Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case series analysis

E. DERKSEN, M. VERNOOIJ-DASSEN, F. GILLISSEN, M. OLDE RIKKERT, & P. SCHELTENS

1 Alzheimer Centre Nijmegen, Centre for Quality of Care Research, Nijmegen, 2 Alzheimer Centre Amsterdam, VU-Medical Centre, Amsterdam, and 3 Department of Geriatrics, Alzheimer Centre Nijmegen, Nijmegen, The Netherlands

(Received 12 August 2005; revised 7 November 2005; accepted 12 December 2005)

Abstract
Adequate diagnostic information can be considered a basic intervention in dementia care. However, clear diagnostic disclosure in dementia is not yet regular practice and the evidence regarding patients’ preferences for or against disclosure is scarce. The aim of this study was to give an in-depth description of the impact of receiving the diagnosis of dementia, both on patients and the patients’ proxies. The method used was the design of a grounded theory interview study. Analysis of the interviews revealed that disclosure had an impact on three key domains: awareness of dementia, partnership, and social relationships. Most patients and carers reported that they had experienced the disclosure of the diagnosis as a confirmation of their assumptions. A minority of patients and carers felt threatened and shocked by the diagnosis, because they did not expect it. The findings of this analysis challenge current opinions and practice about diagnostic disclosure like obstacles anticipated by clinicians such as inducing negative feelings and causing harm. Disclosure of the diagnosis of dementia can generally be carried out without introducing stress for the patient or carer and facilitates guidance. Therefore regular practice should include the careful planning and performance of diagnostic disclosure.

Introduction
In dementia, diagnostic disclosure is not common clinical practice. Only 50% of geriatricians report that they openly discuss the diagnosis with their patients (Carpenter & Dave, 2004; Pinner & Bouman, 2002). When general practitioners diagnose dementia, they tell the diagnosis formally to 47% of their patients (van Hout, Vernooij-Dassen, Hoefnagels, & Grol, 2001). A study of people suffering from dementia showed that only 47% knew their correct diagnosis and 66% said that no one had ever discussed their illness with them (Marzanski, 2000). Memory failure may explain these findings to some extent. Other studies have shown that patients with severe dementia were less well-informed about their diagnosis than patients with mild dementia (Meyers, 1997; Rice, Warner, Tye, & Bayer, 1997). Moreover, when patients are told what is wrong, it is more often expressed in terms such as ‘memory problems’ or ‘confusion’ than in terms of ‘dementia’ or ‘Alzheimer’s disease’ (Woods et al., 2003). The reasons given for not conveying the diagnosis were patient insight, diagnostic (un)certainty, the (perceived) patient’s wish not to be told, and the patient’s emotional stability (Carpenter & Dave, 2004). Nevertheless, it was found that elderly persons suspected of having dementia and their caregivers prefer to be informed of the diagnosis (Fahy, 2003; van Hout et al., 2001) and even patients with severe dementia want to know their diagnosis (Jha, Tabet, & Orrell, 2001).

In some countries a trend can now be seen to include diagnostic disclosure in regular care; memory clinics in the Netherlands, especially in Alzheimer Centres, are an example. Giving adequate diagnostic information can be considered as a basic intervention in dementia care (Husband, 2000; Vernooij-Dassen, 2003). The presumed advantages of disclosing the diagnosis at an early stage include opportunities to: (1) improve the quality of life of dementia patients and their caregivers; (2) blame the disease and not the patient for behavioural changes (Doraiswamy, Steffens, Pitchumoni, & Tabrizi, 1998); (3) address questions concerning cognitive and functional decline; (4) make preparations for planning future care; and (5) initiate secondary prevention and early symptomatic treatment before substantial neurological loss occurs (Meyers, 1997).
Evidence regarding the preferences of the patients themselves and the impact of receiving the diagnosis of dementia is scarce (Bamford et al., 2004; Carpenter & Dave, 2004). There are a few descriptions of a patient's awareness of cognitive problems, but none directly related to disclosure of the diagnosis, as this study is (Clare, 2002, 2003; Husband, 2000).

Objectives

In view of the above, we sought to examine the impact of receiving the diagnosis of dementia on both patients and patients' proxies. A research programme was therefore designed comprising three integrated components: (I) a case study (Derksen et al., 2005) which provided the key domains for the analytic framework to be used in; (II) the analysis of the series of cases presented in this article; (III) the future evaluation of an intervention addressing the impact of disclosure found in the series of case studies. The objectives of this study are to describe and appraise the experiences, beliefs, and fears regarding the diagnosis of dementia in both patients and carers in order to improve communication in future encounters of diagnostic disclosure.

Methods

The patients who were included had received the diagnosis of dementia and were fluent Dutch speakers. Patients ought to be accompanied by their partner or a close friend. Patients were excluded when an illness other than the diagnosis of dementia was more important. We used the method of purposive sampling, which means a deliberate choice of subjects to obtain a full palette of the impact of the diagnosis of dementia on both patients and carers (Pope & Mays, 1995). Informed consent was asked from both the patient and the patient’s proxy. The interviews were held at two moments: two weeks after the diagnostic disclosure and ten weeks later, to study the impact in time. The interviews with the patient and the carer took place separately to safeguard a free expression of thoughts and feelings. An experienced care coordinator, a qualified nurse, carried out the interviews.

A semi-structured interview guide was used, including topics derived from the literature (Bender & Cheston, 1997; Rymer, 2002) and daily practical experience. The interview guide was drawn up in close collaboration with the care coordinator. The main topics were categorized as ‘internal topics’ (referring to the patient) and ‘external topics’ (referring to the patient’s relationships) (Britten, 1995). A panel of four experts (three in dementia care and psychosocial interventions and one in qualitative research) evaluated the validity of the two versions of the topic list (patient and carer), including subtopics and questions. A topic was included when at least three experts agreed on it. Some subtopics and questions were excluded and others reformulated following the experts’ suggestions (Table I).

The proxies were asked about the same topics, but from the point of view related to their personal reaction and coping with the disclosure of the diagnosis of dementia. The interviews lasted from 15–30 minutes; they were videotaped in order to register non-verbal reactions, thereby facilitating the interpretation of the material.

For this study we used the qualitative method of the grounded theory: a constant comparative analysis to identify common themes and issues (Corbin & Strauss, 1990; Wester, 1995). The process of identifying domains involved the coding of non-verbal signs and their interpretations and an ongoing re-evaluation of the material as more data were analysed. The goal of qualitative research is the development of concepts which help us to understand social or health related phenomena in natural settings (Pope & Mays, 1995). We chose
this method because it gives the opportunity of an in-depth exploration of experiences, beliefs, and fears regarding the diagnosis of dementia of both patient and carer within the context of their relationships.

Three domains were identified in the case study on disclosure. These domains were used in this case series study as an analytic framework in the process of (re-) reading the interviews and selecting and coding the data. After two researchers had independently analysed the material, the results were compared and discussed until agreement on the key themes was achieved.

Results

Eighteen pairs of patients and partners participated in the case series. The age of the patients was on average 71 years (SD 7.9). The mean MMSE-score was 22 (SD 4.9; range from 15–30). Almost 80% of the patients were male and 65% had children. Most of the patients (85%) lived together with their partner. The duration of the memory problems varied from less than one year to five years, while 60% of the patients had to deal with memory problems for between one and two years. We included all eligible couples of patients and partners until saturation was reached in the analysis of the data. Saturation was reached after no new aspects of impact were found. The only reason patients and carers mentioned for not participating in this study was their problems with travel to the memory clinic, the first interview took an extra visit.

The interviews were analysed using the qualitative method of the grounded theory (Corbin & Strauss, 1990; Wester, 1995). Three domains were identified in the process of disclosure for both patient and carer: increased awareness of dementia; the impact of the diagnosis on the partnership of the patient and the patient’s partner; and effects on their social relationships. The main themes and sub-themes of impact are shown in Table II.

Besides their own experiences, carers also gave information about the patient’s concerns. This information improved the understanding of the patient’s perspectives and provided more insight into the situation of patient and partner as a couple. We present below examples of statements of patient and partner for each of the three main themes.

Awareness of dementia

Awareness is related to the internal experiences of the patient and the carer. For both of them, the term comprised the awareness and significance of the dementia diagnosis for their personal life.

Awareness of cognitive problems (patient and carer)

Almost without exception, patients and carers showed an awareness of their cognitive problems. Patients expressed their concerns regarding their state of health before the cognitive screening at the memory clinic. They knew that something was going wrong.

P: I am so forgetful # 3-1
P: I have lost a lot of things that were in my head # 5-1

Some patients thought that their cognitive problems were related to a fall or an accident or some kind of physical problem; they did not seem to have considered the diagnosis of dementia.

Diagnosis expected (patient and carer)

Patients and carers reported that they had experienced the disclosure of the diagnosis as a confirmation of their presumptions. Although thoughts about dementia had come to mind, until the diagnosis most patients and carers hoped for another explanation for the patient’s cognitive problems. Patients and carers who had no suspicions

<table>
<thead>
<tr>
<th>Table II. Themes and sub-themes of the impact of diagnostic disclosure in dementia on patient and carer.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>Awareness of dementia</td>
</tr>
<tr>
<td>• Awareness of cognitive problems</td>
</tr>
<tr>
<td>• Diagnosis expected</td>
</tr>
<tr>
<td>• Confusion</td>
</tr>
<tr>
<td>• Feelings of loss and grief</td>
</tr>
<tr>
<td>• Coping behaviour</td>
</tr>
<tr>
<td>Partnership</td>
</tr>
<tr>
<td>• Reliance on partner</td>
</tr>
<tr>
<td>• Notion of partner’s burden</td>
</tr>
<tr>
<td>• Changed relationship</td>
</tr>
<tr>
<td>• Positive experiences</td>
</tr>
<tr>
<td>Social relationships</td>
</tr>
<tr>
<td>• Support given by children, relatives or friends</td>
</tr>
<tr>
<td>• Change of social relationships</td>
</tr>
</tbody>
</table>

| 527 | Impact of diagnostic disclosure in dementia |
of dementia tended to perceive the diagnosis as a shock. In some cases a presumed diagnosis seemed to be related to earlier experiences of the patient or carer with dementia in their families.

C: In the past his mother and two brothers had suffered from dementia, so we had already considered the possibility. # 1-1

Carers reported that, after the diagnosis, things had calmed down for both of them. One carer was shocked about the diagnosis of her husband, because she was also worried about her own memory problems. She was convinced that she would end up with dementia because of her family history.

C: I didn’t expect him to get this; it’s in my family, not his. (She starts to cry). # 6-1

Confusion/mixed feelings (patient)

Although patients expressed feelings of resignation, disclosure of the diagnosis also evoked feelings of confusion in patients. Patients were also relieved if they were not diagnosed with Alzheimer’s disease. One of them did not seem to realize that dementia of another type could also have a severe impact on his life. Another patient did not receive a clear diagnosis, so it was hardly surprising that she was confused. She seemed to realize that Alzheimer’s disease (AD) could be the final outcome, although for the moment she preferred to believe that there was some other kind of problem, but certainly not AD.

Feelings of loss and grief (patient and carer)

The deterioration of cognitive functions meant that patients had to give up activities that were important for their autonomy. Male patients in particular stated that losing their driving licence was felt as a severe restriction and they found it difficult to accept.

C: He knows he isn’t capable of driving now, but he keeps asking: ‘Why can’t I drive my car anymore’. # 2-2

Patients also try to hold on to their autonomy or defend themselves against the concerns of their partner and others, for example in taking the opportunity to leave the house on their own.

P: I hope to go on working in our pub. I am afraid of losing this job. # 3-1

P: I am not that clear anymore. I had to hand my financial affairs over to others. # 15-1

Patients and carers expressed feelings of grief and sadness about the diagnosis of dementia and the cognitive problems they had to deal with. While talking about their feelings some patients became so sad they shed some tears. One carer could hardly talk about her feelings; she could not hide her emotion and broke down in tears.

Patients reported that they felt angry about the diagnosis of AD that they had received. One patient was angry with himself, because he constantly forgot things. His forgetfulness frightened him. Another patient reported that she felt cheated.

Consequences for personal life (carer)

Carers showed an awareness of the consequences of the diagnosis for their personal lives. After the disclosure, they felt more concerned. Carers did not dare leave their partners alone in the evening, or leave the house for a long period of time. Carers also felt that there was less room for their personal lives, because of their responsibility for their partners. Carers reported that their partners constantly made demands of them, which provoked feelings of irritation. The patient’s need for a strict time schedule had also become clear to carers.

C: He becomes more and more dependent on me, he clings to me. # 3-1

C: On Thursdays he always vacuums upstairs. Last Thursday was Ascension Day, so I said: ‘Today is like a Sunday, so we don’t work’. Then he keeps asking: ‘Do I have to vacuum?’ Even when things only change a very little, he feels uncertain. # 2-2

Coping behaviour (patient and carer)

During the interviews, patients exposed how they tried to cope with their cognitive problems and deal with their emotions. A patient reported that she wanted to be brave in this situation and she sought distraction in her hobbies. Another patient wrote little notes to remember the words he constantly forgot. One patient showed that he had not lost his sense of humour. In a way he used humour to cope with the onset of dementia.

P: I make jokes that other people don’t understand. (He laughed). # 5-1

Carers felt burdened by the continuous care for their partners. They expressed a need for respite care and sought time for their own activities.

C: I want to continue making bobbin lace. # 12-1

C: I feel the need for time to relax and recover without the presence of my husband. # 12-1

Another carer wrote her feelings down. Carers also reported the patients’ aggressive behaviour, which they could hardly deal with.

Partnership patients and partners

Patients and partners were aware of the changes in their interpersonal relationships. These changes did not start just after the disclosure of the diagnosis of dementia. The diagnosis confirmed
their assumptions of dementia and made it clear to patient and partner alike that cognitive changes were irreversible and would go on. Although patients reported feelings of being a burden for their partners, carers in particular seemed to realize that they had to find a way to cope with these changes in their relationship.

**Reliance on the partner (patient)**

Patients reported that their relationships with their partners were very important to them. They put their trust in the strength of their long-term relationships and relied heavily on their partner’s strength.

C: In company, my husband often asks me quietly ‘Who was that person?’ or ‘Where have we been?’ because he wants to present himself well to others. He stays with me all the time. # 2-1  
P: I want her with me all the time. # 5-1

One patient told us that after the diagnosis she started to see her ex-partner again, although they still live on their own. The partner also wanted to look after her.

**Notion of partner’s burden (patient)**

Patients reported that they were aware of the increasing burden on their partners. Patients want their partners to stay close to them. One patient realized that, even when his wife was just away for a short time, it seems to him like hours because of his memory problems. Patients expressed their appreciation of their partner’s care.

P: Well, as far as I can see the hardest part will be for my wife. # 1-1  
P: I feel sorry for my wife. # 5-1  
C: He is worried and then he says ‘How awful that you will have such a difficult husband’. # 2-1

**Changed relationship (patient and carer)**

Patients and carers experience a change of roles in their relationships. Partners started to adopt the carer’s role. They tried to adapt their responses to the patient’s changed behaviour.

C: He sometimes doesn’t know where to store things. At first I said to him: ‘What are you doing, you know that, just think for a moment.’ Now I don’t say anything anymore and I just let him be. And then everything goes well. # 1-2

Female carers in particular reported that they had to take over the financial affairs. Carers felt that taking decisions now rested on their shoulders. Both patients and carers reported that still being able to share their emotions was very important to them. In one case the patient did not share his emotions with his partner because he feared negative reactions. His partner reported that the patient seemed to be less suspicious after the diagnosis.

**Positive experiences (patient and carer)**

After three months, carers were able to move their focus from the patient’s disabilities to the patient’s remaining capacities. They seemed to realize that patients tried to do their best in coping with their cognitive problems and stopped blaming them for their mistakes. Despite all the difficulties yet to come, some carers tried to continue doing the things they had enjoyed together, for example a last foreign holiday, or spending more time in their second home in the country.

C: I feel it is the last time, but we enjoy being in Greece and the things we do together like walking and swimming. # 6-1

One patient reported that they had got married after living together for thirty-three years. They wanted to confirm their relationship. Both patient and carer stated that being married also meant that their financial affairs were put in good order.

P: We want to marry because then you confirm ‘Whatever happens, I won’t let you go’. We want to settle things. # 7-2

Patients noticed that the interview itself had also been a positive experience for them.

P: In this interview I just use a few words that I put together. I am still able to take part in a conversation. # 5-1

**Social relationships**

The ‘social relationships’ domain comprises the relationship with (grand) children and also relationships with other relatives and friends.

**Support given by children, other relatives or friends (patient and carer)**

Children usually played an important part in the support of both the patient and the carer. Patients and carers shared the diagnosis and their emotions with their children. They experienced emotional support from their children and expected to receive practical support when that became necessary. The distance between residences certainly changes the frequency and intensity of the practical support the children can provide. In sharing the diagnosis with other family members, neighbours, and friends, carers were selective, depending on the intensity of the relationship and the possibility of future support. A few carers reported that the patients’ family didn’t want to acknowledge the seriousness of the patient’s cognitive problems.

C: Of course, I don’t tell everybody about it, no. But I do tell people who know my husband
well and whom I think might help me when I needed them to. # 2-2

Change of social relationships (patient and carer)

Patients reported that they tried to hold on to their roles in social relationships in which they experienced being valuable to others. Patients showed their sadness about the things they had lost in their social lives or at work. A patient became emotional while talking about his active role in the church and the community, which he had to give up. Patients reported that the onset of cognitive problems affected their ability to work. Another patient was relieved that he had already retired.

P: I just want to stay a grandmother for my grandchildren. # 9-1
P: I have already retired so I can’t be fired because of this. # 10-1

Future (care) planning (patient and carer)

Patients and carers reported that thinking about the future did not start after the diagnosis of dementia was received. Formal disclosure acted as a spur for future (care) planning. Carers and patients seek for information about dementia and opportunities for support, such as respite care or support groups. It is very important for patients and carers to be able to stay at home as long as possible. Both carers and patients realized that this could become difficult in the future, because of an increasing need for care.

C: When you get older you automatically start to think about your future. So we’d been thinking about moving into a smaller house, but now that we know the diagnosis, we’ve decided not to move. # 1-2

Discussion

The findings of this qualitative case-series analysis challenge current opinions and practice about diagnostic disclosure. First, most patients and their partners perceived the diagnosis as a confirmation of their suspicions. Nevertheless, formal disclosure seemed to be an important condition for making decisions about their future and allowed them to express feelings of loss and grief. Patients and carers who had no suspicions of dementia tended to perceive the diagnosis as a shock. Therefore it is important to know what their expectations are about the diagnosis. Second, disclosure of the diagnosis was relevant for carers in reconsidering their response to the changed behaviour of their partners. After the diagnosis, they started to adapt to the role of carer. Third, this phase of adaptation enabled some carers to acquire a better appreciation of the patient’s remaining capacities. Confirmation of the diagnosis enhanced the carers’ awareness of the valuable moments in their relationships.

Furthermore, the results confirmed most of the presumed advantages of diagnostic disclosure mentioned in the literature. Disclosure paved the way for future care planning, as was stated by Meyers (1997). In contrast with the findings of Doraiswaimy (1998), before the diagnosis most carers did not blame the patient for behavioural changes, probably because they expected the diagnosis of dementia. However, carers did change their reactions to the patients’ behaviour. The results of this study seem to contradict other studies that described obstacles anticipated by clinicians such as inducing negative feelings (Husband, 2000) and causing harm (Gillon, 1985). Despite their expressions of feelings of loss and grief, it was clear that disclosure of the diagnosis was a realization to both patients and carers that helped them appreciate the good things in their lives and cope with the situation. In that respect, disclosure did improve their quality of life, as was suggested by Doraiswaimy et al. (1998).

In this study a few patients could not recall the disclosure meeting, but they did remember their screening day. This suggests that the screening sessions were more stressful to them than the disclosure of the diagnosis. This finding corresponds with a study by Connell in which carers reported that the process of obtaining a diagnosis was stressful because it uncovered the patient’s limitations and cognitive deficits (Connell & Gallant, 1996).

In most cases, the themes that arose in the interviews two weeks after the diagnosis and 12 weeks after the diagnosis did not differ substantially. The exception was future care planning; after 10 weeks, thoughts about future care had evolved into concrete plans. In general terms, the difference can be found in patients’ and carers’ increasing awareness of dementia and a further adaptation to the changes in their lives. Some patients and carers showed more emotion in the first interview than in the second. In both interviews, patients exposed that they had done their very best to keep calm. Patients showed that they were capable of putting their thoughts and feelings into words when they were asked to do so. They were still able to use their coping skills. We presumed that the level of cognitive impairment could play a part in the patient’s expectations and their ability to express one self, but we found no indications confirming our presumptions. Being able to express one’s beliefs and feelings is probably more related to level of education and pre-morbid personality. After the diagnosis, more could be done to encourage patients in their coping behaviour. It is crucial to note and appreciate patients’ efforts to take care for themselves. Affirmation of their achievements can be a great support.
The generalizability of the results is not the aim of qualitative research; however, we have a selected group of patients since they were referred to a memory clinic. These patients might differ from patients diagnosed in general practice. Being referred to a specialised clinic because of increasing memory problems can affect the expectations of patients and carers regarding the diagnosis of dementia.

In conclusion, the diagnosis of dementia can be disclosed without causing significant problems for patients or carers and has advantages for both patients and carers. Disclosure gave them the opportunity to express their concerns about the cognitive and behavioural problems and to start adapting to the patient and carer roles. This study revealed that there are several elements that should form part of the process of the diagnostic disclosure of dementia. Before disclosure, health care workers should take notice of patients’ awareness of their cognitive problems. Patients’ and carers’ expectations about the diagnosis must be identified and addressed in the disclosure. Assessment of the patient’s needs for care and the carer’s need for support, including identification of the caregivers’ burden and competence will complete the information needed for comprehensive care advice. In sum, the careful planning and performance of diagnostic disclosure should be part of regular practice, and should take place before starting medical treatment and care, because of the positive effects it has on both patient and carer.

Acknowledgement

This research project was funded by the Dutch Alzheimer Society (Alzheimer Nederland).

References


Clare, L. (2002). We’ll fight it as long as we can: Coping with the onset of Alzheimer’s disease. Aging & Mental Health, 6, 139–148.


