

From Noticing to Suspecting: The Initial Stages in the Information Behaviour of Informal Caregivers of People with Dementia

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Abstract. The information behaviour of informal caregivers of people with dementia was explored, from when the first symptoms of dementia were noticed until a decision to seek medical attention was made. Qualitative methods were applied and interviews conducted with 21 caregivers. Their information behaviour went through a sequence of three stages, in line with Holly Skodol Wilson's temporal model [27]: (1) Information about the disease is noticed; (2) Interpretation of information – Normalizing and discounting; (3) Suspecting – Purposive information seeking begins. As their information need developed, as described by Taylor [15], the caregivers moved from relying on opportunistic information seeking at the first two stages, to using both opportunistic and purposive seeking on the third stage. After they had fully developed their information need, they could seek information that was useful for bridging their knowledge gap, which allowed them to move forward to the decision to seek medical advice for the patients. The second stage of the process was particularly complicated as the caregivers misinterpreted the information about dementia that they came across as signs of something else. More public discussion by professionals about dementia could provide the caregivers and the patients with a better understanding of the disease. This in turn might help to shorten the time spent at the second stage, making it possible for the caretakers to enter the third stage more quickly, and thereby to come to the decision to seek medical advice.

Keywords:: Dementia · Informal caregivers · Information behaviour

1 Introduction

Today's information environment consists of a variety of information sources that can be accessed in various ways and by different means [1]. However, not all members of the society are able to benefit from it and people with dementia are in urgent need for support from their informal caregivers, that is, people who provide assistance outside the framework of organized, paid, professional work [2].

The growing number of elderly people has led to an increase in the number of people with dementia, a disease which has been declared a priority within public health [3]. As a result, the need for research investigating how the burden of their informal caregivers'

can be eased has been emphasised [3]. This calls for awareness of the caregivers' information behaviour and how they assist people at using information for their own advantage. The period leading up to the decision to seek medical advice can be particularly difficult for the caregivers, as it may be filled with uncertainty and concern about what is happening to their family member. At the same time, the benefits of having dementia diagnosed at an early stage have been stressed. An early diagnosis opens up for various possibilities at treatment and care, and allows the patients and the caretakers to make plans for the future [4].

The paper will report from a study about the information behaviour of informal caregivers of patients with dementia, with focus on the time from when they begin to notice signs of the disease, until the conclusions that the patients need medical attention has been reached.

1.1 Informal Caregivers and Information Behaviour

The importance of the work that informal caregivers provide is well known [5]. Several studies exist of the information needs of informal caregivers of different groups [see e.g. [6–8], as well as various aspects of the information behaviour of caregivers of elderly people [9, 10] and patients in palliative care [11].

Information behaviour is an encompassing and multifaceted concept including all aspects of human interaction with information, provoked by the information need of a person who is situated in a certain context [12]. Information need has been described as a cognitive gap [13], or an anomalous state of knowledge of a person [14].

Taylor [15] has identified the advancement of the information need as a gradual development in four levels: (1) the visceral need, or a “vague sort of dissatisfaction”, which cannot be expressed in words; (2) the conscious need, which is ill-defined, and can only be expressed in an “ambiguous and rambling statement”; (3) the formalized need, when it is possible to describe it in statements that are “qualified and rational”; (4) compromised need, when the information need has developed so that can be expressed clearly enough, in terms that fit the information system.

Although Taylor [15] based the model on experience from reference work at libraries but not on a systematic research approach, it is nevertheless believed by the researcher that it may apply to different situations and to be of value for the current study. The first two levels of the model describe what happens when people start to notice that there is a gap in their knowledge and gradually attempt to clarify and formulate what it is that they need to know. As such, these levels can relate to people in various contexts, such as the informal caregivers of people with dementia, and are not restricted to those who end up seeking reference service at a library. At the third level people's thoughts on the subject have developed enough for them to be able to explain their need for information to others in a rational way. In Taylor's model this would be to a reference librarian, but it is believed here that it could in fact be to anyone who is believed to be in a position to help the caregivers at solving their information needs, for example a relative or a close friend. The fourth and final level involves an interaction with an information system, when the caregivers have developed their information needs enough for them to be able to reword their questions so that it fits the system. This could be by doing an internet

search, for example by using Google or search engines at specific websites, it could also involve the use of a library system, or any other way that allows them to retrieve information.

The sense-making theory [13] further describes what happens when people find themselves in situations where they experience a cognitive gap, and as a result perceive an information need. The theory assumes that life is a journey where people take steps through experiences. At certain moments, when they are unable to make sense of what is happening, they are faced with a discontinuity, their path forward is blocked. To be able to continue their movement through time and space they need to create a new or changed sense. The strategies that people use to find answers and solutions, or the methods they employ for information seeking, serve as a bridge over the cognitive gap. Information is seen here as constructed by those involved, it can be anything that allows them to make sense of the experiences, and thereby continue their process through daily life. Similarly, in the Information Search Process (ISP) model [16] it is assumed that, based on previous knowledge, each person understands information in her own unique way. However, for people to be able to come to the conclusion that their previous knowledge is not adequate, they must have received information in some form that allows them to understand this.

Although purposive information seeking, when people set out to seek information with the goal to fulfil their information need, or close their cognitive gap, is well known [12, 17–19], other modes of information seeking have also been identified. This entails opportunistic information seeking, that is when people unexpectedly come across information which they had not intended to seek [12, 17–19]. Including what [17] has been termed as by proxy, or when people receive information through another person.

With few exceptions [20–24], studies that explore the role of information in relation to the support provided by informal caregivers of people with dementia, have mainly focused on the caregivers information needs, in particular at the time when the disease is being diagnosed or after the diagnoses. Thomsell and Lodestone [20] explored how well the information needs of relatives who are living far from the patients are met, compared with the patients caregivers. The findings suggest that, distant relatives' access information less frequently and are more dissatisfied with the information that they receive. The findings from a study by Wald, Faheem, Walker and Livingston [21] indicate that what kind of information the caregivers require differs, depending on the time from diagnosis. While information about the disease, the symptoms and treatments are regarded important at the time of diagnosis, the caregivers want information about the disease process, reaction in crisis and formal services, at a later stage. This was, later on, followed by a need for financial and legal information, as well as support groups. Finally, information about psychological and complimentary therapies were required. Other studies support the existence of these information needs. Wackerbartha and Johnson [22] reported that information about diagnosis and treatment options were most important, and after that legal and financial information, which were of particular importance to less experienced caregivers. Hirakata, Kaseya, Enki and Emera [23] found that the primary concern was to get information about how the disease might progress, how to provide care, and availability of formal care service. A study by Komarahadi, Ruf, Hüell and Härter [24] revealed the importance of information about symptoms, the

course and treatment of dementia, as well as financial support, daily care and interaction with patients.

The findings from the above mentioned studies provide important understanding of the topics that caregivers of people with dementia need knowledge about, at the time of and after the diagnosis of dementia. Less attention has, however, been paid to what happens during the period leading up to the time of diagnosis. In addition, the various aspects of the caregivers' information behaviour has received relatively little academic attention. From the information science perspective, models and theories which relate not only to dementia but also health information in general have been discussed [25]. The review provides a thorough overview of the main information models, and how they can be used to enhance comprehension of the information behaviour of patients and their caregivers. Furthermore, the information behaviour of caregivers suffering from depression, who participated in a training and support research project, have been investigated. Through the program the caregivers were offered an opportunity to share their experiences under circumstances and received professional guidance which were aimed at enhancing their problem-solving skills. The findings shed a light on how caregivers can be helped and strengthened in their role by professionals, through training and support programs [26].

The emphasis of previous studies has been on the information needs of the caregivers of people who are in the process of being diagnosed with dementia or have already received a diagnosis. The present study, however, aims at investigating the initial stages in the informal caregivers' information behaviour, in the period when the first signs of dementia appear, until they realize that medical advice is needed. The importance of detecting the disease at an early stage has been stressed, and for various reasons. This includes for example the possibility of the patients to optimise the benefits of any available treatment, care and support, as well as allowing them to make plans for their future [4]. Thus, shedding more light on the issue at hand might prove useful for health specialists who are responsible for providing information about dementia, and help to support both the patients and the caregivers when making the decision to seek medical attention.

An answer to the following research question will be sought: What characterizes the initial stages in the information behaviour of informal caregivers of people with dementia?

The study draws on the temporal model by Holly Skodol Wilson [27]. The model describes the process of the Alzheimer's disease from the perspective of informal caregivers in eight stages. The first three stages in the model are of interest for the present study. At the first stage "Noticing", the caregivers gradually became aware of something unusual in the patients behaviour. This stage was only recognized in retrospect, as it was no particular cognitive defect or behaviour change had alerted them, instead it came as a result of a cumulative behaviour, which eventually led them to move on to the second stage. The second stage is called "Discounting and normalizing", although [28] it has been pointed out that the sequence of what happens is that the caregivers first normalize the behaviour and after that discount it. Therefore, the term "normalizing and discounting" is more appropriate. At this stage the caregivers had recognised that the patients' behaviour had changed and wondered what might be happening. However, they normalized the behaviour by seeking a rationalized explanation, usually the

patients' old age, and as a result discounted it. This stage lasted until the patients' behaviour either became seriously worse, or a particular incident took place, which was too severe to discount. This led to the third stage, "Suspecting", when the caregivers realized that something serious was happening and began to observe the patient more closely in order to determine how they should react on it, which brought about the decision to seek medical advice.

The conceptual basis for the study is, furthermore, formed by theoretical knowledge about information seeking and models from information science. In particular, Taylors [15] phase model will be used to explain how the caregivers information needs advances in four levels, as they experience the first three stages in the process of the disease, as well as the sense-making theory by Dervin [13], which further helps to describe how the way that the caregivers used to get information and interpreted it, gradually allowed them to create a new sense about the situation, and thereby move on to the conclusion to seek medical attention for the patients.

2 Method

With the purpose of gaining a deep understanding of various aspects related to the participants' information behaviour, from their own point of view, it was decided to employ qualitative methods, inspired by grounded theory [29]. One of the main methods used in qualitative research is interviewing, which 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 [30].

In the study open-ended interviews were conducted with informal caregivers of people with dementia. The interviews sought to address a broad range of issues related to the nature of the caregivers information behaviour, their information needs, how the support was provided and their experience as informal caregivers, supporting their relatives with information. A convenience sample was used, and the participants were recruited through the assistance of an association of interest groups and relatives of people with Alzheimer and related diseases. A group of 21 people participated, 18 women and three men, aged 36 to 76, living in the capital area and smaller towns in the country. Seven of them were supporting their spouses, 13 their parents and one participant supported her sibling.

The interviews were carried out from February to August 2014 and lasted 50–110 min. They were digitally recorded, transcribed verbatim, and the transcriptions checked against recordings. To be able to modify the following interviews and examine more closely any ideas or themes that began to emerge, initial analysis started as soon as each interview had been conducted. The data was analysed as described by Strauss [31]. Open coding was used to question the data at the early stage. Key remarks and concepts were noted, incidents compared and grouped, and some initial themes developed. The data were reanalysed at a later stage with the themes in mind. Axial coding was used and 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.

3 Results

In line with Wilsons [27] temporal model about how the Alzheimer's disease developed, from the perspective of informal caregivers, three stages were identified in their information behaviour process: *Stage 1: Information about the disease is noticed*; *Stage 2: Interpretation of information – Normalising and discounting*; and *Stage 3: Suspecting – Purposive information seeking begins*. In the study, the term patients is used, although the participants did not know, at the time, that their relatives had dementia. Likewise, the participants are called caregivers, even though at the initial stage they may, or may not, have considered themselves as such.

3.1 Stage 1: Information About the Disease Is Noticed

The initial stage describes the process when the caregivers began to notice symptoms of dementia. At this stage, they occasionally detected something unusual in the patients' appearance. But as their thoughts about it were too indistinct, they were not able to put a finger on what might be happening. One of them described it so: *Something that I felt at the time to be incomprehensible*. Another caretaker said that she had started to notice small discrepancies in her mother's behaviour: *She was perhaps in tights that didn't quite fit to the dress*. Thus, the caregivers sporadically came across unexpected information, which caused them an uneasy feeling. However, their ideas at this stage were very unclear, and as a result they were not able to formulate what they needed to know to resolve it. What happened at this state may be compared to what Taylor [14] defined as the first level of an information need, as a vague need for information. A dissatisfaction which the caregivers could not at the time express in words. It was only at a later stage, when they thought back, as is described in Wilson's model [27], that they understood that the patients had in fact been showing signs of dementia. One of them expressed this so: *When I think back, she definitely had symptoms around the age of sixty*. The duration of the first stage varied across the caregivers. In some cases it could last for a considerable time as is well illustrated by one of the caregivers: *In retrospect, this was almost certainly...I could think two years back*.

After the incidents started to increase and the caregivers stopped viewing them as separate happenings, they were able to move on to the second stage in Wilsons [27] temporal model "Interpretation of information – Normalising and discounting".

3.2 Stage 2: Interpretation of Information – Normalising and Discounting

When the caregivers began to connect the isolated incidents' which they had been observing together and interpret it, they became aware that the patients' behaviour had changed. One of them stated: *There were all these weird things that I began to observe*. Another caregiver said: *I think many people had started to notice something*. At this point the caregivers were in a situation where they lacked an overview and understanding of what was happening. Nevertheless, by recognising that something might be wrong and that they needed to find an explanation for it, they had developed

what can be describe as an ill-defined need for information, or what Taylor [15] defined as a second level of an information need.

The caregivers received information by way of opportunistic seeking, in the form of the patients altered behaviour patterns. But rather than interpreting what they noticed as symptoms of dementia, they ascribed it as something else, they normalized and discounted it.

Normalizing and discounting. The subtheme *normalizing and discounting* describes how the caregivers interpreted the information and tried to find what they, at the time, considered a rational explanation.

Patients' characteristics. Some of the caregivers believed that the symptoms that they observed could be explained by the patients' characteristics, such as their age, other medical conditions, personality traits or even their abilities. Wilson [27] found that the patients' old age was the main reason why symptoms of Alzheimer were normalized and discounted. In the present study there were indeed examples of the caregivers interpreting what they noticed as normal symptoms of a person who had reached an old age. One of them noted: *They are just elderly people, they were in their eighties.* But although the likelihood of getting dementia increases with age, it is not confined to old age. In the findings there were examples of the opposite, with the caregivers normalizing and discounting the symptoms, because they considered the patient to be too young to have dementia. One of them said that she had discussed changes in her mother's behaviour with other family members. They did, however, dismiss the possibility of dementia to begin with. She shared her experience as follows: *She was also so young. We were so focused on it. She was just a little over sixty, maybe 62, when all kinds of warning signs started to appear.* As a result, some time passed before the caregivers realised that the patients might have dementia.

In some cases the patients had other medical conditions which made it difficult for the caregivers to interpret correctly what they observed. One of them said, that although she had noticed that her mother was losing some abilities, the thought of dementia did not cross her mind to begin with. She noted: *There was so much there that lead me to think that this was nothing unnatural and not linked to dementia.* The following further illustrates how a caregiver explained why his father's medical conditions had confused him: *He has hereditary hypertension...I thought maybe this could be because he was getting some bleeding or something.* In these cases, the caregivers had a tendency to explain the symptoms of dementia as the signs of another disease.

There were, furthermore, examples of the caregivers mentioning that the personality traits or abilities of the patients had hindered them from interpreting what they noticed correctly. One of the symptoms of dementia can be that the patients start to withdraw from social activities. However, when a patient had not been considered to enjoy interacting with others this personality trait could make it difficult for the caregivers to notice the change in his behaviour, as the following illustrates: *She never was a very social person, so you may not realize it...* Another symptom is that patients may start to misplace things. For caregivers of patients who had always been regarded as careless, it could be problematic to recognize this symptom. One of them explained

this so: *...just since I was a kid, she's the women who lost her gloves, she lost her keys.* Thus, when the caregivers know and are accustomed to certain character traits which are similar to the symptoms of dementia, they may normalise and discount what they notice as a typical behaviour of that person. In addition, there was an example of a caregiver who stated that she and her family had not considering dementia a possibility because of the abilities of the patient: *The idea never came to us that this active and clever woman who had achieved so much...That she was beginning to lose her memory, it was just not an option, it never occurred to us.* In this case the patient's reputation of being a very competent and talented person had influenced the caregiver's interpretation.

Slow progression of the disease. The speed at which dementia gets worse varies, there are differences from person to person and between the different types of dementias. In some cases the caregivers said that the symptoms had started out slowly and gradually become worse and that had made it difficult for them to realize what was happening. One of them explained his experience so: *This starts perhaps just once, and then a long time goes until something else happens that provokes you to think: "Wait, why don't you remember this?" Because it's natural for us to forget perhaps a thing or two.* Hence, the caregivers had to piece together information about disperse incidents over time. Until it was possible for them to get a more complete picture of what was happening, they described the incidents as normal and discounted them.

Denial. There were also examples of the caregivers stating that they had not been ready to acknowledge that the patient might be showing signs of dementia. This is well illustrated by the following: *We always found some excuse. And I think this was just the fear and the grief. This just could not be.* Because the family found it emotionally too difficult to face up to the fact that the patient might have dementia, they tried to interpret the symptoms as signs of something else.

Lack of knowledge. Finally, some of the caregivers claimed that, because they lacked knowledge about dementia, they had not been able to interpret the symptoms correctly. One of them noted that he had not reacted on his father's worries about his mother: *... he starts to complain that she is so forgetful and this and that. And I didn't realize that this was memory loss.* Hence, the caregivers needed more knowledge about the symptoms, as one of them said: *...it would be good to get much more education and information about it.* Another caregiver added that there was a particular need for information in the beginning of the disease process: *...to identify early symptoms.* Furthermore, some of them called for more public discussion about dementia: *...they need to write a lot more in the papers, bring much more to the radio...*, but at the same time it was stressed that this should be done professionally and that the debate must be based on knowledge and respect.

At this second stage in Wilsons [27] model, the caregivers thoughts about what was happening with the patents were still unclear and as a result their need for information poorly defined [15]. Although they did come across information that made them realize that there were changes in the patients' behaviour, their interpretation of the information, or the sense that they made of it, did not provide them with answers that eventually proved to be helpful at bridging their knowledge gap and allow them to move on [13].

This stage lasted until the patients' condition either became seriously worse, or a particular incident took place, which was too critical to normalise and discount. The change led to the third stage, "Suspecting – Purposive information seeking begins".

3.3 Stage 3: Suspecting – Purposive Information Seeking Begins

When the patients conditions had worsened so much that the caregivers had realized that something serious was happening with their health the caregivers moved on to the third stage in Wilsons model [27]. One of them explained what made her suspect that something severe was happening with her husband's health so: *Because there was so much personality change. He started to come with all sorts of ideas, all kinds of conspiracy theories...* While another caregiver described what got her thinking about her mother's condition in the following way: *Her behaviour mostly...and stopped doing things that she was used to do...and we noticed that she got anxiety attacks which we had not experienced before.* Thus, the information that the caregivers detected, and which made them ask themselves if something more serious was happening to their family members than they had understood previously, vary.

In some cases the caregivers together with the patient recognized that they needed to understand better what was going on: *Both we and she herself had realized that there was something, her brain was failing,* said one of them. In other cases, the information were provided by proxy, when persons outside the family alerted the caregivers about how severe the situation was, or as one of them stated: *...others had noticed that something was happening.* Another caregiver said that her father had been recovering from a different disease, when his doctor noticed the symptoms: *She had just started to notice that he had begun to forget his keys and something like that, but nothing serious.* There was, furthermore, an example of a patient who was the first one to understand that something was seriously wrong. Her husband described this so: *In the beginning our friends were joking and saying "well you have Alzheimer" or "it's just the age". But she realized that this was more...*

After the caregivers had acknowledged that they could no longer interpret the behaviour changes of the patients in the way that they had done before, they realized that more information was needed about what might be happening. As a result they began to express their thoughts more clearly and ask questions that could better help them to understand what was going on. By doing so, they managed to develop the third level of information need (formalized need) when it is possible to use "qualified and rational" statements to describe what information is needed [15].

At this stage the caregivers used both opportunistic and purposive seeking, to get information that could help them to clarify what might be happening. They monitored the patients with the purpose of collecting information about their behaviour, before making a decision about the next step: *So when we had been checking her for a while we had realize that this was something strange...*, said one of them. Some described information seeking by proxy, or as one of them noted: *...she immediately contacted me and said: "Something is happening to your mother".* They also communicated and shared information with other members of the family, or their close friends, and compared information in an attempt to clarify what should be done. Sometimes they

searched in information sources to learn about the symptoms that they had noticed and what it might mean. This could be books or other printed sources: *Of course I had been reading and reading, because I was beginning to suspect this*, stated one of them. Some of them used online sources as the following illustrates: *I completely lost myself online... the FAAS site and international websites*. To do this, the caregivers needed to reach the fourth level of information need, the compromised need, when they were able to express what they were seeking clearly enough to fit the information system [15].

Hence, various ways were used by the caregivers, to try to find an explanation, or some confirmation, in order to reach a conclusion about what could possibly be wrong, and what should be done about it. As they sought to create a new sense of what was happening, the caregivers used whatever strategy they possessed to seek information that could help them to bridge their cognitive gap, in order to be able to move on [13].

When the caregivers entered the third stage, the disease had sometimes progressed so much that it took a relatively short time before they reached the conclusion that a medical advice was needed. In other cases, this stage could last for some years.

A few of the caregivers reported that knowledge about dementia had existed within their families, which had helped them to interpret the information. One of them explained this so: *He has several siblings and two of them had been diagnosed with this before they died*. There were also a few examples of caregivers who worked within the health system and therefore had some knowledge about aging diseases. One of them said: *I naturally come from the health sector and I was perhaps the first one who realized that this was not alright, it was not just like a normal old age degradation*. Thus, knowledge about dementia can help people to recognize the symptoms of dementia, which in turn allows them to act more quickly on it and seek medical attention.

4 Discussion and Conclusion

The aim of the study was to explore the information behaviour of informal caregivers of people with dementia, from the time when they first notice a change in the patients' behaviour, until a decision is made that medical attention is needed. The study indicates that Wilson's temporal model [27], together with Taylor's [15] model of the development of the information need and Dervin's sense making theory [13], was helpful at explaining what happens at these initial stages in the caregivers information behaviour. The analysis revealed a certain correspondence between how the caregivers' information behaviour developed and the initial stages in Wilson's temporal model of how caregivers experience the process of the Alzheimer's disease [27]. In line with the model, three stages were identified in the caregivers' information behaviour: (1) Information about the disease is noticed; (2) Interpretation of information – Normalizing and discounting; (3) Suspecting – Purposive information seeking begins.

During the first two stages, "Information about the disease is noticed" and "Interpretation of information – Normalising and discounting", Taylors [15] model was useful at explaining how the caregivers information needs advanced from vague ideas that something might be happening to the patients, to realizing that this was indeed the case and that they needed somehow to explain it. However, as their thoughts regarding this

were very unclear, the caregivers were not able to form questions and seek answers about it, or seek information on purpose. Thus, they only received information that something might be wrong through opportunistic seeking [12, 17–19], as they unexpectedly witnessed the patients altered behaviour patterns. When they sought to interpret the information, they normalized and discounted it as a sign of something else than dementia. As a result, the caregivers attempts to define their knowledge gap and how it might be resolved were not successful. They were in fact stuck in time and space, incapable of bridging the gap in their knowledge and move forward, as described by the sense making theory [13].

When the caregivers understood that they could not normalize and discount the information which they encountered, they moved on to the third stage in their information behaviour “Suspecting – Purposive information seeking begins”. It was during this stage, that the caregivers managed to reach the level of formalized information need [14], when they could begin to ask more direct questions about what might be wrong with the patients, discuss their thoughts about it and compare it with the ideas of others. By doing so, the caregivers were able to reach the fourth level of information need and translate what they wanted to know into a search strategy (compromised need) [14]. This made it possible for them to use more various ways of information seeking, both opportunistic and purposive seeking [11, 17–19], to acquire information that they could make sense of. Thus, it was first after they had fully developed their information need that the caregivers were able to get information that they could use to bridge their knowledge gap, and move forward to the decision that a medical advice was needed for the patients [13].

According to Wilson [27], old age is the main reason why symptoms of Alzheimer are being normalized and discounted at the second stage in the temporal model. Keady and Nolan [28] also found this often to be the case. The findings of the present study show that age could act as a hindrance for interpreting the information encountered as signs of dementia, either because the changes that the caregivers noticed were believed to be normal for a person of old age, or because the patients were considered too young to have dementia. Although the likelihood of getting dementia increases with age it is not confined to old age. The need to be aware of young-onset dementia, where the traditional criteria has been patients younger than 65 years, has been stressed [32]. However, several other factors that lead the caregivers to interpret the information wrongly were identified in the study, such as the patients other medical conditions, their personality traits or even the abilities or talents that they had possessed. In particular, when the disease progressed slowly, it became difficult for the caregivers to piece the information about disperse incidents together to get a more complete picture of what was going on. While lack of knowledge could lead the caretakers to normalize and discount the information that they noticed at the second stage of the information behaviour process, caregivers who had prior knowledge about dementia reported that at the third stage in the process it had helped them to interpret the information that they detected correctly.

It needs to be kept in mind that the findings are from small scale qualitative study, and cannot be generated to the wider population of caregivers of patients with dementia. Nevertheless the findings may help to shed light on what characterizes the initial stages in the caregivers’ information behaviour.

To conclude, having dementia diagnosed as early as possible allows people to benefit from potential treatments, care and support that is available, in addition to making plans about the future [4]. It is therefore essential that informal caregivers and patients have knowledge about the symptoms of dementia so that they can react on it. From the time when the informal caregivers first began to notice symptoms of dementia, until they reached the decision to seek medical attention for the patients, their information behaviour went through a sequence of three stages, where their information need gradually developed from a vague idea about a cognitive gap at the first stage, “Information about the disease is noticed”, to become a formalized need at the third stage, “Suspecting – Purposive information seeking begins”. During these stages the caregivers unexpectedly discovered information. To be able to seek information and knowledge on purpose, and subsequently realize that the patients needed medical attention, it was necessary for them to reach the third stage in the information behaviour process and fully develop their information need. The second stage of the process, “Interpretation of information – Normalizing and discounting”, was particularly complicated as the caregivers misinterpreted the information about dementia that they came across as signs of something else.

More public discussion by professionals about dementia could provide the caregivers and the patients with a better understanding of the disease. This in turn might help to shorten the time spent at the second stage, making it possible for the caretakers to enter the third stage more quickly, and thereby to come to the decision to seek medical advice.

5 Limitations and Implications for Future Research

As noted above, the findings from the study cannot be generalized to the population of informal caregivers of patients with dementia. The purpose with using qualitative methods was to gain a deep understanding of various aspects related to the information behaviour and the support provided by the participants, from their own point of view [28]. Furthermore, since aspects of the information behaviour of informal caregivers of people with dementia were examined which few studies have investigated so far, qualitative methods were chosen because they are considered useful for better understanding phenomena which little knowledge exists about [33]. In future it might be of interest to examine the topic by using quantitative methods in order to find out how findings about information behaviour relate to the wider population of informal caregivers of people with dementia. Achieving more specific knowledge concerning the most important factors regarding the dissemination of information about the early signs of dementia, as well as the disease itself, might of significance for the health professionals who are responsible for providing this information.

The emotional aspect of the caregivers’ information behaviour would also be worth consideration. Previous studies suggest that worries about dementia is widespread in Western populations [34]. Furthermore, there are indications that negative feelings, such as fear of the disease, can lead to people refusing to face up to the possibility that their family members may have dementia and avoid talking about it [35]. Although the participants in the current study did express various feelings, this was not systematically

analyzed, nor was it a specific focus of the study. Nevertheless, in the second stage of the caregivers information behaviour, Interpretation of information – Normalizing and discounting, it was clear that negative emotions were acknowledged and that they played a role in delaying the recognition that the patients may have dementia. Thus, studies aimed at understanding how psychological factors, such as negative emotional reactions towards dementia, affect the caregivers' information behaviour may be useful for identifying how it can be countered.

The focus of the study was limited by the period of examination, from when the signs of dementia began to appear until a decision to seek medical advice was made. In future, it would be of significance to examine the information behaviour of the informal caregivers during and after the time of diagnosis of dementia. How well does the health system, for example, meet the informal caregivers needs for information while the diagnosis is being made? Likewise, how are they supported with information and knowledge after the diagnosis?

As people with dementia are expected to make up an increasing proportion of the population [3], it becomes of increasingly significant for future research to be aimed at how the patients with dementia, and their relatives who care for them, can be supported. Attaining better knowledge and understanding about the complex nature of the informal caregivers' information behaviour, and the diverse factors related to it, can aid to achieve this.

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