision of goods and services adequate to maintain quality of life in old age. (Vaarama & Pieper, 2014.)

Social care-related quality of life (SCRQoL) has been examined using the ASCOT-measurement developed for capturing changes in quality of life in relation to social services in Finland and the UK, for example. It consists of eight domains, such as control over daily life, social participation and involvement, personal safety and dignity. These domains are defined as aspects of quality of life that are important to social care service users and may be compensated for by social care support. (Malley et al., 2012). Similar domains have been found when studying good life in assisted living (AL). According to Pirhonen (2017), good life in AL consists of the possibility of maintaining autonomy and agency, recognition and acceptance of others and the opportunity to maintain and form social bonds with others. With recognition, Pirhonen has referred to the resourcing of care, the daily routines of the facility, and the staff's attitudes (also Pirhonen & Pietilä 2015).

To our knowledge, qualitative studies on how health and social care services impact quality of life in later life has concentrated on older people living in long-term care and informal carers (e.g. Rand & Malley, 2013), using one-to-one interviews. To explore the ways in which the health and social care services are connected to QoL in later life, we draw on focus group interviews conducted with older people living alone. The context of the study lies in the Finnish health and social care services and elderly care (Paljärvi et al., 2011).

Data and methods

The data includes discussions of four focus groups conducted with older people living alone. The data was collected at the end of 2016 and the beginning of 2017 as part of a consortium

project *Inclusive Promotion of Health and Wellbeing (PROMEQ)*. The overall aim of the data collection was to gain more knowledge of older people's quality of life and needs for support in order to build an intervention model for older people living at home. The method of focus group discussion (Bloor et al., 2001) was chosen in order to gain diverse, yet interactive views (Wilkinson, 1998) on QoL.

The participants were recruited via local health and social care service professionals who were asked to hand out invitations to participate in the focus group discussions. Two inclusion criteria were used: living alone and use of health and social care services during the past six months. Satisfaction or dissatisfaction towards the services were not mentioned in the invitation.

A signed consent form was received from each participant. In the beginning of each group session, the moderator reviewed information on confidentiality of the discussions and anonymization of the data with each of the participants. According to the Finnish Advisory Board on Research Integrity (TENK), ethical committee approval was not needed. However, the study was given permission by the municipalities in which the data was collected.

One or two researchers moderated the semi-structured focus group discussions. The first set of focus group discussion sessions concentrated on the participants' perceptions of their own quality of life from the perspective of supportive factors and possible barriers. The older persons were led to discuss the themes using a thematic interview frame based on the four domains of WHOQOL-BREF. The framework included questions regarding everyday life, social relations and knowledge of services. The second focus group sessions began with the moderator's short description of the topics discussed in the first session and continued with a thematic framework built upon these topics. The second framework included themes such as

continuity in everyday life, recognition and appreciation of older people and access and use of services.

All together, the audiotaped data included 12 hours of group discussions, transcribed into 258 pages (font size 12, spacing 1). The data was analysed using thematic analysis (Braun & Clarke, 2006). In the first phase of the analysis, the data was read through several times and coded within the context of supportive and restrictive factors for quality of life. After the initial coding process, codes were collated into themes present in all of the focus group discussions. At this stage, three clear themes related to the quality of life of older people were found: health, social relationships and health and social care services. All of these themes were described as both positive and negative factors in the participants' everyday life (also Bond & Corner, 2004; Farquhar, 1995).

For this article, the analysis continued by focusing on the third theme, i.e. participants' experiences of health and social care services, which were described as important factors impacting their quality of life. At this point a more directed coding process was used to search for excerpts referring to experiences regarding health and social care services. These excerpts were gathered in a new data file of 41 pages (font 12, line spacing 1). This data was categorized into different themes on the basis of how health and social care services were seen as either supportive or restrictive factors for quality of life.

Two clear themes addressing how health and social care services were connected to QoL were identified after reading and re-reading the data. The first theme, present in all the group discussions, was accessing health and social care services, as well as accessing information regarding these services. The first theme was named *access to services and information*. The second theme, found in the analysis, consisted of experiences of how the older people felt

they were treated within the services/by the professionals. The second theme was named *recognition inside the services*.

The excerpts have been translated by the first author. The final versions were approved by the other authors and a professional translator to ensure that the original voices of the participants were not lost (Nes et al. 2010).

Findings

Participants

In total 19 older persons, from three different Finnish regions, participated in the focus group discussions. The participants were divided into four groups (table 1) and interviewed twice during a one-month period.

<Table 1>

The excerpts are identified with “M” referring to a male participant, “F” referring to a female participant (both with detailed numbers for each participant within the group). The code “G” refers to the group number.

Access to services and information

The importance of access to services and information was present in all the group discussions. Most of the participants described difficulties in gaining access to primary and specialized health care services, or being “bounced around” from service to service without getting the help they needed. These experiences were especially present among the participants who were not home care clients, yet had significant health problems. One example was given by an 83-year old male participant (M4, G1) who had been diagnosed with a tumor in his instep. He felt that his condition had not been taken seriously early enough. After “running from doctor to doctor” for two years he finally had surgery, but by

that time his overall condition had declined: “At this age you can’t really get it back however hard you try.”

Many participants also described difficulties in accessing services. Professionals were seen as gatekeepers, or “brakes” inside the system, as one participant put it. Some reported that their frustration had led to a situation in which they did not want to contact local health care professionals, despite concerns or a need for help. As discussed in the next excerpt, the older people felt that their concerns were often belittled or ignored:

F1: You have to have something that limits good life and living at home [before contacting health care]. So that it would be taken seriously, and people wouldn’t be bounced around for the same problem.

F4: Yes.

F5: Back and forth.

F1: Again and again, because the threshold gets higher all the time and you feel that it gets more and more difficult to contact them again for the same reason.

F5: Yes.

F1: Then it can be a problem already, gotten worse. Like for me they said that I could have died anytime.

(Group 4)

The topic was taken up in another group discussion, when the participants discussed the point at which an older person feels that he or she can ask for help. “You have to go really low before you can shout out ‘now I need help, someone has to come’” (F1, G2), described one of the female participants. Many were worried about friends and other older people who had poorer health than the participants themselves and did not have the resources to seek help. The participants felt that these people were left alone and did not have sufficient knowledge about the services they were entitled to.

Accessing health and social care services was closely linked to the importance of autonomy in everyday life. Adequate services were needed to maintain meaningful hobbies and social

bonds and to participate in the surrounding society. In relation to quality of life, many of the participants described the importance of being eligible for taxi services provided by the municipality. The possibility to use a wheelchair taxi for the price of public transport provided an important link to the outside world for the participants with poor functionality. However, the use of a maximum of nine two-way trips per month had to be prioritized for compulsory errands, such as shopping for groceries and visits to the bank.

Alongside the importance of equal access to services, the participants emphasised the importance of accessing information about existing services. Many felt that they did not have enough knowledge on what was available to them and how to apply for it. Several examples were given of how the participants' children had acted as the older persons' advocates. For example, gaining access to taxi services was seen as very difficult, as one female participant described:

It was really strict, you had to apply for it from the administrative court and I couldn't get it straight away. But I had a daughter-in-law who had previously worked as a social worker and she knew how to apply for it. I wouldn't have known how to do it. Then they said that I should be granted financial support for transport services. (F4, G3.)

For those without children or other relatives, gaining access to services was seen as more difficult, or even impossible in the case of poor functionality such as memory disorders. Some described gaining access to services as a battle, which was easy to lose. After a leg amputation one of the participants had tried to apply for an assistant to assist her to the shower:

Home care said that it's not their job, you need to contact the support services. When contacting the assistant services, they said that home care would take care of showering. And after waiting a while, I decided to go by myself and I still do. I didn't want to take anything from them anymore, I'll manage by myself. (F2, G2.)

However, contrary experiences were also described. One female participant said that she received a home care “bolt from the blue” after her rehabilitation period. This was due to her doctor, who had encouraged her to apply for help for bathing and going to the sauna. At the age of 92 it was time for help, the doctor had stated. Overall, access to services was portrayed like a game of chance, dependent on the health and social care professionals’ attitudes towards older people:

Twice I have asked for money from the city. The first time it was for my feet, so that I could start rehabilitating them on my own. Go water running like I used to, for example. They didn’t give any. Then I asked could I get even two taxi tickets to go dancing, it’s a hobby of mine. They said no again. There’s no point in asking anymore, they won’t issue it. However, some people say that you just have to keep on asking. If you’ve asked for it many times, then they’ll give it to you (laughing). (F2, G2)

Further, the participants felt that information often had to be “pulled out” of services. If you didn’t understand or weren’t able to ask, you were rarely given information about existing services even though you were eligible to apply for them. The growing number of different digital services, replacing face-to-face ones, was also seen as a big problem for older people:

F1: Nowadays almost everything goes through this electronic media, information and everything and we should know how to use them, health care services and all. Like she said, when you call for a doctor’s appointment, you have to press one if you want the doctor to call back. Even for that you have to...

F5: I don’t understand a thing [laughing]

F3: Me neither.

F1: Then many older people are left out.

F2: Tablets [pills] I swallow but don’t use any other kinds of tablets.

F5: To that I’d like to add that computers and their maintenance costs and...

Moderator: So it’s also a question of money.

(Group 4)

Several participants raised the importance of money when discussing accessing and using health and social care services. The older people felt that it would be easier to gain adequate

services if they had better pensions or more money up their sleeve. Financial difficulties were experienced by those participants who had increasing medical costs, for example. Many described the balance between “coping alone” and gaining support, which was also linked to financial opportunities, as described in the next excerpt.

F4: I need help sometimes, but they won't give it to me.

F3: And then you do it by yourself.

F4: Yes, I guess I'll do it as long as I can.

F3: Yes.

F4: I used to get care allowance, for example. I had a cleaner coming by and I've had the doctor's appointments and gone to the hospital. Not the smallest allowance, the middle rate. It was 155 euros per month. Now it was taken away from me and I haven't understood how to apply for it again. They can give it to the ones that need it more, if that's the reason. I just don't understand why they first give it and then take it away.

F2: Yes, it's like that nowadays.

F4: They said that I would need help every week. I would need an assistant, but they won't give it to me. But I can wash my hair on my own and eat on my own; also toilet things, more or less. I won't bother applying for it again.

(Group 3)

Recognition inside the services

Those participants who were eligible for home care had more positive experiences of accessing health and social care services. In groups 2 and 3, where most participants had poor functionality, access to the doctor was seen to be fairly good, “nothing to complain about” (F3, G3). However, the amount and content of home care was brought up several times during the group discussions. Many felt dissatisfied with the help given, and that the resources of home care were too tight. One participant recalled a situation in which she had become frustrated about the fact that home care workers always said that washing the dishes or other home chores were not their job:

Then I've said that in that case bring me a list of the things you can do. I've never got such a list. It feels so bad in the heart when you ask for something that's really important to you and they say that it's not their business. And when

they come by, they stay only for five minutes. Support hoses and eye drops, that's it. (F3, G2.)

Later on in the discussion the same participant described the time when she was sent home from the hospital with a suggestion of at least two home care visits a day.

They started calling me: "would you be able to manage with only one visit?", "We are so busy that there's no way we can make it", they said. And when they came in the morning they said "Oh I'm so busy, I have to run there and there". They're always in a hurry when visiting me. I don't understand it. We pay quite a lot for it. Just for someone to say how are you doing. Thanks. (F3, G2.)

The limited time given by the home care workers, as well as their turnover rate, were discussed several times. The fact that professionals only had time to drop by was seen as a negative factor in their everyday life. The short duration of doctor's appointments also prompted heated comments by the participants. Many reflected on their experiences of times past: "if you went to the doctors it was 45 minutes or even one hour, now it's 15 minutes" (F1, G1). However, positive examples were also given. One group discussed a local system in which the patient was given time with a nurse before the doctor's appointment. The nurse had more time to go through the patient's situation, writing it down and sending it to the doctor. This was seen as a helpful protocol for those who felt that it was difficult to be heard during the short appointment. "It's impossible for the doctor to get an understanding of the patient and his or her situation in 15 minutes", one of the participants stated (F1, G4).

Attitudes of professionals were discussed several times during the group discussions. The participants spoke of experiences of being mistreated and of being a burden to the professionals. As one female participant illustrated, the quality of the encounter appeared more important than the actual time spent with the professional:

The home care workers are always so busy, I have a deep experience of it. It was the first time the home care workers came by and the first woman who

came. She had only one foot inside the apartment and the other one still outside when she said that "what do I have to do, I'm really busy". I quietly sat down, took my laptop and started browsing things on it. She came next to me and asked what she should do. I said, "listen, please put your coat on and go back through the door where you have to rush to. I'm not busy, I have time to sit here." She was very embarrassed but didn't apologize. But I saw it in her eyes that she was regretful. Then she asked "what should I do for you". I said, "you have the instructions, read from there". Then she started reading it and did the small things I need, oiling my back, putting eye drops and making an evening snack. (F2, G1)

The participant emphasised the importance of not revealing their tight schedule when visiting older persons, who may have waited for the visit for several hours. Home care visits may also be the only events of the day for many older persons, as she described.

The few words she could... For two minutes she could sit on the chair and hold the older person's hand or shoulder, talk and ask how was your day, did you get anything done etc. It's worth any pill, you know. It's worth any pill. (F2, G1)

Other participants also brought up the importance of hiding or at least controlling the impression of being in a hurry when working with them. Emphasising the role of recognition, one male participant expressed his wish to be accepted as he is. Continuing from the theme brought up by his co-participant (previous excerpt) he brought up the significance of listening and of being heard:

So that you are accepted as you are even though you are different. That you are appreciated and accepted as you are. It's what creates a feeling of togetherness, interaction. The one moment when you are together. When you are in pain or something it's not that easy, but to have even a little time to discuss. To get your thoughts into something other than your own situation. And to see that the other person has the patience to listen and doesn't push you away and say thanks that's enough. It can go like that. You expect that the other one wants to listen. (M1, G2)

Rude and negative encounters with professionals were mentioned in several discussions. For many, they seemed hard to forget even though time had passed since the actual situation. Most

negative experiences were from the health care services, more specifically from doctor's appointments. The older people felt that their concerns were not taken seriously. Some believed that this was due to their old age. The "belittling", referred to in the previous section, was also seen to be linked to depression, as one male participant described. If you were diagnosed with depression, other conditions and symptoms were easily explained by the depression, without further examination or even discussion with the patient.

The older persons felt that few professionals were interested in having a holistic understanding of their situation. Health care professionals were only interested in health issues, as one female participant described:

The patient went to the doctor's appointment and the doctor asked what the problem is. My legs are in such bad shape that I can't get up the stairs. The doctor said that it's not the doctor's problem, move to a house with no stairs. (F2, G4)

Concrete gestures of recognition, or rather the lack of them, were discussed in all of the groups. The participants felt that their needs and personhood were easily bypassed by speaking too quietly, for example. Negative experiences made the older persons wonder if professionals lacked the understanding to speak clearly and slowly, or just the will to do so.

I went to the hospital for a checkup and there was a young man as a doctor. We tried to discuss but I didn't hear everything and he started shouting. I couldn't even understand that much. Then he wrote in the certificate that the discussion was gone through by shouting (laughs). He could have said to bring the chair closer so we could talk. But no, he decided to sit far away. (M3, G1)

Lack of recognition was closely linked to the importance of being treated as an autonomous person who is capable of understanding his own situation and participating in discussions and negotiations related to his own care. These experiences were present especially among those participants who were home care clients. As one male participant described, home care

clients are rarely asked if they want to take a shower. “Even though the older person has something else to do at the time, he or she’s suddenly taken for a wash. They don’t ask if it is a good time” he stated (M4, G2). The participants felt that they had little control over their own situation due to experiences of being bypassed by professionals, who believed they knew what was best for them without discussing things with the older persons themselves.

Discussion

In this article we have examined older people’s perceptions of quality of life from the perspective of health and social care services. The aim was to identify supportive or restrictive factors in relation to quality of life. Two central themes were found in the data: the importance of accessing services and information regarding the services, and the need for recognition within the services/by the professionals. Both themes were connected to the older people’s wish to maintain autonomy in their everyday life, which was seen as an important factor for quality of life. Health and social care services were needed to maintain good (enough) health, as well as meaningful social bonds and participation in the community, highlighting the multidimensional nature of quality of life (Vaarama & Pieper, 2014).

As restrictive factors for quality of life, the older people described difficulties in accessing health and social care services and information regarding these services. They felt that accessing services was difficult and based on sheer coincidence or on the professional’s good will. Kin were seen as important enablers for access (also Victor et al. 2018). The older person’s own financial resources were seen to play an important role in receiving adequate health and social care services, which is in line with current research. In the Finnish context, over ten percent of older people report not visiting the doctor because of their poor financial situation. Older people living alone and with low incomes receive significantly more home care than those with more income, but express it as being inadequate. (Hannikainen, 2018.)

The rate of unmet healthcare needs is also known to be high within ethnic minorities (Jang et al., 2017) and older people in rural areas, with functional disabilities, or in poor mental health (Thorpe et al., 2011).

Access to health services has been the focus of research, policy and practice for several decades (Lombardo et al., 2014). According to Vaarama (2009), good access to appropriate care and help is necessary for older people, but the psycho-social dimensions of QoL also need more attention. This was also evident in our study. The older people experienced lack of recognition of their own personhood and individual needs within the services. The participants felt that they were easily bypassed and left out of negotiations regarding their own care. The discussions emphasised the importance of being treated with respect and dignity despite increased disabilities and a need for care services. However, this did not appear self-evident to all professionals, at least from the perspective of these older service-users. The older people felt burdened not only by health problems, but also by the way they were addressed within the health and social care services. Perceived insufficiency of services and mistreatment were found to be important factors in increasing this burden and therefore negatively impacting quality of life.

The study has limitations. The dataset was originally collected to gather older people's collective views on quality of life in more general terms, not specifically on experiences of access and use of health and social care services. Building the focus group discussions more specifically around the topic of this article could have offered different or more detailed views on the supportive and restrictive factors of health and social care services. However, we found that the data driven approach used in the study offered the possibility to examine older people's perceptions of quality of life more authentically. The important role of access and how older people are treated inside health and social care services were brought up by the participants themselves. In future studies more in-dept interviews are needed on the topic. A

larger sample size and mixed methods would also offer additional understanding on the ways older people's subjective experiences of health and social care services impact quality of life.

This article highlights the importance of developing health and social care services and practices towards a holistic approach, in which the older person's personhood and individual needs are recognized and supported. The older people's message regarding the importance of health and social care services for their quality of life appears clear and coherent. Accessing and gaining information on health and social care services, getting help when needed and being recognized as an autonomous individual with personal needs are important factors when aiming to support the quality of life of older people. Based on the findings it is important to note that these issues do not only need financial resources and structural changes, but also changes in attitudes and in the care culture of professionals. Recognition-oriented practices (Pirhonen 2017) are needed not only in care facilities, but also within primary and specialized health care services, as well as in home care.

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Table 1. Configuration of focus groups.

Focus group	Participants	Average age
Group 1	2 men, 3 women	85 years
Group 2	1 man, 3 women	75 years
Group 3	4 women	87 years
Group 4	1 man, 5 women	73 years