Toegang tot informatie tijdens de zorg voor mensen met dementie: Het perspectief van mantelzorgers en professionele zorgeverleners. Semigestructureerde interviews.

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Master of Family Medicine

Masterproef Huisartsgeneeskunde
Academiejaar: 2021 – 2022

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List van afkortingen

BCFI	: Belgisch Centrum voor Farmacotherapeutische Informatie
CAW	: Centrum Algemeen Welzijnswerk
CME	: Continuous Medical Education
e.g	: For example,
FAZODEM	: Farmaceutische zorg voor personen met dementie
GDPs	: Gross Domestic Product
GP	: General Practitioner
i.e	: That is
OCMW	: Openbaar centrum voor maatschappelijk welzijn
PHCP	: Primary Health Care Professional
PLWD	: People/ Person Living With Dementia
USA	: United States of America
WHO	: World Health Organisation

Dankwoord

Graag wil ik mijn promotor Nele Van Den Noortgate en mijn praktijkopleiders Juan Willems en Liesbeth Deraeve bedanken.
Daarnaast wil ik alle medewerkers van de praktijk Wellington en thuisverpleging Jill danken voor hun inzet en hulp tijdens dit onderzoek.

Bedankt aan de huisartsen, verpleegsters en mantelzorgers die zo enthousiast deelgenomen hebben aan deze studie.

Ook de collega-artsen van het WGC Nieuw Gent wil ik bedanken voor hun tijd omdat de uurroosters soms moesten worden aangepast zodat ik mijn onderzoek kon afronden binnen de strakke deadlines

Tenslotte wil ik dit eindwerk opdragen aan mijn familie, zowel mijn familie in mijn thuisland die me zo goed mogelijk vanuit Rwanda heeft proberen te ondersteunen als mijn familie in België.

Dankzij jullie steun heb ik dit werk tot een goed einde kunnen brengen.

Van harte dank.

Abstract

Context: Dementie is een onbehandelbare progressieve aandoening en blijft een gezondheidsprobleem door de toenemende prevalentie wereldwijd. Eerstelijns zorgverleners hebben een belangrijke rol in de globale zorg voor mensen met dementie. Daarom is het belangrijk hun ervaring over belemmerende en bevorderende factoren in de zorgverlening te herkennen. Deze masterproef verdiept zich specifiek in het aspect communicatie binnen de gezondheidszorg omdat een goede communicatie tussen verschillende zorgverleners belangrijk is voor optimale zorg.

Onderzoekvraag: De doelstelling van deze kwalitatieve studie is de meningen en ervaringen van mantelzorgers en professionele zorgverleners over het verspreiden en delen van informatie rond dementie te exploreren. Er wordt achterhaald welke belemmerende en bevorderende factoren mantelzorgers en professionele zorgverleners ervaren in de eerste lijn.

Methode: In het eerste deel van deze masterproef wordt een oriënterende literatuurstudie via Pubmed, Web of Science en Embase uitgevoerd. Hierbij wordt er een interviewgids opgesteld over de nood aan informatie tijdens de zorg voor mensen met dementie in de eerste lijn. Daarnaast wordt een narratief onderzoek uitgevoerd via google naar beschikbare informatie over mogelijke ondersteuning tijdens de zorg voor personen met dementie. Op deze manier zien we tot wat men zonder medische achtergrond toegang heeft. In het tweede deel wordt een kwalitatief onderzoek met diepte-interviews uitgevoerd. Er wordt gewerkt aan de hand van semigestructureerde interviews. De interviews worden afgenomen via een interviewgids die wordt opgesteld op basis van de resultaten van de oriënterend literatuurstudie. Ze worden opgenomen, getranscribeerd en geanonimiseerd. Belangrijke thema's worden door content analyse geïdentificeerd en verwerkt.

Resultaten: Er worden 5 huisartsen, 5 verpleegkundigen en 6 mantelzorgers geïnterviewd. Bij huisartsen en verpleegkundigen krijgen schriftelijke communicatiemethoden om te informeren over dementie de voorkeur. Hoge werkdruk is de voornaamste belemmerende factor voor effectieve en tijdige communicatie. Voorgestelde oplossingen waren het opstellen van een permanentie waar huisartsen rechtstreeks hun vragen aan kunnen stellen ofwel artsen die altijd telefonisch beschikbaar zijn. Collega's zijn belangrijke bronnen van informatie. Na een tijd brengen familie en patiënten zelf enkel bezorgdheden over acute zaken en spreken ze niet meer over de dementie. Huisartsen vonden dat informatie over relevante opleidingen niet goed verspreid werd. In-persoon, face-to-face communicatie heeft de voorkeur bij mantelzorgers. Moeilijke voorafgaande ervaringen met professionele zorgverleners, onvervulde verwachtingen en meningsverschillen over de noden van de patiënten zijn de belangrijke belemmerende factoren voor een goede communicatie met professionele zorgverleners. Familie, vrienden en kennis zijn belangrijke bronnen van informatie en ondersteuning. Angst voor toename zorgbehoeften en veiligheid voor de patiënten zijn de voornaamste bezorgdheden van mantelzorgers.

Conclusie: Uit de resultaten komen verschillende thema's aan bod. Het is belangrijk om deze te herkennen om de relatie tussen zorgverleners van de eerste lijn en de mantelzorgers te versterken. Dit zal op lange termijn leiden tot een beter kwaliteit van zorg.

1. Introduction

The World health Organisation (WHO) defines dementia as a syndrome of chronic and/or progressive nature, characterised by the deterioration of the cognitive function beyond what might be expected by normal ageing. It is estimated that nearly 50 million people are affected by dementia worldwide and approximately 10 million new cases every year. These estimates are projected to triple by the year 2050 (1). The last census in Belgium, estimated 220 104 cases of dementia of whom 136 624 lived in Flanders (2). Approximately 70% of people living with dementia (PLWDs) live at home with or without the support of family, friends, or acquaintances (1, 2).

In 2015, the total global societal cost of dementia was estimated to be US$ 818 billion (1), which is almost comparable to the yearly Gross Domestic Product (GDP) of Belgium (2). In 2007 Steeman et al. explored the effects of living with dementia from the perspective of PLWDs (3). This review showed that PLWDs were often confronted with the feeling of loss i.e memory loss, disorientation, inability to follow or participate in a conversation. PLWDs need both practical and emotional help and the demand for care increases as the process of dementia progresses. The disease affects their functioning leading to loss of autonomy and greater need of care. The loss of autonomy over the course of the disease can be a source of fear, frustration, and uncertainty.

Due to the complex nature of dementia and the high dependency of people living with dementia, several care providers i.e informal caregivers, health professionals (e.g nurses and doctors) and social workers are involved. Informal care is defined as all evident care that is provided in a small community based on reciprocity (4). More specifically, this is the care provided by family and relatives, friends, acquaintances, and neighbours (5). A broader definition of an informal caregiver is to be found in the work of Spruytte et al. “An informal care caregiver is a person who is willing to provide care on a regular basis to someone in need in their immediate environment. In addition to a care relationship there is also a kinship, friendship or neighbour relationship between the care provider and recipient and the care provider is not professionally and/or renumerated for the care” (6). Currently, there are 600 000 informal caregivers in Flanders and approximately a third of those have been confronted with dementia at some point (2, 7).

Dementia affects the caregiver three times more than the PLWD (2). One in three informal caregivers has dealt with depression and 41% of caregivers must manage high stress levels (8). Informal caregivers are often called upon in the care of PLWDs even though most of them lack formal training in the matter. Psychoeducational programmes are efficient in improving knowledge and providing psychological support for informal caregivers (9). The effectiveness of these programmes is achieved through improving caregiver confidence; reducing caregiver depression,

distress, and upsetting thoughts; improving life satisfaction and response to disruptive behaviours; reducing behavioural and psychological symptoms; and delaying nursing home placement of care recipients (10–14).

In the 2020 report on caregiving in the United States, 62 % of caregivers report needing help or information on a least one aspect of caregiving. Most common topics are the safety of the PLWD at home, administration and eligibility for services, management of their own stress, management of challenging behaviours of the PLWD and critical health decision (15, 16). More than a half of caregivers rely on primary healthcare providers (PHCPs) to get this information, while others prefer the use of family and friends or other institutions (15). Some studies have suggested that information provided by PHCPs is not always satisfactory (17, 18). There has been great improvement in the care of PLWDs through the emergence of multidisciplinary specialised memory/dementia clinics that provide comprehensive care. This includes diagnosis, treatment, extensive caregiver support and education (19). These specialised clinics have an important role in the confirmation of the diagnosis, which further helps by removing uncertainties and improving access to available support (20). General practitioners (GPs) remain the key point in the community care of PLWDs. They have an important role in the identification of early signals, referral for evaluation and post diagnosis care. In order to provide optimal care at the community level, GPs require feedback, insights and advice from the specialised memory clinics. A study in rural Canada found that the greatest challenge encountered by GPs during the provision of care of PLWDs was the lack of clear communication channels with specialised memory clinics (21).

The effective collaboration of all care providers involved in the provision of care of PLWDs and access to information are necessary for the optimalisation of community care of PLWDs (22). Given the projected increase in the prevalence of dementia, it is important to understand the existing and/ or preferred communication channels between the different care providers involved in the care of PLWDs because the access of information is directly linked to better care.

In this master dissertation, we will explore the flow of information between different community-based care providers of PLWDs through the help of three research questions:

- What are the needs/ expected information for different care providers caring for people with dementia at the primary healthcare level?
- What are the expected versus available channels of spreading and receiving information?
- What are the perceived facilitators and barriers in the flow of information?

2. Literature review

An advanced search was performed from January 2021 to May 2021 using the search terms: “information seeking”, “information need”, “informal caregivers”, “non-professional caregivers”, “professional caregivers”, “general practitioners”, “nurses”, primary health care”, “dementia”, “Alzheimer disease” and “cognitive impairment” in three databases including Pubmed, Embase and Web of Science. Articles published in English and between 1995 and end 2020 were included. Once the searches were conducted and duplicates were removed, abstracts were reviewed and if the abstract was not available via the database the full articles were then downloaded and reviewed. Included in the final review were abstract and / articles that included: 1) information seeking behaviour or information need or information sharing, 2) informal caregivers, or professional caregivers or nurses or general practitioners and 3) primary care setting or home setting. Excluded were articles in a specialised centres or Nursing homes. Data collected during the review was used to inform the creation of the interview guide (**additional file 1& 2**).

In 2020, a scoping review analysing the information seeking behaviour of informal caregivers of PLWDs identified four main areas of interest in relation to information need (23). The four categories were 1) *Disease-specific information* these are general information on dementia, treatment modalities, prognosis, and finally identification and understanding of dementia symptoms and behaviour changes; 2) *Healthcare service-related information* these are general information on care e.g how to provide general hygiene? what are the nutritional requirement of a PLWD? what is the best attitudes or way to deal with the behaviour of a PLWD? And safety issues; 3) *Patient care provision* these were mostly inquiries about availability and accessibility of support; and 4) *Caregiver self-care* few studies reported on this issue, but it was mostly questions on how to manage their daily stress. The interview guide for informal caregivers was focused on these four main areas.

The 2010 Dementia action plan of Flanders and its updates in 2016 emphasises the crucial role of GPs in the early detection of signs of dementia, the diagnosis, the care during the diagnosis, the treatment and follow-up of PLWDs (24).

In collaboration, the academic centre of family medicine and the Flanders centres of expertise on dementia provided guidelines for the diagnosis of dementia in the primary healthcare (25). The aim of this guidelines was to assist GPs by giving information on early recognition of sings of cognitive deterioration. Since the etiologic diagnosis of dementia is not easily made (26), the guidelines strongly advice referral to a specialised memory clinic/ centre for the diagnostic assessment after which a detailed report should be sent back to the GPs.

De Lepeleire et al. found in their 2020 study aiming to evaluate how Flemish GPs dealt with dementia in terms of detection, diagnosis, care diagnosis and treatment that GPs were less acquainted with dementia detection and diagnostic possibilities (27). A Dutch study that explored the perceived role of GPs during the diagnosing and care of PLWDs, showed that GPs perceived their role as the identification of cognitive decline and referral to specialised care for further diagnosis (28). The interview guide for professional caregivers was focused on their different roles in the guidelines and interprofessional communication.

A simple google search was also performed using the terms: “dementia”, “Flanders”, “help” and “support”. Common partners seen on multiples websites are the Flanders centres of expertise on dementia and Flanders Alzheimer League. These organisations are also specific points of contact that provide information and support related to dementia. Most websites refer the inquirers to contact the social services of their health insurances for more information.

The next section is a review of some of the available websites and the type of information they provided. Furthermore, there exist other point of contact for people who need information on dementia. These could be general services also providing support for PLWDs and their caregivers. These are the social work service of health insurances, OCMW and Sociaal huis, centre for general welfare (CAW) and service centre (Dienstencentrum).

The website www.dementie.vlaanderen provides an overview of important links with information on dementia and early-onset dementia.

The Flanders centres of expertise on dementia

Its mission and vision are to act as a point of contact for anyone who may require information on dementia. The goal is to provide person-centred information in easy and simple language in other to make it more relatable and easier to apply in the everyday life thereby improving the quality of life of PLWDs and their caregivers.

The Flanders centres of expertise on dementia are also involved in other projects including (i) sensibilisation campaigns to remove the stigma and increase awareness about dementia, (ii) being the links between research and practice; by translating research into guidelines that can easily be put into practice and researching daily challenges in the practice and providing solutions and (iii) training and providing expertise for health professionals and informal caregivers. The website also provides a calendar with all available training opportunities (Dementiekalender vlaanderen).

Centre of documentation on dementia (Documentatiecentrum dementie)

This is a collection of interesting literature on dementia published by or in collaboration with the centre of expertise on dementia. This database is regularly updated.

SaniMemorix

This campaign focuses on the prevention of dementia. Research have made a links between a healthy lifestyle during the ages 40 to 75 years and reduction of the risk of dementia at an older age. This finding lead to the 2020 report of the lancet commission on dementia prevention, intervention, and care (29). The key message here is that what is good for your heart is also good for your brain. Lifestyles changes that protect against dementia are physical activities, decreasing alcohol, consumption of fruits and vegetable. Protective emotional factors include forming stable long-term relations, social contact, constantly challenging your brain e.g learning a new language (30).

Alzheimer Research foundation (Stichting Alzheimer onderzoek)

its aim is to conduct scientific research into the causes and possible treatment methods of Alzheimer's disease and related brain diseases.

Early- onset dementia (Jongdementie)

This is a collaboration initiative of four organisations i.e Flanders centres of expertise on dementia, Memo centre of expertise on dementia, Alzheimer Centre Limburg and Flanders Alzheimer Ligue with the aim to provide information across borders over early onset dementia.

Forget dementia Remember the person (Vergeet Dementie, onthoud mens)

This campaign focuses on raising awareness on dementia and giving PLWDs and their family a voice.

Pharmaceutics care for PLWDs *(Farmaceutische Zorg voor person met Dementie: FAZODEM)*
The FAZODEM-project is a collaboration between the Flemish Network of Pharmacists and the Flanders centre of expertise on dementia to improve the pharmacological care of PLWDs. The aim of this project is to improve knowledge of pharmacists of dementia and special pharmacological care for PLWDs. Pharmacists are also PHCPs easily accessible by the population with their doubts on medication but also sometimes on disease. This sometimes put the pharmacist in a position where they can potentially identify early sings of cognitive deterioration and should sound the alarm (31).

The dementia action plan of Flanders (24) and the caregivers plan of Flanders (32) acknowledge the social and financial contribution of informal caregivers. They are invaluable in providing the first and close care to the PLWDs. They help in the process of diagnosis through the hetero-anamneses, identification, and reporting of the first alarm sings. They are also a great source of support for the PLWDs who are still living at home. Comprehensive dementia care includes care for the informal caregivers. It is estimated that 40% of the care goes to the PLWD and 60% to the caregivers.

Below are some programmes and initiatives that support informal caregivers of PLWDs. The programmes and websites discussed in the following section are all available through the website www.dementie.vlaanderen

The Psychoeducation programme “dementie en nu”

This programme was developed in collaboration of the Flanders centres of expertise on Dementia and the Flanders Alzheimer League. Its aim is to improve the quality of life of PLWDs by encouraging them to live as long as possible independently in their familiar environment.

The target population of the programme are informal caregivers and is offered through various organisations by professional coaches e.g social work services of health insurances, locals service centres (Dienstencentrum) and specialised memory clinics. It is comprised of 1+9 sessions and a variety of topics are discussed such as empathising with the experience of PLWDs, dealing with care, behaviour, finances, safety, how to deal with and communicate with family and how to communicate/ interact with the PLWD. Furthermore, the feelings and thoughts of the caregiver are discussed, balancing capacity and burden and the topic of coping and meaning (33).

Flanders Alzheimer League

This is a non-profit organisation comprised of patients and volunteers in partnership with other self-help groups and organisations such as Flanders centres of expertise on dementia, the regional centres of expertise on dementia and the Flemish patient platforms. Its aim is to support PLWDs, their caregivers and family members in Flanders. The League strives for broad access to customised care and for preserving a better quality of life. They are involved in several initiatives in the Flemish community e.i (i) family groups (PLWDs or early-onset dementia) in which family members and caregivers of people with (early-onset) dementia can exchange information, experiences, and mutual support. (ii) Sensibilisation and community awareness of the limitations of dementia. (iii) Promoting research on dementia and how to best support informal caregivers of PLWDs.

Dealing with Dementia (omgaan met dementie)

This is a website developed in collaboration between Flanders centres of expertise on Dementia and the Flanders Alzheimer League. This website recognised that questions and need for information or support grow with the evolution of the disease and therefore provides tips and information about the care process. And through the website practical information is provided.

Nursing Homecare

Nursing care at home should be prescribed by a doctor and is an important aspect of (i) proving optimal care and (ii) helping the informal caregivers. Because of the easy access and proximity

nurses are often approached with questions over dementia and can be vital importance in the identification of alarm signals of a cognitive deficit and raising the alarm.

Oppas and companionship & balucon Alzheimer

Help for the informal caregiver in need of a break and/or time to focus on/and take care of themselves, is mostly provided through volunteer organisations. These volunteers usually replace the caregiver at home and will provide all daily care to the PLWD.

This allows the PLWD to stay in a familiar environment and the caregiver to rest. It is very important to note that these volunteers are not formally trained or paid for their services.

Buddywerking

This initiative is mostly for people with early-onset dementia. They are paired with a buddy, also a volunteer, and they both regularly participate in daily leisure activities (e.g watching a movie, taking a walk) the aim of this partnership is to help the PLWD to maintain all their remaining function.

Occupational therapy and home modification

Sometimes there is need for home modifications in other to adapt the home to the need and/or safety of the PLWD. More information and advice can be found on the link for support and resources for PLWDs. These home modifications can be effectuated through the help of OCMW, social services of health insurances.

Financial support

More information about availability and application to this sort of financial support is available through the social work service of health insurances, OCMW and Sociaal huis, centre for general welfare (CAW) and service centre (Dienstencentrum).

The social Maps (sociale Kaart)

This is an online platform that provides an overview services, facilities, providers and organisations in the welfare and health sectors in the regions of Flanders and Brussels.

This platform contains contact information of different support providers and the region in which they operate.

3. Methodology

3.1 Study design

A qualitative study was conducted in one city within residents of an urban area. Data was collected through semi-structured interviews using a predetermined set of topics (**Additional file 1 & file 2**). Purposive sampling was used to identify key participants i.e PLWDs and their direct caretakers. Snowball sampling was further used to select other involved healthcare workers and informal caregivers. This study explored participants' thoughts and experiences on the importance of information sharing during the care of people living with dementia (PLWDs) still living at home. Direct content analysis was used to analyse the collected data.

3.2 Participants

The primary researcher (NN) presented the research project during a staff meeting of nursing agencies providing home care in the area. A search of their medical files was conducted to identify potential care recipients and their caregivers.

The following criteria used to define both terms:

- Care recipient: Any person with a diagnosed dementia and who still lives at home. Excluded were people either suspected of cognitive deficit or still undergoing diagnostic investigations. People living in services flats were also exclude from the sample because they dispose of another professional network.
- Caregivers were defined as anyone, without formal medical training who is involved in the daily care of the PLWD.

Nine PLWDs were identified via their medical files. Telephone contact was attempted, and all nine informal caretakers were reached. Five declined to participate in the study but two families suggested an alternative caretaker who were willing to be interviewed.

Health care professionals (nurses and GPs) were purposely selected because they provide regular care for PLWDs. Informal caretakers personally named who best fit the definition of their personal GPs and nurse.

15 Healthcare professionals were contacted, and 10 interviews (5 nurses and 5 GPs) were completed. All interviews were face-to-face and lasted 20-40 minutes. Participants provided informed written consent and were interviewed by the primary researcher.

3.3 Data collection

Between the period of September 2021 to April 2022, semi-structured face-to-face interviews were conducted. Participants were asked the same series of questions using the previously developed interview guide (**additional file 1 & file 2**) and follow-up questions depending on the participants' answers. Topics of discussions included personal experiences caring for PLWDs, the perceived need and/ or lack of information during the care for PLWDs, their current access to existing information and how they share and /or receive information. The interviews were audio-recorded, transcribed verbatim and anonymised.

3.4 Data analysis

Transcripts were analysed using directed content analysis. Common themes (phenomena) were identified through common words and similar explicit or inferred meaning that was contained within the participants' responses. There were no predetermined codes. Themes and codes were created through the identification of specific phenomena that emerged during reviews. Representative quotes were used to illustrate some point of views.

4. Results

4.1 Participants (demographics)

Table 1: is a summary of participants characteristics

General Practitioners: 5	**Nurses: 5**	**Informal caregivers: 6**
Experiences: - < 5 years: 1 - 5-10 years: 2 - > 10 years 2 Type of practice: - Groups: 2 - Solo: 3 Extra trainings - BCFI: all - Specific dementia:1	General experience - 2 years: 1 - > 15 years: 3 - > 20 years 2 Home care experience - 2 years: 3 - > 10 years: 2 Extra trainings - Dementia: 1	Time after diagnosis: - < 5 years: 4 - > 5 years: 2 Living with PLWD: - Yes: 4 - No: 2 Relation: - Partner: 2 - Children: 3 - Professional: 1 Reason for home care: - Wish of patient: 2 - My wish: 3 - Other: 1

4.2 General practitioner

4.2.1 Generalities

Five General Practitioners with different profiles were interviewed (table 1: gives a summary of their characteristics). The years of experiences varied from 2 to 17 years. Of the 2 GPs who practiced in collaboration with other; one reported working in a multidisciplinary community health centre, while the other was working with other 2 GPs. The 3 GPs practising in solo practices also reported some variation to their organisation. 2 GPs were affiliated in a network of solo practices. This arrangement means that they have access to each other's medical files and provide a clear view for replacement should the need occur. The remaining GP was in a fully autonomous practice.

4.2.2 Continuous Medical Education (CME)

All GPs reported following the online training modules offered by the Belgian Centre for Pharmacotherapeutics information (BCFI). Topics covered in these modules were polypharmacy and the management of behavioural and psychological symptoms of dementia. Only one GP reported following an extensive training on dementia when working in France. This was not a standard issue training and the GPs only participated in this training because of their personal interest.

Two of the GPs were not aware of the centres of expertise on dementia also provided training opportunities. Possible reasons discussed were:

Limited access to printed press

Printed press in form of flyers and posters was the most common way that doctor learned about the centres of expertise on dementia and their trainings opportunities. However, these were only found in places frequented by people already interested in dementia.

"I have seen some flyers about them (the centres of expertise on dementia), but it was in places where you would expect people with a specific interest on dementia to gather… for example on a door in a nursing home or a talk café of focus groups of people affected by dementia in different forms. It is not out there for the uninterested." (GP1, 12 years experiences)

"*No, I have never heard of these training opportunities, they (the centres of expertise on dementia should make themselves more visible, an example, could be putting flyers in our waiting rooms... this could be a way to spark curiosity even in the uninterested GP like me, who shows little interest on the topic of dementia*." (GP2, 2 years experiences).

GPs went on to suggest that these organisations should make themselves more visible and use the available doctors mailing list like the BCFI did and advertise their upcoming activities. The format of the BCFI online training was also the preferrable mode of training because of its user friendliness, less time consuming and easily adjustable to one owns planning.

"… They could also email us the upcoming trainings list…" (GP1, 12 years experiences).

"I like the format BCFI uses. Very easily accessible and user friendly. These short, to-the-point presentations are very good for me. Also, you can do it at your own pace, during your own time." (GP2, 2 years experiences).

4.2.3 Colleagues as source of information

Other sources of information mentioned were staff meetings. Two forms of staff meeting were identified:

Weekly staff meeting with other GPs. For those GPs working in groups this a weekly opportunity for the discussion of challenging cases, sharing experiences and eventually help a colleague who is struggling. These are pre-planned staff meeting and there is a nominated person in-charge of the weekly agenda.

"I often discussed my patients with colleagues. We have planned weekly staff meeting but also in-between discussion every day, if it is an emergency." (GP 4, 7 years of experiences).

Multidisciplinary staff meeting in the Hospital. Sometimes GPs are invited to participate in the Hospital multidisciplinary discussion over their patients. These are most informative because they help the GPs to understand what is being done or can be done in the wide psycho-socio- medical sense.

"Yes, I do discuss patients with colleagues. For instant I often participate in the multidisciplinary discussion in hospitals." (GP 5, 17 years experiences).

4.2.4 Communication with specialists

Written communication in the form of medical reports published on the medical platform CoZo and medical letters sent through the medical software is the preferred mode of communication with specialists. In general, all GPs were satisfied with the collaboration. These communications are usually detailed enough and provide clear guidelines as to the follow-up and what is expected of the GPs. In some rare instances medical reports from specialists are not timely published or simply never published on the medical platforms.

All GPs acknowledged that writing and publishing medical report is very time consuming. Some of the suggested reasons for delays and/or failure to publish medical reports on Cozo were:

High work pressure

"I remember times when the Geriatrics departments were understaffed and almost always full. This could be a factor to the delay in publication of medical records on Cozo." (GP 5, 17 years experiences)

Personal life pressure

"Most specialists always publish their medical records on Cozo. I only know of one who does not, but we have worked together for a long time, and I know she is currently having difficulties in her personal life." (GP3, 9 years experiences).

The lack of written communication can result in problems in the care, this is why doctors have come up with a none spoken agreement to work around this inconvenience with the possibility of a direct telephonic line made available.

Emergency contact line

"When I don't find a medical report op Cozo, I immediately call the concerned department in the Hospital. There is always some to answer my question. It also goes both way… should the specialist need information on our patient that are not readily available. They call us directly." (GP 5, 17 years of experiences).

Message on SIILO

Some have gone so far as to give their personal line to most of the GPs with whom their work and favour communication directly through a call or later via a message send on the medical app SIILO.

"Depending on the urgency of the matter, I can either talk to a specialist through the emergency line and get a direct answer or send a message on SIILO to the specialist of my choosing and expect an answer within the day." (GP 4, 7 years of experiences).

4.2.5 Communication with other primary healthcare professionals

All GPs agreed and encouraged that emergency concerns from colleagues should be addressed via direct telephone call.

"If a pharmacist has questions over my prescriptions, I expect them to call me and discuss their concerns with me before delivering the medication. The same goes for nurses or any other healthcare professional, if they notice sudden concerning medical changes, I expect to be immediately contacted." (GP 5, 17 years experiences).

4.2.6 Family concerns

Face-to-face communication is very common because most caregivers (who are also family members) lived in with the PLWD. Family members tends to ask their questions during pre-scheduled consultations/ home visits. They are usually reserved and tend to ask question about other medical issues. They rarely talk about dementia.

"The children of Mrs X mostly ask questions about her diabetes. They have never asked me anything about her dementia." (GP 4, 7 years of experiences)

4.3 Nurses

4.3.1 Generalities

Nurses interviewed belonged to 2 nursing agencies that provided home care in the area. At the time of the interviews all nurses were working as home care nurses (table 1: gives a summary of their characteristics). Their years of experiences varies from 2 to 22 years. Four of the nurses have previous clinical experience in other medical departments such as cardiology, pneumology and general surgery. Only one of them received extra-training on dementia during her tenure at a nursing home. She is often referred to by her colleagues as the contact person on everything to do with dementia and they often refer patients to her. She is the one who usually provides the technical advice on social and financial aspects.

"Nurse 1 does this. She is the one we call when we get questions on financial and social supports. She will come and have a one-on-one conversation with the clients and help them." (Nurse 2, 15 years experiences and 2 years in home care).

"Financial aids form medical materials for examples 'incontinentie premie', I will suggest it to the patient and do the request. But I will also refer them the social worker of their health insurance to explore what other options are available for them." (Nurse 1, 22 years experiences and 15 years in home care).

4.3.2 Communication with doctors

There was a general feeling of satisfaction over their collaboration with doctors. The GPs is the main contact person and is usually available.

Hospitals: written communication on printed paper

When patients have been hospitalised and are discharged home with a new treatment plan. The new treatment plan and the required prescription are given to the patient on paper. Since nurses comes home daily, they can then implement the new changes in the management.

"Patients are usually discharged with letters containing their new treatment plan which we then read and implement. This is easy for us because we do not do our daily round with a computer at hand." (Nurse 4, 17 years experiences and 1.5 years in home care).

General practitioners: medical notes in the home care file/ journal

Routine communication with the GPs like request of prescriptions of chronic medications and daily observations are noted in the at home care file/ journal. This is a paper file kept in the homes of patients.

"Unless it is an emergency, I usually leave a note in the home care file for the GP." (Nurse 3, 2 years of experience in home care).

4.3.3 Family concerns

In most instances a family member is living-in with the patient and they usually speak directly to nurses during their daily visits. Other family members who are not present during home visits contact nurses directly via telephone or uses the home care file to leave each other messages.

"Living-in family members are often present during our daily visits. So… they talk to us then. Sometimes they note their questions in the home care files for us to answer later." (Nurse 4, 17 years experiences and 1.5 years in home care).

Most of the questions that nurses are confronted with are about behavioural changes and safety issues

"I have a patient now, whose memory is really deteriorating. He once went out and got lost on his way back home. And his wife decided to never leave him alone again, but this was starting to be difficult for her… one day, she approached me and asked what she could do. I suggested a day care centre. At first, she was really scared of living her husband at the care of other people. But she has been so satisfied with the care that he is now going there 4 times a week." (Nurse 5, 17 years experiences and 4 years in home care).

4.4 Informal caregivers

4.4.1 Generalities

Six caregivers who provided care for 5 patients were interviewed. (Table 1: gives a summary of their characteristics). 4 caregivers lived in the same household as the PLWD. Most of them were related to the PLWD; 2 partners (1 husband and 1 wife) and children (2 daughters and a son). Time after diagnosis of dementia varies from 2-7 years. All PLWDs were heavily dependent on other people prior to their diagnosis of dementia. The time duration of care prior to diagnosis ranged from 10-20 years.

"My mother has been completely dependent on other people for a while now. Before my father died, I used to take care of her in her home. After the death of my father, it felt right to move her in with me." (Caregiver 2, daughter, 4 years after diagnosis.)

4.4.2 Reasons for choosing homecare

Negative reputation of nursing homes

"Yes, I decided to keep my husband at home. I don't want him in such place." (Caregiver 3, wife, 4 years after diagnosis)

Respecting their wishes

"During her routine medical visits, my mother saw some patients who did not have any caregivers… what shocked her the most was that there was no one to hold their hand. She there and then expressed the wish to never be left alone." (Caregiver 4, daughter, 4 years after diagnosis)

No available place in nursing homes

One caregiver shared that the choice for home care was a temporally solution while they were both waiting for a permanent solution.

"I do not live with my father. I live in Town B, if there is a problem, I could be there in 15 minutes… considering traffic. This arrangement is not perfect. My father is on several waiting lists of different nursing homes. My hope is that he soon finds a place." (Caregiver 5, son, 7 years after diagnosis.)

All caregivers reported having help from other family members, these are mostly children and other siblings.

"I don't do it alone my daughters help a lot. Every day one of them comes to check on their mother." (Caregiver 1, husband, 2 years after diagnosis)

"My sister does not live with us but whenever I need help she comes to relieve me and stay with our mother for a while." (Caregiver 2, daughter, 4 years after diagnosis)

4.4.3 Communication with health professionals

The caregivers report going to the required planned check-ups. Annually with the specialists and monthly with their GPs and all reported some form of disappointment because at some point they do not learn any newer information from these medical visits.

"Yes, we go to the hospital every year for a check-up and the GP comes home every month. They always say everything is ok. They don't say anything else." (Caregiver 1, husband, 2 years after diagnosis).

Recurring themes that expressed the disappointment of informal caregivers were:

Negative experiences during the diagnosis phase

All family members of PLWDs recalled some difficulties during the period shortly before the diagnosis. Most of them recognised it was partly because memories issues were brought to light by another symptoms.

"My mother was diagnosed with Parkinson because she had difficulties walking… the doctor thought she was rigid and was given medications. It was later discovered that she had a…? water in the brain, she then had surgery and a pump was put in place. After the 3 months long hospitalisation, she came home. There was no doubt about it, her memory was not what it used to be. My father was still alive, so he contacted his GPs who advised them to let her be evaluated in the hospital." (Caregiver 4, daughter, 4 years after diagnosis)

Unmet expectations

"My husband went in with a problem of… urine? What do you call it? Yes, incontinent. They said he should get a prostate operation, which he did, and his problems were never solved. And a couple of months later, I hear through my GP that is probably his memory. I should let him be evaluated again. He is still incontinent, he must wear diapers, they haven't solved his problem. (Caregiver 3, wife, 4 years after diagnosis)

Perceived work pressure

Some caregivers just do not ask questions to specialist or cancel their annual check-up because they do not want to increase the hospital workload.

"I rather have the GP contact them. I ask all my question to my father's GP. They are very busy in hospital, you know." (Caregiver 5, son, 7 years of diagnosis).

Conflicting perceptive

"We always go to the annual and monthly check-ups. They only talk about the patch for the memory that I stopped… I stopped them because they changed my husband. He was not good under these drugs." (Caregiver 3, wife, 4 years after diagnosis)

There is nothing to be done

"The memory...? No, I do not ask question about that. They can't do anything about it, right?" (Caregiver 2, daughter, 4 years after diagnosis)

4.4.4 Concerns

Safety

"I am always worried about my mother… Let say she is home alone taking a nap, she wakes up and is confused, has no idea where she is, stumbles, fall and lies on the ground for some time before anyone even found out what has happened." (Caregiver 2, daughter, 4 years after diagnosis).

"…I sometimes think of moving to a calm, rural area but I am worried she will not get used to the new surroundings and this will distress her more." (Caregiver 1, husband, 2 years after diagnosis).

Disease progression and inability to coping with high demanding care

"I am afraid that he will not get better. I am also old and at some point, I won't be able to care for him anymore." (Caregiver 3, wife, 4 years after diagnosis).

4.4.5 Additional sources of information and support

Friends

"*My friend told me about social benefits, and she also helped me to apply for most of them."* (Caregiver 4, daughter, 4 years after diagnosis).

"We have a community, with my neighbours and other caregivers for elderly people. I can count on them to go check on my mother and I would do the same for them." (Caregiver 2, daughter, 4 years after diagnosis).

Internet

"When I first got the diagnosis of my wife, I looked for everything on the internet. I spend hours searching on what I could possibly do to help her. However, I quickly realised… not all sites were accurate, so I stop." (Caregiver 1, husband, 2 years after diagnosis).

"I don't use the internet. I get lost on the web. However, I like to watch short informative video" (Caregiver 4, daughter, 4 years after diagnosis).

5. Discussion

5.1 Main Findings

In this master dissertation we aim to better understand the perceived information need, available sources of spreading information and perceived barriers and facilitators to a successful flow of information amongst different care providers of PLWDs at the primary health care level.

Comprehensive information on a variety of topics on dementia exist on several website initiatives readily available via www.dementie.vlaanderen. Each website represents a project with a specific focus on dementia. There is also a list of available care providers that can support informal caregivers of PLWDs during the provision of home care. Which care providers are available per region can be accessed via the social map platform.

Trained and/or experienced colleagues on the topic of dementia are considered as valuable sources of information. However, health professionals learned also of training opportunities through the centres of expertise on dementia which they were not aware of. The lack of proper dissemination and advertising methods of training opportunities was identified as the main obstacles to participating in trainings for health professionals. The preferred means of communication for health professional was written communication either electronic or printed version. GPs and nurses are more focussed on providing care and treating medical issues because after some time, family members don't really asked questions about dementia they mostly express concerns about other health issues.

Informal caregivers experienced some frustrations during the provision of care for PLWDs and in some instances resort to asking as little as possible because of a perceived inconveniences. Unmet expectations, different perspectives between professional care providers and informal caregivers and perceived high workload of GPs and nurses were some of the limiting factors. Informal caregivers preferred in-person discussion with professional care providers either in a consultation room or at home. Safety and disease progression followed by the inability to cope with the care demand of the person in their care were the main concerns voiced by informal caregivers.

5.2 Comparison with existing literature

The comparison with existing literatures was limited by the fact that we found few studies on the need and/ or access of information by different caregivers during the care of people living with dementia. Some studies exist on the topics for informal caregivers.

However, the topics of need and / or access to information is sometime discussed as secondary outcome during studies about access to healthcare services in general. Also, the flow of medical information in the primary care setting has been discussed in general but not specifically in the care of PLWDs.

5.2.1 Interventions that improve health outcomes

No single intervention was found to improve PLWDs and/or their caregivers' outcomes. Disappointing or inconclusive results were observed in the literature (34, 37). However, it was concluded that while individual interventions alone have no significant effect on final outcomes, combining different interventions do have a positive effect e.g reduce institutionalisation.

Early diagnosis of dementia is desirable in order to improve the quality of life of the PLWDs and their informal caregivers. Clear guidelines on the diagnosis, care diagnosis, treatment and follow-up, help increasing the GPs confidence diagnosis, disclosure, and the management of behavioural issues (34). Guidelines also promotes the early diagnosis of dementia.

Psychoeducational programmes are efficient in improving knowledge and providing psychological support for informal caregivers (9). Different psychosocial interventions were evaluated and it was found that they can not be generalised to all domains. Interventions should be tailored according to specific needs (35). Multiples groups sessions programmes like "dementia en nu" are effective in improving caregiver psychological health.

Group-based supportive interventions like the family groups organised by Flanders Alzheimer League were found to positively impact the psychological welfare of informal caregivers of PLWDs (36).

A review on providing information and /or advise on dementia to PLWDs and their caregivers had a small positif effect on the general disease burden, depression, subjective well-being, ability/knowledge, and symptoms of care recipient (37).

5.2.2 General practitioners and Nurses

Access to Continuous Medical Education for GPs

Facilitating factors to seeking and accessing information through trainings were convenience and method of delivery of the information. The same was observed in a Portuguese study that evaluated the access and implementation of online CME on changing benzodiazepines prescribing patterns (38). Lack of knowledge of the training opportunity was the main barrier. GPs also noted that should

the opportunity be given, they will most likely follow trainings even though they have little interest in the topic. This is also stated in an article that proposed a practice format of CME for GPs in Belgium (39). The same article goes further and states that the learning rewards is best when GPs are push outside their confront zone.

Communication with other health professionals

Written communication in the form of electronic medical report published on Cozo was the preferred mode of communication between doctors and the main barriers associated with this form of communication were delayed or failure to publish the reports. Perceived reasons for these failures were high work- and emotional load. These finding is in accordance with a literature review on communication between GPs and specialists (40). Nurses also favoured written communication in the form of printed letters and notes in de daily journal.

Colleagues were identified by GPs and Nurses as a trusted source of information. A similar sentiment is noted in a literature review on GPs and Nurses information need and seeking behaviours (41). This was again noted in the findings of De Lepeleire et al., GPs felt confident asking for help from a better trained colleague. Flemish GPs went further to draw an analogy to existing contact person for palliative care and felt there should also be a contact person for dementia (27).

5.2.3 Informal caregivers

Emerging themes on the perceived limiting factors to seeking and receiving information were unmet expectations, prior negative experience with healthcare services, perceived workload and mismatch perspective. Similar findings were expressed in previous studies on the perceived stress of informal caregivers of PLWDs during their interactions with healthcare systems (42, 43).

Others trusted sources of information and support were family and friends. A study in rural U.S.A on the perceived support of informal caregivers of PLWDs (44), reported similar results.

A secondary observation was the need for professional support. All caregivers had some extra professional support in form of nurses, day care, professional caregivers, and volunteers. These findings are similar to a Dutch study that evaluated the need of support in different stages of dementia. It was observed that additional professional support should be provided throughout the whole illness process (45).

5.3 Strengths and limitations

The sample size was comprised of professional health workers i.e GPs and nurses and informal caregivers from different backgrounds and had various experiences. This allowed us to capture a wide range of opinions.

There were also some limitations that needed to be acknowledged.

Due to time and operational constraints, the study was limited to a small sample size and small geographical area. The small sample size did not allow to reach data saturation which means there are still other opinions not yet explored. The small geographical area and the urban setting is very specific. Availability of resources may differ from regions to region. Therefore, these findings are not representative of caregivers living in other settings.

Some people recognised that their loved one have memory problems and possibly dementia but do not yet wish for a formal evaluation and diagnosis. "*It is not like they will do something about it*." By including only PLWDs with medical diagnosis, we may have excluded a certain number of PLWDs and who are still living at home.

This study focusses on the perspectives of GPs, nurses, and informal caregivers. But it is also important to explore the perspectives of other nonmedical disciplines in the primary healthcare such as social workers, physiotherapists, pharmacists…

5.4 Implications for future research

GPs are aware of the physical and mental burden of informal caregivers. However, they often fail to provide proper management and support. Psychosocial aspect of dementia care should be included in the training curriculum. All PHCPs should promote the use of available community resources. Some caregivers reported not using services because they were not aware of their existence.

Different themes of concerned were identified during this master dissertation. However, because of the small sample size there could be opinions and/or concerns that were not identified. Studies with a large sample size are required in order to achieve a wide range of opinions and representation of healthcare workers and informal caregivers of PLWDs.

Studies exploring the perspectives and experiences on communication between healthcare care workers and other collaborators e.g paramedical, nonmedical… at the primary healthcare level could be very beneficial to improving the quality of care for PLWDs still living at home.

This master dissertation also explores available information via internet, it is also important understand how this general awareness information is diffused through other media e.g broadcasting (Television and Radio) or printed press.

6. Conclusion

For the GPs and Nurses involved in this master dissertation, written communication was the preferred form of communication. It varies from online publication of medical reports, printed medication plan and daily notes in patient's journal. The main barrier to the use of this mode of communication is lack of time due to high work-and emotional load. Possible solutions to this opening a direct line of communication via telephone that could be used in case of emergency.

Missed trainings opportunities were mentioned due to limited methods of dissemination. Suggested solutions were publishing training opportunities on dementia in more variable places to inspire other GPs and the use of e-mail list of GPs to communicate the trainings opportunities.

GPs and Nurses cultivates an open and direct communication at the primary care level.

The main reasons for choosing home care were the negative reputations of nursing homes, respecting the patient's wish and long waiting list of nursing homes. Informal caregivers preferred face-to-face as a form of asking their questions and receiving their information. Main barriers to an effective communication between informal caregivers and professional health workers were unmet expectations, mismatch perspectives and prior negative experiences with health care services.

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Additional file 1: INTERVIEWGIDS (Zorgverleners: HA en VPK)

Toegang tot informatie tijdens de zorg voor mensen met dementie: Het perspectief van mantelzorg en professionele zorgverleners. Semigestructureerde interviews.

Inleiding

"Mijn naam is Nathalie Nsengiyumva, en ik ben een huisarts-in-opleiding van Universiteit Gent. Dit onderzoeksproject maakt deel van mijn masteropleiding in de huisartsgeneeskunde. Dit onderzoek werd vooraf goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het Universitair Ziekenhuis van Gent en de Universiteit Gent.
Alvast hartelijk dank voor uw medewerking in dit onderzoek.

In dit onderzoeksproject proberen ik te peilen naar welke informatie beschikbaar en / of nodig is voor zorgverleners van mensen met dementie en hoe zij toegang krijgen tot deze informatie. In het eerste deel van dit onderzoek zal ik op zoek gaan op beschikbare digitale informatie voor mensen met dementie in België. Aanvullende informatie werd verkregen via interviews met mensen die in verschillende organisaties werken waar ze familie en mensen met dementie ondersteunen.

Onze doelgroep tijdens dit interview is de mantelzorger van patiënten met dementie; Het is de bedoeling om hun meningen en ervaringen over de toegang tot informatie (over diagnose, behandeling en beschikbare ondersteuning) te gaan exploreren. Daarnaast spreken we ook met huisartsen en professionele zorgverleners, omdat zij een belangrijk rol hebben in de eerstelijns zorg. Het doel is aan de hand van de verkregen resultaten de bestaande informatie rond dementie beschikbaar te stellen voor een breed publiek en waar nodig suggestie te doen om de tekorten op te vange.

Zijn er nog vragen of onduidelijkheden die u eerst met mij zou willen bespreken vooraleer we verdergaan?

Uitleggen: tijdens het interview & bewaren van de data

"Het doel van dit interview is om uw mening over en uw ervaring met de toegang tot informatie over dementie te gaan exploreren. Ik zal met u nagaan welke informatie u gekregen hebt en waar u nog nood aan hebt . Welke zijn uw bronnen, wat geniet uw voorkeur om informatie te delen/ krijgen en wat is uw perceptie van de belemmeringen en facilitatoren informatiewisseling tussen alle zorgverleners van mensen met dementie in de eerstelijns zorg. Dit onderzoek focust zich op mensen met dementie die nog thuis wonen. Het interview duurt ongeveer 20-30-tal minuten.

Ik zal het interview opnemen teneinde ervoor te zorgen dat we een gedetailleerd verslag hebben van wat u zegt. De opname wordt opgeslagen op de beveiligde servers binnen Universiteit Gent en wordt woord-voor-woord getypt. Alle namen, locaties of iets anders dat u zou kunnen identificeren, worden verwijderd, opdat alle informatie anoniem zou blijven en ook anoniem gepubliceerd.

Vertegenwoordigers van de opdrachtgever, auditoren, de Commissie voor Medische Ethiek en de bevoegde overheden hebben rechtstreeks toegang tot de verzamelde data om de procedures van de studie en/of de gegevens te controleren, zonder de vertrouwelijkheid te schenden

U bent vrij om het interview en / of de opname op elk moment te stoppen. Als er vragen zijn die u liever niet beantwoordt, geef dan een seintje en we gaan door met de volgende vraag."

[Zet de digitale recorder aan]

"Vooraleer we beginnen; uw mondelinge (of schriftelijke in het geval van live interview) toestemming alsook uw bevestiging dat u de inhoud van het onderzoek begrijpt, is noodzakelijk.

Alle informatie wordt volledig vertrouwelijk behandeld; u wordt op geen enkele manier geïdentificeerd. We kunnen het interview op elk moment stoppen. Indien u niet akkoord gaat met de opname, kunnen we dit te allen tijde stopzetten.

Heeft u vragen over het onderzoek vooraleer dat we met het interview beginnen?"

Demografische / beschrijvende informatie

- Hoeveel jaren ervaring hebt uw als huisarts/ verpleging? Thuis of ziekhuis?
- Heb u een bijscholing gevolgd over dementie? Zelf, LOK, conferentie?
- Wat is de verhouding ongeveer van mensen met dementie in uw praktijk tov. uw patientenpopulatie ?
    - In een typische werkdag: hoeveel contacten (telefonische, consultatie, huisbezoek) betreffen patiënten met dementie?
    - Zijn deze contacten met patiënten zelf, mantelzorgers of andere zorgverleners?
- Hoeveel van uw patiënten met dementie wonen in een rusthuis ? (ongeveer)

Toegang tot informatie

<u>Algemeen Informatie</u>

- Welke informatiebromen gebruikt u rond het topic dementie? Richtlijnen, articles…Binnenlandse of buitenlandse?
    - Volgens u zijn deze informatiebromen genoeg uitgebrede? Indien, niet. Welke informatie mist u soms?
    - welke informatiebronnen heeft u het nuttigst gevonden? Waarom?
- Hoe gaat u op zoek naar informatie rond dementie? (exploren: Vorming, vb LOK, conferentie, zoeken op internet, infoblad, vragen aan een ervaarde collega…)
    - Wat is de beste tempo om nieuwe informatie te leren? Korte verdiepte sessie op een aspect van de zorg vb diagnose of lange comprehensive sessie waar u een woordje krijgt op alle aspecten vb diagnose, behandeling en opvolging.
- Bent u tevreden met de huidige beschikbare navorming methoden?
    - Zo niet, wat mist u? en hoe zou u het verbeteren?
- Volgens u is er is een rol weggelegd voor eerstelijnscentra in het informeren van artsen?
    - Zo ja, hoe zou u graag deze informatie krijgen?

Informatie rond individuele casus: Patiënt- gerelateerde informatie

"In de volgende vragen kan het handig zijn om een voorbeeld van een casus en/ of een situatie bedenken waarin u (1) diagnose hebt vermoeden en (2) patiënt met dementie hebt opgevolgd in de ambulante setting."

- Welke informatie krijgt u over uw patient met dementie?
    - Exploreren: diagnose, medicatie, follow-up (wanneer en waar), mogelijke ondersteuning, thuissituatie?)
- Gaat u soms zelf op zoek naar informatie?
    - Zo ja, welke informatiebronnen gebruikt u?
    - Exploreren: arts specialiste: (elektronische/ papier brieven, e-mail , telefoon overleg), andere zorgverleners, sociale werkers (mutualiteit, stad, sociaal huis), mantelzorgers
- Hebt u meer informatie over dementie nodig in de opvolging van uw patiënt X/of situatie X ? hoe gaat u op zoek naar deze informatie?
    - Zijn er plaatsen of mensen van wie u dit soort informatie zou verwachten, maar niet gekregen heb?
    - Weet u waarom deze informatie niet door deze mensen of plaatsen is aangeboden/gegeven? (Exploreren: zie boven)
    - Zijn er plaatsen of mensen waarvan u deze informatie het liefst zou willen krijgen? (exploreren: zie boven)
- Weet u wat computer- of telefoontoepassingen of apps zijn vb siilo? Gebruikt u er een? Als er een app beschikbaar zou zijn over de richtlijnen van opvolging van mensen met dementie, zou u deze apps gebruiken?

Informatie delen

Met andere zorgeverleners

- Welke informatie geeft u in het algemeen aan andere zorgverleners van uw patiënten met dementie?
    - Exploreren: klinische, labo, medicatie, follow-up en waar, richtlijnen over de dementie, mogelijke ondersteuning?
- Welke methoden gebruikt u in het algemeen om informatie te delen met andere zorgverleners van uw patiënten met dementie?
    - Exploreren: Direct contact (telefoon, e-mail en elektronische/ papier brief), in persoon: overleg, mantelzorgers (direct, telefoon, sms, e-mail, cozo), in persoon…

Met familie en mantelzorg

- Welke informatie geeft u in het algemeen aan andere familie en/ of mantelzorgers van uw patiënten met dementie?
    - Exploreren: klinische, labo, medicatie, follow-up en waar, richtlijnen over de dementie, mogelijke ondersteuning?

- Welke methoden gebruikt u in het algemeen om informatie te delen met familie en/ of mantelzorgers van uw patiënten met dementie?
    - Exploreren: in persoon (overleg, mantelzorgers) consultatie, huisbezoek, telefoon, sms, e-mail, cozo

Het interview afsluiten

- *"Dat brengt ons bij het einde van het interview.*
  Is er nog iets anders over communicatie en het delen van informatie tussen zorgverleners van mensen met dementie dat u denkt dat we vandaag over het hoofd gezien hebben?
  Heeft u nog aanvullende opmerkingen over de inhoud van het interview of hoe het is verlopen?

  Heel erg bedankt dat je de tijd hebt genomen om vandaag met me te praten. "

  [Zet de digitale recorder uit]

Additional file 2: INTERVIEWGIDS (MANTELZORG)

Toegang tot informatie tijdens de zorg voor mensen met dementie: Het perspectief van mantelzorg en professionele zorgverleners. Semigestructureerde interviews.

Inleiding

"Mijn naam is Nathalie Nsengiyumva, en ik ben een huisarts-in-opleiding van Universiteit Gent. Dit onderzoeksproject maakt deel van mijn masteropleiding in de huisartsgeneeskunde. Dit onderzoek werd vooraf goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het Universitair Ziekenhuis van Gent en de Universiteit Gent.
Alvast hartelijk dank voor uw medewerking in dit onderzoek.

In dit onderzoeksproject proberen ik te peilen naar welke informatie beschikbaar en/ of nodig is voor zorgverleners van mensen met dementie en hoe zij toegang krijgen tot deze informatie. In het eerste deel van dit onderzoek zal ik op zoek gaan op beschikbare digitale informatie voor mensen met dementie in België. Aanvullende informatie werd verkregen via interviews met mensen die in verschillende organisaties werken waar ze familie en mensen met dementie ondersteunen.

Onze doelgroep tijdens dit interview is de mantelzorger van patiënten met dementie; Het is de bedoeling om hun meningen en ervaringen over de toegang tot informatie (over diagnose, behandeling en beschikbare ondersteuning) te gaan exploreren. Daarnaast spreken we ook met huisartsen en professionele zorgverleners, omdat zij een belangrijk rol hebben in de eerstelijns zorg. Doel is aan de hand van de verkregen resultaten de bestaande informatie rond dementie beschikbaar te stellen voor een breed publiek en waar nodig suggestie te doen om de tekorten op te vange.

Zijn er nog vragen of onduidelijkheden die u eerst met mij zou willen bespreken vooraleer we verdergaan?

Uitleggen: tijdens het interview & bewaren van de data

"Het doel van dit interview is om uw mening over en uw ervaring met de toegang tot informatie over dementie te gaan exploreren. Ik zal met u nagaan welke informatie u gekregen hebt en waar u nog nood aan hebt. Welke zijn uw bronnen, wat geniet uw voorkeur om informatie te delen/ krijgen en wat is uw perceptie van de belemmeringen en facilitatoren informatiewisseling tussen alle zorgverleners van mensen met dementie in de eerstelijns zorg. Dit onderzoek focust zich op mensen met dementie die nog thuis wonen. Het interview duurt ongeveer 20-30-tal minuten.

Ik zal het interview opnemen teneinde ervoor te zorgen dat we een gedetailleerd verslag hebben van wat u zegt. De opname wordt opgeslagen op de beveiligde servers binnen Gent Universiteit en wordt woord-voor-woord getypt. Alle namen, locaties of iets anders dat u zou kunnen identificeren, worden verwijderd, opdat alle informatie anoniem zou blijven en ook anoniem gepubliceerd.

Vertegenwoordigers van de opdrachtgever, auditoren, de Commissie voor Medische Ethiek en de bevoegde overheden hebben rechtstreeks toegang tot de verzamelde data om de procedures van de studie en/of de gegevens te controleren, zonder de vertrouwelijkheid te schenden

U bent vrij om het interview en/ of de opname op elk moment te stoppen. Als er vragen zijn die u liever niet beantwoordt, geef dan een seintje en we gaan door met de volgende vraag."

[Zet de digitale recorder aan]

"Vooraleer we beginnen; uw mondelinge toestemming (of schriftelijke in het geval van live interview) alsook uw bevestiging dat u de inhoud van het onderzoek begrijpt, is noodzakelijk.
Alle informatie wordt volledig vertrouwelijk behandeld; u wordt op geen enkele manier geïdentificeerd. We kunnen het interview op elk moment stoppen. Indien u niet akkoord gaat met de opname, kunnen we dit te allen tijde stopzetten.
Heeft u vragen over het onderzoek vooraleer dat we met het interview beginnen?"

Demografische/ beschrijvende informatie

- Wat is uw relatie tot patiënt X?
- Heeft patiënt X andere mensen die helpen in de zorg? Welke?
- Kunt u mij vertellen hoe lang u al voor patiënt X zorgt? Hoe lang heeft patiënt X uw hulp nodig hebben?
- Is dit de eerste persoon voor wie u hebt gezorgd met een vergelijkbare aandoening?
- Wat waren de eerste symptomen die u opmerkte?
- Wat waren de meest verontrustende symptomen voor u?
- Hoe lang had patiënt X symptomen vooraleer dat hij/ zij contact neemt met arts voor de symptomen?
- Heb u gekozen om voor patiënt X te zorgen?

Toegang tot informatie

- Heeft u informatie gekregen over de ziekte, medische behandelingsmogelijkheden en beschikbare ondersteuning?
    - Zo ja, uit welke bronnen? (Exploreren: dokter, andere medische zorgverlener, afdrukmateriaal van dokterspraktijk/ ziekhuizen, familie, vrienden, andere mensen die voor iemand met dezelfde aandoening zorgen, bibliotheek, ander afdrukmateriaal, internet (welke sites), steungroepen, lessen)
    - Zo ja, welke informatiebronnen heeft u het nuttigst gevonden? Waarom?

- Onder welke omstandigheden heeft u de informatie gekregen? Bent u zelf gaan zoeken/ vragen voor de informatie? Of heeft iemand u deze aangeboden zonder dat u erom vroeg?

- Indien u geen informatie gekregen of gezocht heeft, was dit een bewuste keuze?

- Heeft u informatie gekregen over de taken die behoren bij de zorg voor iemand met dementie?

    - Zo ja, uit welke bronnen? (Exploreren: dokter, andere medische zorgverlener, afdrukmateriaal van dokterspraktijk, familie, vrienden, andere mensen die voor iemand met dezelfde aandoening zorgen, bibliotheek, ander afdrukmateriaal, internet (welke sites), steungroepen, Lessen)
    - Zo ja, welke informatiebronnen heeft u het nuttigst gevonden? Waarom?

- Denkt u dat u meer informatie over dementie nodig hebt om voor patiënt X te zorgen?

- Zijn er mensen van wie u dit soort informatie zou verwachten, maar niet gekregen hebt? Weet u waarom deze informatie niet door deze mensen of plaatsen is aangeboden/gegeven?

- Zijn er plaatsen of mensen waarvan u deze informatie het liefst zou willen krijgen?

- Welk aanbod van methoden heb je het liefst? (Exploreren: rechtstreeks van een andere persoon, één op één; didactische manier zoals een les; van een steungroep van anderen die met dezelfde problemen te maken hebben, b.vc familiegroep; geschreven materiaal; internet of andere digitale bronnen; audioprogramma; video.)

- In welke omstandigheden zou u graag over dementie leren? (Exploreren: thuis; in een leslokaal of in een andere groepsomgeving; in de klinische onderzoekskamer van een arts; in de wachtkamer van een arts.)

- Maakt u gebruik van het internet? Weet u hoe u op internet naar informatie over zorgonderwerpen kunt zoeken? Welke zoektermen zou u kunnen gebruiken, of welke sites zou u kunnen bezoeken?

- Weet u wat computer- of telefoontoepassingen of apps zijn? Gebruik u er een? Als er een app beschikbaar zou zijn om voor Patiënt X te zorgen, zou u deze apps gebruiken?

Het interview afsluiten

“Dat brengt ons bij het einde van het interview.
Is er nog iets anders over communicatie en het delen van informatie tussen zorgverleners van mensen met dementie dat u denkt dat we vandaag over het hoofd gezien hebben?
Heeft u nog aanvullende opmerkingen over de inhoud van het interview of hoe het is verlopen?

Heel erg bedankt dat je de tijd hebt genomen om vandaag met me te praten. "

[Zet de digitale recorder uit]

Bijlage 1: informatiebrief

Informatiebrief voor de deelnemers

Totgang tot infromatie tijdens de zorg voor mensen met dementie: Het perspectief van Mantelzorg en professionele zorgverlerners. Semigestructureerde interviews.

Beste,

U wordt uitgenodigd om deel te nemen aan een onderzoeksproject. Neem, voor u beslist deel te nemen aan deze onderzoeksproject, voldoende tijd om deze informatiebrief aandachtig te lezen en dit te bespreken met de onderzoeker of haar vertegenwoordiger. Neem ook de tijd om vragen te stellen indien er onduidelijkheden zijn of indien u bijkomende informatie wenst. Dit proces wordt 'informed consent' of 'geïnformeerde toestemming' genoemd. Eens u beslist heeft om deel te nemen aan de onderzoeksproject zal men u vragen om het toestemmingsformulier achteraan te ondertekenen.

Beschrijving en doel van de studie

U zal binnenkort een e-mail of telefoon krijgen waarbij u wordt gevraagd om deel te nemen aan een interview in het kader van een onderzoeksproject.
Dr. Nsengiyumva Nathalie voert een onderzoek uit naar de beschikbaarheid van informatie over dementie. Dit onderzoeksproject maakt deel van haar masteropleiding in de huisartsgeneeskunde.

Het doel van dit interview is om uw mening over en uw ervaring met de toegang tot informatie over dementie te gaan exploreren.Wij vragen u vriendelijk of u de tijd zou willen nemen om een paar vragen voor ons te beantwoorden. Dit zal ongeveer 20 -30 minuten van uw tijd in beslag nemen.

Dit onderzoeksproject werd vooraf goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het Universitair Ziekenhuis van Gent en de Universiteit Gent.

Deze verzameling van gegevens wordt uitgevoerd door Dr. Nsengiyumva Nathalie onder supervisie van Prof. Dr. Van Den Noortgate Nele.

Toestemming en weigering

De deelname aan deze studie is volledig vrijwillig. U bent vrij om het interview en/ of de opname op elk moment te stoppen. Als er vragen zijn die u liever niet beantwoordt, laat het ons weten en we gaan door met de volgende vraag.”

Voordelen

Deelname aan deze studie brengt voor u waarschijnlijk geen ander voordeel met zich mee. De verkregen resultaten kunnen echter helpen de bestaande informatie rond dementie beschikbaar te stellen voor een breed publiek.

Kosten

Uw deelname aan deze studie brengt geen extra kosten mee voor u, maar biedt ook geen financieel voordeel.

Vertrouwelijkheid

In overeenstemming met de Algemene Verordening Gegevensbescherming (of GDPR) (EU) 2016/679 van 27 april 2016 (die vanaf 25 mei 2018 in voege is) en de Belgische wet van 30 juli 2018, betreffende de bescherming van natuurlijke personen in verband met de verwerking van persoonsgegevens en betreffende het vrije verkeer van die gegevens, zal uw persoonlijke levenssfeer worden gerespecteerd en kan u toegang krijgen tot de verzamelde gegevens. Elk onjuist gegeven kan op uw verzoek verbeterd worden. Uw toestemming om deel te nemen aan het onderzoeksproject betekent dat we gegevens van u verwerken voor het doel van het onderzoeksproject. Deze verwerking van gegevens is wettelijk voorzien op basis van artikel 6, § 1, (b), (e) of (f) en artikel 9, § 2(j) van de Algemene Verordening Gegevensbescherming.

Alle informatie die tijdens het onderzoeksproject verzameld wordt zal geanonimisserd. Enkel geanomimiseerde gevens zullen gebruikt worden voor analyse van de gegevens en in alle documentatie, rapporten of publicaties (in medische tijdschriften of congressen) over het onderzoeksproject. Vertrouwelijkheid van uw gegevens wordt dus steeds gegarandeerd. De verzamelde data zullen verwerkt en bewaard worden op de beveligde Ugent servers. De verwerkingsverantwoordelijke van de gegevens is de instelling van de hoofdonderzoeker van het onderzoekspreoject, Dr. Nsengiyumva Nathalie (UGent).

Vertegenwoordigers van de opdrachtgever, auditoren, de Commissie voor Medische Ethiek en de bevoegde overheden hebben rechtstreeks toegang tot de verzamelde data om de procedures van de studie en/of de gegevens te controleren, zonder de vertrouwelijkheid te schenden. Dit kan enkel binnen de grenzen die door de betreffende wetten zijn toegestaan. Door het toestemmingsformulier, na voorafgaande uitleg, te ondertekenen, stemt u in met deze toegang.

De Belgische toezichthoudende instantie die verantwoordelijk is voor het handhaven van de wetgeving inzake gegevensbescherming is bereikbaar via onderstaande contactgegevens:

Gegevensbeschermingsautoriteit (GBA)
Drukpersstraat 35 – 1000 Brussel
Tel. +32 2 274 48 00
e-mail: contact@apd-gba.be
Website: www.gegevensbeschermingsautoriteit.be

Bijlage 2: informed consent

TOESTEMMINGSFORMULIER VOOR DE DEELNEMERS

Ik heb het document “Informatiebrief voor de deelnemers ”pagina 1 tot en met 2“ gelezen en begrepen en ik heb er een kopij van gekregen. Ik heb uitleg gekregen het doel en de duur van het onderzoeksproject en over wat men van mij verwacht.
Ik begrijp dat deelname aan het onderzoeksproject vrijwillig is en dat ik mij op elk ogenblik het interview kan stoppen.
Ik ben me ervan bewust dat dit onderzoeksproject werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent en de Universiteit Gent en dat dit onderzoeksproject zal uitgevoerd worden volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP). Deze goedkeuring was in geen geval de aanzet om te beslissen om deel te nemen aan het onderzoeksproject.
Men heeft mij ingelicht dat alle verzamelde data verwerkt en bewaard op de beveleigd Ugent servers. Ik ben op de hoogte dat ik recht heb op toegang en op verbetering van deze gegevens.

Ik stem ermee in om volledig samen te werken mte de onderzoeker: Ja/ Nee

Naam en voornaam van de deelnemer	Handtekening	Datum
Naam en voornaam van de arts-onderzoeker*	Handtekening	Datum

2 kopieën dienen te worden vervolledigd. Het origineel wordt door de onderzoeker bewaard de kopie wordt aan de deelnemer gegeven.

Ik verklaar de benodigde informatie inzake dit onderzoeksproject mondeling te hebben verstrekt evenals een exemplaar van het informatiedocument aan de deelnemer te hebben verstrekt.	
Ik bevestig dat geen enkele druk op de deelnemer is uitgeoefend om hem/haar te doen toestemmen tot deelname aan het onderzoeksproject en ik ben bereid om op alle eventuele bijkomende vragen te antwoorden.	

Bijlage 3: Goedkeuring ethische comité

Afz.: Commissie voor Medische Ethiek

Prof. dr. Nele Van Den Noortgate
Algemene Inwendige ziekten en geriatrie - AIZ
ALHIER

contact	telefoon	e-mail	
Commissie voor medische Ethiek	+32 (0)9 332 41 81	Ethisch.comite@uzgent.be	
Ons kenmerk	Uw kenmerk	datum	pagina
BC-09332	NVT	11/03/2021	1/2

Betreft : Advies voor monocentrische studie met als titel:

"Toegang tot informatie tijdens de zorg voor mensen met dementie: Het perspectief van mantelzorg en professionele zorgverleners. Semigestructureerde interviews. - MaNaMa: Nathalie Nsengiyumva"

B.U.N.: B6702021000040

*Adviesaanvraagformulier dd. 4/1/2021 (Volledig ontvangen dd 04/01/2020)
*Protocol: Research proposal
*Begeleidende brief dd. 5/3/2021
*Patiëntenmateriaal: Interviewguide zorgverlener NL, ENG (aangepaste versie)
*Antwoord onderzoeker ontvangen dd. 08/03/2021 met antwoorden op opmerkingen EC dd. 08/01/2021
*Patiënteninformatie- en toestemmingsformulier versie 1 dd. 2/3/2021 (N en Engl)
*Patiëntenmateriaal Interviewguide mantelzorger NL, ENG (aangepaste versie)

Advies werd gevraagd door: Prof. dr. Nele Van Den Noortgate

BOVENVERMELDE DOCUMENTEN WERDEN DOOR HET ETHISCH COMITÉ BEOORDEELD. ER WERD EEN POSITIEF ADVIES GEGEVEN OVER DIT PROTOCOL OP 11/03/2021 INDIEN DE STUDIE NIET WORDT OPGESTART VOOR 11/03/2022, VERVALT HET ADVIES EN MOET HET PROJECT TERUG INGEDIEND WORDEN.
Vooraleer het onderzoek te starten dient contact te worden genomen met HIRUZ CTU (09/332 05 00).

THE ABOVE MENTIONED DOCUMENTS HAVE BEEN REVIEWED BY THE ETHICS COMMITTEE.A POSITIVE ADVICE WAS GIVEN FOR THIS PROTOCOL ON 11/03/2021 IN CASE THIS STUDY IS NOT STARTED BY 11/03/2022, THIS ADVICE WILL BE NO LONGER VALID AND THE PROJECT MUST BE RESUBMITTED.
Before initiating the study, please contact HIRUZ CTU (09/332 05 00).

DIT ADVIES WORDT OPGENOMEN IN HET VERSLAG VAN DE VERGADERING VAN HET ETHISCH COMITE VAN 16/03/2021.
THIS ADVICE WILL APPEAR IN THE PROCEEDINGS OF THE MEETING OF THE ETHICS COMMITTEE OF 16/03/2021.

* *Het Ethisch Comité werkt volgens 'ICH Good Clinical Practice' - regels*
* *Het Ethisch Comité beklemtoont dat een gunstig advies niet betekent dat het Comité de verantwoordelijkheid voor het onderzoek op zich neemt. Bovendien dient U er over te waken dat Uw mening als betrokken onderzoeker wordt weergegeven in publicaties, rapporten voor de overheid enz., die het resultaat zijn van dit onderzoek.*
* *In het kader van 'Good Clinical Practice' moet de mogelijkheid bestaan dat het farmaceutisch bedrijf en de autoriteiten inzage krijgen van de originele data. In dit verband dienen de onderzoekers erover te waken dat dit gebeurt zonder schending van de privacy van de proefpersonen.*
* *Het Ethisch Comité benadrukt dat het de promotor is die garant dient te staan voor de conformiteit van de anderstalige informatie- en toestemmingsformulieren met de nederlandstalige documenten.*

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* *Geen enkele onderzoeker betrokken bij deze studie is lid van het Ethisch Comité.*
* *Alle leden van het Ethisch Comité hebben dit project beoordeeld. (De ledenlijst is bijgevoegd)*
* *The Ethics Committee is organized and operates according to the 'ICH Good Clinical Practice' rules.*
* *The Ethics Committee stresses that approval of a study does not mean that the Committee accepts responsibility for it. Moreover, please keep in mind that your opinion as investigator is presented in the publications, reports to the government, etc., that are a result of this research.*
* *In the framework of 'Good Clinical Practice', the pharmaceutical company and the authorities have the right to inspect the original data. The investigators have to assure that the privacy of the subjects is respected.*
* *The Ethics Committee stresses that it is the responsibility of the promotor to guarantee the conformity of the non-dutch informed consent forms with the dutch documents.*
* *None of the investigators involved in this study is a member of the Ethics Committee.*
* *All members of the Ethics Committee have reviewed this project. (The list of the members is enclosed)*

Namens het Ethisch Comité / On behalf of the Ethics Committee

Prof. dr. P. Deron
Voorzitter / Chairman

CC: UZ Gent – HIRUZ CTU
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Prof.dr. D. DE BACQUER (UG - statisticus, ♂)
Dr. K. DE GROOTE (UZG – kindercardioloog, ♀)
Prof.dr. M. De MUYNCK (UZG – fysiotherapeute, ♀)
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Dr. L. GOOSSENS (UZG – neonatoloog, ♀)
Dr. S. JANSSENS (UZG – geneticus, ♀)
Mevr. K. KINT (UZG – apotheker, ♀)
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Bijlage 4: Goedgekeurd protocol

DIT ONDERZOEK IS EEN KWALITATIEVE ENQUÊTE DAT DE MENINGEN EN ERVARINGEN VAN MANTELZORGERS EN PROFESSIONELE ZORGVERLENERS OVER HET VERSPREIDEN EN DELEN VAN INFORMATIE ROND DEMENTIE EXPLOREERT.

IN HET EERSTE DEEL VAN DIT ONDERZOEK WORDT ER EEN LITERATUUR ZOEK VERRICHT VIA PUBMED, WEB OF SCIENCE & EMBASE OM TE BEOORDELEN WAT ER AL GEKEND IS IN DE LITERATUUR. DAARNA WORDT ER OP EEN EENVOUDIGE WIJS EEN INTERNET ZOEK VERRICHT VIA GOOGLE OP VRIJ BESCHIKBARE INFORMATIE WEER TE GEVEN. OP DIE MANIER ZIEN WE TOT WAT MENSEN ZONDER MEDISCHE ACHTERGROND TOEGANG HEEFT.

IN HET TWEEDE DEEL VAN DE ONDERZOEK WORDT ER INFORMATIE OVER DE MENINGEN VAN MANTELZORGERS EN ZORGVERLENERS VERZAMELD DOOR INTERVIEWS. DEZE INTERVIEWS GEBEUREN ONE-ON-ONE VIA TELEFOON EN ZOOM OF ANDERE VIDEOCHAT MOGELIJKHEDEN. ALS HET BUITEN DE CORONA PERIODE VALT KUNNEN DEZE PERSOONLIJK AFGENOMEN. DE INTERVIEWS WORDEN OPGENOMEN. ALLE INFORMATIE BETREFFENDE DIT ONDERZOEK WORDT IN HET BEGIN VAN DE INTERVIEWS AAN DE BEVRAAGDE GEGEVEN EN ER WORDT MONDELINGE TOESTEMMING (VOOR DE OP-AFSTAND INTERVIEWS) EN SCHRIFTELIJKE TOESTEMMING (VOOR DE LIVE INTERVIEWS)GEVRAAGD. DE VRAGEN IN DE INTERVIEWS ZIJN MEESTAL OPEN ZODANIG DAT DE BEVRAAGDE HUN MENINGEN KAN UITEN ZONDER BEÏNVLOED. ER WORDT GEBRUIKT GEMAAKT VAN EEN INTERVIEWGIDS. AFHANKELIJKE VAN HOE BREED DE ANTWOORDEN ZIJN, KAN ER NOOD ZIJN AAN VERDERE EXPLORATIE MET DE VOORGESTELD ONDERWERPEN IN DE GIDS. DE INTERVIEW IS IN DRIE GROEPEN: (1)PRAKTIJK- EN/ OF ZORG ERVARING,(2) INFORMATIE NODIG EN / OF GEKREGEN EN (3) INFORMATIE DELEN EN/ OF GEVEN. SOMMIGE VRAGEN WORDEN BEANTWOORD EN /OF BESPROKEN VANUIT EEN CASUÏSTIEK PUNT. DIT ZAL HELPEN OM TE VOORKOMEN DAT DEELNEMERS VEEL HYPOTHETISCHE ANTWOORDEN GEVEN MAAR WEL HUN ERVARINGEN COMMUNICEREN.

DE VERZAMELDE DATA ZAL GEANALYSEERD WORDEN DOOR EEN THEMATIEK MANIER. GELIJKAARDIGE ANTWOORDEN ZULLEN VERDEELD WORDEN IN DEZELFDE GROEPEN.

AAN DE HAND VAN DE RESULTATEN WORDEN ER BESLUITEN GETROKKEN OP WAT DE MANTELZORGERS EN ZORGVERLENERS ERVAREN ALS BELEMMERINGEN EN FACILITATOREN IN DE COMMUNICATIE TUSSEN ALLE VERZORGERS VAN MENSEN MET DEMENTIE IN DE EERSTELIJNS ZORG.

BOVENDIEN ZAL ER OOK KUNNEN NAGEGAAN WORDEN OF DE BEKOMENDE RESULTATEN VERGELIJKBAAR ZIJN MET DIE VAN GELIJKAARDIGE ONDERZOEKEN IN HET BUITENLAND. AAN DE HAND VAN DE RESULTATEN WORDT BEKEKEN WAAR ER NOG MEER OP KAN GEDAAN WORDEN IN VERBAND MET COMMUNICATIE OVER DEMENTIE IN DE EERSTELIJNSZORG.