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Accepting support from relatives

Changes in the elderly's information behaviour in relation to health status and living circumstances

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The proportion of elderly people in Iceland's population is growing fast, as it is in other developed countries. The growing proportion of older people in western populations is an established trend; their share is forecast to double from 11% in 2006 to 22% in 2050 (World Health Organization, 2007). In Iceland the population percentage of the elderly is predicted to grow from 10.4% in 2010 to 19.0-23.4% in 2060 (Statistics Iceland, 2010). This poses great challenges for the country's welfare society that needs to prepare for the increasing number of elderly citizens and their prospects for actively participating in society and providing for their quality of life. The traditional definition of "elderly" is the retirement age. In Iceland elderly is defined by law as people who have reached the age of 67 (Lög um málefni aldraðra nr. 125/1999). This has been criticised for not taking into consideration the heterogeneity of the elderly population. Berger (1994), for example, has made a distinction between the young old and the oldest old, i.e., people 85 years and older. Others have stressed that the number of years people have lived is less important than determinants, such as their physical, cognitive and social capabilities (Ries & Pöthiga, 1984). The policy of the Icelandic Ministry of Health is that elderly people can, with appropriate assistance, continue living in their own homes as long as possible (Heilbrigðis- og tryggingarráðuneytið, 2007). While many maintain the ability to take care of themselves into old age, others are dependent on formal support from the public sector as well as assistance from their social surroundings, particularly close relatives, such as spouses or children (Molyneux, McCarthy, McEniff, Cryan, & Conroy, 2008). Icelandic studies have shown that elderly people needing assistance receive most of it from their close relatives (Hlíf Guðmundsdóttir, Kristín Björnsdóttir, & Ragnar F. Ólafsson, 2004; Ingibjörg Hjaltadóttir, Sigrún Bjartmarz, Dána D. Heiðarsdóttir, & Steinunn A. Þorsteinsdóttir, 2010; Landlæknisembættið, 2006).

Information behaviour is interesting in this respect. Information behaviour has been defined as "the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking and information use" (Wilson, 2000, p. 49). Although far from being the only kind of information that older people need to engage in, health information becomes increasingly important as people get older (Guðrún E. Benónýsdóttir, Sólveig Á. Árnadóttir, & Sigríður Halldórsdóttir, 2009). Yet, there are indications that older people (60+) seek health information less often than those who are younger (Ágústa Pálsdóttir, 2005). Furthermore, Brown and Parker (2002) have found that as people grow older, they face more problems in learning new information. Elderly people have been found to have difficulties in understanding the information they receive, such as instructions for medication or official forms for applying for services and benefits. Among the communication barriers that they deal with are, e.g., problems with the visual and auditory presentation of information (World Health Organization, 2007).

It can be assumed that as people grow older, their relatives' role in supporting their information behaviour becomes essential. Close relatives have for example been found to serve as a source of information for the elderly (Shiuan, Su, & Conaway, 1995) and as trusted recipients of health information from their physicians (Brann, 2004). How older people are able, in their everyday life information behaviour, to seek support from their relatives is of significance. Yet to date there has been little attention given to this issue, and very little knowledge about it exists internationally. This paper reports preliminary findings from an ongoing exploratory study, where the aim is to examine the information behaviour of both elderly persons and their relatives, in relation to the changes with increasing age in elderly people's health status and the circumstances under which they live. The purpose is to gain better knowledge of the various aspects related to the elderly and their relatives' need for information, their information seeking and possible problems confronting them. Such a study has not been conducted before and will therefore create new knowledge of great importance. This paper will focus on the viewpoints of elderly people by introducing three of the themes that emerged from the findings.

Methods

To determine factors related to the information behaviour of elderly people and their relatives supporting them, a qualitative study using grounded theory was conducted. Researchers employing qualitative methods often focus on the daily life of the participants (Bogdan & Biklen, 2003; Taylor & Bogdan, 1998). The methods are considered useful in better understanding phenomena about which little is yet known (Strauss & Corbin, 1990). One of the main methods used in qualitative research is interviewing. The qualitative interview seeks to describe the meanings of central themes in the life world of the participants, and how they make sense of their daily life experiences (Kvale, 1996). Furthermore, researchers attempt to interpret the social reality emerging from the interviews (Bauer & Gaskell, 2000). In this study open-ended interviews were conducted with a group of elderly people and their relatives, but the paper will focus only on the viewpoints of the former group. The interviews sought to address a broad range of issues related to the perspectives of elderly people, their information behaviour and the support provided by their relatives, from multiple points of view.

The inclusion criteria for participants were, first, that they had reached retirement age, which in Iceland is 67 years; second, that they were still living in their homes, and third, that they needed assistance from their relatives. A convenience sample was used, and the participants were recruited through the assistance of two gatekeepers who initiated contact between the elderly and the researcher. The participants were eight people, aged 70 to 90. Four were men, and four were women. All interviews were carried out in the participants' homes. The data were collected in May 2010, and the interviews lasted 45-75 minutes. They were digitally recorded, transcribed verbatim, and the transcriptions checked against recordings. As soon as an interview had been conducted, the initial analysis started, through listening to it and writing researcher's notes. This was done so that the following interviews could be modified in order to examine more closely any ideas or themes that began to emerge, as suggested by Bogden & Biklen (2003).

Analysis of the data was conducted as described by Strauss and Corbin (1998). At the early stage of the analysis, key remarks and concepts were noted, and some initial

themes developed. At a later stage the data were reanalysed with these themes in mind and connections made between the main themes and subthemes. The themes were interpreted in terms of the contexts relating to each participant. As previously mentioned, this is an ongoing study, and data saturation cannot be expected at this stage. Therefore, the last step in the coding process, involving the integration of all the themes to develop a theory, has not yet been carried out.

Results

The relatives assisting the elderly participants could be their children, their children-in-law, or their spouse. In one example, a participant receiving help from her children was herself providing support to her husband whose health had started deteriorating. Three of the themes emerging from the interviews are presented below.

Information needs and assistance provided by relatives

Health information behaviour

A considerable part of the participants' information needs was related to changes in their health. Their situation varied in this respect as some of them had children, or children-in-law, who were health specialists, e.g. doctors, nurses or pharmacists, whom they could easily get information and advice from. When asked what he did when he needed information about health matters, one of the men replied: *"I call on the kids"*. Other participants had to use different means to get the health information that they needed.

One of the issues mentioned by participants was that it was not always easy to get an appointment with a specialist. This was mainly because it might take some time to get the appointment, and they found it difficult to press for the appointment. Waiting a long time after getting the appointment also proved difficult for some of them. Sometimes their relatives tried to support them by monitoring the appointment process, and if they felt that it took too long, they cut in and started to make enquiries. One of the women, who said that she and her husband needed to rely quite a lot on help from their son, said: *We were supposed to get appointments by telephoning, but nothing happened. So he started pressing on our behalf to get the appointments.*

In some cases people were no longer capable of going to doctors on their own. One of women, who said that she had started to accompany her husband when he had doctor's appointments, explained the need for this: *"It happened once that he went to the doctor ... and when he arrived he couldn't remember what he was going to do. He got a bit stressed and had forgotten it all"*. After that she went with him to ensure that he could explain his health problems to the doctor. In other cases children went together with their parents when they needed to see a doctor. This could be to provide support when information was anticipated about serious developments in their health. One of the women noted: *"They went with me, my son and my daughter, last time. Because he wanted to do more extensive testing..."* The reason why children went with their elderly parents could also be that they wanted to assist in the information process by asking questions and trying to understand what was happening with their parent's health. One of the women said: *"He was interested in it himself, and then he could add some questions."* Sometimes the participants' relatives encouraged them to ask more questions when they went to see their doctors: *"My kids sometimes say that I'm not efficient enough asking..."* said one of the females. Her children sometimes reviewed a list of items with her so that she could then ask questions about them the next time she met her doctor:

Information about formal support

The participants emphasized the importance of being able to manage on their own. However, when the relatives felt that they could no longer cope without formal support, they stepped in, provided them with information about the possibilities of getting support and persuaded them to apply for it. The quotation below illustrates this: *"It was just one of our children who started to talk about this. I was a bit reluctant at the start, I don't really know how to use it. I found it hard, I'm just sitting and watching while the work is being done. I felt it was a bit difficult not to take part in it."* At first sight it may seem reasonable for people to prepare for older age by seeking information and familiarising themselves about what kind of formal support they can seek from their community. However, it is not easy to cope with the experience of no longer being able to do things on one's own. It means a change of role, where ageing people are no longer participants in the same sense as they were, and this is something they want to postpone for as long as possible. This may explain why, when asked if they knew about the support that the community provided, some of them said that they had not looked into it. The relatives assisted the participants by presenting information about the support they could apply for and helped them all the way through the application process. This could entail getting them the necessary forms, explaining what information had to be filled in, and what it was that they needed to do in order to get the support. One of the women reporting that she had had great problems understanding the forms she had to fill out in order to get the support said: *"I told my daughter, this is somehow so idiotic, and the way this is put up. Then she replied, well mommy, surely this is what they mean..."* Her daughter had brought her the application forms without being asked and explained to her mother what she could apply for and helped her to fill in the required information.

Other information needs

The relatives, furthermore, provided help with information behaviour in relation to various non-health aspects of the participants' everyday life. For example, this could, be seeking and explaining to them information about insurance matters, which some of the participants felt were complicated. *"I'm perhaps not very clear on these kinds of things but my son went over it..."* said one of the women. Financial information was another area that the participants needed assistance with. One of the women said that her daughter assisted her with information about all daily matters related to her finances: *"... she started online banking for me, and she takes care of it all."* Although there were exceptions to this, most of the participants did not use a computer, which probably increased their need for assistance from their relatives. One of the men said: *"Well, I have not had a computer or any such thing"*. This meant that he depended on help from his children or children-in-law when he needed to either find or send online information.

Importance of having a help provider

The participants expressed the wish to cope for themselves while they could still manage. *"One would just like to take as much care of oneself as possible, for as long as possible,"* said one of the men. This was seen as something they had learned since childhood: *"I was raised to cope for myself"* is an example of this viewpoint. Getting used to having to rely on help from others was not an easy process for the participants, and one woman who had been more or less able, until recently, to cope for herself said: *"It's quite a shock for me. It's rather irritating not having get-up-and-go. It's such a strong part of oneself, particularly for us elderly, to be able to cope by ourselves"*. Yet, they also recognised the

significance of being able to seek assistance from their relatives. One of the men said: *"...it's a very good option and definitely not highly enough valued, to have someone at hand... if it is something that I need information about ..."*.

The need for support with information behaviour was associated with the participants' ageing, one of the men explained this as follows: *"I suppose that when I started to grow old I had to get used to it. Sometimes too much, because it was easier."* Thus, although the need for getting support was recognised, the thought still remained that one should try to cope and not take too much advantage of help from others. Ageing was furthermore associated with the feeling that one's capacity was no longer what it used to be. One of the men getting support from his daughter said: *"She is much more perceptive. I have become old, and I'm slow at thinking and such."* And in some cases it was necessary for people to accept that their competence in information behaviour had diminished so much that they had to rely upon their relatives: One of the women described it in this way: *"Anyway, it became so that I couldn't get on unless I got assistance with it."* Yet another instance calling for support was when circumstances had changed, and people suddenly had to manage affairs they were not used to dealing with. *"Well, my husband saw to all matters while he was in good health... I just didn't know anything, or how to do things, when he went"* said one of the women.

Accepting help

The participants seemed to sense their relatives' willingness to support their information behaviour. One of the women, reporting that her son helped her a lot, argued: *"He just has the best intentions and wants to do this,"* and another woman said about her children: *"They are always ready."* The participants also expressed gratitude for the help they got: *"The greatest support comes from my daughter...she and her daughters do everything they can for me"* was the way one of the men put it. In some cases the participants felt that they did not need to ask for help because their relatives were keeping an eye on their needs and offered assistance of their own accord: *"They always come without my asking for it,"* said one of the women.

Although people appreciated their relatives' willingness to help them, they did not necessarily find it easy to ask them for assistance. One of the women said: *"It is of course a bit embarrassing to be nagging at him..."* People also tried to limit their requests and only ask for assistance with the things that were most important, *"You try not to ask for more than you need"* said one of the women. Furthermore, relying on help from others was not always a straightforward matter because people sometimes felt that it called for them to organise their information needs: *"One has perhaps not planned ahead, to tell to examine if differences across the clusters were significant what is needed,"* said one of the women. Depending on others could also result in people giving up on some of the things they might otherwise have decided to look into, particularly if it meant going outside their home and having to ask their relatives to take them by car. An expression of this was: *"Of course it leads to me going less because I need to ask them."*

Summary

The paper has introduced part of an ongoing exploratory study by focusing on three of the themes emerging in interviews with elderly people receiving assistance with information behaviour from their relatives. An important part of the participants' information environment was health information, but other information needs involved formal support for them continuing to live in their homes and information

related to their finances. The relatives of the elderly seem to play an important role in assisting them, both in getting necessary information and in interpreting the information. Although the participants expressed a desire to continue caring for themselves as long as possible, they also recognised the need for support with information behaviour and appreciated the help from their relatives. Adjusting to changed circumstances was, however, not a simple matter for them. They had to get used to the feeling of no longer being able to cope on their own and accept that they were reliant on their relatives, which was not easy. It also called for them to arrange matters differently from what they were used to and organise their information behaviour according to their relatives situation.

The study is at a stage where data saturation cannot be expected. The existing data needs further analysis, and more interviews are required to shed new light on the issue. Therefore, additional themes may emerge in the future. In addition to the perspective of elderly people, one part of the study will focus on the viewpoints of the relatives supporting the elderly's information behaviour. It is necessary to gather knowledge about their side as well, and the future work of the study will also concentrate on this. Furthermore, although the current study did not plan to examine the perspectives of the various groups providing formal support to elderly people, it might nevertheless also be useful to learn their opinions, and how they think elderly people's information behaviour can be supported and strengthened.

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