Informal Caregivers of People with Dementia – The First Stages in the Information Behaviour Process

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Outline of the presentation

- Purpose of the study
- Study background
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Purpose of the study

- An ongoing exploratory study where the aim is to investigate the information behaviour of informal caregivers of people with dementia
- The purpose is to gain better knowledge of how the informal caregivers provide support - the various aspects related to their information behaviour and possible problems confronting them
- The paper will focus on the initial stages in the information behaviour process
  - Research question: What characterizes the first stages in the information behaviour of informal caregivers of people with dementia?
Along with the growing proportion of elderly people in Western populations it is predicted that the number of people with dementia will double in the coming years (Alzheimer Europe, 2008)

Dementia is a general term to describe a category of symptoms such as memory loss, diminishing abilities at communication, thinking and social activities

Dementia is not a normal part of aging although the likelihood of having it increases with age. In contrast with age-related cognitive decline - dementia describes problems with two or more brain functions that are severe enough to affect daily activities (Mayo Foundation for Medical Education and Research, 1998-2015)
Theoretical lens

• A model by Holly Skodol Wilson (1989) which identified the sequence of eight stages, describing the process of the Alzheimer’s disease from the perspective of informal caregivers
  – The first three stages: 1) Noticing; 2) Discounting and normalizing; 3) Suspecting

• Relevant concepts and models from information science, e.g. the four levels of information needs identified by Taylor (1968), sense-making theory by Dervin (1992)
Methods

- Data was gathered from February to August 2014
- Qualitative methods: Grounded theory - Open-ended interviews
- Participants:
  - Recruited through FASS, association of interest groups and relatives of people with Alzheimer and related diseases
  - Informal caregivers of people with dementia, living in the capital area and smaller towns in the country
  - 21 caregivers: 18 women and 3 men, aged 36 to 76
    - Seven supported their spouses, 13 their parents and one her sibling
  - Open-ended interviews with representatives of the welfare system are ongoing
The initial stages in the information process

1. Information about the disease is noticed
2. Interpretation of information, normalising and discounting of symptoms:
   – Barriers to interpret the information as symptoms of dementia
3. Suspecting, purposive information seeking begins
1. Information about dementia noticed

- The process of noticing the first signs of dementia and the reaction of the informal caretakers after the symptoms had started to show
- Characterized by the caretakers thinking back and realizing that the patients had been showing the signs of dementia for some time, without them noticing it or being able to interpret the information correctly
  - In retrospect, this was almost certainly...I could think two years back.
  - When I think back, she definitely had symptoms around the age of sixty.
  - Naturally when I had the diagnosis I started to think back, maybe I should have noticed some of the symptoms a bit earlier.

- Opportunistic information seeking
2. – Interpretation of information
Normalizing and discounting of symptoms

- Describes what happened when the caretakers had become aware that the behaviour of their family member/patient had changed and that something was wrong.

- Instead of interpreting the information that they noticed as possible signs of dementia they ascribed it as something else, thus normalised and discounted the symptoms.

- Opportunistic information seeking:
  - I think many people had started to notice something...
  - So, there were all these weird things that I began to notice.
Barriers to interpret the information as symptoms of dementia

- Patient characteristics
- Slow progression of the disease
- Mislead by the patient alone or together with his/her spouse
- Denial of the disease
- Limited knowledge of the symptoms of dementia
Barriers - Patient characteristics

- **Age: Young age – Old age:**
  - *They are just elderly people, they were in their eighties.*
  - *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.*
  - *My friend’s grandmother had Alzheimer's and I felt unease seeing so many similarities. But she was of course just older, I felt that my mum was so young.*

- **Other medical conditions:**
  - *There was so much that lead me to think that this was nothing unnatural and not linked to dementia.*
  - *He has hereditary hypertension…I thought maybe this could be because he was getting some bleeding or something.*
Barriers – Patient characteristics

• Personality and abilities of the patient:
  – She never was a very social person, so you may not realize it..
  – But she has always, just since I was a kid, she’s the women who lost her gloves, she lost her keys. Somehow just the typical person who does not know quite where she puts away things. And we were just used to it since we were kids.

  – The idea never came to us that this active and clever woman who had achieved so much, spoke several languages and was extremely well read…That she was beginning to lose her memory, it was just not an option, it never occurred to us.
Barriers – Slow progression of the disease

• The speed at which dementia worsens varies from person to person and between the different types of dementias. Slow progression can make it difficult to realize what is happening:
  – *This happened slowly…*

  – *This is so subtle. 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. We don´t remember everything.*
Barriers – Being mislead

• The patient alone or together with a spouse succeeded at misleading the caretakers:
  – He was very clever and is still pretty devious.
  – Mom has lived alone after we moved away from home, which makes this also somehow more difficult. And that´s perhaps ... she has clearly been able to hide this incredibly well for us.
  – When my father was alive the two of them were extremely close. They were always together and they covered-up for each other. We could see that afterwards.
  – Dad naturally protected her completely and I didn´t realize this until he died...I think it´s strange how you can ...He protected her, I can see that.
Barriers - Denial

- And we started to talk together my brothers and sisters and they were exactly at the same opinion as me. They just said, “No, no, no, no…We always found some excuse. And I think this was just the fear and the grief. This just could not be.
General knowledge about dementia and the symptoms is lacking:

- ...and he starts to complain that she is so forgetful and this and that. And I didn’t realize that this was memory loss.
- And Alzheimer is not known in the family. There is no precedent for it.
- Alzheimer is like, it’s rather recently that discussions about it started. Of course this has been a disease here for years and we knew so little about it before. And it would be good to get much more education and information about it.
- ...they need to write a lot more in the papers, bring much more to the radio...
3. – Suspecting - Purposive information seeking begins

- The caretakers started to realize that they could no longer explain the behaviour changes and that more information about what was happening might be needed.

- Various ways were used to gather and explain the information:
  - **Information seeking by proxy:** ... and she immediately contacted her and said: "Something is happening to your mother."
  - **Monitoring the patient:** So when we had been checking her for a while and had realize that this was something strange...
  - **Communicating and sharing information with others:** But my sister and I talked about this between us, probably for about two years before ...
  - **Searching for information sources:**
    - I completely lost myself online…the FAAS site and international websites
    - Of course I had been reading and reading, because I was beginning to suspect this.
Knowledge about the disease helped

- Obviously, I come from the health sector and I was perhaps the one that realized that this was not quite okay, this was not just like a normal old age degradation.

- He had several siblings and two of them had been diagnosed with this before they died. So this is known within the family...I had seen how it developed with the others so I know what to expect.
Summary

- The initial stages in the caregivers information behaviour process are complicated. Various barriers exist which can delay the decision to seek medical advise an get a diagnosis.

- The analysis revealed that there is a certain correspondence between the first stages in the caregivers information behaviour process and the initial stages in Wilson´s temporal model of how the course of the Alzheimer´s disease is experienced.

- Concepts and definitions of various ways of information seeking, together with Robert Taylor´s identification of the four levels of information needs as well as Dervin´s sense-making theory, further helped to explain the information behaviour.
Thank you for the attention!

Questions?