

The Meaning of Healthy Life Period for Older People after Serious Illness: A Regional Study of Four Participants in the Age of 70-92 Living in the Arctic Region of Norway

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Abstract

Introduction: To find life meaningful for retired persons living with serious illness and loss of partners is still possible though advanced age. Affiliation and complicity, meeting new neighbours because of moving from home to a new elderly home and being social active is important for their health.

Objective: To identify what the participants think is important in their surroundings in order to extend their healthy life period.

Study design: A follow up study from the first study held with 19 persons in 2009 and 2010.

Sample: Four persons living in their own home were interviewed during 2016.

Methods: A qualitative and semi-structured interview-guide with participants. Data is analyzed by qualitative content analysis by Kvale.

Result: The persons have the last seven years experienced being more depending to help and support from others because of increased needs.

Conclusion: Life goes on in spite of severe illness and loss of one's partner. It seems to be important to take up old habits and hobbies. To participate in social activities with like-minded peers sharing the same values and the same way of thinking gives life new meaning, health and motivates them to recover.

Keywords: Participation; Aging; Social activities; Illness

Introduction

The objective of this article is to identify what the participants find important in their environment to extend their healthy life period. It is about finding the meaning of life after a life-changing situation. The life-changing situation in this context is severe illness, loss of a life partner, moving from one's home into sheltered housing and role change. In different ways, older people convey that life does not consist of a chain of single events, but that they ascribe meaning to these events and try to link them together to a greater whole: a life story [1]. This is a continuous process. Memories of the past are not carved in stone, but change with new experiences and new meanings we ascribe to them.

This is a qualitative follow-up study of a quantitative study involving 19 informants in Northern Norway [2]. The informants were recruited from towns and villages in the Arctic area (Troms and Nordland). Their ages ranged from 70 to 92, they lived at home and could manage by themselves with more or less help from the health care providers. Recent years have seen several key reforms in public health and care

services in Norway. One of these was the "Coordination Reform", one of the main goals of which was to give local authorities more responsibility to care for patients after severe illness. This means in practice that older patients were discharged from hospitals to their homes as soon as possible. Community care nurses now have a wider field of responsibility, while older people at home need more help and care. This places greater demands on health care personnel. The home care services stated that the municipality has no available personnel waiting for assignments. This means that substitutes have to be hired for weekends, public holidays and vacations [3,4]. Another challenge for many local authorities in Northern Norway is the geographical size. This indicates the challenges facing health workers in the Arctic regions, especially in rural areas, in attempting to provide follow-up care to patients at home after recent discharge. In addition to long distances, climatic conditions are also challenging. Human beings living in the world understand the world in a meaningful way [5]. When caring for people who are ill, clinical judgement cannot be separated from ethical considerations because clinical judgement determines what is good for the person and what to do in each particular situation [5]. This depends on an understanding of worthwhile goals in caring practice.

Our background is a standing point. Our background understanding stems from the culture, sub-culture and family we belong to [5]. Our history of illness, treatment and social life in Northern Norway has changed our opinion of how we understand our needs when illness affects our lives [6]. How to cope and find meaning in illness can be understood by interacting with people who have these experiences [5]. The situation dictates that we live in this world in an involved way. People can experience the same situation quite differently. Bodily intelligence, personal, social, historical and cultural background understandings, experience of meaning, degree of involvement and other characteristics will influence how a person experiences a certain situation [5].

The context

Northern Norway is a part of the Arctic region that is inhabited by several ethnic groups; the ethnic Norwegian, the indigenous Sami people and the national minority the Kven people. The region Troms and Nordland has experienced a pragmatic Norwegianization, where Saami and the Kven people (people of Finnish descent) have more or less “disappeared” into Norwegian culture [7]. However, there are villages where the Sami language and identity have been preserved. History, local industry and cultural interaction across ethnic groups have meant that there still are remnants of the traditional collective culture and life view, especially amongst older people [2] and this seems to exist across ethnicity. Everyone belongs to a network of family, friends and neighbors, who provide assistance when needed. The ability to mobilize and provide assistance for each other is a cultural capital of knowledge, ideas and habits inherited from earlier generations and passed on to new ones [8].

Our previous study from 2009-2010 included 19 older participants interested in promoting their health [2]. This may suggest greater knowledge among older people about how they themselves can enhance their own health. Older people know more about good health in general and are keen to look after themselves to avoid being a burden on society and their family. This is particularly true of women. They can get by with little, even human contact. How socially active they are depends on their environment; this will vary greatly between people in isolated rural areas and those living in towns and villages. In addition to the geographical differences, there are also cultural differences. Older Sami women choose settings where they meet socially, culturally and religiously like-minded people [1].

The present article is based on a new study from 2016 with four survivors from the first study from 2009. The four from the previous study were interviewed about the changes that have happened to them during seven years, how they have coped with these changes and how they feel about their new situation. All had experienced serious illness or changes in their lives.

Selection

After several invitation form editors, we contacted earlier informants from a list of name from 2009 to hear if they were interested in participating again. This had been mentioned to them back in 2009. Because of high age some denied to participate, the health situation or had died. As a result we ended up with 4 participants who could take part from the 2009 study (Sarah, Ann, Milly and Olga). The selection criteria were illness or a change in the life situation.

Individual interviews of about one hour were conducted with each of the four women aged 70 to 95 years. Because of the desire to share their experiences, three of the informants were interviewed on two separate occasions (Ann, Milly and Olga). Two of women had suffered from serious illness (Sarah and Ann) since we interviewed them in 2009. Two of them had lost their husbands after caring for them for a long time (Milly and Olga). Sarah and Milly lives in a center of a rural municipality, while Ann lives in a rural area. Olga lives in a small town. Milly and Olga had both Sami background.

Method

The follow-up study used the same semi-structured interview as in the 2009 study. The topic areas in the interviews were based on the same questionnaires used in the initial interview. Besides age, gender, education and place of residence, they dealt with kinship, network, social relations, activities, hobbies, internet, public care, their current role in community and cultural diversity. We added some more question; how they had been threatened in hospital and after coming home, do they still want to stay at home and why they or the husband moved to a shelter or nursing home. The last added questions took the form of narratives. We felt that the narrative orientation would respect the narrative culture in the Arctic and way of communicating, in which questions dealing with difficulties are not given direct answers [9].

The interviews were transcribed and analyzed on the basis of Kvale and Brinkmann`s content analysis [10].

Ethical implications and the position of the researchers

The study observed the ethical guidelines for research in the social science and took account of the ethical practices for research on older people. We have respected the anonymity of the informants and told about the informants with respect and dignity. The researcher`s viewpoint are important [1]. Due to our own experiences and our own points of view as next of kin observing old parents, old relatives, old patient experiences and interactions with staff from home care services, hospitals and nursing homes, we had to be active listeners. The danger to over-identify with our own experiences has to be mention. The first author is a Sami women and the second author is a mental health nurse. This is a limitation, but also a strength in the interview and analyzing process.

Results

The interviews revealed changes in the life situation of the four informants interviewed for the second time after eight years. The informants` stories present some important insights. They have some features in common, but also some differences in what was emphasized during our conversations. In their stories, the informants placed themselves in contexts where their illnesses and new situation is reflected in their individual experiences. We have divided the findings in four themes:

1. Day to day state of health and variations in health
2. Abuse by health care providers
3. Strain caused by long-term care duties for spouse
4. Community of like-minded peers

Day to day state of health and variations in health

The participants experienced different health problems due to their age. Several were troubled with poor eyesight and reduced hearing, which meant that they could no longer read the newspaper, keep up with Facebook, use their tablet or watch TV. They experienced this as a loss [1]. One of the women who participated in the first study, Sarah (92), told us that she had installed modern equipment from the technical aids center that looked like a computer with a lamp that could light up and enlarge the letters. She said that she was not able to use it because she did not remember how to:

Some days I feel better and then I manage, it has something to do with how I feel. When I haven't slept well, I have a bad day. I guess I'm sitting still too much (Sarah).

When I arrived home after the heart attack, I felt insecure and afraid. Some days were worse than others (Ann).

Hearing loss was also a problem in everyday life, according to Sarah and Milly and felt to be worse than poor eyesight. Listening to the radio as a positive stimulus or having a chat with the neighbor opposite in the housing brightened up their days. If their hearing aid did not function and started beeping, this meant poor communication with others. Sarah needed more help with her technical aids:

The staff don't always know anything about the hearing aid or the reading aid. My hands are a bit shaky.

When first interviewed, Sarah lived in an apartment in her daughter's basement. At the second interview, she has moved to sheltered housing. When her husband died, she sold their house and moved in with her daughter who lived in a different place. Now she was living in a one-floor apartment that was easy to look after; this was in a building with three other residents with whom she could socialize, if she wanted to. They shared a hallway between their apartments. Sarah used a relator, had reduced hearing and eyesight and had to use many technical aids, such as a telephone amplifier. She found that she heard better on the phone than when talking to people with face to face. Her sister called her every evening at nine, which was the highlight of her day:

I don't regret at all moving into this shelter (Sarah).

After starting on medication for depression, her hands started to tremble. Because of this, it was difficult for her to change the batteries in her hearing aids because they were so tiny. She had trouble walking after two previous falls. She was still scared of falling again and sat a lot in her apartment. Her habit of food was taken care of and supported by home care service who brought dinner from a kitchen to the flat once a day and they also helped her with breakfast and afternoon tea/coffee by shopping this for her, because her next of kin was sometimes unable to do so. Including habit of food is very important for the weight and physical activity and prevent falling.

Abuse by health care providers

A different matter raised by the participants was a feeling that the staff were abusing them. The abuse consisted of having to take tests and fill out forms and insufficient care with the husband suffering from dementia. Two of the participants, Sarah and Ann (80) were tested with a Folstein mini-mental state form (MMS test). Sarah was being treated for depression and had been tested with an MMS test. Ann was tested when she was admitted to the rehabilitation ward. Ann said she felt it was offensive to have to take the test. She did not like being asked

what time it was and found this a complete lack of respect by the health providers:

After all, I do have a medical certificate from my doctor stating that my brain's ok.

Ann felt abused by this action. It is obvious that the way the personnel used the MMS test gave the women a subordinate role. Ann was a widow with two adult sons, a daughter-in-law and grandchildren. She was living alone in her house a few kilometers from the town center. When we first interviewed her, she had been discharged from hospital to her home. Even after two months, she had still not received any help from home care, even though she had a severe heart attack. She had seemed insecure and afraid, with many questions she needed answers to. However, the second time we interviewed her she had received home help and a welfare contact. Her everyday life was easier. Ann had also had a stay in the rehabilitation ward and it was there two health workers gave her the MMS test. Today Ann is in better shape.

Olga (70) was concerned about the busy home care. She had a husband suffering from Alzheimer and she asked: Is it a good care visiting my husband for five minutes each time?

She experienced the busy home care as supervision rather than care. Olga experienced the busy home care as supervision rather than care [9]. To some extent, she adapted to the busy day of the community health care and found alternative offers that could help and support her. Linked to the activity center there is a public health nurse for the elderly where she can get advice and guidance around her life situation two days in the week.

Strain caused by long-term care duties for the spouse

Two of the female participants, Milly (80) and Olga had a heavy burden of care while their husbands were alive. Both husbands had Alzheimer's disease. Olga cared for her husband at home before he was admitted to a nursing home. After their death, their own health deteriorated. For Milly, the joy of moving to a comfortable apartment was tempered by her husband's gradual weakening. Both Milly and Olga emphasized how they had struggled with difficult care work. Milly had felt alone with a heavy duty of care. Being there for her husband was a matter of course. When Milly's husband turned violent, she became quite exhausted. Instead of bringing this up with the home care nurse, she swallowed her pride and suffered in silence with the violence. It was difficult for Milly to talk about the violence and it took two visits from the interviewer before she opened up about the violence she had suffered.

There are different types of domestic abuse. The term "silent violence" is used to describe the violence inflicted on people with a heavy duty of care by their partner, which negatively affects their health. Milly's marriage was one of traditional gender roles. When her husband's health deteriorated, he needed her help in the rehabilitation phase to be able to live at home. Milly was not entirely willing to take on this role.

Yes, it may be tough and last a long time. All my life I've made sacrifices for my husband and children and I want to live a freer life now I've retired.

Nevertheless she believed in destiny and had chosen to stay at her husband's side until death parted them, she reluctantly agreed with the home care services and her children to care for him. Milly became the one who had to make sacrifices. Her husband found it hard to accept

his new situation of being dependent on his wife and Milly felt that neither home care nor her children gave her the necessary relief. The violence took place while she had to bear this burden.

At the first interview, Milly was living with her husband in a one-level comfortable apartment. Milly had a large family with children, grandchildren and great-grandchildren:

I couldn't have coped with the work that comes with having a house. We had a house, but it was too much boring housework. Therefore we sold it and bought an apartment and I haven't regretted it one day since.

At the second interview, Milly had become a widow. For the last two years, she had functioned as a caregiver for her husband:

It put my life on hold.

Her husband had developed vascular dementia and she had experienced both physical and psychological violence. Although her husband was receiving home care, the nurse had never asked how she was managing as a caregiver. She did not mention it herself either. Now she had a hearing loss and used a hearing aid. She believed it was because of all the foul things she had to hear from her husband. Now Milly's hearing was improving and she felt she was in better health. She had a good network, many hobbies and good helpers. Having been a caregiver for her husband before he was admitted to the nursing home had taken its toll on her health.

A community of like-minded peers

For Sarah, Ann, Milly and Olga receiving public assistance was a new situation. They were proud women who wanted to manage by their own. Sarah found a good neighbor in 84-year-old Rosie at the shelter, who visited her several times a day. She grew fond of Rosie and at Christmas she chose not to spend the night at her daughter's, but instead quickly return to her apartment.

I didn't want Rosie to be alone on Christmas Eve. We have so much in common; we're both widows and we both have bad health.

Ann is often on the go with the welfare contact she was given by the council. She is special fond of company to the church on Sundays. It gives her peace, she says. Milly and Olga is participating in the local activity center. Here they could reflect on their new experiences and gather motivation to take charge in their new situation. The activity center did not only address their social needs, they also received health advice. Getting a little social care motivated them to manage their new situation.

Many more people would need home care if it wasn't for this activity center. Look at the woman over there (pointing). She is suffering from dementia and could not be living at home without the activity center. She is not doing knitting any more. Come and be with us, says Olga to her. You are not doing knitting any more, but you talk. The woman came (Olga).

For Milly and Olga, the activity center became a "sanctuary". After living a life "on hold" as caregivers they could take up their many hobbies. When Milly's husband was admitted to a nursing home, she became very active. The same with Olga. Olga ran a knitting group and took part in Sami organizational work. Milly take up knitting and sewing with Sami symbols (Sami handcraft). Meeting over a cup of coffee at the activity center and having a good chat was rehabilitation. It gave their life new meaning now that they lived alone.

In the town the activity center has been in danger of closing down several times. As a result, the residents' association organized a fund-raising by the users that went to running the center. Now they won't dare, said Olga.

In the first study, the old people were interested in promoting their own health. Now they showed how they could also take joint responsibility in the community welfare.

Discussion

The collective oriented generation involves a way of life that is a contrast to the individual way of life of today. Being able to regain ones dignity and identity after illness is important. In addition to medical and health care, it includes meeting others, regaining ones dignity in a community of meanings with a collective historical and cultural generation. Here the Arctic context plays its part in general and the Sami and Kven context in special.

Sarah, Ann and Milly experience health failure like reduced hearing, reduced eyesight, heart attacks and anxiety after falling and illness. The health-related variations influence the day-to-day condition. Sarah and Ann experience that they are exposed to a routine of the MMS-tests, which they feel are degrading. In addition to receiving help from the health care system, three of the women are after a while able to partake in meaningful social activities. Milly and Olga emphasize straining care giving over time to their spouses, something that in many ways makes them exhausted. They mainly talked about how they had taken care of their husbands after the men got Alzheimer's disease. The findings can be compared to gender studies on care [11]. The story about the Sami women Milly is about something more. It is unintentional violence – where the violence is set off because of exhausting circumstances and cognitive impairment. The abuse is performed by Milly's husband who has experienced colonial violence during his childhood. The concept colonial violence includes both domestic, cultural and structural violence. Milly's husband is both the victim and the offender. The silence around family violence is widespread among the Sami people [12].

Both women and men are exposed to family violence with an advanced care giving responsibility in all ethnic groups. Male violence takes on another form than female violence, which often is of a more serious matter.

The elderly are not a homogenous group, but have different interests, needs and wishes. Some of the elderly likes better to be on their own, while other likes it better at an activity center, retirement association or in more hobby-related associations [2]. Everyone can find different social and cultural offers that are adapted to each circumstance of life, needs and functional ability. In this lies a valued community which was established on beforehand (before they were sick) and which they know could utilize in a health promoting and rehabilitating phase [13]. There laid the health promotion; to meet someone with the same cultural background who share your values and understood your way of thinking.

In the local communities, the belief in powers beyond the control of man were very much alive. Throughout childhood, the children were taught to believe in some superhuman principles that tied man and nature together. This viewpoint of the individual and society created the framework around the respect for reciprocity in everyday life, where most people shared a common experience foundation, which

created a community that reached far beyond the family and neighborhood [14].

When they became ill or the situation changes, they had a common experience of shared background. Together with older local people, they share the difficulties with someone who understood them, recognized them and accepted what they brought up (cultural community). Experiencing inadequate follow-up after illness, they receive advice from their friends.

In the town Olga could receive professional advices related to her illness. This made her and other elderly feel more secure in their everyday life. The collective cultural capital, which is inherited from earlier generations and passed on to new, becomes a resource when one partner is old [2]. To have a good network is a source to quality of life in which the "healthy" period during old age is prolonged and by letting the elderly partake in the work with enhancing their own life situation, they receive strength through sense of coherence (SOC) [15]. Allowing the participants, even though they are older, to decide, they can feel active [2,5,15]. It is of value that the participants themselves learn to use their own resources and possibilities in order to have a better life in interaction with others. Having meaningful company with others contributes to consciousness and learning of the participants [16]. Having someone listen seems to be just as health promoting as it is to talk [17]. Through client participation, equality is gained and took place in environments where people participate in a community. They share their experiences with loss as a result of a change in roles, frustration because of the welfare state, participation and personal development together with others and possibilities of self-development [18]. The activity center is still an important health promoting arena and a social arena with health promotion over the cake dish. Mutual local cultural background and values, a sense of humor together with gallows humor and a culture of oral storytelling seem to be important factors when it comes to enjoying their time at the activity center. With the activity center situated in a town and in the center of the municipalities, they find their peers. Through different memory- and story-telling, they are able to see constructive connections in the past, that they have provided the community something meaningful and by reconciling with the circumstances as they are, they find inner balance [1]. This meaningful community with other elderly who have been in the same situation, contributes so that there are created different constellations within the activity center.

Conclusion

The persons have the last seven years experienced being more depending to help and support from others because of increased needs. To recover it seems to be important to take up old habits and hobbies after severe illness and the loss of one's partner. To participate in social activities with like-minded peers sharing the same values and the same way of thinking gives life new meaning and motivates them to recover. This provided continuity and content in their lives and taught them that life goes on even in old age. These findings concur with other research from Arctic areas [19]. Findings from Northern Sweden show that the oldest old are just as capable as younger generations of recovering physically and mentally after severe illness. More research is required to determine whether older people in the Arctic are particularly resilient.

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Conflict of Interest

The authors declare no conflict of interest.

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