

Informal caregivers' views on information exchange in dementia care networks: a qualitative study

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DUTCH SUMMARY

Titel: Visie van mantelzorgers op informatie-uitwisseling in dementie zorgnetwerken: een kwalitatief onderzoek.

Inleiding: Patiënten zijn in toenemende mate betrokken bij gezondheidsbesluiten. Bij het nemen van beslissingen kunnen de patiënt en professional gebruikmaken van 'gezamenlijke besluitvorming'. Eén van de voorwaarden voor gezamenlijke besluitvorming is adequate informatie-uitwisseling. Veel sectoren in de gezondheidszorg hebben problemen met informatie-uitwisseling, zo ook in de ouderenzorg bij het bieden van zorg rond dementie. Zorg voor dementerende ouderen wordt gekenmerkt door samenwerking tussen professionals en mantelzorgers, die samen met de dementerende persoon een dementie zorgnetwerk vormen. In deze zorgnetwerken wordt gebruik gemaakt van gezamenlijke besluitvorming. De rol van de mantelzorger wordt, naarmate de dementie toeneemt, steeds groter. De mantelzorger heeft om die reden een sleutelrol in een dementie zorgnetwerk. Diverse studies suggereren dat het probleem van informatie-uitwisseling rondom besluitvorming veroorzaakt kan worden door de verschillende visies van leden van het zorgnetwerk op informatie-uitwisseling.

Doel: Inzicht verkrijgen in de visie van mantelzorgers van ouderen met dementie op informatie-uitwisseling rond besluitvorming in dementie zorgnetwerken.

Methode: Met behulp van de principes van de gefundeerde theorie-benadering werden 20 interviews uit een bestaande database geanalyseerd, voordat saturatie werd bereikt. Als aanvulling op de analyse werd de QUAGOL methode gebruikt om gedegen inzicht te krijgen in de data.

Resultaten: Vijf elementen werden ontdekt die inzicht verschaffen in de context waarin de visies van de mantelzorgers op informatie-uitwisseling vorm krijgen. Dit zijn: de vragen en informatiebehoefte van de mantelzorger; de ervaren last; de ingrijpendheid van een besluit; de relatie tussen mantelzorger en persoon met dementie; en de positie van de mantelzorger in diens familie en dementie zorgnetwerk.

Aanbevelingen: De accurateheid van de vijf elementen dient verder getest te worden. Als de elementen nauwkeurig blijken, kunnen deze gebruikt worden bij het ontwikkelen van methoden die dementerenden, mantelzorgers en professionals helpen bij het adequaat uitwisselen van informatie, bijvoorbeeld beslissingen.

Trefwoorden: "Gezamenlijke besluitvorming" / "mantelzorger" / "Alzheimer" / "wederzijdse beslissing" / "informatie-uitwisseling"

ENGLISH SUMMARY

Title: Informal caregivers' views on information exchange in dementia care networks: a qualitative study.

Introduction: Patients have an increasingly important role in health care decisions. In deciding on the best course of action, the patient and professional can use Shared Decision-Making as a guide for decision-making. One of the conditions for Shared Decision-Making is information exchange. In health care settings, professionals and patients experience difficulties with information exchange, and dementia care is no exception. In dementia care, all carers of persons with dementia are interconnected in a dementia care network, in which they share care decisions. The informal caregivers' influence in decision-making is large, and continues to increase as a person's dementia progresses. The informal caregiver has therefore a key role within dementia care networks. Several studies have suggested that everyone involved holds a different view on information exchange in decision-making, which may cause the observed problems.

Aim: To gain insight in the views of informal caregivers of persons with dementia on information exchange regarding decision-making in dementia care networks.

Method: Based on the principles of the grounded theory approach, 20 interviews of an existing database were analysed before reaching saturation. Thorough insight was gained using the QUAGOL method.

Results: Five elements emerged that provide insight in the context of informal caregivers' views regarding information exchange: informal caregivers' questions and information needs; experienced burden; the intrusiveness of care decisions; the relationship between the informal caregiver and person with dementia; and the informal caregivers' position within their family and dementia care network.

Recommendations: The accuracy of the elements should be tested. If shown accurate, they can be used to develop methods that help patients, informal caregivers and professionals with adequate information exchange in decision-making, for instance a decision aid.

Key words: "Shared decision-making" / "Family carer" / "Alzheimer" / "Mutual decision" / "information exchange"

INTRODUCTION

In modern day healthcare, patients have an increasingly important role in health decisions. In deciding on the best course of action, the patient and professional can use Shared Decision-Making [SDM] as a guide for decision-making. Coulter and Collins (2011) and Légaré (2008) describe SDM as a process that leads to mutual agreement on the best course of action, based on the professional's clinical expertise and the patient's knowledge, values, preferences and impact on daily life. Edwards and Elwyn (2009) and Joosten et al. (2008) researched the effects of SDM and found that SDM led to better informed patients who were more aware of advantages and disadvantages of a decision, more satisfied with the decision, and less unsure about the decision they made. Due to these positive effects on a patient's self-efficacy, SDM has been increasingly used in health care. One of the health care branches where SDM is implemented as care standard is dementia care.

Worldwide, an estimated 24 million people were diagnosed with dementia in 2001. This number is expected to double every 20 years, to reach 81.1 million diagnosed patients in 2040 (Lange & Poos, 2007; Qiu, De Ronchi & Fratiglioni, 2007; WHO, 2012). In Western Europe, two-thirds of people with dementia lives at home with help from informal and professional caregivers (Alzheimer Nederland, 2012; Alzheimer Scotland, 2009; Alzheimer's Society, 2011b; Health council of the Netherlands, 2002).

In caring for a person with dementia [PWD], informal caregivers [ICG] and professionals are interconnected in a dementia care network that includes and surrounds the PWD. A dementia care network occurs naturally as a result from the shared care for PWDs. Within these networks, all members offer support to the PWD and each other, and make care decisions (Alzheimer's Society, 2011a), covering all decisions regarding everyday care, care services and care planning (Alzheimer's Society, 2011b). ICGs take up two roles in dementia care. On one hand they are the PWD's advocate, but on the other hand ICGs will act in their own interest. PWDs need someone to make decisions for them, due to their increasing cognitive impairments, such as deteriorating communication skills (Samsi & Manthorpe, 2013).

One of the conditions for successful SDM is adequate information exchange (Coulter & Collins, 2011), which Collins (2011) dictionary defined as 'a discussion that involves exchanging ideas and knowledge'. Without the necessary and appropriate information, no informed decision can be made. Neglecting the importance of information exchange leads to non-optimal care, since limited information exchange will result in ambiguous roles for every person involved in decision-making (Bennett & Hallen, 2005; Hirschman et al., 2004; Monaghan & Begley, 2004). In Western Europe, this ambiguity problem is currently being

addressed with the introduction of dementia care standards, guidelines and reports (Alzheimer Nederland & Vilans, 2012; NICE, 2006; Peeters, Francke & Pot, 2011). All reports describe what is expected of professionals in dementia care. Ideally, professionals in SDM have a supportive role towards the PWD and ICG (Alzheimer Nederland & Vilans, 2012; Peeters, Francke & Pot, 2011). The ICG's influence in decision-making is large and continues to increase as a person's dementia progresses (Hamann et al., 2011; Hirschman et al., 2005; Huizing et al., 2006; Horton-Deutsch, Twigg & Evans, 2007; Karlawish et al., 2005). The ICG therefore has a key role within dementia care networks. Professionals aim to support the ICGs and PWDs, but to do so, professionals need to know about the ICGs' and PWDs' needs, norms and values.

Several researchers noted the importance of obtaining insight in why information exchange is difficult (Clarke, Alexjuk & Gibb, 2011; Hamann et al., 2011; Hirschman et al., 2005; 2006; 2008; Livingston et al., 2010). Despite their awareness of the existing problems, none of these studies has provided profound insight in why information exchange was difficult. They do, however, suggest that the viewpoints and needs of PWDs, ICGs and professionals regarding information exchange differ, a suggestion that is supported by other studies (Hirschman et al., 2004; Kaplan & Frosch, 2005; Wackerbarth & Johnson, 2002). They did not elaborate these viewpoints, nor is the accuracy of the suggestion known. True insight in information exchange in dementia care networks requires research on the separate and different views [including thoughts, experiences, values and perceptions] of PWDs, professionals and ICGs, and the development of evidence-based theories. Due to their key role within dementia care networks, this study focused on ICGs' views.

Problem statement & aim

Adequate information exchange is an essential component of SDM. Research suggests that different views of professionals, ICGs and PWDs on roles in information exchange regarding decision-making, result in non-optimal information exchange. Currently, information exchange in dementia care networks is insufficient. Thorough analysis of ICGs' views, including thoughts, experiences, values and perceptions on information exchange in dementia care networks, provides necessary insight to optimise information exchange. With this insight, we aim to contribute to information exchange dementia care, and provide care that matches with the views and expectations of ICGs. To gain insight, we investigated the research question:

“What views do informal caregivers of Dutch elderly with dementia hold on information exchange in dementia care networks, regarding care decisions?”

METHODS

We performed a secondary analysis of existing data, by applying principles of the grounded theory approach (Creswell, 2007; Strauss & Corbin, 1990). This design is most fitting with our aim of theory development and relatively unexplored topics. Our study [from hereon: ICG-study] took place between January 2013 and July 2013, and is part of a large longitudinal qualitative study on dementia care networks [from hereon: DCN-program]. The DCN-program gathered data between 2010 and 2012, for which ethical approval was received from the Dutch Isala Clinics' Medical Ethical Review Committee [#10.11113].

Population and sample

The DCN-program contacted ICGs who were part of a dementia care network. Networks consisted of five members: one person with any form of dementia, two ICGs, and two professionals. Dementia care networks were recruited by contacting ICGs via the Alzheimer Society, Alzheimer Cafe's, and health care organisations located in two Dutch cities. If an ICG was interested in participating, their dementia care network was contacted and informed about the study. Each participant signed an informed consent form. Trained researchers conducted semi-structured interviews based on an interview protocol; each interview was audio-taped. Every participant was individually interviewed three times, at six-month intervals. All interviews were anonymously and verbatim transcribed.

Of all contacted networks, 25 completed the interviews, resulting in 144 interviews with ICGs. The topic of information exchange was specifically addressed in the second interview cycle. Therefore, only interviews with ICGs from the second interview cycle were selected, reducing our sample to 48 interviews. Networks with PWDs living in care homes were excluded; the DCN-program indicated these care networks did not discuss different care decisions in the interviews, limiting the sample to 38 interviews. Thick description would provide insight in the context of the situation, but was only possible when interviews with both ICGs of a care network were included. Two networks only contained one ICG and were excluded, resulting in 36 possible interviews. Five networks were randomly selected, before theoretical sampling was used to select additional networks, leading to a total of 20 included interviews.

Analysis

The analysing process was performed using the steps of the grounded theory approach (Creswell, 2007; Strauss & Corbin, 1990). Additionally to the open coding step, the QUAGOL

method (Dierckx de Casterlé, 2011) was used, which helped to gain thorough insight in the data. We performed every step of both the grounded theory and the QUAGOL method to analyse the data; overlapping steps were used to validate the outcomes. Besides the use of established methods, several measures were taken to improve trustworthiness. Methodological and theoretical memo's (Creswell, 2007) were kept to provide insight in the analysing process of open, axial and selective coding, and to secure transparent reporting. Lead researchers CS and JJ monitored and checked the analysing process, using the memo's, codes and interview schemes.

Researchers AS and KH independently used open coding strategy to code ten interviews. The codes were discussed and reviewed until intercoder agreement was reached, resulting in a coding list with definitions. Axial coding was started by four researchers [CS, AS, KH and an external expert] who clustered visually laid out codes into categories. Each category was named with a fitting category label. AS and KH finished the axial coding process by discussing and presenting a coding tree.

Researcher AS continued analysis while every step was checked by KH, reducing the chance of researcher subjectivity (Maxwell, 2005). Selective coding was marked by including and reviewing additional interviews to identify and check codes, and the emergence of core themes (Creswell, 2007). Inclusion of additional interviews was based on theoretical sampling (Creswell, 2007), with regard to the core themes (see Figure 1) and saturation of these themes. Saturation of the core themes was achieved when no new data emerged from the interviews. Inspiration9 software was used to describe the core themes in an abstract way, resulting in five elements (see Figure 1).

[Figure 1]

RESULTS

[Table 1]

Saturation was achieved after analysing 20 interviews. Characteristics of these networks are given in Table 1. The data resulted in a description of five elements that provides insight in the context of ICGs' views regarding information exchange. They are: ICGs' questions and information needs (1), the experienced burden (2), the intrusiveness of care decisions (3), the relationship ICGs have with the PWD (4), and the ICGs' position within their families and dementia care networks (5). All elements are described below.

Questions and information needs

The questions and information needs that ICGs mentioned were based on their experiences, and the current stage of the PWDs' dementia. Half of the ICGs had experienced problems and reported information needs that would help them solve these problems. The other ICGs did not describe problems, nor did they mention specific information needs. ICGs reported a need for "*practical, honest information*", "*information by empirical experts*", "*how to cope with dementia*" and "*how to apply the information in the current situation*".

Half of the ICGs searched for information, either reluctantly or actively. The other half did not search for information. The ICGs who searched for information mainly searched for information in books and on the internet, or via friends and family. Several ICGs used their own personal or professional experiences with dementia. Professionals were another information source. ICGs did not express a strong opinion on professionals: only a few ICGs described being content or disappointed with the professionals' role in providing information. The others did not elaborate on the professionals' role, nor on received information from professionals.

ICGs discussed the decisions they faced and the importance of the PWD's stage of dementia therein, mainly regarding living situations. The ICGs who faced decisions about living situations gathered information on the possibilities: "*I went with my sister, we made an appointment to visit [the nursing home]*". ICGs who not faced these decisions did not describe information needs regarding living situations. Furthermore, ICGs who aimed for the PWD to remain at home, reported informational needs to make this possible, and had no interest in information regarding care home possibilities: "*If I wanted to know about it, I would find something*".

Experienced burden

All ICGs considered caregiving a burden, almost half considered caregiving even an excessive burden. More than half ICGs experienced support from others, the other half experienced only some support, or no support at all. The less supported ICGs generally spoke of excessive burden and troubled relationships with the PWD and/or family.

The excessive burdened ICGs took care of PWDs who lived at home, but had decided to place the PWD on the waiting list for nursing or care homes. An ICG mentioned: "*twenty-four hours caregiving is too much for one person*".

ICGs were generally focused on managing the current situation and did not anticipate future events. Remarks along the lines of: "*Tell me when the moment is there, but not now. Now, all is well*", and "*if I have that information, it just raises questions*" illustrate their views. Typically, the excessively burdened and unsupported ICGs described non-optimal

information exchange. They *"have to set priorities"* or *"don't have time"* for other than essential tasks.

Care decisions

The ICGs typically shared care decisions with others in the dementia care network. However, the extent to which decisions were shared, differed per decision. Consulting with others was more frequently mentioned for important decisions. Small decisions were often taken without consultation. Consultation involved discussing options, preferences and (dis)advantages: ICGs said to *"ask daughter for advice"*, to *"discuss every possible option with brother"*, and *"[the professional] provided information, we discussed advantages and disadvantages"*. It was uncommon for the PWD to be involved in decision-making. However, their values did matter: *"the opinion of the PWD is guiding in the decision"*.

Relationships

Half of the ICGs described their relationship with the PWD, family and the other ICG as good. The other half described one or more troubled relationships. The ICGs who had good relationships with the PWD described their reasons for caregiving as 'love': *"you don't do it to gain something, you do it out of love"*. They said to be *"willing to do everything"*. The ICGs who described troubled relationships with the PWD said or seemed to feel obligated to provide care, as was it their 'duty': *"If I ever were in this situation, I would want to be helped"*, and *"I never felt like a child with my parents [...] so now I deliberately take some distance. I have my reasons for caregiving but it isn't out of love"*. Dutiful caregivers described more distance towards the PWD and were less inclined to exploit all possibilities regarding information exchange and care decisions: *"I have given my time to her [PWD], but I could do other things, only, because of this I don't"*.

Most respondents described non-optimal usage of information exchange within their care network; decisions were made alone or with one other person. These ICGs described that the *"other caregiver is stubborn"*, *"other caregiver is dominant"*, or they *"don't get to be involved"*.

Position in network and family

Every network consisted of two ICGs and one PWD as core members. Of the two ICGs in dementia care networks, one was generally more involved in information exchange and decision-making than the other. Leading ICGs were either self-appointed, or adopted this role based on circumstances; several ICGs said family members were not capable of the

responsibility, other ICGs reasoned that it was easiest, since they lived closest to the PWD. Some of these leading ICGs were content with the situation, others indicated they "*wished that other caregivers took more initiative*". The second ICG is often kept slightly aloof, expecting that "*the first caregiver is perfectly able to take care of PWD*" and "*first caregivers ask for help when necessary*". The second ICG was generally even less involved when the leading ICG was the PWD's spouse.

ICGs expressed their thoughts about how roles should be carried out: "*professionals need to provide responsible and appropriate care*". ICGs' expectations of their own roles depended on their view regarding other roles. ICGs did not describe any expectations of the PWDs regarding information exchange.

DISCUSSION

We described five elements that provide insight and explain the context of ICGs' views on information exchange in decision-making; the ICGs' questions and information needs, the experienced burden, the intrusiveness of care decisions, the relationship between ICGs and PWDs, and the ICGs' position within their families and care networks.

Our findings suggest that the ICGs' information needs depend on the PWD's stage of dementia. This is supported by Forbes et al. (2012), who provided a description of information that is typically needed at each stage. The experiences that ICGs in our ICG-study previously acquired were also key to their information needs. Alzheimer Europe conducted a study (Georges et al., 2008) that showed that ICGs needed more information than they received. As Beinart et al. (2012) described, ICGs benefit most from tailored information.

Tailored information does not only provide the ICG with the best fitting information, it also reduces caregiver burden (Beinart et al., 2012). The ICG-study showed that all ICGs experienced burden. Most burdened and unsupported ICGs did not properly exchange information within the dementia care network. Forbes et al. (2012) provided a possible explanation for this, describing that ICGs who were close to physical and/or emotional burnout were less likely to seek information.

Decisions were often made by one ICG, who shared this decision with others in the dementia care network. Remarkably, PWDs seemed nearly excluded in decision-making in our ICG-study. This does not strike with other research, where PWDs are said to be involved in decision-making (Hamann et al., 2011; Hirschman et al., 2005; Horton-Deutsch, Twiggs & Evans, 2007). However, our findings concerning the centrality of the PWD's values are

consistent with this literature. We cannot provide an explanation for the different findings of PWD's involvement.

In every network, one ICG took the lead in decision-making. ICGs expressed different opinions regarding the decision-making process, but they fulfilled their part nonetheless. Our findings showed that a troubled relationship between ICGs and PWDs was related to experiencing more burden. The positive side of this discovery suggests that good relationships are related to less experienced burden. This is supported by Ball et al. (2010) and Shim, Barroso and Davis (2012), both describing how good relationships reduce caregiver burden. Forbes et al. (2012) described the positive influence of trusting relationships between professionals, ICGs and PWDs on caregiver burden.

We described the ICG's position in network and family as an element for views on information exchange. Interestingly, no research was found that provided insight in ICGs' positions in care networks, not in dementia care or any other care sector. It is possible that the ICGs' positions and relationships are considered the same. Our findings suggest, however, that there is a difference.

One literature aspect that not emerged from our data is ethnicity, and its effect on the ICGs' experiences and preferences. Botsford, Clarke and Gibb (2012) described how culturally appropriate information can help ICGs cope with dementia. When tailored information is culturally appropriate and based on ICGs' experiences and dementia stages, ICGs will benefit most from the information.

Another striking discovery in our ICG-study is the lack of pro-active searching for information. Only half of the ICGs searched for information, which was almost always based on their current needs. Wackerbarth and Johnson (2002) described what information is considered essential for dementia care, and Forbes et al. (2012) described information needs in every stage of dementia care. These descriptions do not correspond with the received information ICGs described in the ICG-study. It is unclear whether ICGs did not remember receiving the information, or did not receive it at all. Either way, it is the professionals' responsibility to make sure ICGs have the information they require and that it suits their needs, as described in the care standards (Alzheimer Nederland & Vilans, 2012).

To ensure information is properly exchanged in every situation, dementia care networks need an instrument that guides them through information exchange and decision-making. A decision aid might be a fitting instrument. Stirling et al. (2012a) described that decision aids can provide decisional support and information to ICGs and professionals, which they would not receive otherwise, thus improving information exchange. The use of decision aids has helped to reduce caregiver burden as well (Stacey et al., 2011). Developing a decision aid, based on the five described elements could help professionals,

ICGs and PWDs with information exchange and decision-making. However, before a decision aid is developed, the accuracy of the five elements should be tested in other dementia care networks.

Limitations and strengths

Our ICG-study was based on existing data. This made objective analysis possible, but made it also somewhat difficult to truly get a grip of the data and underlying meaning. Some interviewers did not ask ICGs to elaborate on their answers, which might have provided more insight in information exchange, received information and the role of professionals therein.

The analysis process was individually performed by two independent researchers, resulting in objective analysis. The elements are, after testing their accuracy, transferable to other care network settings, where ICGs, patients and professionals are interconnected.

CONCLUSION

This study is the first study on ICGs' views regarding information exchange in dementia care networks. Analysis showed that all 20 included ICGs did exchange information, and all ICGs had their own view regarding information exchange. We described five elements that provide insight in the context of ICGs' views regarding information exchange. These five elements are; ICG's questions and information needs, the experienced burden, the intrusiveness of care decisions, the ICG's relationship with the PWD, and the ICGs' position within their family and dementia network. Further research regarding the accuracy of the elements is required, before they are used in theory development. When their accuracy is confirmed, the elements can be used to develop a method that optimises information exchange and decision-making in dementia care networks.

REFERENCES

- Alzheimer Nederland, 2012. Cijfers en feiten over dementie. Available from: <http://www.alzheimer-nederland.nl/media/38133/factsheet%20dementie%20algemeen%20-%20publieksversie%20-%2016%20feb%202012.pdf> [Accessed 2012, 4/7].
- Alzheimer Nederland & Vilans, 2012, Zorgstandaard dementie, definitief concept 1st edn, Vilans, Utrecht.
- Alzheimer Scotland, 2009, About dementia: some facts and figures, Alzheimer Scotland, Edinburgh. Available at: <http://www.alzscot.org/assets/0000/0151/dementiafactsheet.pdf> [Accessed 2013, 6/1]
- Alzheimer's Society, 2011a, Living Alone, Alzheimer's Society National Dementia Helpline, England. Available from: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=107 [Accessed 2013, 6/1].
- Alzheimer's Society, 2011b, Caring for a person with dementia, Alzheimer's Society. Available from: <http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200343> [Accessed 2013, 6/1].
- Ball, V., Snow, A.L., Steele, A.B., Morgan, R.O., Davila, J.A., Wilson, N. & Kunik, M.E., 2010, "Quality of relationships as a predictor of psychosocial functioning in patients with dementia", *Journal of geriatric psychiatry and neurology*, vol. 23, no. 2, pp. 109-114.
- Beinart, N., Weinman, J., Wade, D. & Brady, R., 2012, "Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review", *Dementia and geriatric cognitive disorders extra*, vol. 2, no. 1, pp. 638-648.
- Bennett, H. & Hallen, P., 2005, "Guardianship and financial management legislation: what doctors in aged care need to know", *Internal medicine journal*, vol. 35, no. 8, pp. 482-487.
- Botsford, J., Clarke, C.L. & Gibb, C.E., 2012, "Dementia and relationships: experiences of partners in minority ethnic communities", *Journal of advanced nursing*, vol. 68, no. 10, pp. 2207-2217.
- Breslin, G., Gilmour, L., Weber, P., 2011, *Collins Dictionary & Thesaurus of the English Language*, 5th edn, HarperCollins Publishers, Glasgow.
- Clarke, C.L., Alexjuk, J. & Gibb, C.E., 2011, "Information in dementia care: sense making and a public health direction for the UK?", *International journal of older people nursing JID - 101267281*, vol. 6, no. 3, pp. 237-243.
- Coulter, A. & Collins, A., 2011, *Making shared decision-making a reality. No decision about me, without me*, 1st edn, The King's Fund, London.

- Creswell, J.W., 2007, *Qualitative inquiry & research design. Choosing Among Five Approaches*, 2nd edn, Sage Publications, California.
- Dierckx de Casterlé, B., Gastmans, C., Bryon, E. & Denier, Y., 2012, "QUAGOL: a guide for qualitative data analysis", *International journal of nursing studies*, vol. 49, no. 3, pp. 360-371.
- Edwards A., Elwyn G., 2009, *Shared decision-making in Health Care. Achieving evidence-based patient choice*. 2nd edn, Oxford University Press, United Kingdom.
- Forbes, D.A., Finkelstein, S., Blake, C.M., Gibson, M., Morgan, D.G., Markle-Reid, M., Culum, I. & Thiessen, E., 2012, "Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study", *Rural and remote health*, vol. 12, no. 4, pp. 2201.
- Georges, J., Jansen, S., Jackson, J., Meyrioux, A., Sadowska, A. & Selmes, M., 2008, "Alzheimer's disease in real life--the dementia carer's survey", *International journal of geriatric psychiatry*, vol. 23, no. 5, pp. 546-551.
- Hamann, J., Bronner, K., Margull, J., Mendel, R., Diehl-Schmid, J., Buhner, M., Klein, R., Schneider, A., Kurz, A. & Pernecky, R., 2011, "Patient participation in medical and social decisions in Alzheimer's disease", *Journal of the American Geriatrics Society*, vol. 59, no. 11, pp. 2045-2052.
- Health Council of the Netherlands, 2002, "Aanbieding advies 'Dementie'". Available from: <http://www.gezondheidsraad.nl/sites/default/files/02@04NR.PDF>. [Accessed 2013, 6/1].
- Hirschman, K.B., Xie, S.X., Feudtner, C. & Karlawish, J.H., 2004, "How does an Alzheimer's disease patient's role in medical decision making change over time?", *Journal of geriatric psychiatry and neurology*, vol. 17, no. 2, pp. 55-60.
- Hirschman, K.B., Joyce, C.M., James, B.D., Xie, S.X. & Karlawish, J.H., 2005, "Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them?", *The Gerontologist*, vol. 45, no. 3, pp. 381-388.
- Hirschman, K.B., Kapo, J.M. & Karlawish, J.H., 2006, "Why doesn't a family member of a person with advanced dementia use a substituted judgment when making a decision for that person?", *The American Journal of Geriatric Psychiatry*, vol. 14, no. 8, pp. 659-667.
- Hirschman, K.B., Kapo, J.M. & Karlawish, J.H.T., 2008, "Identifying the factors that facilitate or hinder advance planning by persons with dementia", *Alzheimer Disease and Associated Disorders*, vol. 22, no. 3, pp. 293-298.
- Horton-Deutsch, S., Twigg, P. & Evans, R., 2007. "Health care decision-making of persons with dementia", *Dementia*, vol. 6, no. 1, pp. 105-120.

- Huizing, A.R., Berghmans, R.L., Widdershoven, G.A. & Verhey, F.R., 2006. "Do caregivers' experiences correspond with the concerns raised in the literature? Ethical issues relating to anti-dementia drugs", *International journal of geriatric psychiatry*, vol. 21, no. 9, pp. 869-875.
- Joosten, E.A., DeFuentes-Merillas, L., de Weert, G.H., Sensky, T., van der Staak, C.P. & de Jong, C.A., 2008, "Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status", *Psychotherapy and psychosomatics*, vol. 77, no. 4, pp. 219-226.
- Kaplan, R.M. & Frosch, D.L., 2005, "Decision Making in Medicine and Health Care", *Annual Review of Clinical Psychology*, vol. 1, no. 1, pp. 525-556.
- Karlawish, J.H., Casarett, D.J., James, B.D., Xie, S.X. & Kim, S.Y., 2005. "The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment", *Neurology*, vol. 64, no. 9, pp. 1514-1519.
- Lange, J.D. & Poos, M.J.J.C., 2007. "Neemt het aantal mensen met dementie toe of af?", RIVM, Bilthoven. Available from: <http://www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/psychische-stoornissen/dementie/trend/> [Accessed 2013, 6/1].
- Légaré, F., 2008, "Establishing patient decision aids in primary care: update on the knowledge base", *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen*, vol. 102, no. 7, pp. 427-430.
- Livingston, G., Leavey, G., Manela, M., Livingston, D., Rait, G., Sampson, E., Bavishi, S., Shahriyarmolki, K. & Cooper, C., 2010, "Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK", *BMJ (Clinical research ed.)*, vol. 341, pp. c4184.
- Maxwell, J.A., 2005, *Qualitative research design. An interactive approach*, 2nd edn, SAGE publications, London.
- Monaghan, C. & Begley, A., 2004, "Dementia diagnosis and disclosure: a dilemma in practice", *Journal of clinical nursing*, vol. 13, no. 3a, pp. 22-29.
- National Institute for Health and Clinical Excellence [NICE], 2006, "Dementia. Supporting people with dementia and their carers in health and social care", NICE, London. Available at: <http://www.nice.org.uk/nicemedia/live/10998/30318/30318.pdf> [Accessed 2013, 4/4]
- Peeters, J., Francke, A.L. & Pot, A.M., 2011, "*Organisatie en invulling van "casemanagement dementie" in Nederland*", 1st edn, NIVEL, Utrecht.
- Qiu, C., De Ronchi, D. & Fratiglioni, L., 2007. "The epidemiology of the dementias: an update", *Current opinion in psychiatry*, vol. 20, no. 4, pp. 380-385.

- Samsi, K. & Manthorpe, J., 2013, "Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers", *International psychogeriatrics / IPA*, vol. 25, no. 6, pp. 949-961.
- Shim, B., Barroso, J. & Davis, L.L., 2012, "A comparative qualitative analysis of stories of spousal caregivers of people with dementia: negative, ambivalent, and positive experiences", *International journal of nursing studies*, vol. 49, no. 2, pp. 220-229.
- Stacey, D., Bennett, C.L., Barry, M.J., Col, N.F., Eden, K.B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Légaré, F. & Thomson, R., 2011, "Decision aids for people facing health treatment or screening decisions", *Cochrane database of systematic reviews (Online)*, vol. (10), no. 10, pp. CD001431.
- Stirling, C., Leggett, S., Lloyd, B., Scott, J., Blizzard, L., Quinn, S. & Robinson, A., 2012a, "Decision aids for respite service choices by carers of people with dementia: development and pilot RCT", *BMC medical informatics and decision making*, vol. 12, pp. 21-6947-12-21.
- Strauss, A. & Corbin, J., 1990, *Basics of qualitative research: Grounded theory procedures and techniques*, 1st edn, Sage, Newbury Park, California.
- Wackerbarth, S.B. & Johnson, M.M., 2002, "Essential information and support needs of family caregivers", *Patient education and counseling*, vol. 47, no. 2, pp. 95-100.
- World Health Organization, 2012, *Dementia - a public health priority*, 1st edn, World Health Organization, United Kingdom.

Table 1: Characteristics of dementia care networks

Sex of informal caregiver (N = 20):	
Female	(15)
Relationship informal caregiver to person with dementia:	
Spouse	(4)
Son / daughter	(12)
Son-in-law / daughter-in-law	(3)
Other	(3)
Sex of person with dementia (N= 10):	
Female	(7)
Age of person with dementia:	
70 - 74	(2)
80 - 84	(5)
85 - 89	(2)
Unknown	(1)
Living situation person with dementia:	
Independent living	(7)
(Alone)	(5)
Home for the Elderly	(3)
(Alone)	(1)

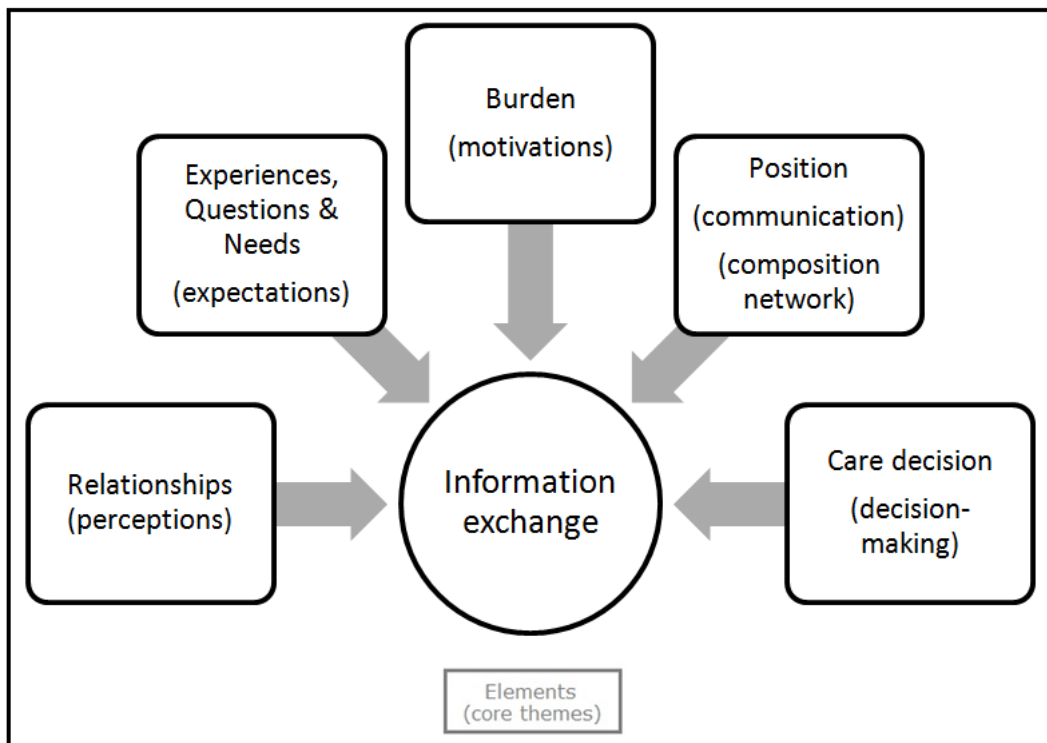


Figure 1: Elements related to information exchange in dementia care networks