

## Relatives as supporters of elderly peoples' information behaviour

### Abstract

**Introduction.** The paper presents results from an exploratory study with the overall purpose of gaining knowledge of various aspects related to support at information behaviour that Icelandic elderly people, still living in their homes, receive from their relatives. The paper will focus on the viewpoints of the relatives and how they describe their own situation as informal information supporters of the elderly information needs.

**Method.** A qualitative study was conducted. Open-ended interviews were taken with 14 relatives, nine women and five men, aged 37 to 74. Their backgrounds varied as to education, work experience and residence.

**Analysis.** Analysis of the data was conducted according to grounded theory as described by Strauss and Corbin and the themes that emerged interpreted in terms of the context relating to each participant.

**Results.** The relatives provided divers support. In addition to monitoring the condition and situation of the elderly, it involved considerable information seeking, mediating and interpreting information. As well as information management and making arrangements for everyone involved with the support to be kept informed.

**Conclusions.** Three main topics of information needs were identified: health information health, information about formal support from the state or municipality, and financial information. The relatives further provided information about the elderly housing. The relatives expressed complex feelings about their role as informal information supporters. The findings presented, together with previous findings, suggest that the connection between the elderly experience of dependency for support and the relatives providing the support is complicated and needs further investigation.

## Introduction

The paper presents results from an exploratory study where the overall purpose is to gain knowledge of various aspects related to support at information behaviour that elderly Icelanders, still living in their own homes, receive from their relatives, as well as possible problems confronted by both groups. The paper will focus on the viewpoints of the relatives and how they describe their own situation as informal information supporters who assist the elderly at getting their information needs satisfied. To date, few studies have examined this issue and there is a great need to gain more knowledge about it.

Western societies need to prepare for increasing number of elderly people, with the fastest growing group those who are 80 years or older ([Statistics Iceland 2010](#)). In correspondence with findings about older peoples residential preferences ([Stefánsdóttir and árnason 2004](#)) the policy of Icelandic authorities is to make it possible for them to continue living in their own homes as long as possible ([Ministry for Health and Social Security 2007](#)). This calls for awareness of how older people can be assisted at living independently in their homes, e.g. at getting the information which are necessary for them to deal with daily matters and be active participants in society. Although it may be assumed that many older people can take care of themselves into old age, formal support from the state or municipality is important to ensure

that they do not need to move into elderly institutions. However, studies indicate that it is close relatives that provide most support ([Hjaltadóttir et al. 2010](#)). In Iceland, family ties are strong. Findings show that 21% of people aged 67 to 80 years, in the capital city Reykjavík, received at least one visit a day by family member or a friend, or went on a visit to them, and 46% said that this happened several times a week ([Capacent Gallup 2007](#)). There are indications that relatives not only provide informal support but also have various influences on the elderly use of formal service ([Birkel and Reppucci 1983](#)). The role as informal supporter can, though, provoke contradictory feelings. Aronson ([1990](#)) found that women supporting their elderly mothers expressed a sense of responsibility and a wish to live up to cultural assumptions that saw women as the supporters of choice but they also felt that this constrained their wishes for independency.

Studies of how families support older people have mainly centred on aspects other than information behaviour. Yet, there is evidence that older people face various difficulties at seeking and interpreting information ([Brown and Parker 2002](#); [Eriksson-Backa 2008](#); [Pálsdóttir 2005](#)) and that close relatives seek health information online for them ([Fox and Rainie 2000](#)) and supply them with information ([Su and Conaway 1995](#)). Relatives of elderly people with serious illnesses seek information from their doctors to gain better understanding of how they can care for them ([Hirakawa et al. 2011](#)) and sometimes act as trusted recipients of confidential health information from their physicians ([Brann 2004](#)). A conceptual framework explaining the information needs of relatives that act as informal supporters has been developed by Hepworth ([2004](#)).

Various terms have been used to describe how people support others to get their information needs satisfied. McKenzie ([2003](#)) talks about information seeking by proxy, when people are referred to an information source through a gatekeeper or an intermediary. Abrahamson and Fisher ([2007](#)) suggested the term lay information mediaries for those who act as informal information seekers for others. However, the term most frequently used is probably gatekeeping (see e.g. [Agada 1999](#); [Lu 2007](#); [Metoyer-Duran 1991](#)). Lu ([2007](#)) defines gatekeepers as those who shape and inform people's knowledge through the act of filtering and transmitting information. He provided an integrated framework describing three types of gatekeepers: 1) nominated 2) socially positioned, and 3) culturally certified. What is of most interest here is culturally certified gatekeeping where, because of cultural ideology but not expertise knowledge or access to information sources, certain people are legitimated to have the authority to provide others with information. However, few studies exist on this and the definition calls for a more profound analysis. In the present study it can be argued that both parties were forced to accept their roles. The relatives, because of cultural norms, as informal supporters of the elderly information needs and the older people, who are in a position of having to accept support. It was, therefore, considered that the term informal information supporters would best describe the role of the relatives.

The paper will focus on the viewpoints of the relatives and how they explain their own situation as informal information supporters. Previous reporting's from the study have centred on findings of how elderly people experienced the support from their relatives ([Pálsdóttir 2012](#)), as well as the importance of opportunistic discovery of information ([Pálsdóttir 2011](#)). However, to get a more complete picture of how the elderly information needs can be supported it is necessary to investigate the topic also from their relatives perspective. In order to address this, following research questions have been developed:

1. What is the nature of the information needs for which the relatives support the elderly?

2. How do the relatives experience their role as informal supporters of elderly persons' information needs?

## Methods

Qualitative methods, using grounded theory, were used in the study. This was chosen because the methods are considered useful for better understanding phenomena which little is known about ([Strauss and Corbin 1998](#)). Open-ended interviews were conducted. Based on knowledge drawn from previous studies the interviews sought to address a broad range of issues; the nature of the information need, how the support was provided, and the relatives experience as informal information supporters. A convenience sample was used and participants recruited through the assistance of gatekeepers who had contacts within the local communities. The relatives were a group of fourteen people, including the elderly children and their children-in-law. In one case a grandchild and in another an elderly spouse participated in the support. Their work experience and residence varied. Table 1 shows the relatives sex, age and educational background.

Table 1: Characteristics of the relatives sex, age and education

Relatives	Sex	Age groups	Education
1	female	50-60	university
2	male	60-70	university
3	male	60-70	university
4	female	50-60	secondary
5	male	50-60	secondary
6	female	50-60	primary
7	male	50-60	secondary
8	female	30-40	university
9	female	50-60	university
10	female	50-60	university
11	female	50-60	university
12	male	50-60	university
13	female	50-60	university
14	female	70+	secondary

All interviews, lasting 45-95 minutes, were carried out from May 2010 to June 2011 in participants' homes, with the exception of one interview conducted at the participant's workplace. They were digitally recorded, transcribed verbatim and transcriptions checked against recordings. As soon as an interview had been conducted, initial analysis started through listening and writing researcher's notes. This was done so that the following interviews could be modified to more closely examine ideas or themes that began to emerge, as suggested by Bogden and Biklen ([2003](#)). Analysis of the data was conducted as described by Strauss and Corbin ([1998](#)). At the early stage, open coding was used to question the data. Key remarks and concepts were noted, incidents compared and grouped, and some initial themes developed. As the interviews progressed the themes became better developed. At a later stage, axial coding was used to reanalyse the data with these themes in mind, questions

asked about the conditions, actions/interactions, and consequences of the themes, and the data organized by making connections between the main themes and subthemes. The themes were interpreted in terms of the contexts relating to each participant.

## **Results**

The results include topics of information which the relatives assisted the elderly with: information about health, housing, finances and formal support. Information about recreational activities was mentioned by a few participants but formed a minor part of the support and will not be explicitly discussed. The presentation also includes results about the relative's management of the support and their experience of being informal information supporters of the elderly. The figures at the end of quotations refer to the participants numbers in Table 1.

### **Health information**

Support with health information is classified in three categories: a) Information sought for the relatives own use; b) Mediating information between doctors and the elderly; c) Observing the elderly and providing information to them or their doctors.

#### **Health information sought for the relatives own use**

When the elderly health started to decline their relatives sometimes felt that they needed to act on their own to learn what might be happening and how they could react on it, without the elderly knowing it. One of them had worries about his father who had had a series of driving accidents and started to advocate for him to stop driving. For this he needed information about how aging could affect people's driving abilities and said:

The course of events was that I contacted a gerontologist who works at [place] which led to us to meet the family doctor. (Respondent 5)

The reason could also be a suspicion that the elderly were not well able to receive information from their doctors:

There have been examples when we have asked her doctor what is happening, particularly because she is very deaf. (R2)

In another case a relative, whose father had become seriously ill, got her parents' permission to go with them to doctor's appointments:

When I started to ask questions and they just shrugged and didn't know and couldn't answer I just asked if I might join them because I wanted to know about these things. And it was no problem on their behalf. (R1)

After that she sometimes went with her parents to doctors' appointments but when she noticed that her father's condition had suddenly become much worse she decided to act on her own to get more information:

And then I went to the hospital and asked... (R1)

## **Mediating information between doctors and the elderly**

The relatives also went, at the elderly request, with them to see doctors. One of them said about his mother:

...she's for example very reluctant to do go alone to a doctor. (R2)

Another one said that after he had started to make enquires on his own his parents expected him to go with them:

My mother has told me, we are going now, we have an appointment with the geriatrician Tuesday next week, does that suit you? So, she clearly wants me to carry on... (R5)

The reason that the relatives went with their parents could be to assist at explaining their health condition and ask questions, as well as to help remembering the answers and explain them.

## **Observing the elderly: providing information to the elderly or to their doctors**

The relatives, furthermore, tried to assist by keeping a close check on the elderly health condition and provide either them or their doctors with information when considered necessary. This was sometimes done by keeping an eye on the older persons needs to see a doctor and assist at making appointments. In particular, specialists often have long waiting lists and the relatives sometimes tried to help by making enquires and press for getting an appointment. One of them said about his sister:

she makes appointments, talks with the doctors and helps in that kind of way. (R2)

Another way of assisting was by monitoring the elderly health condition and contacting a doctor if necessary:

I just went to the casualty ward and talked with some doctor. Just to tell him what was happening. And what could be done? Then, immediately the wheels started turning". (R1)

In another case a relative contacted the family doctor with complains when she noticed that her mother had problems with the medication described for her:

He sent her home with 100 of those strong pills and I didn't think it was right so I just phoned him. (R4)

The support could also consist in the relatives keeping a watch on the elderly health behaviour and provide them with information if they felt it might help:

Of course we have to cut in if we notice that she is not eating or something like that. I just find something about an old person who dehydrated and tell her about it. I have told her that if you dehydrate you lose your memory and so on. (R13)

## **Information about housing**

Providing information about maintenance or renovations so that the elderly homes better suited their needs was among the things that the relatives took care of.

In the last two, three years we have been pointing out what needs to be done and persuaded them to do it, (R6)

said one of them. This was particularly important when the elderly had developed health problems and had difficulties using present facilities:

For example last year the bathroom was renovated. Dad has artificial joints in both knees and one hip and because of this he had started to avoid climbing into the bath tub. (5)

is an example. The relatives provided information about the whole process, e.g. what needed to be done, how and by whom, and the financial cost.

We have examined the financial cost and together with them decided on how things can be done. (R5)

If the elderly lived in an apartment block it could also call for information about mutual things:

...to be around in the block, the cooperative, meetings, everything in relation to that. (R13)

In some cases people had developed health problems which made it difficult for them to continue living in their present home. One of the relatives described her father's situation so:

...he had almost stopped going out because he was so worried about going up the stairs. (R13)

When the relatives noticed that the situation had become too difficult it could lead them to try to persuade the elderly to move somewhere more convenient,

...we started to discuss whether they wanted to change flat... (1)

This could mean quite a lot of work in seeking and mediating information to the elderly:

...we began to look into the possibilities and bring them information. (R1)

The whole process, however, could take considerable time and effort and, furthermore, financial and legal information needed to be provided as well as assistance at closing the contract, as another participant told:

It took me almost four years to get them to move. So when they finally found something that they could accept I just finished the business. (R13)

## **Information about financial matters**

Support with financial information included various issues. Sometimes the elderly needed assistance at both getting the relevant information and interpreting it. One of the relatives said:

We go together with them to the insurances and things like that. Because when people have become old they don't quite know how to react. (R6)

In other cases more assistance was required:

...I handle all his financial matters. The online bank and also if it's needed to go to the bank, get signatures, and I'm constantly busy and all over because of this. (R10)

Particularly, getting information about allowances or reimbursements from the social insurance system or the municipality could be problematic:

...there are so many things about the system that I don't have any idea about. What are people entitled to? And you are never told about this. You always have to go and ask, how is this and what next, and why is this so? This is perhaps what I think is most inconvenient. (R1)

The relatives also advised and even encouraged the elderly about spending money as one of them told whose father had been planning to wait for quite a long time before buying a new hearing aid:

...a year or two until he could get the next allowance... (R5)

He explained to his father that his finances allowed him to buy the hearing aid immediately and persuaded him to do so. In other cases the assistance had more social aspect:

Sometimes we go shopping, just the two of us, I and my mother-in-law, and then we share a shopping basket and she asks me about this and that. (R6)

### **Information about formal support**

One way of helping was by seeking information about formal support that the elderly were entitled to from the community or state, as well as following up on matters to ensure that they received the support. The more fragile the elderly health was, the more important it was that their relatives assisted with this:

I was trying to get more help. Naturally, she could never be alone during the day, (R4)

said a relative whose mother needed day-care. They also explained to the elderly what kind of formal support they were entitled to:

I tell her, you have a right to this or a right to that. (R12)

Sometimes they found it easy to get the necessary information:

She gave very good information about how we should approach this. (R14)

Others complained that finding relevant information was not simple:

You see it was possible by being a bit, not exactly aggressive, but firm. (R9)

Another relative described how difficult it could be to find information in the following way:

But it's a jungle, it's a complete jungle. (R10)

Furthermore, knowing what support could be applied for was not always enough. In some cases information about the application process were needed, which could also prove to be problematic:

At least we need to be very resourceful, like with whom we speak and how we talk to them, (R12)

is an example.

### **Monitoring the elderly situation and management of the support**

Supporting the information needs of the elderly required a considerable management on the relatives' behalf. In some cases mainly one person provided the support. This could be because other close relatives were not in a position to participate or because they were living in different parts of the country:

We didn't move here until [year], we lived in [town]...In fact we just came here on visits and I hardly needed to take care of these matters at that time, (R7)

Although relatives living far away could not support on daily basis they sometimes tried to step in when something urgent came up. One of the relatives told about difficulties getting information about formal support for her parents and said:

But then my brother came here and helped me. (R11)

Being alone with the responsibility of supporting an elderly person could be demanding as one of them said about his sister:

...she had had enough and was extremely pleased when she got help. (R7)

In other cases two or more relatives shared the support:

...we have divided the work between us. (R2)

This could take several forms and sometimes required quite a lot of organisation:

We have a complete system... (R9)

said one. Sometimes people divided the work with regard to each other's strengths or knowledge in specific areas:

We take more care of the social part. My sister who used to work in the health sector, she takes care if something comes up where a doctor is needed. (R2)

When people needed to deal with more complicated matters, special arrangements might be required:



It's been a big issue and a lot of work... Sometimes we just take a week at the time each, or one of us takes this bit, tries to stay in contact with this person...and I with someone else. (R9)

Furthermore, when those who usually assisted the elderly person were for some reason not available, the grandchildren sometimes stepped in:

...then I had the supervision. Went to her daily and that kind of things. And then I was trying to understand the system... (R8)

To be able to assist, the relatives needed to monitor the elderly situation closely:

phone them and check if there's something, if they are okay and so. (R11)

This required information gathering about various issues as one of them described:

...if she needs anything, you know personal things. (9)

The information could also be aimed at a special condition of the elderly:

We have to look after that she's eating and try to encourage her to eat. (R13)

The support also called for information management on the relatives behalf, e.g. what information was needed and whom to contact to seek it:

I write down, one of them said: names, and the phone numbers always behind in brackets...just to remember, you know this one does this and the other one that. (14)

Thus, information about various issues, such as what had already been done and what was still lacking, as well as how to approach things, must be available. Apart from seeking information outside the family, the relatives also needed to make arrangements about communication within the family. This could demand quite a lot of information flow between them:

We take care that all of us brothers and sisters are aware of what is going on...Of course it is a great relief to know that. (R2)

It was necessary for everyone involved to stay informed and the relatives needed to find ways to ensure it.

### **The relatives experience as informal supporters of the elderly**

The relatives sometimes expressed worries about the elderly situation:

She's alone at home and there are a thing or two which I worry that might be lacking. (R3)

The feeling of having neglected their parents was also expressed:  
I feel that I have never taken enough care of my mother. (4)

However, it also happened that they felt that the elderly were reluctant to accept support:

...she's a rather problematic elderly person, not to except support. (13)

Getting the elderly to accept that they needed help could call for some persuasions and in some cases they needed to be ready for the elderly resentment:

I realized that there was a danger of me becoming the bad guy for a while. But I prepared for it...To be good you sometimes have to be bad also. (7)

Although the relatives saw the elderly reluctance to accept support as an obstacle they also realized that it could be hard to be in the positions of having to ask for help:

They felt that we were always taking too much care of them. (R1)

The relatives also related this to the elderly upbringing, which had emphasised the importance of being self-reliant:

She's just the kind of a person, a bit of the old time, and she wants to be as small a burden to society as possible, with minimal expenses, and she underplays her difficulties. (R3)

Awareness that it is a challenge for older people to adjust to the role of not being independent was also emphasised:

...to show a sincere understanding of how difficult it's to become old and loose the sense of security. (R11)

Being able to put themselves in the elderly shoes further helped at understanding their feelings. One of the relatives, who had to change his carrier at middle age said:

It was difficult for me and that's why I understand my dad so well. It's difficult to accept that something that you, or to change something when you were not ready. (R5)

The role of being informal information supporter was not always easy for the relatives who might experience a conflict about the elderly needs and how they were able to handle it. They could e.g. be frustrated over the elderly demands but at the same time understand that this was related to the process of aging:

...things have to happen immediately. It's this, perhaps it's being an elderly person. Things need to be done when it suits them. (R11)

Some of the relatives had, furthermore, started to age and experience health problems themselves. One of them said:

It's tough on me to take care of mum. It's a serious intervention in my life and of course all our lives. (R9)

There were, furthermore, examples of the relatives having to go through an introspection to resolve an old conflict or bitterness towards the elderly in order to feel sure that they could assist them in a way that they themselves were content with:

I went into this whole-heartedly right from the beginning. But at the same time I had to work at this... And I didn't let him feel it or, not for one minute... Because, obviously I'm extremely fond of him and very thankful for how he was (R10).

Another relative mentioned how important it was to think about the support in a positive way:

...I think it's important not to let her feel it, and not to feel it ourselves, that she's a burden... And I think I need to see it as an opportunity to go through this. (R8)

## Discussion

The article presents findings about an issue that has previously not been investigated as known, namely the how relatives of elderly people, still living in their own home, support their information needs. The empirical findings show that the relatives provided the elderly with diverse support. In addition to monitoring the condition and situation of the elderly it demanded substantial time and effort on information seeking, providing and interpreting information to the elderly. It, furthermore, required an information management and making arrangements for everyone involved with the support to be kept informed. Supporting the elderly therefore demanded considerable information behavioural activities. A comparison with previous findings from the study shows that both the relatives and the elderly mentioned support with information about health, formal support from the state or municipality and finances ([Pálsdóttir 2012](#)), which relates to findings by Hepworth ([2004](#)) who identified the arrangement of health care, formal support and financial support as the primary tasks of informal carers.

Assistance with health information was most prominent and formed a considerable part of the support. With growing age people usually suffer from health problems which they need information about ([Benónýsdóttir, et al. 2009](#)), at the same time they also deal with a range of barriers at seeking and interpreting information ([Brown and Parker 2002](#); [Eriksson-Backa 2008](#); [Pálsdóttir 2005](#)). It is therefore vital for them to receive support. The assistance was classified in three categories: a) health information sought for the relatives own use, instigated by them noticing that the elderly had developed health problems and consequently they needed information about how to react. The information was derived from doctors, either with or without the elderly knowledge. Seeking information about a person's health behind her back is clearly a very sensitive and serious matter which involves both ethical and legal issues. The findings suggest that this was only done when the relatives considered it vital, for them to be able to support the elderly. This corresponds with findings by Brann ([2004](#)) that doctors sometimes enclosed patients confidential information to their relatives; b) mediating information between doctors and elderly people, by going with the elderly to doctors' appointments, assisting by explaining the problem, asking questions and interpreting the answers; c) observing the elderly health condition and providing information to either them or health professionals.

The relatives also assisted with finances, which could involve support with specific issues or taking complete care of the elderly finances. Relevant financial information from the social insurance system, the municipality, or in relation to formal support were considered particularly difficult to find, an opinion shared by the elderly. For both groups a significant way of getting hold of the information was by discovering it opportunistically ([Pálsdóttir 2011](#)). With a growing proportion of elderly people in the population, society needs to find ways to adequately meet their information needs. In particular, it is unacceptable that older people and their relatives that act as their informal information supporters have difficulties finding information about issues important for the elderly well-being and quality of life. It is therefore vital that the institutions that are responsible for providing the information make an effort at improving the situation and thereby enable elderly people to better cope in modern society.

Other topics included information about formal support from the state or municipality and housing, a topic not mentioned by the elderly. Both topics become particularly important when older people find it difficult to perform various daily activities or to use the present facilities in their homes. Previous findings show that the elderly also spoke about support at getting information about family members and friends. Although clearly important to them, they did not seem to consider it as information but rather conversations about people ([Pálsdóttir 2012](#)), which may also explain why the relatives did not mention this topic.

Aronson ([1990](#)) found that women supporting their elderly mothers acted according to social ideology of women as informal carers but at the same time felt that this called for self-denial and constrained their wishes for independence. Although the relatives in the present study did not indicate such negative feelings about their role as informal information supporters, they nevertheless expressed complex feelings. On the one hand, they were worried about the elderly situation and even felt that they were not helping them enough. The support could though be quite demanding and require a great deal of work. Furthermore, to be able to provide appropriate support could demand them to resolve old conflicts or grudges against the elderly person. In addition, they sometimes felt that the elderly were not as ready to receive support as they themselves would have liked, which could cause them irritation, worries, or to prepare for the elderly resenting interference. On the other hand, the relatives expressed an understanding of the elderly wishes for not becoming a burden and were sympathetic of how difficult it might be to ask for help with things that they were used to manage on their own. Findings about how the elderly felt about receiving support further show that losing their role of independence and having to depend on support from their relatives, was a difficult experience which might lead the elderly to constrain their information needs ([Pálsdóttir 2012](#)).

## **Conclusion**

The empirical findings are drawn from a small scale qualitative study and cannot be generated to the wider population, but may provide an insight into the nature of the support that the relatives provided the elderly with and how they experience their role as informal information supporters. The support that the relatives provided was diverse and required substantial information behaviour activities on their behalf. Through comparison with previously reported findings ([Pálsdóttir 2012](#)), three main topics of information needs were identified: health information, information about formal support from the state or municipality, and financial information. The present findings show that the relatives also assisted with information about the elderly housing. The relatives expressed complex feelings about their role as informal information supporters. The findings presented here together with those previously reported ([Pálsdóttir 2012](#)) indicate that the connection between the elderly experience of dependency for support and the relatives providing the support is complicated and needs further investigation.

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