Medical Decision Making

Rational decision-making about treatment and care in dementia: A contradiction in terms?

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ABSTRACT

Objective: To gain caregivers’ insights into the decision-making process in dementia patients with regard to treatment and care.

Methods: Four focus group interviews (n = 29).

Results: The decision-making process consists of three elementary components: (1) identifying an individual’s needs; (2) exploring options; and (3) making a choice. The most important phase is the exploration phase as it is crucial for the acceptance of the disease. Furthermore, the decision is experienced more as an emotional choice than a rational one. It is influenced by personal preferences whereas practical aspects do not seem to play a substantial role.

Conclusion: Several aspects make decision-making in dementia different from decision-making in the context of other chronic diseases: (1) the difficulty accepting dementia; (2) the progressive nature of dementia; (3) patient’s reliance on surrogate decision-making; and (4) strong emotions. Due to these aspects, the decision-making process is very time-consuming, especially the crucial exploration phase.

Practice implications: A more active role is required of both the caregiver and the health care professional especially in the exploration phase, enabling easier acceptance and adjustment to the disease. Acceptance is an important condition for reducing anxiety and resistance to care that may offer significant benefits in the future.

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1. Introduction

Empowering patients to make decisions about the treatment and care that they receive is a crucial element of modern health care. Physicians must decide which treatments to recommend, while patients must decide whether to comply with the recommended treatment [1], or find appropriate care elsewhere. In the past few decades, social scientists have studied the complex relationship between physicians and their patients. In the 20th century, the physician’s authority was regarded as essential to a successful patient-physician relationship [2–4]. Current 21st century health care policy is aimed at strengthening patient decision-making to promote more active participation by consumers [5]. The nature of the doctor–patient relationship has thus changed from paternalistic to participatory decision-making. In line with this relationship, there has been an important change in the objectives of the Dutch health care system, i.e., the transition from a supply-led system to a demand-led one [6]. This demand-led system implies that patients are able to make rational and conscious choices. This development has been accompanied by an increase in the variety of available treatment options. The assumption is that an increase in these options is related to an improvement of the quality of care, as patients have the opportunity to decide which treatment fits his or her needs best. Decision-making is a complex process and patients’ preferences for involvement in decision-making are highly variable [7].

Patient decision-making is especially important in the case of chronic diseases. Due to the long-lasting nature of these diseases, patients have more experience with the course of the disease and thus have clearer wishes regarding their needs.
Furthermore, they have more time to consider their options and thus to make more conscious choices [8]. However, while these assumptions are generally true, there are exceptions. Decision-making regarding treatment and care in the case of dementia is probably different from decision-making in the context of other chronic diseases. However, few studies have investigated the decision-making process in dementia. In advanced dementia patients residing in nursing homes this process seems to be particularly challenging, owing to the emotional and value-laden choices that must be made; and the need for surrogate decision-making due to severe cognitive deficits [9]. These emotional and value laden decisions, and the use of proxy decision makers are also described in Palliative care where a shared decision making process is often described in which patients, their relatives and the physician jointly make decisions regarding the ending of life. However, these patients are still cognitively capable of making the choices which is not the case in dementia [10]. Decision-making in dementia has also been described as a more complex and dynamic process that focuses on maintaining tolerability in the caregiving situation [11]. In addition, decision-making capacity is often impaired in patients with dementia [12–14]. These studies thus focused on more severely impaired dementia patients residing in care homes and on decision-making capacity. There is a lack of knowledge concerning a more in-depth exploration of the decision-making process itself in ambulant dementia patients. Examination of clinical practice in the field of dementia reveals that current treatment options are often not sufficiently utilised by the patients and/or their caregivers [15]. It is not clear why this is the case and which factors play a role in the selection of a well-considered choice from the available treatment options. It is possible that the participatory decision-making process is hampered in the case of dementia patients and their caregivers. The current study aimed to gain more insight from caregivers into the decision-making process with regard to treatment and care in the case of ambulant dementia patients in the Netherlands. We wanted to discover the grounds on which decisions and choices are based and gain knowledge about facilitating and obstructing factors regarding decision-making about treatment and care in the case of dementia by means of in-depth, exploratory focus group interviews.

2. Methods

2.1. Study participants

This study was approved by the Medical Ethics Committee of the Maastricht University Hospital. Between June 2007 and August 2008 patients were recruited from the following facilities: (1) the Maastricht Memory Clinic (MMC); (2) the Diagnostic Observation Centre for PsychoGeriatric patients within the Maastricht University Medical Centre (DOC-PG, i.e., an outpatient facility providing multidisciplinary assessment using somatic screening, psycho-geriatric assessment and evaluation of the required levels of care [16,17]); (3) the department of mental health for the elderly at the Community Mental Health Service (CMHS) of Maastricht; and (4) the Geriant Foundation (a foundation specialising in the diagnosis, treatment and case management of dementia) which operates in the region to the north of Amsterdam (with 600,000 inhabitants) in the Netherlands.

Participants were included if they (1) were diagnosed with a cognitive disorder or dementia; (2) lived at home; (3) had an informal caregiver or proxy who was able to answer the interview questions; and (4) had received a proposal for treatment or care from their health care professional.

2.2. Procedure

Two different approaches were used to gain insight into the decision-making process, namely: (1) semi-structured telephone interviews and (2) focus group interviews.

A semi-structured telephone interview, which took approximately 15–20 min, was conducted with an informal caregiver of the patient. This interview aimed to inventory the utilised and non-utilised care and treatment options, the reasons for not utilising care or treatment and the needs of the patient and/or the caregiver required to improve care and treatment. Results from these data are described elsewhere [15]. Participants were also asked whether they wanted to participate in the focus group interviews.

During the second phase of the study possible factors involved in the decision-making process were explored in depth. This took place in a qualitative manner using focus group interviews. In the focus group interviews a semi-structured guide was used in which several topics, such as the diagnosis, information about dementia, care and treatment options, and decision-making, were discussed. These topics are outlined in Box 1. The interview took approximately 150 min. Four focus group interviews were organised: two in the north region of the Netherlands, and two in the south on different dates. The interviews were hosted by different researchers and consisted of relatively small groups because of the complexity and sensitivity of the topic [18].

Data triangulation (involving different times, locations and persons) was used to ensure the credibility and validity of the results of the focus group interviews [19,20]. Focus group interviews are especially useful for exploration and discovery, and they reveal a lot of information about topics that are poorly understood. Furthermore, hearing how participants react to each other can provide an in-depth view of their experiences and opinions [21].

2.3. Analyses

The background characteristics of the participants (including both patients and their informal caregivers) were summarised using descriptive statistics in SPSS version 15.0.1. Grounded Theory Analysis (see Glaser and Strauss [22] for a detailed description) was used for the analysis of the focus group interviews. This is a systematic qualitative research methodology in the social sciences that allows researchers to study subjective experiences and to generate a model or theory by means of inductive categorisation. In this type of analysis, the first step is data collection, which should be based on a variety of methods. Subsequently a series of codes are extracted from the data, which are grouped into similar concepts. From these concepts, categories are formed, which are the basis for the creation of a theory. This

Box 1. Discussion themes of the focus group interviews

- The diagnosis: (How should it be communicated, what is important to mention, who should tell the patient? etc.)
- Information about dementia: (What would you like to know, when would you like to know this and how do you find out?)
- Care and treatment options: (What options are there, how do you find out about them?)
- Making the decision: (What choices do you make, why do you make certain choices, how a choice is made, what would help you to make the choices easier?)
approach contradicts the traditional model of research, in which the theory is the starting point [22].

The focus group interviews were all videotaped, and, based on these tapes, the interviews were transcribed (i.e., the interviews were completely written out). These transcripts and additional notes that were made during the focus group interviews were read in full by two assessors (CW and MdV). This researcher triangulation [20] was used to ensure the trustworthiness of the data analysis. While reading the transcripts, notes were made and important quotations and answers were underlined. In case of unclear passages the videotapes were consulted. Each participant’s answers and quotations were then placed under the appropriate themes. Subsequently, the themes were ordered and categories were formed. Both assessors agreed on these categories. Finally, themes and categories that were identified and agreed upon were discussed with a third experienced researcher (FS). In this way, a “flowchart” (see Fig. 1) was developed that describes factors or determinants that influence the decision-making process.

### 3. Results

#### 3.1. Participants in the focus group interviews

A total of 252 patients agreed to participate in the telephone interviews. Their demographic and clinical characteristics are described elsewhere [15]. In April and May 2008, four focus group interviews were held: two in Maastricht (A and B), one in Den Helder (C), and one in Heerhugowaard (D). Of the 252 patients, 34 indicated that they were willing to participate in the focus group interviews and they were all contacted. Eventually, 26 people participated in these focus groups, i.e., seven and five in Maastricht, five in Den Helder and nine in Heerhugowaard. The participants of the focus group consisted of 13 females and 13 males. Most were spouses (n = 11) or children (n = 12) of the patients. Most patients suffered from dementia. The characteristics of the participants were comparable to those of the participants from the telephone interviews (p ≥ 0.05). Their characteristics are summarised in Table 1.

#### 3.2. The focus group interviews

Analyses of the focus group interviews revealed that the decision-making process consists of three elementary components: (1) identifying individual needs; (2) exploring options; and (3) making a choice. In Fig. 1, these three categories are schematically described. In the following section the categories are described and clarified by means of quotations. Each quotation is assigned a code; the letter stands for the location of the focus group interview (A and B are the interviews conducted in Maastricht and C and D are the interviews from Den Helder and Heerhugowaard, respectively), whereas the number indicates the individual within the focus group.

##### 3.2.1. Identifying individual needs

The basic assumption of the decision-making process is that every patient and caregiver has specific needs. These needs are based on the problems that one has experienced and one’s individual preferences. They continuously change due to the progressive nature of dementia and due to adaptation.

“You come across different types of care as the dementia progresses. It starts with support at home, such as domestic or personal home care. Later, things like day care are more important as you become more stressed and need some time to yourself. The care becomes more and more intense. Finally there probably is no other choice than hospitalization.” (A4)

Dementia is an emotional process in which many difficult problems may be experienced. It starts when the diagnosis is communicated to the patient, which is important for future care planning. Although it is difficult to imagine any worse news than your doctor saying, “You have dementia”. disclosure of the diagnosis helps patients and caregivers to come to terms with their condition and to cope with the situation [23,24].

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**Table 1**

<table>
<thead>
<tr>
<th>Caregivers (n = 26)</th>
<th>Patients (n = 26)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male/female (n)</td>
<td>Male/female (n)</td>
</tr>
<tr>
<td>13/13</td>
<td>8/18</td>
</tr>
<tr>
<td>Spouse (n)</td>
<td>Alzheimer’s dementia (n)</td>
</tr>
<tr>
<td>11 (7 husbands, 4 wives)</td>
<td>18</td>
</tr>
<tr>
<td>Child (n)</td>
<td>Vascular dementia (n)</td>
</tr>
<tr>
<td>12 (5 sons, 7 daughters)</td>
<td>3</td>
</tr>
<tr>
<td>Other (n)</td>
<td>Other dementia (n)</td>
</tr>
<tr>
<td>3 (1 nephew, 1 niece, 1 sister)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Mild cognitive impairment (n)</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

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**Fig. 1.** Flowchart of the decision-making process in dementia.
“When dementia is diagnosed, your relationship changes a lot. You are essentially trying to find your own position in a changing situation. This is a very radical and time-consuming process. It is not something you learn overnight, and there are a lot of emotions involved. You need to learn to cope with these emotions.” (C5)

Subsequently, one has to deal with a progressive loss of cognitive and functional abilities over time. As dementia progresses, patients require increasingly more supervision and assistance in daily living.

“My brother and sisters and myself made a “duty-roster” regarding the care for our father. Everyday someone visits him to check his fridge to see whether he eats sufficiently and to see whether he has washed and dressed himself properly. This way, he can remain living on his own, and we are all reassured that no accidents have happened.” (D6)

3.2.2. Exploring the options: moving towards a choice

Identifying individual needs is the starting point for further guidance and treatment. These needs, which are different for each individual, must be translated into a solution in terms of appropriate care and treatment options. This task is not easy. Before a solution is available, the options for care and treatment need to be explored. This exploration is a complicated, time-consuming and continuously changing process.

There are several ways to explore one’s options. Health care professionals play an important role because they can guide, give advice and inform the patients and their caregivers about the possibilities.

“We have a lot of faith in our case manager. He knows the entire dementia network and whatever question or needs we have, he takes care of it.” (D3)

Another way to explore one’s options is by discovering the experiences of fellow sufferers. Fellow sufferers or people who are in the same situation can share their experiences with the patients and caregivers to make the options clearer.

“We read a lot about Alzheimer’s disease, looked it up on the internet and talked with friends whose parents are in the same situation. You are not alone. It is nice that other people understand your situation and that you recognise theirs.” (A10)

Finally, patients and caregivers can try to obtain more information themselves or even visit a day-care centre in order to experience it. It is important that by regularly talking about the options and listening to other people’s stories, the topic becomes more familiar and easier to deal with.

“It was very important to me that my husband went to day care but he did not want to go. We talked about it for a long time and I told him he should try it first before saying he did not like it. Finally he tried it, and he loved it after going for the first time.” (B6)

People differ in the way that they explore their options. Roughly, three different groups of people can be distinguished. The first group of people prefers having a complete overview of the care and treatment options, actively searching and investigating these options, and making independent decisions. A second group also prefers having a complete overview of the care and treatment options, but wants to be guided more by health care professionals.

The third group is highly dependent and relies solely on the competent judgement of the health care professionals. The type of person making the decision might have implications for the care one ultimately receives.

“We are all rather independent and not afraid to say what is on our minds. So we actively found the care that suited us best. If you cannot or will not do this because you are more hesitant or passive, you might end up last in line.” (B2)

Regularly discussing and revising these options is an important part of the process of accepting and adjusting to the disease. This process is ongoing due to the progressive nature of dementia.

“The regular visits to the psychologist were very helpful. It is really important you have someone to talk to during the dementia process who understands you.” (B6)

3.2.3. Making a choice

Finally, a definite choice has to be made whether or not to make use of certain care or treatments. This choice is often very emotional rather than rational.

“We had a choice between more intensive care at home or day care in a nursing home. Our General Practitioner (GP) recommended the first option, and the case manager recommended the second option. We just did what felt best.” (C4)

Caregivers often take the lead in considering the care and treatment options and eventually in making a choice. However, they often experience the patient’s refusal and denial as a major interfering and hampering factor.

“It all depends on the patient. When the patient says no it all ends. It is impossible to make the choice for him or her.” (A5)

Sometimes the need for care support becomes an acute necessity and choosing from several options is no longer possible.

“Dementia is an emotional process which you enter together. Eventually you reach your limit but you do not know when that limit is getting nearer. I started to have a bad temper when I reached my limit. It is important that you learn how you can anticipate this.” (B2)

Furthermore, the personal preferences of both the patients and caregivers must be considered when choosing a certain treatment.

“A characteristic of my wife is that she is a very social person, she loves being in a group. An activity in a nursing home is therefore just the thing for her.” (B3)

“Oh no, my husband does not like interacting in a group at all. He prefers to be alone in a chair.” (B1)

Additionally, decision-making should involve “team-work”. It is important to involve the patient, several relatives and the health care professionals and work as a team.

“I know my mother better than the case manager does. My case manager explains what options there are and what they mean, and I make the decision together with my mother and my sisters. If you work as a team, you make the best choices.” (C1)

Finally, practical aspects are sometimes considered but they do not appear to play a major role in making a choice.
"I do not have a car, so the discussion groups have to be near my house." (D7)

"I think my father would love it if the ride to day care took longer. He could enjoy the views from the car. I do not think that distance matters." (D6)

Overall, the decision-making process as it relates to dementia is a complicated, emotional, time-consuming and continuously changing process.

4. Discussion and conclusion

4.1. Discussion

This article provides new insights into the complex, dynamic and emotional decision-making process that patients suffering from dementia and their caregivers undergo when reviewing their options for treatment and care. The results show that the basic assumption of the decision-making process in dementia is that patients and their caregivers have individual needs that are continuously changing due to the progressive nature of dementia and due to the fact that they are able to adapt to their situation. Subsequently, these needs must be translated into solutions in terms of appropriate care and treatment, which is achieved by exploring one's options. This exploration is a crucial and time-consuming part of the decision-making process, in which patient and caregiver often need help, as it is important that they are drawn towards a choice and become familiar with the changing situation. Finally, a choice must be made. This choice is experienced more as an emotional decision rather than a rational one mainly because it is influenced by personal preferences and, to a smaller extent, by practical aspects.

An important specific aspect of decision-making in dementia is that caregivers often have to take the lead in considering the options and making a choice because, due to cognitive and functional impairment, persons with dementia experience a decline in their ability to make decisions [12–14,25]. Efforts have to be made to ensure that decisions made by the proxies are based on the prior attitudes and values of the patient [26]. These caregiving decisions become more drastic as the disease progresses and they contribute greatly to the caregiver's burden [11]. Moreover, this burden is aggravated due to behavioural problems of the patient such as agitation or refusal to cooperate [15,27,28].

The degenerative nature of the disease makes dementia especially difficult to accept. A lack of acceptance by the patient and/or caregiver significantly hampers the decision-making process. Therefore, in the case of dementia, professionals need to play a more explicit role in the decision-making process by anticipating transitions in care and outlining options for care and treatment in advance in order ‘to soak’. These professionals should make dementia and the care and treatment options that are available the subject of discussion as soon as possible. This is necessary to enable both the patient and caregiver to adapt and come to terms with their situation. This patient–physician relationship (which has changed from a paternalistic relationship to a more participatory one over the years) can either be an informative one or it can entail more guiding or compelling, depending on the wishes of the patients or caregivers.

The phase of exploring one’s options should be initiated soon after receiving a diagnosis. It is therefore important that a timely diagnosis is made, which can both help caregivers become aware of and make better use of services [29] and be viewed as a precondition for improving dementia care [30,31]. A timely diagnosis allows those affected by dementia to make adequate plans for the future and access education and dementia support services [32]. Early service utilisation is likely to have important implications such as reducing caregiver burden and delaying institutionalisation which may result in cost savings [33]. Early awareness of the options is necessary to avoid situations in which the need for care support has become an acute necessity, thereby removing patient’s and caregivers’ choices [15].

There are several potential weaknesses of the present study that should be discussed. First, although there are a lot of advantages to focus group interviews, there are also some drawbacks that require consideration [34]. In particular, the quality of the focus group interview is dependent on the skills of the interviewer. In this study, we used two interviewers, one of which was an expert in conducting focus group interviews and the other an experienced clinician.

Another important drawback is that the group approach may encourage a group response whereby key individuals may keep their own beliefs and views to themselves. In addition, the presence of one dominant person may influence the rest of the group. However, the experienced interviewers ensured equal input from the participants by actively involving everyone in the discussion. In the current article, we used different quotations to indicate the various viewpoints within the group. Finally, due to our relatively small sample size, the generalisability of the results may be questioned, although the results seem potentially transferable. Moreover, using the focus group interviews with a relatively small n enabled us to explore the decision-making process in depth.

4.2. Conclusion

In conclusion, an important and novel finding of our study is that decision-making in dementia consists of three different phases namely identifying needs, exploring options and making a choice. The exploration phase is the most crucial phase. In this phase it is important that professionals are actively involved in helping patients and caregivers gravitate towards a choice and become familiar with and accept the changing situation. A lack of exploring could be the reason why current treatment options are often not sufficiently utilised by the patients and/or their caregivers. More emphasis on this exploration phase in clinical practice might make accepting and adjusting to the disease easier. Acceptance is an important condition for reducing anxiety and resistance to care and treatment options that may offer significant benefits in the future. Another novel finding is that decision making in dementia is influenced by personal preferences and that practical issues do not seem to play a substantial role in the making of a choice. Health care professionals should explicitly ask the patients and caregivers what their preferences are at an early stage of the dementia to create a tailored care and treatment plan and to adjust the role of the professional which can be informative or more guiding or compelling according to their wishes.

Decision-making regarding treatment and care is different in the case of dementia from decision-making in the context of other chronic diseases, in which experience with the course of the disease leads to clearer wishes regarding patient's needs. This difference is due to several specific aspects of dementia: (1) the difficulty of accepting that one has a neurodegenerative disease; (2) the changing needs that result from the progressive nature of the dementia; (3) the patient's need to rely on surrogate decision-making as the disease progresses and their cognitive capacity deteriorates; and (4) the strong emotions that overwhelm rational decisions. Due to these factors, the decision-making process, is very time-consuming, especially the exploration phase.
4.3. Practical implications

Although in general the patient–physician relationship has changed over the past few decades from a passive one into one that is more focused on empowering the patient, this change does not seem to be applicable to dementia. In the case of dementia, rational decision-making is a contradiction in terms as the patient’s cognitive capacities are affected and a more active role is required of both the caregiver and the physician or another health care professional, who very often have to make decisions on the patient’s behalf. From the perspective of the caregiver a rational decision-making model cannot be applied because although emotion is an indispensable aspect of rational decision-making [35], rationality is often overwhelmed by emotions.

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