

CASE REPORT

The impact of diagnostic disclosure in dementia: a qualitative case analysis

Els Derksen,¹ Myrra Vernooij-Dassen,¹ Freek Gillissen,²
Marcel Olde-Rikkert³ and Philip Scheltens²

¹Centre for Quality of Care Research, Alzheimer Centre Nijmegen, The Netherlands

²VU- Medical Centre, Alzheimer Centre Amsterdam, The Netherlands

³Department of Geriatrics, Alzheimer Centre Nijmegen, The Netherlands

ABSTRACT

Objective: The aim of this study was to give an in-depth description of the impact of disclosure of the diagnosis of dementia on a patient and the patient's partner.

Methods: Grounded theory interview study.

Results: Analysis of the interviews revealed that disclosure had an impact on three key domains: awareness of dementia, interpersonal relationship and social relationships. Disclosure was perceived as a confirmation of the pre-test ideas of both patient and carer. Formal disclosure of dementia was especially relevant for the carer in reconsidering her response to the patient's changed behavior.

Discussion: Receiving the diagnosis of dementia can be considered as a crucial moment in the process of becoming aware of the changes in one's life. Moreover, disclosure marks a new phase in the process of caring by the caregiver.

Key words: Grounded theory, carer, relationships

Introduction

Disclosing the diagnosis of dementia to a patient is not common in clinical practice (Pinner and Bouman, 2002). There are presumed advantages of disclosing the diagnosis at an early stage including opportunities to: 1) improve the quality of life of patients and caregivers, 2) blame the disease and not the patient for behavioral changes (Doraiswamy *et al.*, 1998) and 3) make preparations for future care planning (Meyers, 1997). Evidence about the preferences of the patients themselves is scarce (Bamford *et al.*, 2004). Recently,

Correspondence should be addressed to: Els Derksen, Centre for Quality of Care Research/ 229 P.O. Box 9101, 6500 HB Nijmegen, The Netherlands. Phone: + 31 243615305. Fax + 31 24 3540166. E-mail e.derksen@kwazo.umcn.nl. Received: 4 Feb 2004; Revision requested 4 Mar 2004; Revised version received: 28 Apr 2004; accepted: 29 Apr 2004.

The patient, Robert, is 82 years old and lives with his wife. For about two years, Robert and his wife have noticed that he has increasing problems with his memory. They have six children and their relationship with all of them has always been good. Until two years ago, the patient was still active in his own company, even though one of his sons took charge after Robert retired.

Robert and his wife live in a large house. After the children had left home, his wife wanted to move to a smaller house, but Robert did not agree. Robert and his wife sing in their church choir. In the past, Robert was a board member of several organizations. The triad of "Church, State, and Society" was of key importance to him. His wife is an active volunteer in a hospital and in a home for the elderly. Robert describes himself as a man of few words, a hard worker.

Over the last years Robert has gradually lost his interest in politics. Nowadays, he falls asleep when reading the newspaper or watching the news bulletin. His wife gets cross with his inaction and passivity: "At home he just sits there, doing nothing." They try to go out almost every day, to do some shopping, or visit relatives or friends. Robert no longer dares to drive, so his wife does. At home she tries to let him participate in such household activities as washing the dishes.

After Robert's wife had read about the possibility of a one-day screening at the memory clinic, they discussed the matter with their children and with their GP and decided to make an appointment. Two weeks after the screening, the neurologist discussed the diagnosis of probable Alzheimer's Disease with Robert and his wife.

Figure 1. Case History: Robert

it was found that both elderly persons suspected of having dementia and their caregivers wished to be informed of the diagnosis (van Hout *et al.*, 2001; Fahy *et al.*, 2003). Moreover, there are a few descriptions of a patient's awareness of cognitive problems, but none directly related to disclosure of the diagnosis (Husband, 2000; Clare, 2002; 2003).

Here we present an in-depth exploration of experiences and beliefs based on a case history of disclosure of the diagnosis of dementia and its effects on both patient and carer. A qualitative case analysis is appropriate to study a topic that is poorly understood and adds to the understanding of the context in which behaviors take place (Mays and Pope, 1995). A second aim of this case study was to derive key themes of the impact of disclosure, which could be used more generally in the analysis of a series of cases.

Method

Case selection

This case was selected from a group of 20 pairs of patients and relatives who participated in a larger project on disclosure of dementia diagnosis. The case was selected at random from a group of patients who were native Dutch speakers; lived freely with a partner; were capable of expressing personal feelings about the situation. Written informed consent for participation in this study, including

Table 1. Topics of the interview guide (patient and carer)

INTERNAL TOPICS	TOPICS RELATED TO SOCIAL ENVIRONMENT
Emotions	Relationship with partner
Physical signs and symptoms	Relationships with family and friends
Future perspective	Other relationships
Self-esteem/personality	Practical consequences
Having purpose in life	

publication, was obtained from both patient and partner. Names and other identifiable characteristics have been changed to safeguard anonymity.

Data collection

The interviews were held by their care co-ordinator at two and ten weeks after disclosure, in order to describe changes in the impact of disclosure over time (Britten, 1995). The interviews with the patient and the carer took place separately. A semi-structured interview guide was used, including topics judged relevant in recent literature (Bender and Cheston, 1997; Rymer *et al.*, 2002) and daily practical experience. The four interviews lasted 15–30 minutes and were videotaped. The partner was asked about the same topics, but from her own point of view. Table 1 shows the topics of the interview guide.

Data analysis

The videotapes were transcribed, including non-verbal observations. The qualitative method of the grounded theory was used: a constant comparative analysis was carried out to identify common themes and issues (Corbin and Strauss, 1990). A second researcher analyzed the interviews following the same procedure. After comparison and discussions, consensus was reached on the themes and sub-themes presented in this article. At the end of this phase, the list of themes was checked with the interviewer.

Results

Three domains were identified in the process of disclosure for both patient and carer: *increased awareness of dementia*, the impact of the diagnosis on their *interpersonal relationship*, and effects on *social relationships*. The carer not only provided information about her own experiences, she also gave information about the patient's concerns. This improved understanding of the perspective of the patient and provided more insight into their situation as a couple. We

subsequently present examples of statements of patient and partner as evidence of the impact of the diagnosis of dementia on each of the three domains.

Awareness of dementia

Awareness of the diagnosis of dementia is related to the internal experiences of the patient and the carer. The patient became aware of the memory loss even before the screening at the memory clinic. For both the patient and the carer, receiving the diagnosis of dementia was a *confirmation of their suspicions*. The patient had been apprehensive of such a diagnosis.

P (Patient): Let me put it like this, we had our suspicions.

C (Carer): We already knew (she smiled). . . . Until you know for sure, you still hope for another explanation of his problems, but it was no news.

Although the patient expressed feelings of resignation in the interview, the confirmation of their suspicions also evoked *feelings of confusion in the patient*.

I (Interviewer): Had you reckoned with this possibility?

P: Yes, but then you have to accept it.

I: Do you also feel relieved, now that you know what's going on?

P: I don't know if you can be relieved when it has to end like this, I don't know. (He shrugged his shoulders).

The deterioration of his cognitive functions meant that the patient had to give up some activities that were important for his *autonomy*. Although he had agreed not to drive his car anymore, he said that it felt like a severe restriction. He accepted this *loss*, but in other areas he tried to defend his autonomy against the concerns of his wife and others, for example, in taking the opportunity to leave the house on his own.

C: On Monday he goes to the physiotherapist just 5 minutes from our house and sometimes I ask him "Shall I walk with you?" He answers "Are you crazy, do you think I can't do that myself?"

The carer was aware of *the consequences for her personal life*. After the disclosure of the diagnosis she felt more concerned about her husband: she did not dare leave him alone in the evening.

Interpersonal relationship

Both the patient and the carer said that they had experienced changes in their interpersonal relationship. These changes started some time ago, but the disclosure of the diagnosis confirmed these feelings of change and made it clear

to both of them that these changes were irreversible and would go on. Although the patient expressed the feeling of being a burden for his wife, as the carer, she in particular, seemed to realize that they had to find a way to cope with these changes in their relationship. At different moments in the interview, the patient shared the information that his relationship with his wife was very important to him. He *relied on her strength* very much. The patient also said that he was *aware of the increasing burden on his wife*. However, he put his trust in the strength of their long-term relationship.

P: But I was sitting there next to my wife, when I heard the diagnosis. She knew that this would go wrong.

P: Well, as far as I can see, the hardest part will be for my wife. I hope that we can manage this together.

C: We can talk about it, and that it is hard for me as well.

The carer had become aware of the *changed relationship* with her husband during the last year. She found that making decisions now rested on her shoulders. A conversation about the essential things in life wasn't possible anymore, although they were *able to share their emotions*. After the diagnosis they still share their emotions, even regarding the onset of his cognitive problems. The carer also showed how important it was for her to hold on to the good things in their lives.

C: Right from the beginning we could talk about it together.

C: Well of course you feel sad about it, but there is so much left for us to enjoy. We have a house in the country where we often spend the weekend.

Through the confirmation of the diagnosis, the carer became more conscious of the patient's inability to deal with the problems of daily life; she tried to *change her responses to his behavior* and not to correct him all the time. She realized that his cognitive problems had already put her into another role; she had turned from a partner into a carer. She also showed an *appreciation of the patient's remaining capacities*. She spoke proudly about a good response by her husband. They nearly had an accident with the car while she was driving. Her husband reacted just in the right way; she felt that he supported her and made her feel confident enough to drive home. The patient also mentioned this incident, but he wasn't aware of the appropriateness of his reaction and the feelings it induced in his wife.

C: We returned from our house in the country. I was driving and the sun was causing me a lot of trouble. He was sleeping, and then all of a sudden I grazed the crash barrier. Fortunately we weren't injured and two drivers stopped to ask if there was anything they could do. My husband said: "No thank you, the engine is working all right and my

wife will drive us home safely". (She laughed and continued). "I didn't dare drive anymore, but he made me do so. He said to me: "If you just keep calm, you can do it." Well, he was so fantastic at that moment. (She smiled and looked proud)

After the patient's retirement, the carer tried to involve her husband in domestic tasks. She found it hard to see that he was not doing anything at all, because she knew her husband as an active person. She did not seem to realize that his difficulties with new tasks were caused by the onset of dementia rather than not being used to these domestic tasks. In the second interview, she showed more insight into this problem of his losing his initiative. She realized that he enjoyed the activities they did together. His wife also took care of their personal finances. Taking over these tasks was a *change of roles* for both of them: he had to let go of a task that had confirmed his role as the breadwinner; for her, it meant an increase in her workload.

Social relationships

The disclosure of the diagnosis also affected the social relationships of both the patient and his carer. The domain "social relationships" comprised the relationship with their children and their relationships with other relatives and friends. For both the patient and the carer, it was important that they *shared the diagnosis with their children*. They were confident that they could ask them for help whenever necessary. The carer said that their children also advised her on how to react to the patient's behavior and she had accepted this advice.

P: Yes, of course, the boys will have to face the problems that my wife can't deal with.

C: The children also say: Mum, you mustn't keep asking him: "What are you doing?" or "Do you have to do it like that?" And they are right; it's better if I don't.

Also the *support from the people of the church choir* was important for both the patient and the carer. The vicar also came to visit them to express his sympathy. The patient appreciated this support; he felt that the vicar was someone who was acquainted with these situations. The patient also felt sad, he realized that he had *lost his active role in the church* and the community and this evoked *feelings of loss and grief*.

Regarding *future (care) planning*, the patient and his wife decided to stay in their present house after receiving the diagnosis of dementia. His wife wants to prevent him becoming disoriented in new environment. The patient seemed to realize that maybe in the future he would have to move to a nursing home,

because of an increasing need for care. The carer also started to think about future care planning. She thought that it would be sensible for him to visit a day-care center for people with cognitive problems.

P: If at a certain moment there is nothing more you can do, and you even need nursing care to go on living, then we might have to.

C: I think that starting day-care would be wise. For me it's important that he learns something; when he has some diversion, he is much better. In the evenings we go to the choir meetings. Often I don't feel like it, but I join him because he likes to go. He talks to everyone and when we return home he's a different person.

Discussion

This qualitative case analysis revealed three findings. First, the patient and his partner perceived the diagnosis as a confirmation of their suspicions. Nevertheless, knowing the diagnosis seemed to be an important condition for making decisions about their future. Second, disclosure of the diagnosis was relevant for the carer in reconsidering her response to the changed behavior of her husband. After the diagnosis, she started to adapt to the role of carer. Third, this phase of adaptation enabled the carer to acquire a better appreciation of the remaining capacities of the patient. She valued the fact that he still had a regard for her as his partner and carer. Confirmation of the diagnosis enhanced the carer's awareness of the valuable moments in their relationship; she realized that there was still so much for them to enjoy together.

In this case, the themes in the first and second interviews did not differ substantially. The exception was future care-planning: after ten weeks, their thoughts about future care had evolved into concrete plans. In general terms, the difference between the first and the second interviews can be found in an increasing awareness of dementia and a further adaptation to the changes in their lives.

In brief, the disclosure of the diagnosis marked a new phase in the process of increasing awareness of the changes in their lives, resulting from the onset of Alzheimer's disease, for both the people concerned. Disclosure gave them the opportunity to start with the adaptation to the patient and carer roles. Furthermore, the results in this case confirmed the presumed advantages of diagnostic disclosure mentioned in the introduction. Disclosure paved the way for future care-planning (Meyers, 1997). Despite their expressions of feelings of loss, it was clear that disclosure of the diagnosis was an eye-opener to them to realize the good things in their lives. In that respect one might say that disclosure can improve their quality of life (Doraiswamy *et al.*, 1998).

This case history showed that reactions on disclosure of diagnosis could be categorized in three domains, based on a qualitative analysis of a single process of disclosure. The analysis of a series of cases is required to be able to describe the heterogeneity in reactions and to develop an intervention model. Considering the positive effects of disclosure perceived by both patient and carer, clinical practice might change into informed care-planning.

Acknowledgement

This research project was funded by the Dutch Alzheimer Society (Alzheimer Nederland). The authors wish to thank especially the patient and his partner who trusted their history to us.

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