UNIVERSITY OF TWENTE.

Shared decision-making in dementia

treating neuropsychiatric symptoms of nursing home residents with dementia

Master Thesis Health Psychology & Technology
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Preface

This research is the final proof of competence for obtaining my M.Sc. Health Psychology and Technology. One and a half year ago I decided to quit my job as a social nurse at the Municipal Health Services in Groningen to start the (pre) master Health Psychology and Technology in a new city. It was an exciting step but a step that I will never regret. During my master I learned a lot and worked on several interesting projects. Time flew by and before I knew, it was already time to start writing my master thesis. I was lucky to get the opportunity to write my thesis on the interesting and important topic of dementia. A topic that I was already familiar with because of my background as a nurse.

So here it is, my final thesis. I would never have been able to write this thesis without the help of some people, therefore I would like to express my gratitude to them. At first I would like to give a special thanks to my supervisor Dr. Sarah Janus, researcher at UNO-UMCG, for giving me the opportunity to work on this research. But above all, for her constructive feedback and continuous support during the process of this research. I would also like to thank Cecile Nieuwenhuys, research officer at UNO-UMCG for planning the observations for this study and keeping me up to date about the conducted interviews. Furthermore I would like to thank my two university supervisor Dr. Stans Drossaert and Dr. Erik Taal for their constructive feedback and support. A special thanks for Stans Drossaert who supported me through the whole process of writing my thesis, from the start of finding a topic to finishing my thesis. Finally, I would also like to thank my boyfriend, Jan-Willem, for giving me advices during the process of writing my thesis and cheering me up when I needed it. Above all, I want to thank my parents that have always supported me and encouraged me to take the step to start my master, thanks to them I can soon call myself Master of Science!

Abstract

Background. Approximately 60% to 90% of all patients with dementia are affected with neuropsychiatric symptoms (NPS). Although non-pharmacological interventions are advocated as initial treatment, prescriptions of psychotropic drugs (PDs) that can cause serious side effects, are still high. Informal caregivers can play an important role in interventions that prevent occurrence or escalation of NPS. Despite the importance of involving informal caregivers, it is not yet clear in what way informal caregivers are involved in decision-making regarding treatment of NPS. Therefore, the current study aims to get a complete view on the current way of shared decision-making regarding treatment of NPS.

Methods. The current study consists of two sub studies containing interviews and observations. In-depth interviews with a total of 7 quadruplets have been conducted. A quadruplet consists of the informal caregiver, primarily responsible nurse, physician and psychologist; all connected to the same patient. The aim of the interviews was to get an understanding of the decisional process regarding treatment of NPS from perspectives of both professionals and informal caregivers. Furthermore, observations of five behavioral consultations in nursing homes were carried out. Two weeks after the observation, a short follow-up was conducted. The aim of the observations was to get a complete view on decision-making and the involvement of informal caregivers in daily practice.

Results. It appeared that, although there was some involvement of the informal caregiver in most cases, SDM is not often practiced. Although informal caregivers are often not present during the phase of discussing treatment options, in the interviews, professionals indicated to take the perspectives of the informal caregiver into account either explicitly (by asking) or implicitly. Furthermore, the interviews showed that informal caregivers are only informed about a treatment decision or presented with one treatment option and are asked for their consent. From the observations it appeared that preferences of informal caregivers were hardly discussed. Only in one patient, involvement of the informal caregiver was mentioned.

Conclusion. The current study showed that SDM with the informal caregiver is not often practiced. Despite the complexity of SDM regarding treatment of NPS, improvement on this topic is needed. To improve SDM it is advised to involve the informal caregiver in an earlier stage to explore treatment options in consultation with the informal caregiver. Additionally future research with a larger sample size is needed to confirm the results of the current study.

Samenvatting

Achtergrond. Van alle patiënten met dementie wordt 60 tot 90 procent getroffen door neuropsychiatrische symptomen (NPS). Hoewel niet-farmacologische interventies worden bepleit als eerste behandeling worden psychofarmaca met mogelijk ernstige bijwerkingen, nog erg vaak voorgeschreven. Mantelzorgers spelen een belangrijke rol in niet-farmacologische interventies die het voorvallen of escaleren van NPS voorkomen. Ondanks het belang van het betrekken van de mantelzorger, is het nog onduidelijk hoe mantelzorgers op dit moment betrokken worden in het besluitproces. Daarom richt dit onderzoek zich op het in beeld krijgen van het huidige gezamenlijke besluitproces met betrekking tot behandeling van NPS.

Methode. Het huidige onderzoek bestaat uit twee sub studies bestaande uit interviews en observaties. Diepte-interviews met 7 quadruplets zijn uitgevoerd. Een quadruplet bestaat uit de mantelzorger, eerst verantwoordelijk verpleegkundige, arts en psycholoog. Het doel van de interviews was om beeld te krijgen van het huidige gezamenlijke besluitproces vanuit de perspectieven van professionals en mantelzorgers. Aanvullend zijn er vijf observaties van gedragsvisites in verpleeghuizen uitgevoerd. Na de observatie heeft een korte follow-up plaatsgevonden. Het doel van de observaties was om een beeld te krijgen van het besluitvormingsproces en het betrekken van de mantelzorger in de dagelijkse praktijk.

Resultaten.Uit de resultaten bleek dat, hoewel in de meeste gevallen de mantelzorger op enige wijze betrokken was, gezamenlijke besluitvorming vaak niet wordt uitgevoerd. Hoewel de mantelzorger vaak niet aanwezig is gedurende de fase ‘bespreken van behandelopties’, bleek dat professionals de perspectieven van mantelzorgers zowel expliciet als impliciet meenemen in de discussie. Tevens bleek dat mantelzorgers vaak achteraf worden geïnformeerd of slechts één behandeloptie krijgen voorgelegd waarvoor toestemming wordt gevraagd. Uit de observaties bleek dat de voorkeuren van mantelzorgers nauwelijks besproken worden. Slechts bij één patiënt kwam het betrekken van de mantelzorger ter sprake.

Conclusie. Dit onderzoek toont aan dat gezamenlijke besluitvorming met de mantelzorger nauwelijks wordt toegepast. Ondanks de complexiteit van gezamenlijke besluitvorming met betrekking tot de behandeling van NPS, is verbetering nodig. Om besluitvorming te verbeteren wordt geadviseerd de mantelzorger eerder te betrekken om in overleg met de mantelzorger behandelopties te onderzoeken. Ten slotte is vergelijkbaar onderzoek met meer participanten noodzakelijk om de resultaten uit dit onderzoek te bevestigen.

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Introduction

1.1 Dementia

Dementia is a syndrome characterized with deterioration in cognition, behavior and daily functioning. Worldwide around 50 million people have dementia and every year there are nearly 10 million new cases (WHO, 2017). In the Netherlands, around 254.000 to 270.000 people are diagnosed with dementia (Prince et al., 2015; Alzheimer Nederland, 2017). Of these people about 70.000 are admitted to care- or nursing homes (Monitor langdurige zorg, in volksgezondheidszorg.info, 2018). Not only cognitive impairments but also neuropsychiatric symptoms (NPS) are exceedingly common in people with dementia. Approximately 60% to 90% of all patients with dementia are affected with NPS during the course of the disease (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Lyketsos et al., 2002). These NPS include e.g. feelings of depression, apathy, aggression, anxiety, disinhibition, delusions and hallucinations (Cerejeira et al., 2012).

NPS are, besides the burden of the patient, related to various other negative consequences such as increased use of health care sources and higher levels of caregiver stress (Brodaty & Donkin, 2009; Chiao, Wu, Hsiao, & Hsiao, 2015). Therefore, NPS contribute significantly to the costs of dementia care (Brodaty & Donkin, 2009). To lower health care use, costs and caregiver burden effective treatments for NPS are needed.

1.2 Dementia and prescription of psychotropic drugs

Psychotropic drugs (PDs) are only moderately effective in the treatment of NPS and are associated with serious side effects (Seitz et al., 2013). Common side effects are for example falls and sedation (Jeste et al., 2008), and even associations between PDs and an increased risk of death have been found (Schneider, Dagerman, & Insel, 2012). Because of these side effects there is the need for safe and effective alternatives and therefore, non-pharmacological interventions should be used as initial treatment (Seitz et al., 2013; Zuidemat et al., 2018).

Despite the fact that non-pharmacological interventions are advocated as initial treatment, PD prescriptions in residents with dementia are still high in Dutch nursing homes. A literature review of 12 large studies on PD prescription in Dutch nursing homes by Zuidema, Koopmans, Schols, Achterberg, and Hertogh (2015), showed that psychotropic medication was prescribed in 54%-68% of nursing home residents. The high rates of prescribed PDs are not in line with the guideline of the Dutch association of elderly care physicians for the treatment of NPS in (elderly with) dementia (Zuidema et al., 2018) This guideline advocates non-pharmacological interventions as an initial treatment, and only advises pharmacological therapy in specific situations. Effects and side effects of PDs are advised to be monitored at least every month (Zuidema et al., 2018).

1.3 Factors related to the prescription of psychotropic drugs

Several factors seem to influence the prescription of PDs (Cornegé-Blokland, Kleijer, Hertogh, & Van Marum, 2012; Janus et al., 2018; Smeets et al., 2014). A study by Smeets et al. (2014), who conducted interviews with nurses and physicians, showed that knowledge and experience play a significant role in the prescription process. When nurses have limited knowledge and experience with NPS, there seems to be a greater need for PDs (Smeets et al., 2014). Also unfounded high expectations about the effectiveness by nurses and family may lead to PD prescriptions (Cornegé-Blokland et al., 2012). Additionally, physicians believe that antipsychotics are associated with positive consequences for the staff such as reduced workload, distress and psychological stress (Janus et al., 2018) which might lead to an increased prescription of PDs. Effective communication between nursing home staff and family may prevent occurrence or escalation of NPS (Smeets et al., 2014). Family usually knows the patients’ preferences, wishes and needs, which may help preventing or managing NPS (Smeets et al., 2014). This could eventually lead to a decrease in PD prescriptions.

1.4 Non-pharmacological interventions

Several non-pharmacological interventions have been found to be effective in treating NPS (Kales, Gitlin, & Lyketsos, 2015; Livingston et al., 2014; Oliveira et al., 2015). Music therapy, activities tailored to the abilities and interests of the patient and sensory interventions such as light and auditory stimulation (‘snoezelen’) are examples of non-pharmacological interventions that have found to be effective in treating NPS (Livingston et al., 2014; Oliveira et al., 2015). According to a qualitative synthesis of 63 studies of Gitlin, Liebman and Winter (2003), also interventions aimed at tackling environmental factors like over- or under-stimulation and a lack of routine are found to be effective in treating NPS (Gitlin, Liebman & Winter, 2003). Non-pharmacological interventions with the strongest evidence base are those involving the informal caregiver (Kales, Gitlin, & Lyketsos, 2015). Informal caregivers can help with identifying underlying causes of symptoms, followed by selecting non-pharmacological strategies to modify these causes (Kales, Gitlin, & Lyketsos, 2015). As can be concluded, for patients with NPS a wide variety of treatments exists. However, these treatments do not describe who decides which treatment should be applied and how decisions regarding treatment of NPS are made.

1.5 Decision-making models

Three models that describe the process of decision-making are 1) the paternalistic model, 2) the informative model and 3) the shared decision-making model (SDM). In the paternalistic model, the physician acts as a guardian of the patient. The physician decides what is best for the patient and there is limited patient involvement (Cole, Kiriaev, Malpas, & Cheung, 2017). A preference for the paternalistic model is not uncommon in elderly people. This is also shown in a small study of Cole et al. (2017). In this study interviews among 37 elderly people showed that 73% of the participants indicated that they would want their doctor to make decisions when they no longer have the capacity to do so. Trust, expertise and dependency were important reasons for letting the physician decide on their behalf (Cole et al., 2017). Opposed to the paternalistic model, in the informative model the patient makes the decision based on the information received from the professional (Sandman & Munthe, 2010). The physician provides the patient with all relevant information and subsequently the patient selects the treatment he/she wants. Within this model there is no role for the physicians understanding of the patients values or his/her judgements (Emanuel & Emanuel, 1992).

Shared decision-making is advocated as the preferred decision-making model to engage patients in the process of decision-making (Stiggelbout, Pieterse, & De Haes, 2015). Important factors in this model are that decision-making is being shared by both patient and physician and that the final decision is mutually agreed upon by patient and physician (Sandman & Munthe, 2010). SDM engages patients in the process of deciding about diagnosis, treatment and follow up. SDM is especially helpful for clinical situations with multiple evidence based options and when variation exists in how people weigh their risks and benefits (Fiks & Jimenez, 2010), like is the case in decisions about treatment of NPS. The model of SDM is based on building a good relationship in clinical encounters so that information is shared and patients feel supported and encouraged to express their preferences and views during the decision-making process (Elwyn et al., 2012). According to Stiggelbout, Pieterse & de Haes (2015), SDM consists of four steps: (1) First, the professional informs the patient that a decision is to be made and that the patient's opinion is important. (2) Than, the professional explains the options and the pros and cons of these options. (3) Consequently, the professional and patient discuss the patient's preferences and the professional supports the patient in their decision. (4) At last, the decisional role preference of the patient is discussed, a decision is made or deferred and a possible follow-up will be discussed (Stiggelbout et al., 2015).

1.6 Shared decision-making in patients with dementia

When it comes to dementia care, decision-making is a complex process. People with dementia are often cognitively impaired and final decisions about medical care are often made by informal caregivers (Miller, Whitlatch, & Lyons, 2016). According to the Dutch law, spouses or other family members are legally obliged to take medical decisions if the patient is no longer able to take these decisions (art. 465 lid 3 BW Boek 7, 2017), which is often the case in patients with NPS. Besides this legally imposed right, involving informal caregivers is also seen as a core element of dealing with NPS of nursing home residents with dementia (Zwijsen, Lange, & Pot, 2013). Informal caregivers are likely to understand potential causes of the patient's behavior. This can help in guiding non-pharmacological interventions and reduce PD prescriptions (Smeets et al., 2014; Tjia et al., 2017).

Although the importance of the involvement of informal caregiver has been indicated by studies suggesting informal caregivers can help in guiding non-pharmacological interventions (Smeet et al., 2014; Tjia et al., 2017), several studies confirm that in the decision-making process regarding prescription of PDs, family members are not always addressed and adequately involved (Cornegé-Blokland et al., 2012; Tjia et al., 2017). For example, structured questionnaires with informal caregivers conducted by Cornegé-Blokland et al., (2012), showed that 16% of informal caregivers were not consulted about prescription of PD, and 56% of the informal caregivers found themselves not sufficiently informed on the possible side effects of PDs (Cornegé-Blokland et al., 2012). However, these studies merely focused on involvement of informal caregivers regarding prescription of PDs and not on involvement of informal caregivers regarding non-pharmacological interventions, which is advocated as initial treatment of NPS. This causes a lack of understanding in how SDM is currently applied regarding treatment of NPS which involves both PDs as non-pharmacological interventions as treatment options.

Clear information, communication and relationships between professionals and informal caregivers facilitate SDM regarding the care for elderly diagnosed with dementia (Petriwskyj et al., 2014). In the qualitative meta-synthesis of 16 studies of Petriwskyj et al. (2014), relationships with nursing home staff were found as important for informal caregivers in feeling understood and listened to. Lack of time and opportunities for discussions with staff members were seen as barriers for SDM by informal caregivers. In this study, both staff and informal caregivers reported that essential information about changes to care or treatment requiring permission of informal caregivers, was only shared spontaneously. They reported that greater explanation prior to acting should be provided to the informal caregiver (Petriwskyj et al., 2014). Although several barriers and facilitators regarding SDM in dementia care are found, no previous study focused on SDM in the specific situation of treatment of NPS.

1.7 Current methods to manage NPS

Even though informal caregivers are seen as core elements of dealing with NPS of nursing home residents, informal caregivers are not addressed in current methods to manage NPS, as is the case in the Dutch care program GRIP (Grip op Probleemgedrag). GRIP is an approach to help identify underlying causes of- and managing NPS, which was proven to be effective in decreasing problem behavior and use of PDs (Zwijsen, 2014). This method aims to structure the treatment of NPS and increase multidisciplinary consultation between physician, psychologist, nurse and possible other disciplines (Zwijsen, 2014). The GRIP method consists of the following steps: Signaling behavior, analyzing behavior by investigate, exclude and identifying underlying causes, describe treatment and treatment goals and evaluate (Zwijsen, 2014). In practice in some nursing homes this method is applied during the behavioral consultation. A behavioral consultation is a multidisciplinary consultation in which physician, psychologist and at least one nurse, discuss NPS of nursing home residents. Problems regarding the behavior and possible treatments are discussed and (if applicable) previously set up interventions are evaluated (Van Klaveren, 2017).

It can be concluded that informal caregivers are not specifically addressed in methods developed for managing NPS. Therefore, family may not be structurally involved in decision-making. This despite the fact that SDM is especially relevant in deciding about treatment of NPS, since multiple evidence based options are available and variation exists in how people weigh their risks and benefits (Fiks & Jimenez, 2010). Furthermore, SDM with informal caregivers is especially important because research found that family usually knows the patient's preferences, wishes and needs, which may help in preventing or managing NPS (Smeets et al., 2014). Although it is clear that informal caregivers are often not adequately involved in the decisional process regarding prescription of PDs, there is a lack of understanding on how SDM is currently applied with informal caregivers regarding treatment of NPS, which involves both treatment with PDs and non-pharmacological interventions. Therefore, research is needed on how SDM is currently applied regarding treatment of NPS.

1.8 Current study

To improve SDM regarding treatment of NPS, it would be important to know how SDM regarding treatment of NPS is currently applied and which factors are seen as barriers and facilitators of SDM. To get a complete view on SDM regarding treatment of NPS, this study combines interviews with both professionals and informal caregivers with observations of behavioral consultations. In the interviews for each patient, the involved professionals and informal caregivers were interviewed which made it possible to compare the opinions of physicians, psychologist, nurses and informal caregivers regarding the decision-making process. To our understanding, this is the first study on SDM regarding treatment of NPS to combine interviews from multiple perspectives with objective observations. For this study, the following research question is stated: *"In what way is shared decision-making with the informal caregiver applied in the current decision-making process regarding treatment of neuropsychiatric symptoms."*

This study contains the following sub questions to answer the research question of this study:

1) How is the informal caregiver involved in the process of decision-making regarding treatment of NPS

2) *How do participants experience the involvement of the informal caregiver*

3) What are the barriers and facilitators of shared decision-making?

Methods

2.1 Design

This study originates from an ongoing research project: "*Shared decision-making in psychotropic drug prescription in nursing home residents with dementia. A study to explore active involvement of caregivers."* conducted by the UNO-UMCG (Universitair Netwerk Ouderenzorg-Universitair Medisch Centrum Groningen). This ongoing study aims to provide insight into decision-making regarding PD treatment among patients with NPS in nursing homes by conducting a mixed method research combining survey research, file research, interviews and observations.

To answer the research question of the current study, two sub studies were conducted. In study A, interviews were conducted to get a better understanding of how SDM with the informal caregiver is applied in the current decisional process regarding treatment of NPS according to physicians, nurses, psychologists and informal caregivers. Furthermore, the interviews were conducted to find out which barriers and facilitators are experienced by the previous mentioned participants. In study B, observations of behavior consultations were conducted to get an objective view on the daily practice of decision-making and the involvement of the informal caregiver regarding treatment of NPS.

2.2 Study A: interviews

2.2.1 Participants and procedures

In study A, in-depth interviews with a total of 7 quadruplets have been conducted. A quadruplet consists of the informal caregiver, primarily responsible nurse, physician and psychologist; all connected to the same patient. Primary contact persons, spouses and children were approached as informal caregiver. All participants were interviewed face-to-face and the different participants within a quadruplet were interviewed separately to prevent socially desirable answers.

To identify and select participants for this study, purposive sampling was applied. This means that physicians that already filled in the survey of the ongoing UNO-UMCG study were approached to participate in the interviews. The physicians subsequently selected 7 patients that met the following inclusion criteria: the patient was (1) admitted to a nursing home, (2) diagnosed with dementia, (3) not terminally-ill, (4) informal caregiver was available to participate in the study, (4) patient used one or more PDs related to NPS. After the patient was selected the primarily responsible nurse, psychologist and informal caregiver of the patient were contacted to participate in the interview. Sample characteristics of the participants and selected patients can be found in table 1.

The interviews were conducted by three researchers of the UNO-UMCG research team and took place in the participating nursing homes or in the home of the informal caregiver. All interviews lasted between 30 and 60 minutes and were transcribed verbatim. All data is treated confidentially and the data is pseudonymized. The necessary ethical approval was obtained from the Ethics Committee of the University Medical Centre of Groningen and from the Behavioral, Management and Social sciences ethics committee of the University of Twente. Informed consents were signed by the participants prior to the interviews (appendix D).

Table 1.
Sample characteristics participants interviews

Role (N=7)	**Mean age**	**Gender**	**Relationship to patient**
Patient	78 (59-94)	Female 3 Male 4	-
Physician	46 (33-58)	Female 4 Male 3	-
Psychologist	41 (26-60)	Female 4 Male 3	-
Nurse	39 (23-49)	Female 7 Male 0	-
Informal caregiver	56 (26-82)	Female 6 Male 1	Daughter 3 Spouse 4

2.2.2 Instrument

To conduct the in-depth interviews an interview protocol (appendix A) was developed based on a short literature study. The interview focused on the most recent decision regarding the start/stop of a prescription or adjustment of the dose of a PD. Although the interviews focused on PD use, also information about the use of non-pharmacological interventions was gathered. All interviews focused only on a single patient and situation, except for one interview in which 2 patients and their situations were discussed. This interview was done with a psychologist treating two clients, who both participated in the study. Since it concerns in-depth interviews, the interview started with an open question to stimulate the participant to tell their story. Based on the story, new open questions were asked. The interview started with exploring the facts, participants were asked to describe what happened in the specific situation. Subsequently the interviewer elaborated on how the participants experienced that situation. This was followed by what the participants' wishes and preferences are regarding the decisional process. During the interview, experiences were of greater value than facts. The interviews were conducted in Dutch but in this report, final quotations were translated to English for more clearance.

2.2.3 Data analysis

The data was thematically analyzed by the first author of this report (E. W.). Thematic analysis identifies, analyzes and reports patterns (themes) within data (Braun & Clarke, 2006). The following phases of the thematic analysis have been applied: 1) familiarizing with the data, 2) generating initial codes, 3) searching for themes, 4) review themes, 5) defining and naming themes, 6) producing the report (Braun & Clarke, 2006). To answer the sub-questions of this study, relevant themes were selected to build a preliminary framework. From this the following themes emerged: 1) signaling, 2) discussing options, 3) decision-making, 4) experiences of involving informal caregiver, 5) barriers of SDM, 6) facilitators of SDM. Relevant text fragments were allocated to the themes using a deductive approach. Subsequently the themes were divided into relevant subthemes using an inductive approach. The codes were created by the first author of this report (E.W.) and adapted in consultation with a researcher of the university of Twente (Dr. S. D.) and a researcher of the UNO-UMCG (Dr. S. J.). Atlas.ti 8.3 was used to create the codes. The labels for the final themes and subthemes can be found in appendix B. The results were mainly analyzed in terms of cases (1 case is a quadruplet of physician, psychologist, nurse and informal caregiver). When it comes to the topics ‘points for improvement’ and ‘barriers and facilitators’ the results were analyzed per participant.

2.3 Study B: Observations

2.3.1 Participants and procedures

In study B, observations of five behavioral consultations in nursing homes were carried out. Because little research in this area has been carried out, this small-scale study is a more exploratory study. To identify and select participants for this study, purposive sampling was used. Physicians that filled in the survey of the ongoing UNO-UMCG study, were approached for participating in the observations. Subsequently the physician asked permission from the informal caregiver of the patient and other professionals for the researcher to be present during the behavioral consultation. The observations were conducted by one researcher of the University of Twente (E.W.) using a predefined observation scheme (appendix C). The duration of the observation was approximately one hour, depending on the duration of the behavioral consultation. The number of patients with NPS of dementia discussed during each behavioral consultation varied from 1 to 5. In total 13 patients were discussed during 5 behavioral consultations. The data of the observations was gathered between October 15th and December 10th, 2018. Two weeks after the observation, a short follow-up containing two questions was conducted. The observations were executed in nursing homes in the following cities: Enter, Emmen, Rijssen, Schiedam and Zwolle. All data is treated confidentially and the data is pseudonymized. Ethical approval was obtained from the Ethics Committee of the University Medical Centre of Groningen and from the Behavioral, Management and Social sciences ethics committee of the University of Twente. Informed consents were signed by the participants prior to the observations (appendix D).

2.3.2 Instrument

To observe the participants in sub study B, an observation scheme (appendix C) was developed based on the four steps of shared decision-making according to Stiggelbout, Pieterse & de Haes (2015). The observation scheme includes the occurrence of the topics

PDs, non-pharmacological interventions and problem behavior. Also, the professional that initiates the topics, the professionals involved in the discussion and the main aspects of shared decision-making are included in the observation scheme. Additionally, the number and nature of the decisions made, and by whom decisions were made were observed. To complement the observation scheme, field notes were made to describe the context and setting of the observed situation. The inclusion of these field notes is important because field notes can enhance the data and provide a rich context for the analysis of the data (Phillippi & Lauderdale, 2018). Two weeks after the observation, a follow-up telephone call was conducted with one of the professionals that was present during the behavioral consultation. In the follow-up call it was checked if the decisions were carried out as discussed, if the informal caregiver was informed about the decision and how he/she was informed. If the informal caregiver was not informed, reasons for not informing the informal caregivers were asked.

2.3.3 Data analysis

The data was analyzed by one researcher of the University of Twente (E.W.) using descriptive statistics and thematically analyzing the field notes. The observations were described by using frequencies. The data was categorized in the following categories: 1) involved professionals, 2) discussing psychotropic drugs, 3) discussing non-pharmacological treatment, 4) nature of the decision, 5) involvement of informal caregivers.

Results

3.1 Results sub study A: Interviews

This section describes the results of the interviews with physicians, nurses, psychologists and informal caregivers of 7 cases. The results are described in terms of cases (n=7). A case is a quadruplet of physician, psychologist, nurse and informal caregiver. When there were opposite opinions between participants within one case this was mentioned. The focus of the interviews was to give a description of the decisional process regarding the start, stop or change of a PD. The decisional process as described by the participants was divided in three phases: signaling, discussing options and decision-making. The decisional process and the involvement of the informal caregiver is described based on these phases.

3.1.1 Overall involvement of informal caregiver

In 5 of the 7 cases the informal caregiver was involved in the decisional process. For our study 'being involved' means: professionals explicitly taking the opinion of the informal caregiver into account when it comes to the treatment of NPS. The following quotes illustrate the involvement of informal caregivers.

> *Nurse (2):"She (daughter) first wanted to see if there were other options like distraction and other therapies. So we first went through that process."*
>
> *Psychologist (4): "With this two patients there have been several contact moments (with the informal caregiver) about how to solve certain problems."*
>
> *Nurse (5): "Her husband was really engaged. We could tell that he went through a lot, nothing comes as a surprise to him. It is unbelievable what he went through at home (with the patient). So together with him we set up a plan."*

In the two cases where the informal caregiver was not involved in the decisional process, the informal caregivers seemed satisfied with the decision-making process.

> *Interviewer: "Okay so you are satisfied with the current course of events. Is the communication, how the communication goes, are you also satisfied with that?"*
> *Informal caregiver (3): "I am satisfied with that."*

On top of that, the informal caregivers that were not involved in the decisional process, expressed great confidence in the professionals and therefore left the decision to them.

> *CV (3):"If they would ask me I would tell them that they have more knowledge about it than I do. For me it is fine, because I can't decide about it. I don't know if it is good or not."*

In only 2 of the 7 cases a conversation took place with the informal caregiver about how they wanted to be involved in the decisional process. Agreements about involvement of the informal caregiver were made between informal caregiver and professionals.

> *Nurse (7): "Well this daughter was very engaged with her mother and at the time of admission (of her mother) she made very clear agreements about when she wanted to be informed and how exactly she wanted to be involved."*

> *Nurse (2): "From that moment we agreed (with informal caregiver) this is the way we will do it."*

3.1.2 Phase 1: Signaling

The first phase that was distinguished is 'signaling', in this phase the problem behavior of the patient is signaled and brought up for discussion. Nursing staff, all professionals, informal caregiver and psychologist were mentioned as the ones who signaled the problem behavior and brought it up for discussion.

In most cases participants believed that the *nursing staff* signaled the problem behavior and brought up the behavior during consultations with other professionals.

> *Interviewer: "Who signaled that?" Psychologist (1):" Yes, the nursing staff. And subsequently they mention it during the physician consultation."*

In three cases professionals felt that *all professionals signal the behavior jointly* but still the nursing staff are the first to mention the problem behavior.

> *Physician (2): "I think we did that (signal the behavior) together. The nursing staff are often the first to mention like: ' I can see that this man is not happy, he is not feeling well.'"*

Four participants (related to 3 different cases) perceived that besides professionals, also *the informal caregiver* played a role in signaling problem behavior.

> *Informal caregiver (4): "I thought the medication she had was very unpleasant, in my opinion it didn't take the restlessness away."*

Only once the *psychologist* was mentioned to have signaled the problem behavior.

> *Physician (7): "Particularly the psychologist. The psychologist was very involved at that time."*

In sum, although occasionally also other parties are involved in signaling, most often the nurses are the ones who signal any behavioral problems and initiate the discussion about treatment of NPS.

3.1.3 Phase 2: Discussing options

The second phase in the decision-making process is the phase *'Discussing options'*, in which different treatment options are discussed. In this phase the following themes are described: (1) professionals involved, (2) topics discussed, (3) ways of contact with the informal caregiver, (4) considering the preferences of informal caregivers, (5) which other perspectives are taken into account by professionals.

Professionals involved

During the phase *'discussing options'*, in all cases there was a close consultation between physician, psychologists and nursing staff, sometimes complemented with other disciplines e.g. a physiotherapist. In 4 of the 7 cases professionals mentioned explicitly that they had a behavioral consultation to discuss the problem behavior of the patient. The behavioral consultation is a consultation between professionals that is structurally taking place.

Professionals can bring up problem behavior of patients and subsequently treatment options are discussed. The following quote illustrates who is involved in the behavioral consultation and what is discussed:

> *Nurse (1): "Yes, we first have a behavioral consultation. So that is where the physician, psychologist, behavioral consultant are present and someone from the nursing staff and our team leader. At the behavioral consultation we first explain the situation and then we focus on what precisely we can do about it."*

In the 3 other cases it was not mentioned that a behavioral consultation structurally took place but consultations were reactively organized between nursing staff, physician, psychologist and other disciplines when the problem behavior was present. This is illustrated in the following quote:

> *Nurse (3): "And you know at that moment, in that meeting, we just involved the psychologist, physician, occupational therapist. Everyone, all disciplines were present at that consultation."*

It is noticeable that informal caregivers were not present during the behavioral- or reactively organized consultations. Only in one case the informal caregiver was present when options were discussed between professionals.

> *Nurse (5): "And we also, 3 times, I believe, we discussed it during a physician consultation on Friday. Three times we just invited her husband like:' Join us again next Friday, so we can agree on a common line.'"*

To conclude, during the phase of discussion in all but one case the informal caregiver was not present and discussing treatment options took place between physician, psychologist and nurse, sometimes complemented with other disciplines.

Topics discussed

The following topics were discussed during the phase of discussing options: (1) use of non-pharmacological interventions, (2) use of PDs and (3) physical causes. In all 7 cases *use of non-pharmacological interventions* were discussed. The non-pharmacological interventions varied widely. Some examples of the most applied non-pharmacological interventions are offering activities, applying day structure or change way of approaching the patient. The following quote shows the kind of non-pharmacological interventions that were mentioned:

> *Psychologist (2): "Applying behavioral interventions to his mood. And a day program and we also tried to offer him some activities. For example, he really liked cycling so we also tried to offer him some cycling activities. We used quite a lot of interventions to improve his mood, or improve his functioning."*

Also the *use of PDs* was discussed in all 7 cases. Professionals believed that the use of PDs were only discussed when non-pharmacological interventions did not work. Yet, one of the informal caregivers felt that the use of PDs was proposed prematurely. According to the physician in this case professionals consider use of PDs sooner than family does because of their experience. The following quotes consecutively illustrate the described situation:

> *Nurse (7): "Well if that doesn't seem to work sufficiently, than you reach the point that in the next behavioral consultation the word 'medication' is used, that we are going to talk about that."*
>
> *Informal caregiver (2):"And then they pretty soon suggest like: "maybe we should do something with Haldol or antidepressants. While I think, he is only here for six weeks now."*
>
> *Physician (2):"To me it is always very difficult. I have the idea like, we want the best option for the patient and through our experience we often sooner consider medication while the family is not yet ready for it. We see certain things and we know, this is not going to work with changing the way of approaching the patient. We need medication here."*

Professionals in 4 cases stated that they discussed and performed *physical examination* to exclude physical abnormalities as a cause of the problem behavior.

> *Physician (7): "At least I physically examined her, to see if there were nophysical abnormalities causing the behavior. No abnormalities were found."*

From this can be said that use of non-pharmacological interventions and use of PDs were discussed in all cases. Although professionals feel they only talk about use of PDs when other interventions do not work, informal caregivers might not always feel the same way. Furthermore, possible physical causes and physical examination were discussed in only 4 cases.

Ways of contact with the informal caregiver

From the interviews, three different ways of contact with the informal caregiver could be distinguished. Consecutively the following ways of contact with the informal caregiver are described: (1) Predetermined moments of contact, (2) undetermined moments of contact and (3) access to the client portal. In all 7 cases there were *predetermined moments of contact* between the professionals and informal caregivers. A predetermined moment of contact is defined as a consultation between professionals and the informal caregiver that is structurally taking place regardless of the patient's behavior. These predetermined moments vary from a consultation twice a year to a consultation every six weeks. As described by one of the nurses, people with young dementia are discussed more often than older people with dementia because the course of the disease is less stable in young dementia. The predetermined consultations are not necessarily about the treatment of the problem behavior but can also be about the general condition of the patient. The following quote shows how the informal caregiver is involved in decision-making by the predetermined contact moment:

> *Nurse (1):"I always call his wife two weeks in advance (of the multidisciplinary consultation) like: "Do you have anything of importance that I should bring in to the meeting. . . . And with all our findings taken together, after the multidisciplinary meeting, we get back at his wife during the consultation with her, which we have every 3 months."*

Besides the predetermined moments of contact, *undetermined moments of contact* regarding treatment between professional and informal caregiver were also mentioned. An undetermined moment of contact regarding treatment is defined as a contact between informal caregiver and professional related to the (treatment of) problem behavior of the patient, that is not structurally taking place. In 5 of the 7 cases there were undetermined moments of contact regarding treatment options. What is discussed when the informal caregiver was involved during these contact moments was not always clear as can be seen in the following quotes:

> *Psychologist (4):"Pretty soon (answering the question when the informal caregiver got involved). We can't do it right away, you have to see it as a first professional meeting between physician and psychologist. But if we advance in the process, especially when it comes to changing medication, than the family will certainly get involved."*
>
> *Physician (5):" In the end we left it the way it was, and we spoke a lot more often to her husband. He also was very open to try all various kind of things."*

It is noticeable that no undetermined contact moments regarding treatment took place in the two cases without involvement of the informal caregiver.

Finally, informal caregivers in 4 of the 7 cases reported they had *access to the client portal* and were able to read the daily reports of the nurses, which were sometimes complemented with a report of the physician. As stated by the informal caregivers this provided them with information about treatments and treatment effects.

> *Informal caregiver (4):"Because when I read the reports and the additional information, it (medication) sometimes helps, but other times she is still shouting."*
>
> *Informal caregiver (2):"And then I talked with them about sleeping hygiene. Because I read in the reports that he, if he was awake at night and he couldn't sleep, they put him in front of the tv. But we all learn that watching tv in the evening is not good for your night's sleep."*

Although the access to the client portal can provide the informal caregiver with information, it could also lead to professionals thinking the informal caregiver is already informed about the condition of the patient as one physician said:

> *Physician (2): "His daughter is also taken into account, she can also read along in the client portal. She can see in the reports of the nursing staff that there is no*

> *improvement. So at some point in time she herself comes up with: 'Maybe we should consider using medication.'"*

In sum, in all cases predetermined moments of contact took place between informal caregiver and professionals. Undetermined moments of contact only took place in the cases where the informal caregiver was involved in the decisional process. Furthermore, in all but one case where the informal caregiver was involved, it was mentioned that the informal caregivers had access to the client portal.

Considering the preferences of informal caregivers

During the phase of '*discussing options'* professionals either (1) explicitly or (2) implicitly took the preferences of the informal caregivers into account when discussing treatment options with other professionals. *Explicitly taking the informal caregiver into account* was defined as having talked with the informal caregivers about specific treatment options, and taking the preferences regarding these options into account. In 5 of the 7 cases both professionals and informal caregiver felt that the preferences of the informal caregivers were explicitly discussed and were taken into account by the professionals.

> *Informal caregiver (2): "Because I actually said: 'I don't want to use Haldol'. And then they started that (non-pharmacological intervention). And in my opinion they reacted pretty quickly."*

> *Physician (5): "So he wasn't a fan of that, to change the medication. That was kind of scary for him. So we respected that and we left it the way it was."*

In these 5 cases the informal caregivers mentioned they explicitly expressed their opinions about treatment preferences or they described that there were short lines of communication between them and the professionals. It is noticeable that especially children expressed their opinions compared to spouses that had short lines of communication more often. The following quotes illustrate the described situations:

> *Informal caregiver (2):"So I said something about it and I could feel that they were not used to this, that I said something, that I thought it was strange to start antidepressants to improve his sleep."*

> *Informal caregiver (5):"Yes we run into each other continuously. In my opinion this concerns both physician as psychologist. The building is very round, so you continuously run into each other. And then there is always time for some information exchange."*

Besides explicitly taking the informal caregiver into account, *professionals also implicitly took the informal caregivers into account*. Implicitly taking the informal caregiver into account can be defined as what the professionals think are the preferences of the informal caregivers regarding treatment or involvement without having talked about it, and taking these ideas about the preferences into account. In the two cases without involvement of the informal caregiver, professionals stated they did not actively involve the informal caregiver because of (fear of) an overburdened informal caregiver.

> *Nurse (1):" I do not want to burden her with all kind of things, that it gets too complicated for her. I think it is only burdening her."*
>
> *Psychologist (3): "It (the fact that informal caregiver was overburdened) makes that we involved him a lot less than we would normally do."*

From this can be concluded that in the cases where there were short lines of communication or the informal caregiver explicitly expressed their opinion, the professionals explicitly took the informal caregiver into account. Especially children of the patient seem to express their opinion about treatment preferences. In the two cases where professionals implicitly took the informal caregiver into account there was no involvement of the informal caregiver (which were both spouses).

Which other perspectives need to be taken into account when discussing treatment options?

Although involving the informal caregiver is important, professionals also have to take other perspectives into account. From our study three categories emerged: interests of (1) the client themselves, (2) the nursing staff and (3) other residents. There is a continuous consideration between the interests of the different people involved in- or around the patient. The interests of the client itself play an important role in the decision but on the contrary, professionals are also responsible for the safety and well-being of other residents.

> *Psychologist (4):”Well and then there is this continuous consideration that on the one hand you want to be there for her (patient), to help her manage the fear, at a professional level. But on the other hand you also have to deal with 7 other residents, that also need care. At this point you have to mediate, which makes that this could be a reason to think about psychotropic drugs.”*

Additionally also the nursing staff needs to be taken into account, both physicians, psychologists and nurses described the impact of the patients behavior on the well-being of the nursing staff.

> *Physician (6):”That was in particular because he showed more aggression, also towards the nursing staff. And for example during the general daily care he really physically hit and pushed the nursing staff. Well at that moment I thought, enough is enough.”*

Besides this, one of the nurses specifically emphasized the impact of patients behavior on their own well-being versus the preferences of the informal caregiver.

> *Nurse (4): ”Well, you know, they (family) are only there for a few hours and we take care of her (patient) around 8 hours a day. They are usually there around noon and then she just had oxazepam so than she is sleeping. Well and I can imagine that if you come to see your mother, that is not a nice thing to see.”*

To conclude, during the phase of discussion in most cases the informal caregiver was not present during the discussion of treatment options. The discussion took place between physician, psychologist and nurse. Topics discussed in all cases were use of non-pharmacological interventions and use of PDs, in some cases also possible physical causes were discussed. In all cases there were predetermined moments of contact. Undetermined moments of contact and access to the client portal were only found in cases where the informal caregiver was involved in the decisional process. Although the informal caregiver was not present during the discussion of treatment options, professionals did explicitly and implicitly take the informal caregiver into account during this discussion. Additionally perspectives of patient, nursing staff and nursing home residents need to be taken into account when discussing treatment options.

3.1.4 Phase 3: Decision-making

The final phase in the decision-making process is the phase '*decision-making'*, in which a treatment decision is made. In this phase the following themes are described: (1) involvement of the informal caregiver in the decision, (2) who is contacting the informal caregiver after treatment decision, (3) satisfaction about involvement of the informal caregiver, (4) points of improvement regarding the involvement of the informal caregiver.

Informal caregiver involvement in the decision

From the interviews two types of involvement could be distinguished, 1) no involvement and just informing the informal caregiver about the decision and 2) asking the informal caregiver for permission. In two cases there was no involvement of the informal caregiver, in both two cases the informal caregivers were spouses of the patient. Professionals *just informed the informal caregivers* after the decision was made. This is illustrated by the following quotes:

> *Informal caregiver (1):"No they call me like, we should give him some extra medication because he is restless."*

> *Nurse (3): "The physician was always calling him to say we are going to change this or that. We are going to increase this or that, or we stop using this. He was always informed."*

Although the nurse in this case stated that the informal caregiver was informed, he could not remember ever being informed about prescription of PDs.

> *Informal caregiver (3):"But about medication, they never talked about it."*

In five cases the professionals made a treatment decision, proposed this treatment to the informal caregiver and *asked for their permission*. It is noticeable that informal caregivers were only presented with one treatment option. In these cases informal caregivers were both spouses and children. The following quote shows how treatments were proposed to the informal caregivers:

> *Physician (5):"And then we proposed it and we explained what the side effects were and the pro's and con's. And then he agreed with it."*

Although the professional stated that they asked the informal caregiver for permission, this does not always mean that the informal caregiver knows what he or she gave permission for as can be seen from the following quote:

> *Informal caregiver (7):"Because now they only need my permission and I give it to them. But I do not always know what I give permission to."*

In sum, in two cases the informal caregiver (spouse) was just informed about the decision. In five cases the professionals made the treatment decision and proposed only one treatment option to the informal caregiver without giving any alternatives.

Contact with informal caregiver after treatment decision

After deciding to start/stop or change the dose of a PD, the professionals informed the informal caregiver or asked permission for the treatment. Although in most cases there seemed to be some kind of agreement about the physician being responsible for changes in PDs, from the interviews there seemed to be indistinctness about who got in contact with the informal caregiver after a decision was made. In one case psychologist and nurse believed the physician had contact with the informal caregiver but the physician stated he could not remember if this was the case.

> *Physician (3):"I can't remember.. (answering the question if he had contact with the informal caregiver about the decision)."*

In another case both physician and nurse stated it is often the case that the nursing staff has contact with the informal caregiver.

> *Physician (4): "In practice you see that a lot of things are messaged by the nursing staff."*
>
> *Nurse (4):"Both, we both speak to the family. But most of the time it is me who talks to them."*

Professionals are not always informed about who talked to the informal caregiver.

> *Nurse (5): "No it could be like that for sure (that the physician had contact with the informal caregiver), but it could also be that this was not the fact, I can't tell you."*

Especially psychologists stated they were not informed about who had contact with the patient about the decision regarding PD, in 3 cases the psychologist assumed that physician or nurse had contact with the informal caregiver.

> *Psychologist (3): "I assume the physician informed him in advance."*

From this can be concluded that although in most cases there was some kind of agreement about the physician being responsible for changes in PDs, still there was indistinctness about who got in contact with the informal caregiver after a decision was made.

Satisfaction about involvement of the informal caregiver

In most cases there was satisfaction about the involvement of the informal caregiver in the decisional process. Both professionals and informal caregivers in 5 of the 7 cases stated they were satisfied about the involvement of the informal caregiver in the decisional process.

> *Physician (5): "What I like about this case is that we really did it together. Also together with the informal caregiver."*

Although in five of the seven cases there was satisfaction about the involvement of the informal caregiver, in 2 of those 5 cases the informal caregivers (both children) stated that although they are satisfied now, in the past professionals did not always considered their opinion. They felt their involvement improved over time.

> *Informal caregiver (4):"I have to say, lately they really listen to what I have to say, it is way better than at the beginning."*

Disagreement between professionals and informal caregiver about satisfaction regarding the involvement of the informal caregiver was noticed in 2 of the 7 cases. In one of these cases professionals stated they were satisfied about the involvement of the informal caregiver and believed that the informal caregiver was satisfied too.

> *Physician (7): "When it comes to decision-making (answering the question if she is unsatisfied about involvement of informal caregiver), I don't think so, because we discussed everything with her. And if she would say that it is not the case than that would be interesting information for me."*

On the contrary, the informal caregiver in this case (which was a child of the patient) expressed dissatisfaction about the involvement in the decisional process. The informal caregiver felt not being taken into account and also expressed dissatisfaction about the way of communication as can be seen from the following quotes:

> *Informal caregiver (7): "And we pointed that out from the beginning, my mother is a difficult woman so you have to try and keep it simple, she responds well to that. You can say this a 100 times but they just don't act to it."*
>
> *Informal caregiver (7):"In my opinion the conversation was really steered by the physician. And I can understand this at some point. But I think that at that moment, because of the stress around the delay of my train, I was really susceptible for what the physician recommended."*

In the other case where disagreement between the informal caregiver and professionals was established, the informal caregiver (which was a spouse of the patient) stated he was satisfied with his involvement. In contrast to professionals who stated that they could have involved him more in the decisional process.

> *Informal caregiver (3): "No that was fine, I don't know how else."*
>
> *Nurse (3): "Yes I would have tried. I would have tried to sit down and talk with him once in a while."*

In sum, in most cases there was satisfaction about the involvement of the informal caregiver by both professionals and informal caregivers. Although there was satisfaction in most cases, informal caregivers (children of the patient) in two cases pointed out that their involvement improved over time. Furthermore, in two cases there was disagreement between informal caregiver and professionals about satisfaction regarding involving the informal caregiver. In one case informal caregiver was not satisfied and in another case it was the professional that was not satisfied.

Points of improvement regarding the involvement of the informal caregiver

During the interview the participants were asked what they would have liked to see different in the decision-making process. Points of improvement were analyzed per participant (n=28) instead of per case. Only points of improvement regarding the involvement of the informal caregiver are mentioned here. Only one of the informal caregivers (child of the patient) mentioned points of improvement regarding their involvement in the current decisional process. At first the informal caregiver stated she wanted to have *more face-to-face contact* instead of the contact moments by phone.

> *Informal caregiver (7): "Well, despite those phone calls, we could also meet each other once in a while, without the telephone line in between. So to say that after the decisions are made, we come together and discuss it face-to-face, that would be nice."*

Additionally this *informal caregiver perceived the undetermined moment of discussing the use of PD's as unpleasant.*

> *Informal caregiver (7): "Because for them it is easy when I run into them it is like: 'we need to discuss something'. While at that moment I am dealing with the clothes of my mother that disappeared and not with the medication of my mother so to say. I will not discuss that in between."*

Professionals mainly wanted to change the amount of informal caregiver involvement, as five professionals stated they wanted to *increase the involvement of the informal caregiver or involve the informal caregiver in an earlier stage.*

> *Nurse (7): "It is more that I have the feeling like, she already reported to us that she is a little bit overburdened. And then at some point you get a phone call of the physician. And actually that is the moment at which we want to start medication. And maybe, if I put myself in her place, it can feel like: "Oh no, I have to make a decision right now". While you actually want to give her some time to think about it."*

One psychologist also believed that it would have been good to *plan a consultation to talk about the preferences of the informal caregiver regarding his involvement.*

> *Psychologist (3): "When it comes to her husband I think it would have been good too actively involve him sooner. But also to ask him how he would feel when we would arrange another first contact person. In my opinion her husband was burdened a lot."*

One physician and three *psychologists perceived shared decision-making as the ideal decision-making model* but on the contrary also expressed their doubts about what is the best way to implement SDM in daily practice.

> *Psychologist (6):"In my opinion, when it comes to decision-making, you want to do this together. So at least with a physician, me and someone of the family. The family is a bit difficult in this, like do they have to be present or is it more like we discuss our opinion with them, so first check how they feel about it."*

To conclude, in the phase of decision-making informal caregivers were only informed about the decision or professionals asked permission for a treatment decision to the informal caregiver, without giving any alternatives. Furthermore, although in most cases there was some kind of agreement about the physician being responsible for changes in PDs, there was indistinctness about who got in contact with the informal caregiver after a decision was made. Despite this, in most cases there was satisfaction about the involvement of the informal caregiver by both professionals and informal caregivers. Although there was satisfaction in most cases, informal caregivers in some cases pointed out that their involvement improved over time. Only one of the informal caregivers (child of the patient) mentioned some points for improvement. She liked to have more face-to-face contact and perceived the undetermined moments of discussing PDs as unpleasant. Professionals mentioned they wanted to increase the contact with informal caregiver or involve them at an earlier stage. Also planning a consultation to talk about the informal caregivers involvement was mentioned. Furthermore professionals perceived shared decision-making as the ideal decision-making model, although they had doubts about how to implement shared decision-making in practice.

3.1.5 Barriers and facilitators of shared decision-making.

Participants mentioned 4 barriers and 3 facilitators for SDM as can be seen from table 2. The barriers and facilitators were analyzed per participant (n=28). During the interviews there was not specifically asked for barriers and facilitators, but they emerged from the question of how participants thought about the involvement of the informal caregiver in decision-making. Barriers were only mentioned by the professionals, facilitators were mentioned by both professionals and informal caregivers. One of the most described barriers of involving the informal caregiver was that involving the informal caregiver in the decisional process *costs time*. Professionals stated that because of the high workload they do not always have time to plan a meeting with the informal caregiver. Another barrier mentioned by professionals was the *fear to overburden informal caregivers.* Professionals stated that when (they believed) an informal caregiver was overburdened, the informal caregiver got less involved in the decisional process. In one case two other barriers for shared decision-making were mentioned. The first one is that according to all three professionals in that case *informal caregivers have to bring up reasonable arguments* to be able to take part in the decisional process. Besides this, in the same case all three professionals also believed *that a critical family is experienced as difficult,* which could lead to a decrease of involvement of the informal caregiver in the decisional process.

Besides the barriers participants also described three facilitators of shared decision-making. One of the most described facilitators by both informal caregivers and professionals is that the *informal caregiver can provide the professionals with important information about the patient.* As described by the participants the informal caregiver is the one that has the longest relationship with the patient and therefore knows the patient best. Another facilitator for SDM mentioned by both informal caregiver and professionals was an *informal caregiver that is frequently visiting the nursing home.* Participants believed this ensured a lot of informal contact between professionals and informal caregiver and enabled both informal caregiver and professional to approach each other. According to participants *critical informal caregivers* also have a positive effect on SDM. Participants mentioned that the amount of communication between professional and informal caregiver increased when informal caregivers were more critical towards professionals.

Table 2

Barriers and facilitators of shared decision-making

Barriers	**Example quote**	**(n)**
Shared decision-making costs time	*Physician (4): "When it comes to time management it is often difficult. You need to find a way to get 4 parties together. In practice I get a lot of notifications a day, and to organize a meeting for all those notifications…"*	4
Fear to overburden informal caregivers	*Nurse (3): "Yes exactly. At first we had the feeling that we needed to give him (informal caregiver) some time for himself and let him rest."*	4
Informal caregivers have to bring up reasonable arguments to be able to take part in decision-making	*Nurse (2): "I think the role she had in this situation was good. And I would want that for all family members. If they have a realistic view on the situation at least, for me that is an important condition."*	3
Critical family is experienced as difficult	*Nurse (2): "The team had a hard time with it, because they felt that she (informal caregiver) had an opinion about everything."*	3
Facilitators		
Informal caregiver can provide the professional with important information about the patient	*Nurse (3): "Yes because I think that they know her best. So in that way actually, well who knows his partner or mother best. So they might have really valuable information for us."*	9
Informal caregiver is frequently visiting the nursing home	*Physician (5): "So we really collaborated. But that is also because this husband is here every day and he is easily approachable."*	7
Critical family increases communication	*Physician (4): "Some families insist on consultations because they want to be informed about everything. So you kind of make a selection. And with those families I will always discuss things and others often accept it."*	4

3.2 Results sub study B: observations

This section describes the results of the observations of 5 behavioral consultations which all took place in different nursing homes in the Netherlands. This section consequently describes (1) who are involved in the behavioral consultation, (2) which topics are discussed, (3) nature of the decisions made and (4) involvement of the informal caregiver.

3.2.1 Who are involved in the behavioral consultation

As can be seen from table 3, composition and number of professionals present, but also number of patients discussed during the behavioral consultation varied widely between the five observations. Physician, psychologist and nurse were nearly almost present, except for one behavioral consultation in which there was no physician present. During one behavioral consultation besides the presence of a nurse, psychologist and physician, the consultation was complemented with the presence of a behavioral consultant and an activity counselor. As can be seen from table 3, no informal caregiver was present during the behavioral consultations.

Table 3

professionals involved and number of patients discussed during the 5 observed behavioral consultations

Consultation	**Physician (n)**	**Psychologist (n)**	**Nurse (n)**	**Activity counselor (n)**	**Behavioral consultant (n)**	**Informal Caregiver (n)**	**Patients discussed (n)**
1	1	1	1	0	0	0	3
2	1	1	1	1	1	0	5
3	0	1	2	0	0	0	1
4	1	1	1	0	0	0	2
5	1	1	3	0	0	0	2

3.2.2 Topics discussed during the behavioral consultation

As shown in table 4, several topics were discussed during the behavioral consultation. Topics that were discussed in all 13 patients were *'description of the patients behavior'* and '*use of non-pharmacological interventions'*. '*Possible causes of the problem behavior*' was discussed in all but 2 patients. Followed by '*use of PDs'* which was discussed in all but 4 patients. From the field notes it was noticeable that when the topic 'use of PDs' was discussed, the discussion was often about lowering the dose of the PD. The topic that stands out is *'involvement of informal caregiver'*, only in one patient the involvement of the informal caregiver was mentioned.

Table 4

Topics discussed per patient, as observed during the behavioural consultations

Consul-tation	**Patient**	**Description of Patients behavior**	**Use of non-pharmacological intervention discussed**	**Possible causes problem behavior**	**Use of PD discussed**	**Involvement of informal caregiver**
1	A	Yes	Yes	Yes	Yes	No
	B	Yes	Yes	Yes	Yes	No
	C	Yes	Yes	Yes	Yes	No
2	D	Yes	Yes	No	No	No
	E	Yes	Yes	Yes	Yes	No
	F	Yes	Yes	Yes	Yes	Yes
	G	Yes	Yes	No	Yes	No
	H	Yes	Yes	Yes	Yes	No
3	I	Yes	Yes	Yes	No	No
4	J	Yes	Yes	Yes	Yes	No
	K	yes	Yes	Yes	No	No
5	L	Yes	Yes	Yes	No	No
	M	Yes	Yes	Yes	Yes	No

3.2.3 Nature of the decision made

In most patients the behavioral consultation resulted in the decision of starting a non-pharmacological intervention as can be seen from table 5. Examples of non-pharmacological interventions that were started are: change the way of approaching the patient, involve other discipline like physiotherapist and start new activities. Professionals decided to lower the dose of the PD in 3 patients, in one of these 3 patients professionals additionally started a non-pharmacological intervention. Finally in one patient the decision was deferred. It was noticeable that there was not a specific professional that made the decision, since decisions in all cases were made based on mutual consultation.

Table 5

Nature of the decisions made

Nature of the decision	**Patients (n)**
Start non-pharmacological intervention	8
Lower dose of PD	2
Lower dose of PD and start non-pharmacological intervention	1
Change moment of PD use	1
Defer the decision	1

3.2.4 Involvement of the informal caregiver in the behavioral consultation

The observations showed hardly any involvement of the informal caregiver since no informal caregiver was present during the behavioral consultation and the informal caregiver was only mentioned in the discussion of one patient. It was mentioned how the informal caregiver wanted to be involved in decision-making and that a meeting with the informal caregiver was planned. Furthermore there was discussed what role the informal caregiver could play in non-pharmacological interventions.

During the follow-up, it was asked if the informal caregiver was informed about the decisions made during the behavioral consultation. In six patients the informal caregiver was informed about the decisions made during the behavioral consultation. In four patients the psychologist did not know if the informal caregiver was informed. In all these cases they assumed that physician or nurse informed the informal caregiver about the decisions. Two psychologists mentioned that in the case of change in PDs the nurse and/or physician are/is responsible for informing the informal caregiver. Informal caregivers of 2 cases were not informed about the use of non-pharmacological interventions. One of the psychologists stated that the decision to start with non-pharmacological interventions is often not discussed with the informal caregiver while when it comes to change/start or stop of a PD prescription, this is almost always discussed with the informal caregiver. Additionally, it was said by one of the psychologists that less invasive interventions are not always discussed with the informal caregivers as they are always able to read those decisions in the client portal.

4. Discussion

This study provides a unique view on the perspectives of both professionals and informal caregivers into the decisional process regarding treatment of NPS. In the interviews for each patient, the involved professionals and informal caregivers were interviewed which made it possible to compare the opinions of physicians, psychologists, nurses and informal caregivers regarding the involvement of the informal caregiver in the decision-making process. Additionally the interviews were combined with observations to get a complete view on the current decisional process. To our understanding, this is the first study on SDM regarding treatment of NPS that combines interviews from multiple perspectives and observations. This study started with the following research question: "*In what way is shared decision-making with the informal caregiver applied in the current decision-making process regarding treatment of neuropsychiatric symptoms".*

It appeared that, although there was some involvement of the informal caregiver in most cases, SDM is not often practiced. The interviews and observations show that informal caregivers are often not physically present during treatment discussions. Treatment options are mainly discussed between physician, psychologist and nursing staff. However, the professionals indicated during the interviews to take the perspectives of the informal caregiver into account either explicitly (by asking in advance) or implicitly. The interviews showed that if the informal caregiver was assertive or was involved in the patients' life, the professionals explicitly took the informal caregiver into account. This is in line with previous research, which showed that informal caregivers involvement in the patient's life facilitated shared decision-making (Mariani, Vernooij-Dassen, Koopmans, Engels, & Chattat, 2016). Besides explicitly-, professionals also indicated to implicitly take the informal caregiver into account. Professionals sometimes do not involve informal caregivers in the decisional process because they *assume* that the informal caregiver is overburdened and he/she does not want to be involved in decision-making. Making assumptions about preferences regarding involvement might not be the best thing to do since previous research with breast cancer patients showed that physicians are not able to predict decision-making preferences of their patients (Bruera, Willey, Lynn Palmer, & Rosales, 2002). Additionally the interviews show that informal caregivers are only limited involved in decision-making since they are only informed or asked for consent for the final decision made by the professionals. The informal caregivers that actively consented to a treatment decision were only provided with one treatment option. Therefore, not all the conditions for SDM are present. This is also found in a study of Sainio, Lauri & Eriksson (2001), cancer patients that actively consented to a treatment were not given any alternatives when making a treatment decision. The observations confirmed the results of the interviews: professionals contacted the informal caregivers for consent after the decision was made and informal caregivers in all but one case, were not involved. Taking all these points together, the informal caregiver is only limited involved in decision-making. Therefore, it is recommended to involve the informal caregiver in an earlier stage to explore possible alternative treatment options in consultation with the informal caregiver.

Another finding of our study is that spouses and children differ in their preferences regarding involvement in the decisional process. It seemed that especially children insisted on getting involved in the decisional process in comparison to spouses who more often expressed their trust in professionals and were satisfied with leaving the decision to the professional. This is in line with previous research showing that most elderly people preferred the paternalistic model of decision-making (Cole et al., 2017). Overall the majority of the informal caregivers and professionals were satisfied with the involvement of the informal caregiver. Two informal caregivers stated that their involvement improved over time, they felt more involved in the decisional process over time. This seemed to be due to the fact that they persistently expressed their opinions which makes that professionals have no choice but involve these caregivers in the decisional process. This is also seen in research among cancer patients, this study showed that participants felt they needed to be independent and assertive to get the information they needed (Sainio et al., 2001). Furthermore although some informal caregivers were satisfied with not being involved in the decisional process, it has been argued that even if the informal caregiver is more deferential towards the professionals, these individuals should also be provided with all relevant information (Jeste et al., 2008). They should be given the opportunity to participate in decisions to the extent they are comfortable with. Therefore, it is recommended that informal caregiver’s added value in decision-making is emphasized and decision-making preferences are discussed with all informal caregivers

In contrast to the interviews, in which professionals indicated taking the informal caregiver into account, the observations did not show that informal caregivers were taken into account by the professionals. In only 1 of the 13 patients, the preferences of the informal caregiver were discussed. This is in line with previous research showing that participant reports of SDM differ from the observations of neutral observers (Wunderlich et al., 2010). Since there is a difference between reported-, and observed SDM, it is recommended for future studies to combine interviews with observations.

The results of this study show that improvement of SDM regarding treatment of NPS is needed. The reason of SDM not being adequately applied may be related to the complexity of this topic. Research already confirmed the complexity of SDM in triads (Charles et al., 2013; Fiks & Jimenez, 2010). An example of a triad decision is the decision between physician, parents and children (Fiks & Jimenez, 2010). Although regular triad decision-making is already found to be complex, SDM regarding treatment of NPS differs at several points from regular triad decisions, which makes the decision-making process even more complex. At first, one of the complexing parts of SDM regarding treatment of NPS is the variety of people that get affected by a decision. Not only the patient's condition and the potential treatment, but also the preferences of the informal caregiver and the safety of other residents and the nursing staff play an important role in the decisional process. Due to their cognitive decline, in this study patients were not able to participate in decision-making. A previous study confirms the challenge of SDM in dementia care. Groen-van de Ven et al. (2016) described that both dementia patients, professionals and informal caregivers differ in their views of the situation and the urgency of both medical and social decisions. Second, the amount of informal contact between professionals and informal caregiver differs from other triad decisions which only consists of formal consultations (Charles et al., 2013). Since in dementia care the informal caregiver visits the institutionalized patient, there seems to be more informal contact between informal caregiver and professionals. On the one hand this seemed to be beneficial since it enables both professional and informal caregiver to easily approach each other, on the other hand it seemed to lead to unwanted situations since treatment of NPS is discussed during those visits while the informal caregiver may have other things on his/her mind.

Because of the complexity of this topic, it is important to get a better understanding of SDM regarding treatment of NPS. Therefore, barriers and facilitators were explored, which resulted in the final research question: '*What are the barriers and facilitators of shared* *decision-making regarding treatment of NPS'.* In the interviews, four barriers and three facilitators of SDM were mentioned. The barrier that was mentioned most often is that SDM costs time. Time constraint is also confirmed in other studies as the main barrier of SDM (Gravel, Légaré, & Graham, 2006). Other barriers that were mentioned are: fear of overburdening the informal caregiver and unreasonable arguments of informal caregivers. It seemed that professionals had the opinion that only caregivers that have a good understanding of the topics discussed, have the right to be involved in decision-making. Facilitators that were found are: informal caregivers can provide professionals with important information and informal caregivers frequent presence at the nursing home makes them easily approachable. A critical family was seen as both a barrier as well as a facilitator. On the one hand, professionals might not involve critical informal caregivers because they are experienced as demanding, but on the other hand, critical family also seemed to increase communication. This is possibly due to the fact that a demanding family forces professionals to involve them in the decisional process to keep them satisfied. This is also seen in the fact that informal caregivers that express their opinion about their preferences seem to be more involved in the decisional process.

4.1 Strengths and limitations

The results of this study give insight into shared decision-making with informal caregivers regarding the treatment of NPS. One of the strengths of this study is that multiple data sources were used including observations and interviews from the perspectives of three different staff groups and informal caregivers. By using multiple data sources attempts were made to give a complete view on the involvement of informal caregivers in decision-making. The fact that there were seven separate cases in which all parties presented their view on the same event made it possible to gain insight in the complex process of SDM. Another strength of this study was that the in-depth interviews allowed the respondents to express their point of view without evoking ideas that respondents would not otherwise have. Furthermore, it prevented participants from socially desirable answers because they were not specifically asked about SDM but the focus was on their thoughts and feelings regarding the process of decision-making.

Besides these strengths also some limitations in the current study need to be taken into account. The first limitation in this study is recall bias. Some participants could not initially remember the specific patient during the interview. In those cases, the participants made use of the client portal, which in most cases triggered their memory and helped them to recall the cases. Second, the data was only coded by one coder. Although the codebook was discussed with a second coder, codes were drawn up by only one coder which could be a threat to the reliability of the study. Another limitation in this study is that participants were not directly asked about barriers and facilitators of SDM. Participants were asked about how they felt about the involvement of the informal caregiver. Therefore very few participants mentioned barriers and facilitators of SDM. Additionally, because of time constraints only a limited number of quadruplets was used in this study. Therefore, complete saturation of the data was not reached. Further research on this topic with more quadruplets is recommended to reach saturation in the interviews.

When it comes to the observations, the sample size consisted of only five observations. This is a very small sample size and limits the generalizability of the results. Therefore, in future research it is advised to increase the sample size. Furthermore, the observations of the behavioral consultations were used to represent decision-making in daily practice. Since decisions in daily practice take place in various settings and not only during the behavioral consultation, this should also be considered as a limitation of this study. For future research, it would be interesting to observe multiple settings in which decision-making takes place, to get an objective view on decision-making in daily practice. Finally the observations were conducted by only one researcher which can also be seen as a limitation since this can cause a threat to the reliability of the study.

4.2 Recommendations

Based on the current study several recommendations for both clinical practice and future research can be made. At first, as shown by the results preferences and added value of informal caregivers were hardly mentioned during the behavioral consultation and not always taken into account during the phase of discussing treatment options. Therefore, it is recommended to involve the informal caregiver in an earlier stage and a more structural way. This can be reached by including the informal caregiver in the GRIP method by adding the topic ‘informal caregiver’ to the phases ‘analyze’, ‘describe treatment’ and ‘evaluate’ in the method. When the GRIP method would also include the informal caregiver, this will probably lead to more attention for the informal caregiver and eventually better treatment decisions. Furthermore, it is recommended to create more structural contact moments with the informal caregiver. This could e.g. be linked to the behavioral consultation by contacting the informal caregiver before and after discussing the patient during the behavioral consultation. This will give the opportunity to emphasize the importance of their involvement and explore possible treatment options together with the informal caregiver which will probably result in better treatment decisions. Additionally, discussing treatment options might also stimulate spouses to take part in SDM, because it may cause that they realize that their preferences count and make them realize what considerations are important for them (Say, Murtagh, & Thomson, 2006). These advices might improve earlier and more structured involvement of the informal caregiver in shared decision-making and eventually improve treatment of NPS.

Second, it is recommended to perform a similar study with a larger sample size and video observations to increase the reliability, which will give a better base for the recommendations in this study. By using video observations, multiple researchers can observe the behavioral consultations which will increase the reliability of the study. Further research is needed to confirm if the recommendations that were made have a positive effect on SDM regarding treatment of NPS. Finally, future research should explicitly focus on the barriers and facilitators of SDM in this complex situation to improve the process of SDM and eventually improve treatment decisions.

5. Conclusion

The current study showed that shared decision-making is not often practiced in treating neuropsychiatric symptoms of dementia. Despite the complexity of SDM in this context, improvement on this topic is needed. Although in most cases there was some kind of involvement of the informal caregivers in the decisional process, in the end professionals made the final decision. Informal caregivers were only presented with one treatment option and gave their consent for this option or were only informed about the treatment. Informal caregivers that were more involved with the patient’s life or that expressed their opinion seemed to be more involved in the decisional process than informal caregivers that had a more passive attitude. Decision-making preferences differed among informal caregivers, especially spouses expressed great confidence in professionals and left the decision to them, in contrast to children of the patients who all explicitly expressed their preferences regarding treatment options which resulted in more involvement in decision-making. Future research with a larger sample size that focuses on both observations and interviews is needed to confirm the findings in the current study and to get a better view on the complex topic of shared decision-making in treating neuropsychiatric symptoms of dementia.

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7. Appendices

7.1 Appendix A) Interview protocol

Achtergrond

Er wordt gebruik gemaakt van een film metafoor. Een scène. Eerst de feiten; hoe is het gelopen, wat is er precies gebeurd? Daarna ingaan op de ervaring en de wenselijke situatie. Is er sprake van informed consent of shared decision making? Tijdens het interview zijn ervaringen belangrijker dan feiten.

Dit document dient als een houvast. Voor als je vastloopt tijdens het interview.

Strategie → Beginnen met een open vraag om het ononderbroken vertellen van een verhaal door de geïnterviewde te stimuleren. Aan de hand van het verhaal kan de interviewer nieuwe open vragen (en mogelijk enkele gesloten vragen voor verificatie) stellen. Geen suggestieve vragen.

De interviewer kan checken of de dikgedrukte onderdelen genoteerd in dit document aan bod zijn gekomen. Vragen horend bij de onderdelen kunnen toegespitst worden op de door de geïnterviewde geschetste situatie en kunnen bijvoorbeeld worden gesteld wanneer het onderwerp niet is genoemd door de geïnterviewde, maar wanneer het antwoord wel van toegevoegde waarde kan zijn.

De onderdelen zijn bruikbaar wanneer de geïnterviewde kort van stof is. Niet vastklampen aan de onderdelen. Niet alle vragen stellen. Alleen gebruiken wanneer de openingsvraag kort wordt beantwoord. Ter aanvulling.

Doorvragen: “Kunt u dit nader toelichten?”, “Wat bedoelt u hier precies mee?”, “Kunt u hier een concreet voorbeeld van geven?”, “Kunt u hier iets meer over vertellen?”

Nadat het interview formeel beëindigd is, ontstaat vaak een informeel gesprek. De informatie kan behulpzaam zijn bij de interpretatie van datgene wat tijdens het interview naar voren is gekomen. De interviewer dient de geïnterviewde altijd eerst om toestemming te vragen voordat hij/zij aantekeningen maakt.

Suggestie: Maak na elk interview een samenvatting van vijf tot tien regels, waarin de belangrijkste elementen van het interview terugkomen. Dat maakt het makkelijker om het overzicht te houden. Reflecteer op het verloop van de interviews. Eventuele knelpunten kunnen worden verbeterd, de vragen die niet lopen, kunnen geherformuleerd of verwijderd worden, de volgorde kan worden aangepast enzovoorts.

Het is niet erg wanneer de naam van de cliënt wordt genoemd tijdens het interview. Maar focus op ‘de heer’, ‘mevrouw’, ‘uw echtgenoot/echtgenote’, ‘uw vader/moeder’, ‘uw broer/zus’…

… het voorschrijven van een psychofarmacon/de aanpassing van de dosering van een bestaand psychofarmacavoorschrift → Specificeer indien mogelijk.

Introductie/Inwijding

Graag wil ik mijzelf eerst kort voorstellen: Mijn naam is dus Rianne Wijbenga en ik ben onderzoeksmedewerker in het UMCG op de afdeling Huisartsgeneeskunde en Ouderengeneeskunde. Naast dat ik werkzaam ben binnen het onderzoek naar de besluitvorming rondom onbegrepen gedrag bij mensen met dementie ben ik ook betrokken bij twee andere onderzoeken met als doelgroep mensen met dementie in verpleeghuizen.

Binnen het ‘Gedeelde Besluitvorming’ onderzoek willen we onderzoeken hoe de besluitvorming er momenteel uit ziet met betrekking tot de behandeling van het onbegrepen gedrag en hoe tevreden cliëntvertegenwoordigers, artsen, psychologen en verzorgenden hierover zijn. Ook willen we weten wat de wensen en ideeën van de cliëntvertegenwoordigers, artsen, psychologen en verzorgenden zijn met betrekking tot de besluitvorming.

Vandaag wil ik het met u hebben over het laatste moment van besluitvorming voor het voorschrijven van een psychofarmacon (of: een gedrag beïnvloedend medicijn) of de aanpassing van de dosering van een bestaand psychofarmacavoorschrift (of: een al voorgeschreven gedrag beïnvloedend medicijn). De voorschrift of de aanpassing was nodig voor de behandeling van het onbegrepen gedrag van uw naaste/de cliënt. Het interview zal in totaal ongeveer 30 minuten in beslag nemen.

Vindt u het goed dat ik dit interview opneem en dat er later een transcript (= geschreven weergave van gesproken tekst) van het interview wordt gemaakt? En dat ik aantekeningen maak tijdens het interview?

Er zijn geen goede of foute antwoorden. Verder wordt het interview anoniem verwerkt. Dat betekent dat uw persoonlijke gegevens losgekoppeld worden van uw antwoorden in het interview. U mag zich altijd op elk moment terugtrekken uit het interview. Als u na het interview niet meer wilt dat antwoorden worden gebruikt voor het onderzoek dan worden de gegevens verwijderd. Het streven is om binnen dit onderzoek ongeveer 40 interviews af te nemen. Aan de hand van deze 40 interviews wordt een algemene terugkoppeling gegeven.

Hebt u voordat we beginnen nog vragen?

Dan start ik nu de opname.

Afsluiting

Dan zijn we nu bijna aan het eind van het interview. U hebt tijdens dit interview onder meer verteld dat … [samenvatting: Feiten, Ervaring, Wenselijke situatie]. Heb ik het zo goed begrepen?

Is er nog iets niet ter sprake gekomen over bijvoorbeeld onbegrepen gedrag, psychofarmaca, het besluitvormingsproces, maar wat u wel graag wilt benoemen?

Ik wil u heel hartelijk bedanken voor dit interview; voor uw medewerking en eerlijkheid. Het interview zal dus anoniem worden verwerkt. Mocht u willen dat antwoorden niet meer worden gebruikt voor het onderzoek dan worden de gegevens verwijderd. Ten slotte zal er sprake zijn van een algemene terugkoppeling aan de hand van alle interviews die wij in het kader van het ‘Gedeelde Besluitvorming’ onderzoek hebben afgenomen.

Dan stop ik nu de opname.

Topics	**Inleidende tekst + (voorbeeld)vragen**
‘Small talk’ (optioneel)	Kunt u een korte beschrijving van uw naaste/patiënt geven? [Optie: parafrase]

Feiten	Dan wil ik u nu vragen om terug te denken aan het laatste moment van besluitvorming voor het voorschrijven van een gedrag beïnvloedend medicijn, ook wel een psychofarmacon genoemd, of de aanpassing van de dosering van een al voorgeschreven gedrag beïnvloedend medicijn, dus een bestaand psychofarmacavoorschrift. Zoals eerder aangegeven, de voorschrift of de aanpassing was nodig voor de behandeling van het onbegrepen gedrag van uw naaste. Had het laatste moment betrekking op het voorschrijven van een gedrag beïnvloedend medicijn, dus een psychofarmacon, of de aanpassing van de dosering van een al voorgeschreven gedrag beïnvloedend medicijn, dus een bestaand psychofarmacavoorschrift? Om welk medicijn ging het? Kunt u voor mij de situatie schetsen; wat is er precies gebeurd rondom het voorschrijven van het psychofarmacon/de aanpassing van de dosering van een bestaand psychofarmacavoorschrift? / Hoe is het proces tot besluitvorming voor het voorschrijven van het psychofarmacon/de aanpassing van de dosering van een bestaand psychofarmacavoorschrift verlopen? [LET OP: parafrase, samenvatting] **Onderdelen (plus vragen)** die ter sprake kunnen komen: **Gedrag van naaste:** Welk gedrag van uw naaste heeft uiteindelijk tot de nieuwe behandeling geleid? **Gedrag van naaste:** Wat was volgens u de oorzaak van dit gedrag? **Gedrag van naaste:** Wie heeft het gedrag gesignaleerd? **Tijdlijn:** Na het signaleren van het gedrag, wie is naar wie gegaan? Wie werd wanneer bij het besluitvormingsproces betrokken? **Tijdlijn:** Hoe lang duurden de symptomen voordat een behandelactie werd ondernomen? **Communicatie:** Weet u wie in eerste instantie om deze medicamenteuze behandeling heeft gevraagd? Bij wie werd om medicamenteuze behandeling gevraagd? **Communicatie:** Is er contact geweest met u over de medicamenteuze behandeling van … [gedrag]? Zo ja, kunt u hier iets meer over vertellen? Op welk moment werd u bij de behandeling betrokken (**tijdlijn**)? Wie heeft contact opgenomen met u om de behandeling van uw naaste te bespreken? Was het contact in persoon of bijvoorbeeld telefonisch? Op welk moment van de dag vond het contact plaats? Werd u ook geïnformeerd over andere behandelopties? In hoeverre begreep u de inhoud van het gesprek/de gesprekken? **Behandeling & Beslissingsproces/Besluitvormingsproces:** Wie heeft de uiteindelijke beslissing over de medicamenteuze behandeling van het onbegrepen gedrag genomen?

	Behandeling & Beslissingsproces/Besluitvormingsproces: Weet u waarom er werd gekozen voor medicamenteuze behandeling? **Behandeling & Beslissingsproces/Besluitvormingsproces:** Is er daarnaast ook voor een andere behandeling gekozen? Zo ja, welke behandeling? **Behandeling & Beslissingsproces/Besluitvormingsproces:** Welke rol had u bij de besluitvorming rondom het voorschrijven van het psychofarmacon/de aanpassing van de dosering van een bestaand psychofarmacavoorschrift? Heeft degene/hebben degenen (specificeren) de behandeling met u overlegd? Is er naar uw mening gevraagd? [shared decision making] Is er om uw toestemming voor de behandeling gevraagd? [informed consent: cliëntvertegenwoordiger op de hoogte brengen van de medicamenteuze behandeling en vragen om toestemming] **Behandeling & Beslissingsproces/Besluitvormingsproces:** Waren alle betrokkenen het eens met de keuze voor de medicamenteuze behandeling? [LET OP: parafrase, samenvatting; samenvatting zou na ieder onderdeel kunnen]
Ervaring	Wanneer de cliëntvertegenwoordiger al tijdens het ‘Feiten’ onderdeel een ervaring deelt: Er pas op ingaan wanneer het ‘Ervaring’ onderdeel aanbreekt (indien mogelijk). Deelt de cliëntvertegenwoordiger geen ervaring tijdens het ‘Feiten’ onderdeel: Hoe hebt u het besluitvormingsproces voor het voorschrijven van het psychofarmacon/de aanpassing van de dosering van een bestaand psychofarmacavoorschrift ervaren? [LET OP: parafrase, gevoelsreflectie, samenvatting] **Onderdelen (plus vragen)** die ter sprake kunnen komen: **Gedrag van naaste:** Hoe was het voor u dat uw naaste [gedrag] liet zien? **Tijdlijn:** Na het signaleren van het gedrag, hoe hebt u het ervaren dat … [wie] … [wanneer] bij het besluitvormingsproces betrokken raakte?

	Tijdlijn: U noemde dat de symptomen (specificeren) [tijdsduur] duurden voordat een behandelactie werd ondernomen; wat vindt u hiervan? **Communicatie:** Wat vindt u van het contact dat er (niet) is geweest met u over de medicamenteuze behandeling van … [gedrag]? U noemde dat u [moment/stadium] werd betrokken bij de behandeling; wat vindt u hiervan/dit moment (**tijdlijn**)? Heeft volgens u de juiste persoon contact opgenomen met u om de behandeling te bespreken? En wat vindt u van de manier waarop (in persoon/telefonisch)? **Communicatie:** Hoe reageerde u toen u te horen kreeg dat het psychofarmacon werd voorschreven voor … [gedrag]/dat de dosering van het bestaande psychofarmacavoorschrift zou worden aangepast? **Communicatie:** Hoe was het voor u om de inhoud van het gesprek/de gesprekken over de medicamenteuze behandeling van … [gedrag] niet volledig te kunnen begrijpen? **Behandeling & Beslissingsproces/Besluitvormingsproces:** Hoe hebt u het ervaren dat … de uiteindelijke beslissing over de medicamenteuze behandeling van het onbegrepen gedrag heeft/hebben genomen? **Behandeling & Beslissingsproces/Besluitvormingsproces:** Voelde u zich voldoende geïnformeerd over de gekozen behandeling (**communicatie**)? **Behandeling & Beslissingsproces/Besluitvormingsproces:** Voelde u zich voldoende geïnformeerd over de andere behandelopties (**communicatie**)? / U vertelde dat u niet bent geïnformeerd over andere behandelopties; hoe was dit voor u (**communicatie**)? **Behandeling & Beslissingsproces/Besluitvormingsproces:** Wat vindt u van de uiteindelijke beslissing/de gekozen behandeling? **Behandeling & Beslissingsproces/Besluitvormingsproces:** Wat is uw gevoel over de rol die u hebt gespeeld bij de besluitvorming? [LET OP: parafrase, gevoelsreflectie, samenvatting; samenvatting zou na ieder onderdeel kunnen]

Wenselijke situatie	Bent u uitdagingen tegengekomen tijdens het besluitvormingsproces? Zo ja, welke? Hoe bent u met deze uitdaging(en) omgegaan? Hoe tevreden bent u met de manier(en) waarop u met deze uitdaging(en) bent omgegaan? Is er iets wat u graag anders had gezien met betrekking tot het besluitvormingsproces voor het voorschrijven van het psychofarmacon/de aanpassing van de dosering van een bestaand psychofarmacavoorschrift? Zo ja, kunt u hier iets meer over vertellen? Zijn er volgens u aspecten die de besluitvorming met betrekking tot de medicamenteuze behandeling van onbegrepen gedrag lastig maken? Zo ja, kunt u dit nader toelichten? (denk aan vertrouwen, informed consent, familiebelang, belang cliënt, verantwoordelijkheid, relaties, waarden, macht, begrip voor elkaar) [LET OP: parafrase, gevoelsreflectie, samenvatting] Welke rol wilt u hebben in het besluitvormingsproces rondom medicamenteuze behandeling? Welke rol is volgens u weggelegd voor bijvoorbeeld een arts, psycholoog, verzorgende in het besluitvormingsproces? Wat vindt u belangrijk als het gaat om het besluitvormingsproces? [Samenvatting van het bovenstaande over de wenselijke situatie ("u zegt dus dat…")] Hoe zou je dit volgens u voor elkaar kunnen krijgen? Wat verwacht u van anderen daarin?

7.2 Appendix B) Codebook study A

Signalling	Phys	IC	Psy	Nurse	Total	Quote
Nurses signal	5	4	7	5	21	*"P(03-059): Dus het is meestal, niet altijd, vanuit de zorg omdat zij natuurlijk de meeste ure, oren en open op de afdeling hebben. "*
Family signals	1	1	1	1	4	*"CV (04-020): De druppels die ze had vond ik helemaal niet fijn, ik had het idee dat dat de onrust niet wegnam."*
Professionals signal together	1	0	2	0	3	*"A(02-049): Ik denk dat we dat met z'n allen wel gedaan hebben. De afdeling geeft dat vaak als eerste aan van: goh, ik zie dat die man niet happy is, niet lekker in z'n vel zit."*
Psychologist signals	1	0	0	0	1	*"A(03-059): De psycholoog vooral. Kijk de psycholoog is in die tijd ook erg betrokken geweest."*

Phase of discussing options	Phys	IC	Psy	Nurse	Total	Quote
Professionals involved						
Behavioral consultation without informal caregiver	2	0	5	4	11	"*V(02-004): Ja dan doen we eerst een gedragsoverleg. Dus dan zit zeg maar de arts erbij, psycholoog zit erbij, gedragsconsulent zit erbij en iemand vanuit de zorg en onze teamleider. Daar leggen we eerst de situatie voor, gaan we kijken van joh wat kunnen we precies."*
Not-structural consultation between professionals	3	0	2	2	7	*Nurse (10-080): En ja weet je, dan moet op dat moment wordt gewoon in dat overleg hebben wij de psycholoog betrokken, we hebben de ouderenarts erbij betrokken, ergotherapie, iedereen, alle disciplines waren daarbij.*
Topics discussed						

Discussing physical causes	3	0	1	2	6	*“A(03-059): In ieder geval heb ik haar lichamelijk onderzocht, of er geen lichamelijke afwijkingen waren voor het gedrag. Dat is niet gevonden.”*
Discussing non-pharmacological intervention	7	6	7	7	27	*“P(02-049): Gedragsinterventie toe te passen ook op zijn stemming. En een dagprogramma, en geprobeerd ook wat activiteiten aan hem aan te bieden. Hij hield bijvoorbeeld van fietsen, ook wat fietsactiviteiten aan te brengen. We hebben best veel interventies ingezet om zijn stemming, om zijn functioneren te verbeteren.”*
Use of PD’s because other interventions do not work	4	2	4	7	17	*“V(03-059): Nou goed en als dat dan niet voldoende blijkt te werken, dan kom je op een punt dat dan in de volgende gedragsvisite dat dan het woord medicatie gebruikt wordt, dat we dat gaan bespreken.*

Phase of discussing options	Phys	IC	Psy	Nurse	Total	Quote
Contact moments with IC						
Predetermined moments of contact with IC	3	6	0	4	13	*“V(02-004): Ik bel sowieso mevrouw 2 weken van tevoren op van: Heeft u nog bijzonderheden die ik mee moet nemen in dat gesprek ….. En al onze bevindingen samen dat koppelen we dan, na dat MDO, naar die vrouw terug in dat gesprek dat we 1 keer in de 3 maanden dan hebben.”*
Undetermined moments of contact regarding treatment with IC	4	5	4	4	17	*“A(03-064): Uiteindelijk hebben we het wel zo gelaten, en echtgenoot hebben we in die periode ook veel meer gesproken. En hij stond er heel erg open voor om allerlei dingen te proberen.”*

Phase of discussing options	Phys	IC	Psy	Nurse	Total	Quote
Taking IC into account						
Professionals implicitly taking the IC into account	2	0	2	3	7	*"P(03-059) Dan was ze er wel wat meer in betrokken. Het was redelijk reactief nu, maar wel wetende hoe zij in de situatie staat".*
Professionals explicitly taking the IC into account	5	5	3	4	17	*"V(02-049): Zij wou eerst kijken of er andere dingen mogelijk waren dus afleiding, andere therapieën. Dus dat proces hebben we eerst gedaan."*
IC gives opinion about treatment preferences	2	3	1	3	9	*"V(04020): Nee de familie gaf duidelijk aan, ze wilden geen medicatie voor de onrust. Ze willen een echte moeder."*
Short lines of communication between IC and professionals	0	2	0	4	6	*"CV (13-096): Ja ik heb een hele goede verstandhouding met ze, dus als er wat is kan ik altijd daar terecht."*

Phase of discussing options	Phys	IC	Psy	Nurse	Total	Quote
Taking different perspectives into account						
Taking patient into account	6	4	5	7	19	*"V(02-004): We waren ook echt bang dat hij weg zou gaan lopen, dat hij dus een gevaar voor zichzelf werd."*
Taking nursing staff into account	4	0	6	4	14	*"V (10-080): Nou op een gegeven moment ook echt fysiek mijn collega's te benaderen… ja het was echt niet meer handelbaar…"*

Taking other residents into account	5	0	2	3	10	*"V(03-064): En zei loopt terug en pakt een brandblusser van de gang en wil hem dus gooien naar die bewoner die zei van daar heb je d'r weer. Zo lichtgeraakt is ze. En toen zei ik, dit kan niet dit is te gevaarlijk".*

Phase of decision making	Phys	IC	Psy	Nurse	Total	Quote
Involvement of IC in decision						
Informing IC about decision	0	2	1	2	5	*"CV(02-004): De dokter heb al gezegd dat ze dat gaan geven en dan bellen ze mij op om te zeggen dat ze dat gaan doen."*
Asking informal caregiver for permission	4	4	1	5	14	*"V(03-059): En dan wordt daar uitgelegd van we hebben dit gezien, we denken dat dit ermee te maken heeft en we denken dat dit zou kunnen helpen. En dan wordt er in overleg.. want die wordt daar wel in betrokken of we het wel of niet gaan starten."*

Phase of decision making	Phys	IC	Psy	Nurse	Total	Quote
Contact with IC after decision						
Physician has contact with IC after decision	3	2	2	3	10	*"A(13-096): Ik heb haar de voordelen uitgelegd en nadelen uitgelegd, de bijwerkingen die eventueel kunnen optreden. En nouja toen ging zij daarmee akkoord om dat te starten.*
Nurse has contact with IC after decision	4	3	1	3	11	*"V (02-004): Ja wij (verzorgenden) koppelen alles terug naar familie. We proberen wel nauwe contacten te hebben met familie om alles uit te leggen van dit gaan we doen, of dit is besproken, dit speelt er en we gaan nu de volgende stappen ondernemen. We*

						gaan een gedragsconsulent inzetten of we zijn met medicatie gestart."
Physician and nurse both have contact with IC after decision	1	0	0	1	2	*"V (04-020): Beide, we spreken beide de familie. Maar meestal doe ik het wel."*
There is indistinctness about contact with the IC after the decision	1	0	3	1	5	*"P(02-049): Ik heb niet met haar medicatie besproken, nee dat heb ik niet gedaan. Maar ik neem aan dat de zorg of de arts dat wel heeft gedaan."*

Phase of decision making	Phys	IC	Psy	Nurse	Total	Quote
Satisfaction about involvement IC						
Satisfied about involvement of IC	4	5	1	5	15	*"A (03-064): Wat voor mij in deze casus leuk geweest is, is dat we die heel erg samen hebben gedaan. Maar ook samen met de wettelijk vertegenwoordiger."*
IC has the feeling not being taken into account	0	1	0	0	1	*"CV (03-059): En dat hebben we ook vanaf het begin aangegeven, mijn moeder is gewoon een moeilijk vrouw dus probeer het zo makkelijk mogelijk te houden, dan reageert ze daar gewoon goed op. Dat kun je 100 keer zeggen maar daar wordt gewoon niet zoveel mee gedaan."*
IC is unsatisfied about the way of communication	0	1	1	0	2	*"CV (03-059): Alleen het gesprek werd wel heel erg gestuurd vanuit de arts vind ik zelf. En ik snap het wel aan de ene kant. Maar ik denk dat ik er op dat moment, vanwege alle stress rondom de trein die vertraging had heel simpel gezegd, een beetje*

						vatbaar was voor wat de arts mij aanbeveelt."
Communication with informal caregiver is improved compared to at the start of admission of the patient	0	2	0	2	4	*"CV (02-049): Ik vond het contact goed. Daarin zie ik echt een hele duidelijke verbetering ten opzichte van de eerste twee contacten die ik met die nieuwe basisarts had in januari en februari. Nu is echt heel duidelijk dat ze zich inspant om mij te betrekken in haar gedachtegang en waarom ze denkt dat iets nodig is en wat ze er van verwacht."*
Informal caregiver expressed their wish to be involved	1	1	0	3	5	*"CV (-02-049): Ja ik heb dat echt heel duidelijk moeten zeggen hoe belangrijk dat voor mij is (betrokken worden)."*
IC has confidence in professionals	0	3	0	0	3	*"CV(10-080): Kijk, die zouden geen beslissing nemen wat niet kan. Dus als mijn advies nodig is, dan zal hij dat beslist ook wel zeggen, dat geloof ik wel."*
Point of improvement: more involvement of IC	0	0	2	3	5	*"V(03-059): Het is meer dat ik er dan aan zit te denken van ja, zij geeft aan van ze is al een beetje overbelast. En dan op een gegeven moment krijg je dan toch een telefoontje van de arts. En eigenlijk is dat dan ook het moment waarop je dan wilt gaan starten. En misschien, als ik me dan even in die dochter verplaats, dan kan het misschien wel overkomen van oh jee, nu moet ik iets. Terwijl je haar ook wel graag de tijd wil geven om daar even over na te denken."*
Point of improvement: Plan a consultation to talk about preferences regarding involvement of informal caregiver	0	1	0	0	1	*"P (10-080): Qua meneer denk ik het was misschien goed geweest hem eerder actiever te betrekken maar ook te vragen hoe hij er tegenover zou staan om een andere eerste contactpersoon te regelen. Ik vind dat het heel veel is geweest voor meneer."*

More face to face contact	0	1	0	0	1	*“CV(03-059): Ja nou ja, ondanks die telefoongesprekken zouden we nog wel eens keer bij elkaar kunnen komen zonder die telefoonlijn ertussen. Zeg maar dat je gewoon nadat die beslissingen zijn gemaakt om dan vervolgens nog even goed in het echt te bespreken, dat zou wel prettig zijn.”*
No informal consultations about PD’s	0	1	0	0	1	*“CV(03-059): Want het is voor hun steeds makkelijker als ik hen tegenkom dan is het van oh, ja dan moeten we dit nog even bespreken, terwijl ik eigenlijk met de kleding bezig ben die is verdwenen en niet met de medicatie van m’n moeder zeg maar. Dat ga ik dan niet nu ook nog tussendoor bespreken.”*
Shared decision making is desirable	1	0	3	0	4	*“P(13-096): Ik denk dat als je het over de besluitvorming zelf hebt dat je dat tezamen wilt gaan doen. Dus in ieder geval denk ik de arts zowel ik en iemand van de familie.”*
Barriers of SDM	Phys	IC	Psy	Nurse	Total	Quote
(fear of) overburdening Informal caregiver	0	0	2	2	4	*“P(10-80): Het (overbelasting cv) maakt dus dat we hem minder betrokken hebben, denk ik, dan dat we normaal zouden doen.”*
Shared decision making costs time	2	0	1	1	4	*“A(03-064): Bij mijn dagelijkse praktijk zie je dat je toch wel veel beslissingen zelf neemt, die je niet allemaal gaat overleggen met de wettelijk vertegenwoordiger… En dan is een afspraak gewoon veel lastiger te maken omdat zij allemaal hun eigen leven hebben. En als ik dan elke keer moet wachten tot ik een afspraak heb, ja dat gaat gewoon niet.”*

According to professionals IC’s have to bring up reasonable arguments to be able to take part in making a decision	1	0	1	1	3	*“V (02-049): En ik denk dat de rol die ze nu had gewoon goed is. En ik zou dat zelf het liefste voor alle familieleden hebben. Als je tenminste reëel naar dingen kunt kijken, dat is wel echt de voorwaarde.”*
Critical family is experienced as difficult	1	0	1	1	3	*V (02-049): Het team had het er wel moeilijk mee omdat ze zoiets hadden van, ze vindt overal iets van.”*

Facilitators of SDM	Phys	IC	Psy	Nurse	Total	Quote
Involving IC is easier when IC is often visiting the nursing home	2	2	0	3	7	*“A (03-064): Dus dit is wel heel erg samen opgegaan. Maar dat komt ook omdat deze meneer elke dag hier is, en heel makkelijk te bereiken is.”*
IC can provide professionals with important information about the patient	1	3	3	2	9	*“V(10-080): Ja want ik vind toch dat zij haar het beste kennen. Dus in die zin daar gewoon het meeste, ja die kent zijn partner of zijn moeder het beste. Dus zij hebben voor ons misschien wel hele waardevolle informatie.”*
Critical IC’s increases communication	1	1	1	1	4	*“A (04-020): Sommige families willen per se overleggen want ze willen overal van op de hoogte zijn. Dus je maakt een beetje een selectie. En met die familie zou ik dat altijd wel bespreken en de ander accepteren het vaak wel.”*

7.3 Appendix C) Observation scheme study B

Onderwerp	
Wie is betrokken bij het overleg	Functies:
Gedragsproblematiek	Geïnitieerd door: Uitleg gedrag + beschreven door: Mogelijke oorzaken:
Psychofarmaca	Geïnitieerd door: Wat wordt er over gezegd:
Niet-farmacologische interventie	Geïnitieerd door: Wat wordt er over gezegd:
Wettelijk vert. weet dat beslissing genomen moet worden en dat mening van belang is	Wet. Vert. volledig geïnformeerd Wet. Vert. alleen geïnformeerd dat besluit moet worden genomen: Wet. Vert. wordt nog geïnformeerd door:
Relevante opties en voor-, nadelen van opties zijn uitgelegd	Ja, door: Alleen relevante opties zijn uitgelegd door: Nee
Behandelvoorkeur wet. Vert is besproken + weegt mee in beslissing	Ja: nee
checken of informatie is begrepen	Ja, gecheckt door: Bij: nee
checken of er nog vragen zijn	Ja, door: nee
Rol voorkeur wet. Vert. is besproken	Ja: nee
Rol voorkeur is bekend	Niet besproken ja, bekend bij: rol voorkeur niet bekend
Behandelbesluit is genomen	Ja, door: besluit uitgesteld, door: nee
Uitkomst behandelbesluit:	Psychofarmaca: Niet-farmacologische behandeling:

7.4 Appendix D) Informed consent interviews and observations

Geachte lezer,

Door middel van deze brief willen wij u graag informeren over het onderzoek naar de besluitvorming rondom onbegrepen gedrag bij mensen met dementie. Het onderzoek wordt uitgevoerd door het Universitair Medisch Centrum Groningen (UMCG). We vragen uw hulp voor dit onderzoek.

Waarom is besluitvorming rondom probleemgedrag belangrijk?
Onbegrepen gedrag is het gedrag dat door de bewoner, medebewoners, verzorging en/of familie niet begrepen wordt en als problematisch wordt ervaren. Vaak is dit gedrag erg belastend voor de bewoner zelf, medebewoners, familie en verzorgenden. De behandeling van probleemgedrag bij mensen met dementie is echter erg complex. Er is vaak niet één beste behandeling. Het effect van een behandelbeslissing tussen medicatie of alternatieve interventies is voor het dagelijks leven bij de persoon met dementie groot. De cliënt is immers erg kwetsbaar.

Voor cliënten met dementie in het verpleeghuis is het vaak niet meer mogelijk om mee te beslissen over een behandeling. Daarom nemen vaak de naasten, dit zijn vaak familieleden, deze plek in. De familie vertegenwoordigt vaak de cliënt in gesprekken met de arts of andere hulpverleners, wanneer deze niet meer handelingsbekwaam is. Er is echter nog weinig bekend over hoe de familie bij de behandeling van probleemgedrag betrokken wil worden. Naast de familie en de artsen spelen ook de verzorgenden en psychologen een grote rol bij de besluitvorming. Ze hebben dagelijks contact met en verlenen zorg aan de cliënt. Ook van hen is niet bekend hoe zij betrokken worden bij het besluit.

Wat gaan we onderzoeken?
We willen onderzoeken hoe besluitvorming over de behandeling van het probleemgedrag verloopt. Hiervoor willen we graag 5 keer bij een gedragsvisite in verschillende verpleeghuizen aanwezig zijn en aantekeningen maken.

Waar hebben we uw hulp bij nodig?
Wij vragen u toestemming om de gedragsvisite bij te wonen en hierbij aantekeningen te maken. We zullen geen persoonsgegevens verzamelen. U kunt toestemming geven door het onderstaande formulier in te vullen.

Wat gebeurt er met de verzamelde gegevens?
De verzamelde gegevens zullen we anoniem opslaan in een beveiligd bestand. Na analyse, kunnen de resultaten van het onderzoek gepubliceerd worden in wetenschappelijke artikelen. We zullen de onderzoeksgegevens na afloop van de studie 15 jaar anoniem bewaren.

Vrijwilligheid van deelname
Deelname aan dit onderzoek is natuurlijk geheel vrijwillig. Wilt u niet deelnemen aan het onderzoek? Geen probleem. Deze beslissing heeft geen nadelige gevolgen voor u.

Op de hoogte blijven?
De verwachting is dat medio 2019 de eerste resultaten van dit onderzoek bekend zijn. Wilt u hiervan op de hoogte blijven? Laat dan uw e-mailadres op het toestemmingsformulier achter.

Contactgegevens
Heeft u na het lezen van deze brief nog vragen? Neem dan contact op met de onderzoekers
Esther Warmelink, master studente psychologie, Universiteit Twente:
e.warmelink@student.utwente.nl; 06-10310224
Dr. Sarah Janus, onderzoeker, UMCG Ouderengeneeskunde: s.i.m.janus@umcg.nl; 050-361 6737

Hoe geeft u toestemming?
Als u besluit om deel te nemen aan het onderzoek zouden wij u willen vragen om het toestemmingsformulier te ondertekenen. Met deze toestemmingsverklaring bevestigt u uw voornemen om aan het onderzoek mee te werken. De onderzoeker zal het formulier eveneens ondertekenen en bevestigt daarmee dat hij/zij u heeft geïnformeerd over het onderzoek door middel van deze informatiebrief. Wanneer u afziet van deelname, heeft dit vanzelfsprekend geen enkel gevolg voor u.

Wij willen u hartelijk bedanken voor het nemen van de tijd om deze informatie door te nemen.

Toestemming

Studie: Besluitvorming rondom de behandeling van probleemgedrag bij mensen met dementie

Door dit formulier te ondertekenen verklaar ik dat:
− Ik de informatiebrief over dit onderzoek heb gelezen
− Ik aanvullende vragen heb kunnen stellen
− Mijn vragen genoeg zijn beantwoord
− Ik genoeg tijd heb gehad om te beslissen of ik mee wil doen aan het onderzoek
− Ik weet dat meedoen geheel vrijwillig is
− Ik weet dat ik op ieder moment kan beslissen dat ik niet meer mee doe; daarvoor hoef ik geen reden te geven

Ik geef hierbij toestemming om de gegevens van mij te gebruiken voor de doelen die in de informatiebrief staan.

Naam: _________________________________

Functie: _________________________________

Handtekening:

Datum: ______ / ______ / ______

Onderzoeksresultaten:

☐ Ik wil graag op de hoogte gehouden van de studieresultaten.

Email:____