

Information exchange with professionals in dementia decision-making: views of informal caregivers

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Status: Definitive
Date: July 5, 2013
Words total: 3495
Words Dutch summary: 298
Words English abstract: 296
Journal: International Journal of Geriatric Psychiatry
Reference style: Harvard
Maximum words: 3500

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Research Internship 2: Master Thesis

Dutch summary

Titel: Informatie uitwisseling met professionals in dementie besluitvorming: de visie van mantelzorgers

Inleiding: Wereldwijd zijn er naar schatting 24 miljoen mensen met dementie. De meerderheid woont thuis en is grotendeels afhankelijk van mantelzorgers. Mantelzorgers worden steeds meer betrokken bij het nemen van beslissingen voor deze thuiswonende dementerende personen. Belemmeringen bij het nemen van beslissingen zijn onder meer gebrekkige informatie uitwisseling en ondersteuning. Dit leidt tot onnodige stress bij mantelzorgers. Gezamenlijke besluitvorming, wanneer goed gefaciliteerd door professionals, kan adequate informatie uitwisseling ondersteunen, zodat mantelzorgers juiste beslissingen kunnen nemen.

Doel en onderzoeksvraag: Om inzicht te krijgen in de rol van professionals in informatie uitwisseling moet de zienswijze van mantelzorgers op professionals met betrekking tot het uitwisselen van informatie bij besluitvorming worden onderzocht. Dit inzicht kan leiden tot handvatten voor adequate informatie uitwisseling tussen mantelzorgers en professionals.

Methode: Deze kwalitatieve studie werd uitgevoerd volgens de principes van de gefundeerde theorie-benadering. De onderzoekspopulatie bestond uit mantelzorgers van mensen met dementie uit Nederland die deel uitmaakten van een dementie zorgnetwerk. De software Atlas.ti is gebruikt.

Resultaten: De visie van mantelzorgers op professionals met betrekking tot informatie uitwisseling is afhankelijk van de aard van de betrokkenheid. Professionals werden beschouwd als actief of passief betrokken. Mantelzorgers waren positief over de informatie uitwisseling van actief betrokken professionals. De informatie uitwisseling van passief betrokken professionals was vaak niet in overeenstemming met hun behoeften.

Conclusie: De informatie uitwisseling van professionals was volgens mantelzorgers vaak niet voldoende. Veel beslissingen werden besproken door mantelzorgers met betrokkenen in het zorgnetwerk, maar deze besluiten zijn niet onbetwistbaar op basis van gezamenlijke besluitvorming. Beslissingen werden voornamelijk gebaseerd op goed gevoel en gezond verstand.

Aanbevelingen: Deskundigheidsbevordering voor professionals op het gebied van dementie en ondersteuning tijdens het proces van informatie uitwisseling in de besluitvorming, kan ervoor zorgen dat mantelzorgers gelijkwaardige partners worden in besluitvorming.

Trefwoorden: Mantelzorger / Gezamenlijke besluitvorming / Professional / Informatie Uitwisseling / Dementie

English abstract

Title: Information exchange with professionals in dementia decision-making: views of informal caregivers

Background: Worldwide, there are an estimated 24 million people with dementia. The majority lives at home and are largely dependent of informal caregivers. Informal caregivers are increasingly involved in care decisions for persons with dementia. Barriers to make such decisions include lack of information exchange and support. This creates unnecessary stress in informal caregivers. Shared decision-making, when facilitated by professionals, can support adequate information exchange, enabling informal caregivers to make care decisions.

Aim and research question: In order to gain insight into the role of professionals in information exchange, informal caregivers' views on professionals regarding exchanging information in care decisions should be examined. This insight might result in indications for adequate information exchange between informal caregivers and professionals.

Method: This qualitative study was conducted using the principles of the Grounded Theory approach. The study population consisted of informal caregivers of persons with dementia from the Netherlands who were part of a dementia care network. The software Atlas.ti was used.

Results: Informal caregivers' views on professionals regarding information exchange in decision-making are depended on the nature of involvement. Professionals were considered to be either actively or passively involved. Informal caregivers were positive about information exchange of actively involved professionals. The information exchange of passively involved professionals was too often not consistent with their needs.

Conclusion: The information exchange of professionals was too often not appropriate. Many decisions were discussed by informal caregivers with members of the care network, but these decisions were not indisputably based on shared decision-making. Decisions were mainly based on good sense and gut feeling.

Recommendations: Improvement of expertise for professionals regarding dementia and support during the process of information exchange in decision-making, to ensure informal caregivers are equal partners in decision-making.

Keywords: Informal Caregiver / Shared Decision-making / Professional / Information Exchange / Dementia

Introduction

Worldwide, there are an estimated 24 million people with dementia and this number is expected to double in the next 20 years (Qiu, De Ronchi & Fratiglioni 2007). The majority of people with dementia lives at home (Health Council of the Netherlands 2002). Dementia is characterized by multiple cognitive deficits that include memory impairment (American Psychiatric Association 2000). People with dementia change from healthy, autonomous members of society into being largely dependent of others, both physically and mentally (Ferrario et al. 2003).

In caring for a person with dementia (PWD), informal caregivers (IG) and professional caregivers are interconnected with the PWD in a so-called dementia care network. Professional caregivers are trained professionals including general practitioners (GPs), home care employees, case managers and various specialists. An IG is usually a close family member (Knapp & Prince 2007).

Due to the cognitive and functional impairment, the PWD is less able to make care decisions, including everyday care, care services and care planning (Alzheimer's Society 2011). Therefore, IGs are increasingly involved and necessary in processes of making care decisions, while the involvement of PWDs decreases (Health Council of the Netherlands 2002). From an emancipatory point of view, a process of decision-making in which all parties are equally involved is considered as worthwhile.

The key principles of shared decision-making (SDM) have been conceptualised as a process that involves all care network members. All parties are included in the process of decision-making, which consists of: 1) involvement of patients in decision-making process; 2) explore ideas, fears, and expectations of the problem and possible treatments; 3) portrayal of equipoise and options; 4) identify preferred format and provide tailor-made information; 5) checking process: understanding of information and reactions; 6) checking process: acceptance of process and decision-making role preference; 7) make, discuss or defer decisions; 8) arrange follow-up (Elwyn et al. 2000). When SDM is used, patients and IGs are better informed, more aware of advantages and disadvantages of a decision, satisfied with the decision and less doubting the decision they made (Stacey et al. 2011). Furthermore, SDM can help reduce power imbalance in medical consultations, giving a person the opportunity to make their own treatment decisions. SDM enables them to participate as information-givers, and not merely as passive recipients of 'medical facts' (Edwards, Davies & Edwards 2009). Persons with dementia and their IGs from a wide range of settings appear to favour a SDM approach over a passive or autonomous role (Elwyn et al. 2001).

SDM is considered to be a key strategy for health care that is patient-centred as well as evidence-based (Legare 2008). Information exchange, a discussion that involves exchanging ideas and knowledge (Collins 2013), is one of the core elements of SDM (Coulter & Collins

2011). Information exchange is important to reduce someone's uncertainty and concerns. Adequate information exchange and support from professionals facilitates care decisions (Livingston et al. 2010). Members of dementia care networks can make informed decisions if they combine sufficient clinical knowledge with the PWDs values, preferences and goals (Edwards & Elwyn 2006).

Effective SDM is not yet the care standard in dementia care. Decision-making in dementia is a complicated, emotional, time-consuming and continuously changing process (Wolfs et al. 2012). There is a lack of communication in dementia care networks and a high rate of misunderstanding (Whitlatch 2008). An obstacle in decision-making includes insufficient information exchange (Hirschman, Kapo & Karlawish 2006). Many PWDs and their IGs require more information, more involvement in treatment decisions and more care and support from professionals than they currently experience (Coulter & Collins 2011). Professionals do not always facilitate SDM (Edwards, Davies & Edwards 2009), which leads to lacking information exchange and increases IGs' stress (Schmall 1995).

SDM depends on building a good relationship so that information is exchanged and PWDs and their IGs are supported to deliberate and express their preferences and views during the decision-making process (Elwyn et al. 2012). To facilitate the process of SDM, professionals should know what IGs' views and expectations are about information exchange. It is unclear whether the IGs' expectations match the actual exchange of information with professionals in decision-making. Insight in the IGs' views (thoughts, experiences, values and perceptions) on professionals regarding information exchange in decision-making is necessary to improve information exchange in dementia care networks.

Problem statement and aim

IGs are increasingly involved in care decisions for PWDs. The poor information exchange in dementia care networks creates unnecessary stress in IGs, and leads to misunderstanding within the care networks. In order to gain insight into the role of professionals in information exchange, IGs' views on professionals regarding exchanging information in care decisions should be examined. This insight might result in indications for adequate information exchange between IGs and professionals regarding decision-making. Based on that, professionals will be able to provide IGs with adequate support, and dementia care networks will be able to make appropriate care decisions.

Research question

What views do informal caregivers of Dutch elderly with dementia hold on professionals regarding exchanging information in care decisions?

Method

This qualitative study was conducted using the principles of the Grounded Theory approach because the intent was to move beyond description and to generate a theory (Strauss & Corbin 1990, Creswell 2007). Our study was part of a research program 'Shared decision-making in care networks of older people with dementia'. We used the existing data set of the research program. The study of the research program and its consequences for the participants were submitted to the regional METC (Medical Ethical Committee) of Isala Clinics. On December 2, 2010, the committee issued a 'no objection' for the study (#10.11113).

Participants and data collection

The research program recruited dementia care networks through health care organisations, Alzheimer cafés and on the website of the National Alzheimer's Society. Each participant was informed about the study and asked to sign an informed consent form. The data collection took place in the region of one urban city and one rural city in the Netherlands. A total of 25 care networks were recruited.

The data collection consisted of individual, semi-structured, one hour interviews with dementia care networks. Each care network consisted of five members: one PWD, two IGs and two professionals. All care network members were interviewed three times, with six-month intervals. The interviews were conducted using topic lists. The content of these lists was based on several decision-making theories. Topics involved changes in the situation of the PWD and relating decisions. Interviews were audio-taped and transcribed verbatim and anonymous.

The study population of our study consisted of IGs who were part of the recruited care networks. Due to the focus on information exchange in the second interview cycle, only these interviews were used for our study. Care networks with PWDs living in care homes were excluded; the research program indicated these care networks did not discuss different care decisions in the interviews. To create thick description of care networks, interviews with both IGs were included.

Of the 50 interviews with IGs, 36 were available for this study, since five PWDs lived in a care home, and in two care networks no second IG was interviewed. Five care networks were randomly selected and inclusion of additional interviews was based on theoretical sampling (Creswell 2007) with regard to the core themes and saturation of these themes.

Analysis

The analysing process was based on principles of the Grounded Theory approach (Strauss & Corbin 1990, Creswell 2007) using the QUAGOL method to identify conceptual meanings

and patterns (Dierckx de Casterle et al. 2012). The data was analysed in a cyclical process, alternating the selection and analysis of interviews.

Each interview was read thoroughly. The essence of each interview was summarised in a narrative interview report before moving to the next transcript. Of each narrative interview report, a conceptual interview scheme was created according to the QUAGOL method which provided concepts that appeared relevant.

The actual coding process consisted of open, axial and selective coding, Atlas.ti 7.0 software was used. The data was divided into categories, and labelled with a code. With researcher AS, intercoder agreement was achieved by encoding the first ten interviews, which resulted in a code tree with definitions. Axial coding was applied by four researchers (KH, AS, CS & an external expert), categories were discerned and related. Each category was named with a fitting category label. Selective coding was marked by including and reviewing additional interviews to identify and check codes, and the emergence of core themes (Creswell 2007).

A schematic overview of both IGs of each care network was made with Inspiration9 to aggregate data elements, and was further developed into an overview of all included care networks. When no new concepts were identified from the data, theoretical saturation was reached and analysis ceased (Boeije 2008).

To enhance trustworthiness several measures were taken. By analysing the data in collaboration with AS, CS and JJ, inter-rater reliability has been secured (Armstrong et al. 1997). Every step in the analysis was checked by AS, reducing the chance of researcher subjectivity (Maxwell 2005). Disagreements were resolved through team discussions every three weeks with KH, AS, JJ en CS. Methodological and theoretical memos were used as tools for analysis and interpretation of the results to avoid researcher subjectivity (Boeije 2008).

Results

36 interviews with IGs were available from the existing database, of which 20 interviews were analysed before saturation was reached. A socio-demographic description of the included IGs is shown in table 1.

IGs described their views on professionals regarding information exchange. These views can be divided into two categories: IGs considered professionals to be either actively or passively involved. IGs' views on both categories are elaborated using the four elements of views: thoughts (that which one thinks), experiences (that what someone encountered or has undergone), values (that what someone renders desirable or useful) and perceptions (insight or intuition someone has gained by perceiving).

[Table 1]

Professionals actively involved in information exchange in decision-making

Multiple professionals were actively involved in the care networks according to IGs. In the views of IGs their involvement was characterised by being involved in decision-making, exchanging information before decision-making, discussing options with IGs, and regular contact with other care network members.

Thoughts

Positive thoughts of IGs dominated regarding involved professionals. IGs experiencing pleasant collaborations considered the involvement of professionals as enrichment in taking care of the PWD. IGs expected professionals to be the main care source, and their own informal care as complementary. IGs considered the manner professionals approached them as important.

“The involvement of the case manager is convenient.” (Daughter, care network 8)

“Patient meetings with professionals are accurate and pleasant.” (Daughter, care network 2)

In some cases, professionals did more than IGs expected.

“I’ve never phoned the case manager with problems before. She came immediately.”
(Spouse, care network 6)

Experiences

IGs were pleased when professionals were pro-active and provided suggestions. IGs frequently mentioned that their contact with pro-active professionals was good. The pro-active attitude of professionals made IGs feel supported. IGs felt that professionals provided adequate dementia care.

“I experience support from the entire care network.” (Spouse, care network 2)

“The contacts with nurses were pleasant; they know how to deal with dementia”
(Daughter, care network 8)

IGs with actively involved professionals felt they received sufficient information from professionals. Some IGs said they had not missed any information.

Values

An important value IGs mentioned was having a good relationship with professionals (especially with GPs), in view of future events. The GP was considered the most suitable person for decision-making. Multiple IGs said they valued trust to be essential and therefore kept in close contact with professionals. Easy access to professionals was seen as valuable. IGs valued conversations with professionals, since it made them feel involved in the PWD's care.

"You must care for the PWD with each other." (Daughter, care network 5)

IGs believed that the case manager should perform multiple tasks. The case manager had to function as a spokesperson for the PWD, served as a source of information and advice, and was expected to inform IGs when something went wrong. Several IGs discussed their concerns with professionals.

"I've regularly meetings with the case manager; afterwards I've a better perspective of the situation." (Niece, care network 3)

Perceptions

IGs described their perceptions regarding several aspect of decision-making. Involved professionals usually met the expectations of IGs; information was exchanged, commitments were fulfilled, and decisions were made together. In some networks, professionals provided the decisive vote in decision-making. Professionals seemed to be able to properly assess the situation, and involved professionals expressed corresponding views.

In general, IGs still considered their past decisions to be correct. Only one IG regretted not accepting an admission for a nursing home, after he received conflicting information from professionals about admission to a nursing home.

Informal caregivers highly valued the information that professionals provided, but based most of the decisions on good sense and gut feeling.

Professionals passively involved in information exchange in decision-making

The second category in the views of IGs were passively involved professionals. These professionals were characterised by an inferior role in information exchange and decision-

making. IGs did not ask professionals for information or advice, contacts were irregular, and there was no trusting relationship. Mainly negative views were mentioned.

Thoughts

IGs had negative, mainly unspoken thoughts and expectations of passive professionals. One IG said that there was no proper communication between home care employees. Another IG expected that the case manager and home care employees would discuss the PWD's alcohol consumption, but there was no real agreement with these professionals.

IGs felt that professionals sometimes did not take the IGs' considerations into account, and did not provide appropriate information. In hindsight, IGs learned that there was much more, useful information to know.

"In practice, it's much more difficult than they (professionals) said" (Spouse, care network 2)

Experiences

Experiences with passively involved professionals were typically about IGs' different expectations from professionals. In some cases IGs experienced no coordination, not-fulfilled agreements and the absence of familiar faces. Furthermore, multiple IGs mentioned that the contact they had with professionals and the contact among professionals was very limited.

"There is no coordination between the two domestic workers." (Son in-law, care network 8)

"The elderly psychologist came every six weeks, but stopped those visits because the psychologist said that home care employees could assess the situation better." (Daughter, care network 5)

"The home care coordinator has decided that PWD should go to day care, she didn't consult with us. PWD now goes every day to the day care." (Spouse, care network 1)

"It's been a while since there has been an evaluation with the home care employees." (Daughter, care network 5)

Values

In general, IGs could contact professionals in case of questions or problems. However, IGs almost never attempted to contact the passively involved professional. There seemed to be a

high threshold to ask for advice or help. Some IGs indicated that they not yet needed to contact professionals.

“Unfortunately, I have to take the initiative to get in contact with professionals.” (Daughter, care network 3)

“My mother almost never calls the home care employees for PWD, even though it’s actually needed.” (Daughter, care network 1)

Perceptions

Decisions were often based on good sense and gut feeling, sometimes without advice or information from professionals.

“My brother makes the major decisions; I would prefer to discuss these decisions with the GP”. (Daughter, care network 7)

Most IGs said they had no need for information. Others mentioned that they missed information, mainly about how to deal with dementia. The information IGs received, was often not suitable to their needs.

“I actually think (the information) is a bit too sweet. Patients are sometimes aggressive, that’s my experience.” (Spouse, care network 10)

IGs’ perceptions of home care employees differed. The quality of care that employees provided was different, and some did not cope well with dementia.

“The day care is not well adapted to people with dementia.” (Spouse, care network 2)

“Nobody knows the answer on how to approach a PWD.” (Spouse, care network 2)

Discussion

IGs’ views on professionals regarding information exchange in decision-making are depended on the nature of involvement of professionals within the care network. Two different categories of professionals were described: actively involved professionals and passively involved professionals. IGs were positive about the actively involved professionals, and critical about the passively involved professionals. Despite IGs’ positive views, improvement is needed, especially in information exchange prior to a decision. Information

exchange of passively involved professionals was too often not consistent with the IGs' needs. IGs described many decisions that were made in dementia care networks, but these decisions were not indisputably based on SDM. Decisions were mainly based on good sense and gut feeling.

In our study, it became clear that some IGs needed more contact with professionals to improve the relationship. The importance of relationships is emphasised by Robben et al. (2012), who described that the context in which information was provided, is equally important as the information itself. Even if the information would meet all the IGs' preferences, it would be of limited significance if the professional and IG did not have a genuine trusting relationship.

In the study of Givens et al. (2012), the majority of participants expressed almost unanimous dissatisfaction about the level of communication with GPs. In addition, IGs expressed that because of a lack in communication regarding medical events, they were essentially unable to act as the PWDs' advocate and engage in SDM.

The care networks differed in information exchange. Some IGs used information from professionals for decision-making, while others mainly used information from relatives, and the internet, which is confirmed in the study of Hirakawa et al. (2011). Livingston et al. (2010) mentioned in their study that IGs need appropriate information for decision-making. IGs differ in their desire for and response to information, but IGs generally require more information than they currently receive (Chang et al. 2010).

The involvement of professionals in dementia care networks differed per care network and per professional. Not every professional seemed to be well informed about dementia care. In the report of Peeters et al. (2012) was suggested that a case manager can be used to train other professionals. They believed the case manager is the only professional that is very aware of dementia care and supporting IGs.

The steps of SDM (Elwyn et al. 2000), especially those describing information exchange, were not completely conducted in the ten care networks. IGs did not mention they explored ideas and expectations, nor did they considered several options. Although information exchange did take place, information was often missing or information was not appropriate.

IGs expressed a strong preference for involved professionals in information exchange and decision-making. They valued good and trusting relationships with professionals. However, it appeared that many professionals still do not have this role in dementia care. To ensure that IGs and PWDs make adequate decisions, it is important that professionals are aware of IGs' views. This is in line with previous research showing that IGs of PWD have substantial needs for professional support (Peeters et al. 2010; van der Roest et al. 2009). IGs are more able to fulfil an equal role in SDM when professionals pay attention to the wishes and needs of IGs in information exchange.

The results of this study should be interpreted in light of certain limitations. This study used existing data, therefore it was not possible for the researcher to explore the emotions of the IGs, nor was it possible to ask more in-depth questions regarding their answers. Therefore it is possible that we do not have a whole fundamental understanding of the views of IGs about information exchange. However, by analysing views of IGs based on actual experiences, the obtained results are thorough.

The results of this study are from IGs from different cities in the Netherlands. The characteristics of IGs and PWD in our study are comparable with national findings in dementia care (Aguglia et al. 2004; Givens et al. 2012; Paton et al. 2004; Rothera et al. 2008; Wackerbarth & Johnson 2002). Therefore, presumably the results are applicable to countries where society and health care services are equivalent to the Netherlands.

Conclusion

The views of 20 IGs who participated in this study can be divided into two different categories. IGs considered the professionals with whom they cared for PWD in dementia care networks to be either actively or passively involved in information exchange in decision-making. IGs were satisfied with the actively involved professionals concerning information exchange, the content of the information, and the support in decision-making. Passively involved professionals did not provide IGs with proper information and support for decision-making. Despite their satisfaction with professionals, IGs felt there was room for improvement of information exchange, which is supported by literature findings. Information exchange occurred in all care networks; however, SDM is often not used.

Recommendations

Recommendations include improvement of expertise for professionals regarding the course of dementia and support during the process of information exchange in decision-making, to ensure IGs are equal partners in decision-making.

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Tables

Table 1. Socio-demographic description of interview samples

Informal caregiver (N = 20)	
Gender	
(Male)	6
Relationship to person with dementia	
(Spouse)	4
(Daughter)	8
(Son)	2
(Daughter in-law)	2
(Son in-law)	1
(Granddaughter)	1
(Niece)	2
Person with dementia (N = 10)	
Gender	
(Male)	2
Age	
(70-79)	2
(80-89)	7
Marital status	
(Widowed)	5
(Married)	4
(Single)	1
Type of dementia	
(Alzheimer Disease)	7
(Vascular Dementia)	2
(MCI)	1
Living situation	
(Independent living)	7
(Home for elderly)	3