Perception on education about advance care planning for general practitioners:
A qualitative intervention improvement study

Student: Lisa Vanbrabant

Promotor: Prof. Geert Goderis, ACHG- KU Leuven

Praktijkopleider: dr. Theo Raskin

Master of Family Medicine
Masterproef Huisartsgeneeskunde
Academiejaar: 2017-2019

Deze masterproef is een examendocument dat niet werd gecorrigeerd voor eventueel vastgestelde fouten. Zonder voorafgaande schriftelijke toestemming van zowel de promotor(en) als de auteur(s) is overnemen, kopiëren, gebruiken of realiseren van deze uitgave of gedeelten ervan verboden. Voor aanvragen tot of informatie i.v.m. het overnemen en/of gebruik en/of realisatie van gedeelten uit deze publicatie, wendt u tot de universiteit waaraan de auteur is ingeschreven.

Voorafgaande schriftelijke toestemming van de promotor(en) is eveneens vereist voor het aanwenden van de in dit afstudeerwerk beschreven (originele) methoden, producten, schakelingen en programma's voor industrieel of commercieel nut en voor de inzending van deze publicatie ter deelname aan wetenschappelijke prijzen of wedstrijden.

Content

Abstract (Dutch) 4
Abstract (English) 5
Introduction 6
Method and materials 10
Research design and recruitment of participants 10
Data collection 10
Data analysis 10
Research team and reflexivity 11
Ethical aspects 11
Results 11
Experience with the ACP conversation 11
Perception on education concerning advance care planning for GPs 13
Comparison between patients, caregivers and GPs 15
Discussion 16
Conclusion 18
References 19
Appendix 21
Codebook Nvivo 12 Pro 21
Approval protocol 23
Approved protocol 27

Abstract (Dutch)

Introductie

Vroegtijdige zorgplanning (VZP) heeft de voorbije twee decennia meer en meer een prominente rol ingenomen in de huisartsenpraktijk. Het is bewezen dat het bespreken van de voorkeuren en wensen van de patiënt rond medische zorg betreffende het levenseinde de kwaliteit van leven significant positief beïnvloedt. Onderzoek toont aan dat artsen en andere eerstelijns zorgverleners zich vaak onvoldoende voorbereid voelen om dit onderwerp te bespreken met patiënten. Tevens kan kennis omtrent VZP significant verschillen tussen zorgverleners. De Federatie Palliatieve Zorg Vlaanderen geeft het advies om voor alle hulpverleners van de eerste lijn opleiding te voorzien rond VZP. Onderzoek toont aan dat de kennis van artsen rond VZP toeneemt wanneer zij worden opgeleid. Bovendien voelen hulpverleners zich ook meer zelfzeker om een gesprek te initiëren. Tot op heden is er weinig onderzoek verricht naar de perceptie van artsen, patiënten en mantelzorgers wanneer een educatieprogramma voor VZP wordt geïntroduceerd. Dit kwaliteitsverbeterend project onderzoekt de perceptie over educatie rond VZP bij artsen, bij zowel huisartsen, patiënten en mantelzorgers.

Methode

Het kwaliteitsverbeterend project bestond uit drie fasen. De deelnemende huisartsen volgden gedurende een dag een opleiding ' Palliatieve zorg- Zorg in verbinding'. Vervolgens selecteerde elke huisarts twee tot vier patiënten die beantwoordden aan de inclusiecriteria. Indien patiënt akkoord ging, werd hun mantelzorger betrokken. In totaal werden vijftien personen waaronder acht patiënten, drie mantelzorgers en vier huisartsen geïncludeerd. Semigestructureerde interviews werden afgenomen bij patiënten en mantelzorgers. Een focusgroep werd georganiseerd voor de deelnemende huisartsen. Alle interviews werden bestudeerd op basis van de QUAGOL richtlijnen. De kwalitatieve data-analyse werd uitgevoerd met behulp van het Nvivo 12 Pro software programma.

Resultaten

Bijscholingen omtrent VZP zijn telkens zeer leerrijk en vanuit verscheidene standpunten worden handvaten aangereikt maar ondanks het gebrek aan routine wordt deze informatie vaak vergeten waardoor de invloed op gespreksvoering beperkt blijft. Zowel patiënten als mantelzorger waren zeer tevreden over het verloop van het VZP gesprek, ook al was het concept hun onbekend. Ze voelden zich beter voorbereid naar de toekomst toe en de bespreking van zorgnoden was ook een houvast. Er was een goede overeenkomst tussen de opinies van patiënten, mantelzorgers en huisartsen inzake opleiding rond VZP bij artsen. Iedere deelnemer benadrukte het belang van educatie omtrent VZP. Algemene consensus betrof dat kennis en communicatievaardigheden de belangrijkste elementen zijn. De deelnemende huisartsen waren van mening dat studenten Geneeskunde voldoende informatie moeten krijgen over VZP tijdens hun opleiding en vervolgens dit ook moeten oefenen om hun communicatievaardigheden te ontwikkelen. VZP zou verplicht moeten worden opgenomen in de vervolgopleiding van huisartsen in opleiding. Intervisiegroepen leverden een zinvolle bijdrage in hun navorming rond VZP. Andere eerstelijns zorgverleners waaronder verpleegkundigen kunnen een ondersteunende rol spelen in het VZP proces. Patiënten en mantelzorgers beaamden het belang van voldoende kennis over VZP bij huisartsen. Het empathisch vermogen, het betrekken van familie en uitleg geven in duidelijke taal waren de belangrijke gesprekstechnieken. Zowel artsen als patiënten en mantelzorgers waren overtuigd dat opleiding rond VZP een positieve invloed had op het zelfvertrouwen van de huisarts, de arts-patiënt relatie, de kwaliteit van het VZP-gesprek en de levenskwaliteit tijdens de laatste levensfase.

Conclusie

Bijscholingen omtrent VZP zijn telkens zeer leerrijk maar ondanks het gebrek aan routine wordt deze informatie vaak vergeten. In het algemeen ervaren patiënten en mantelzorgers het VZP gesprek als aangenaam. Educatie is essentieel om VZP in de huisartsengeneeskunde te verbeteren. Kennis en communicatievaardigheden moeten de hoekstenen vormen in zowel de opleiding van studenten en huisartsen-in-opleiding als in de navorming van huisartsen. Andere eerstelijns zorgverleners kunnen een ondersteunende rol innemen in het proces rond VZP. Het optimaliseren van specifieke opleiding wordt aanbevolen ter bevordering van hun kennis en vaardigheden. Verder onderzoek is noodzakelijk om deze resultaten te bevestigen.

Sleutelwoorden: vroegtijdige zorgplanning, educatie over vroegtijdige zorgplanning, effect van educatie, zorgverleners, patiënt, mantelzorger

Abstract (English)

Objective

Advance care planning (ACP) has become more important in general practice the last two decades. It is known that discussing the patient's wishes and preferences about medical care management significantly improves the quality at the end of life. However, physicians and other health care professionals (HCP) often feel unprepared to discuss this topic with their patients. Knowledge about ACP can differ significantly among them. Therefore, the Federation of Palliative Care of Flanders advises to provide adequate education about ACP to all HCP. When they are educated about ACP, there is a general increase of knowledge and they feel more confident to initiate ACP conversations. To date, little research is conducted on the perception of physicians, patients and caregivers when a program of advance care planning is introduced. This qualitative improvement intervention study investigates the perception of general practitioners (GP), patients and caregivers on education of advance care planning among physicians.

Methods

The qualitative improvement intervention project consists of three parts. First, the participating GPs followed a training course 'Palliative care- Care in connection' about advance care planning during one day. Next, each GP selected two up to four patients that met the inclusion criteria. If the patient agreed, their caregiver was involved. In total, fifteen people were included consisting of eight patients, three caregivers and four GPs. Semi-structured interviews were conducted with patients and caregivers. A focus group was organized for the participating doctors. All interviews were examined on the basis of the QUAGOL guidelines. The qualitative data analysis was analysed via the Nvivo 12 Pro software program.

Results

Trainings about ACP are very educational and every time experts approach it by different views to implement ACP in daily practise but because of the lack of routine, this information is often forgotten by which the influence on discussing ACP is limited. Patients and caregivers were very pleased with the way the ACP conversation was executed by their GP, even though the concept was unknown by them. They felt better prepared towards the future and considered talking about ACP was as a grip. The perceptions of patients, caregivers and GPs concerning education about ACP for GPs was similar. Every respondent emphasized the importance of training concerning ACP. Overall consensus implied that most attention must be given to knowledge and communication skills in education about ACP of GPs. According to the participating GPs, medical students must receive sufficient information about ACP and practise to develop their communication skills during their medical training. ACP must also be incorporated obligatory in the education of doctors-in-training. Peer groups contributed much to their training about ACP. Patients and caregivers accentuated the importance of the GPs knowledge about ACP. Empathic capacity, involving family and comprehensible language were the most important elements GPs should manage. Both the physicians as well as the patients and caregivers were convinced that education about ACP had a positive influence on the GPs confidence, relationship between GP and his patients, the quality of the ACP conversation and the quality at the end of life**.**

Conclusion

Trainings with regard to ACP are very instructive but because of the lack of routine this information is often forgotten. In general patients and caregivers felt comfortable during the ACP conversation. Education concerning ACP is necessary in order to improve ACP in general practice. More training concerning knowledge and communication skills ought to be the cornerstones in the training of medical students, GPs-in-training and GPs. Other primary health care workers can play a supporting role in the ACP process and optimising applied training is recommended in order to improve their knowledge and competences. Further research is necessary to verify these outcomes.

Keywords: advance care planning, education about advance care planning, effect of education, health care professional, patient, caregiver

What is known?
✓ Physicians do often feel unprepared to initiate the advance care planning conversation. ✓ Knowledge about advance care planning has often a low level and can differ significantly among primary health care professionals (e.g. general practitioners, specialists, nurses, social workers). ✓ Education interventions concerning advance care planning significantly improve knowledge and communication skills. Physicians feel more confident to initiate conversations about this subject.
What is new information?
✓ Not only general practitioners, but also patients and caregivers support education about advance care planning among general practitioners. ✓ According to patients, caregivers and general practitioners, knowledge and training of communication skills are the most important elements in education of advance care planning.

Introduction

Even though advance care planning (ACP) has acquired more and more recognition the past two decades, patients often do not discuss their wishes regarding the end of life with their general practitioner (GP). Consequently, medical interventions may be performed that the patient did not want or that life may be unnecessarily prolonged without maintaining quality of life. Therefore, medical care management as a physician for patients who have reached the end of life is not always easy if ACP is not discussed in advance. Quality of life is essential, especially towards the end of life. The Federation of Palliative Care of Flanders developed a guideline on ACP in 2015. The authors described ACP as a continuous process in which the patient's wishes and preferences regarding future care will be respected when he is no longer able to express his will.[1]

Together with other primary health care professionals (HCP) and relatives, GPs play a pivotal role to ensure that the patient's wishes are accomplished at the end of his life. Research demonstrated that patients prefer to communicate their health status with their GP. In addition, a conversation about ACP would have a beneficial effect on the quality of life during the final phase.[2] Nevertheless, misconceptions about ACP still exist among physicians. They fear taking away the patient's last hope or they assume that the patient is not ready to discuss this subject.[1]

The Federation of Palliative Care of Flanders advises in his guideline 'Advance care planning' to provide sufficient information and education about ACP to all primary HCP. Particularly training of physicians is of great importance since they play a central role in initiating a conversation about ACP. Nurses and social workers are also important because they are often more involved in the personal and daily life of patients.[1, 3] Although they are supposed to initiate the ACP process, physicians and other HCP often feel unprepared to start a dialogue with their patients. Research also demonstrates that knowledge about ACP can differ significantly among HCP. A summary is presented in table 1. A survey about conceptualisation of ACP showed that among GPs, there are different ideas and opinions about ACP.[4] Physicians and other HCP often feel insufficiently prepared to initiate conversations about the end-of-life treatment planning.[5] A cross-sectional pilot study conducted with 193 physicians and nurses demonstrated that the knowledge about ACP of both doctors and nurses is low which implicates the necessity of improvement in their competence.[6] However Blasco *et al.* (2010) investigated the knowledge of ACP among physicians, nurses and social workers, they concluded that physicians had a good knowledge about ACP although their expertise about the content and legal context was very low.[7] Another study that explored the knowledge of ACP among GPs and medical specialists showed that the level of knowledge varied significantly.[8] Despite their experience, the knowledge level concerning ACP among emergency nurses was low.[9] Research about the perception of ACP and influence of experience on the perception of ACP among nurses employed in a hospital, demonstrated that the nurses had little experience with advance directives (AD). They respected the wishes of patients but they indicated not having the capability to initiate a conversation about AD themselves.[10] A systematic review about the knowledge of ACP among social workers concluded that they had a good knowledge about AD. Especially those who worked with elderly people in the health care services were very well informed.[11]

Subsequently, several studies have been set up to investigate the effect of educational programs on the competences about ACP of HCP. Table 2 summarises the findings from literature. Fulmer et al. (2018) investigated the perception of ACP and conversations about end-of-life care among GPs, cardiologists, pulmonologists and oncologists. The results showed that only a minority had received formal training on ACP communication and end-of-life care. Physicians who received training, felt more confident in providing information compared to doctors who did not receive education.[12] Communication-oriented interventions about the end of life demonstrated a significant impact on communication skills and confidence of the HCP. They felt more comfortable during a conversation. Also a significant improvement in empathy was noted and the number of burnouts among doctors decreased significantly.[13] Researchers analysed the effect of a short multimodal education program among 148 GPs and specialists. After the training, the doctors had acquired more confidence to initiate a conversation about early care planning and their approach towards patients improved.[14] The confidence among doctors- in- training increased after completing a program about end-of-life communication. They developed more confidence about end-of-life conversations after a three-day training on communication skills.[15]Studies about end-of-life care among social workers concerning education and training are contradictory. One study reported that the majority (89%) of the social workers had received training on end-of-life care.[16] Another survey showed that 60% of social workers in nursing homes had not received any training at all.[17]

To date, little research is conducted on the perception of physicians, patients and caregivers when a program of advance care planning is introduced. This implies education of GPs on advance care planning and the reintroduction of these conversations by the physicians with their patients.

This qualitative improvement intervention study investigates the perception of GPs, patients and caregivers on education of advance care planning among physicians.

Table 1: Knowledge of advance care planning (ACP) among health care professionals (HCP)

Author and year of publication	Patient population	Study design	Measured outcomes	Result
De Vleminck *et al.* (2016)[4]	36 GPs	5 focus groups	Experiences with attitudes towards barriers and facilitators of ACP, ways to improve ACP in general practice on the basis of topic guide	– Conceptualisations of ACP differed among GPs and practice of ACP can be different which leads to reduced effectiveness of ACP
Gorman *et al.* (2005)[5]	Residents in a hospital	Systematic review	Experience of residents with end-of-life decisions	– Residents felt unprepared to handle decisions about end-of-life – Exposure to end-of-life discussions had a positive effect on gaining confidence
Flores *et al.* (2013)[6]	192 primary care physicians and nurses	Questionnaire	Knowledge of AD, the use of AD ant attitudes towards AD with dichotomous and Likert scale	– General knowledge of AD is low
Champer Blasco *et al.* (2010)[7]	475 primary health care workers (GPs, dentists, nurses, social workers, assistant clinics, administrative assistants)	Self- administrated questionnaire	Current knowledge about ACP	– Primary care workers have a general knowledge about ACP – Knowledge is insufficient concerning law, content and registers – No significant differences between professional groups
Cartwright *et al.* (2013)[8]	650 specialists and 350 GPs	Postal survey	knowledge and self-reported practice of ACP	– Significant misunderstanding of terminologies and systems around substitute decision-making for incompetent people
Jezewski *et al.* (2007)[9]	579 emergency nurses	Descriptive, correlation, mailed survey to determine	the knowledge of, attitudes toward and experiences with AD	– The nurses' knowledge about AD was rather low (68% correct)
Silva *et al.* (2014)[10]	139 nurses (working in a hospital)	Questionnaire	Nurses' perceptions, socio-demographic and professional experiences with AD	– 95% had no experience with decisions about AD – Approximately 73% was prepared to reflect with the patient about AD
Wang *et al.* (2017)[11]	Social workers	Cross-sectional surveys, qualitative interviews (systematic narrative review)	Social workers' perspectives and experiences regarding implementation of ACP	– Social workers considered ACP as their duty and responsibility – They play an important role in promoting and implementing ACP through an array of activities

Legend: ACP= advance care planning; GP= general practitioner; AD= advance directive

Table 2: Effect of educational interventions on advance care planning (ACP) among health care professionals (HCP)

Author and year of publication	Patient population	Study design	Measured outcomes	Result
Fulmer *et al.* (2018)[12]	736 physicians (primary care specialists; pulmonology, cardiology, oncology subspecialists)	37-item telephone survey	Attitudes and perceptions of barriers and facilitators to ACP	– 29% reported that they had had formal training about end-of-life conversations
Walczak *et al.* (2016)[13]	Patients, caregivers, HCPs, multiple stakeholders	Systematic review	Interventions for end-of-life communication of health care workers	– Communication skills interventions, conducted with HCPs had a great impact on changes in skill, confidence, comfort, preparedness and knowledge in relation to specific communication skills – An end-of-life family conference with a bereavement brochure was significantly reduced by the impact of patients' illness and death on caregivers, caregiver psychological morbidity, expressions of guilt and provision of non-beneficial treatments to patients. It also increased patient and nursing staff input into end-of-life discussions.
Detering *et al.* (2014)[14]	148 GPs	Educational programme including pre-reading, a DVD, interactive patient e-simulation workshop and a training manual	Developing and evaluating an interactive ACP programme	– Significant change in confidence – Significant improvement in scores of e-simulation – No changes in ACP knowledge
Clayton *et al.* (2013)[15]	22 junior-doctors	Individualised training program including teaching session, sessions with an expert facilitator and patient simulator and audio-visual take-home messages	End-of-life communication	– Communication skills were significantly improved – Significant changes in confidence in communicating about relevant topics
Gutheil *et al.* (2011)[16]	844 social workers both working in health and aging and other sectors	Questionnaire	Training in end-of-life issues	– Social workers in health and aging were significant more trained compared with social workers other than (88.8% vs. 53.2%; p< 0.001) – >75% of social workers in health and aging received end-of-life training in continuing education programs
Sherwood *et al.* (2012)[17]	A purposive sample of 15 social work assistants came from 11 facilities	Qualitative interviews (systematic narrative review)	Exploring the knowledge and attitudes of social service workers	– Contradictory results concerning knowledge about AD: 89% health care social workers received training in end-of-life issues compared with 60% of social workers active in nursing homes didn't receive training regarding AD in the United States – Social workers in South Korea didn't get education of training concerning advance care planning

Legend: ACP= advance care planning; GP= general practitioner; AD= advance directive; HCP= health care professional

Method and materials

Research design and recruitment of participants

In order to have an in-depth understanding of the perceptions of the GPs, patients and caregivers concerning the effect of education of GPs on the ACP conversation, a qualitative improvement intervention study design was considered the most suitable. The grounded theory from Glaser and Strauss was stated as the methodological orientation to underpin the study. The qualitative improvement intervention project consisted of three parts. GPs, active in the region Engelmanshoven- Gelinden- Heers were asked face-to-face and by email if they wanted to participate to this study. The three fellow GPs from the general practice where the interviewer was active and also one GP who worked in Heers, agreed to participate. Next, the physicians of the participating family group practices attended on 21 April 2018 a course 'Palliative care- Care in connection' during a day which focused on advance care planning. During the period from 21 April 2018 till 13 December 2018 (study period), each GP selected two up to four patients that met the inclusion criteria. A caregiver must be a person from the immediate social environment who provides support for a patient with a specific care need. The inclusion criteria for patients comprised of a subscribed informed consent, male or female sex, age above fifty, living at home and mental competence. Mental incompetence, residential in a nursing home and dementia were the exclusion criteria. Inclusion criteria for the participating GPs consisted of a signed informed consent and participation to the symposium 'Palliative care- Care in connection'. Exclusion criteria included a blank informed consent form and no attendance at the symposium. If the patient agreed, the conversation was conducted in the presence of the caregiver. Subsequently, semi-structured interviews were conducted with the included patients and caregivers at their home. A focus group was organized for the participating physicians in the general practice of the interviewer. In total, fifteen people were included in the qualitative improvement intervention study, consisting of eight patients, three caregivers and four GPs. Two patients and one caregiver dropped out after the conversation about advance care planning with their GP. They preferred not to participate to the semi-structured interview. Reasons why they did not want to participate included not wanted to talk about the ACP and a lack of time to engage in the semi-structured interview.

Data collection

Questionnaires for the semi-structured interviews and focus group were provided by the interviewer. The composition of the questionnaires was based on findings from literature in order to get a view on the perceptions and opinions of the interviewees. The questionnaires were adapted to the interview groups and were added in the attachment. It served as a guidance to each interview. All interviews were audio recorded and were transcribed afterwards. The duration of the semi-structured interviews varied from 30 minutes to one hour. The duration of the focus group was about 45 minutes. Although the sample is quite small, data saturation was achieved. Results from data were repeated in both the semi-structured interviews as well as data conducted from the focus group.

Data analysis

All data were investigated through qualitative research methods. Both the semi-structured interviews and the focus group were examined and coded according to the QUAGOL principle. All interviews were read thoroughly several times. After compiling narratives reports to conceptual interview schemes and a constantly process of rereading and comparing, coding themes were derived from the data. A cross-analysis of the concepts was proceeded and all concepts were integrated in a conceptual framework in order to obtain a response to the research question. The results were illustrated with quotes to support the data extracted from the interviews. The qualitative data analysis was analysed through the Nvivo 12 Pro software program. A coding tree is added to the appendix.

Research team and reflexivity

Both the semi-structured interviews with the patients and their caregiver as well as the focus group with the GPs were conducted by the author of this qualitative improvement intervention study. At the time of the study, the interviewer was a GP –in– training. The sex of the interviewer is female. The researcher had little experience in conducting semi-structured interviews and observing focus groups but adequate preparations were made in order to guarantee quality of data from the interviews. The patients, caregivers and GPs were aware of the function of the interviewer in their general practice. All participants signed the informed consent and were aware of the purpose of the study.

Ethical aspects

Ethical approval for this qualitative improvement intervention study was given by the ethical committee of the Catholic University of Leuven.

Results

Participant characteristics

In total, fifteen people were included in the intervention study, consisting of eight patients, three caregivers and four GPs. Two patients and one caregiver dropped out after the conversation about ACP with their GP. They preferred not to participate to the semi-structured interview. All participant characteristics are displayed in table 3 and table 4.

Table 3: Summary of patient and caregiver characteristics

Participant characteristics	Patients (N)	Caregivers (N)
Age		
50 – 60 years	/	3
60- 70 years	1	/
70- 80 years	3	/
>80 years	2	/
Sex		
Male	1	1
Female	5	2
ACP in the past		
Yes	/	/
No	6	3
Mentally competent		
Yes	6	/
No	/	
Living at home		/
Yes	6	
No	/	

Legend: N= Number; ACP: Advance care planning

Table 4: Summary of GP characteristics

GP characteristics	GP(N)
Age	
25 – 45 years	3
> 46 years	1
Sex	
Male	3
Female	1
Work experience as GP	
5- 10 years	2
11- 20 years	1
> 20 years	1

Legend: N= number; GP= General practitioner

Experience with the ACP conversation

The GPs stated that the ACP process could be intensive. They experienced it often as time-consuming and stressful. Discussing patients' preferences concerning medical care when their health is deteriorating, is not something that comes spontaneously. It is a subject that needs to be initiated to patients. Thereby, it is difficult to establish a conversation about ACP because patients often do not comprehend the concept which can lead to resistance and fearful reactions and talking about their deteriorating health status or the end of their lives is often frightening for them as well for their family. In addition, initiating and phasing ACP is important to give patients the opportunity to get acquainted with the subject and to reduce their resistance. The GPs also noticed that patients were not used to think about their future selves and expected their GP to take this responsibility.

However, during a dialogue, GPs get to know their patients better by hearing several aspects of their life stories and that makes it very interesting.

> *GP: "My experience? I think it is time-consuming and stressful. You have to plan it a little bit together with the patient, discussing it for a moment. It takes some time. You cannot say: we will do it next week. You have to initiate the subject first. Do you prefer to talk about it or not? I do not always find it easy to implement ACP."*

> *GP: "I think patients themselves do little know about the meaning of ACP. I think it is important to phase ACP. What I do know is, I explain what ACP is and then I immediately start these conversations and ask them what they think about it themselves. It is sometimes too much for patients because they do not know what ACP means and therefore, you see them already going backwards."*

> *GP: "The culture does not allow to say: do you want to be reanimated? I have also had a reaction: "Am I so bad, am I going to die?" (each GP nods yes). Then I explain that that is not the case but it is the intention that counts. If your heart does not beat anymore, would you like to be reanimated or not?"*

The training pointed out the relevance of ACP and they considered that every training gives direction to implement the appropriate approach for approximating problems that physicians are faced with and are stuck with during ACP conversations (as explained before). Every GP has his own interview techniques and if these are never evaluated, they continue to repeat their developed routines. By attending trainings concerning ACP, GPs get acquainted with other angles to improve their communication skills. One GP stated that every training he attends, encourages to do ACP conversations. Another GP stated that the training did not have a significant influence on his way of interviewing, although it was very interesting because of the routine a GP has every day. Especially during the winter months when the workload is excessive, they considered it something to do later and passed it to the background.

> *GP: "The training about ACP demonstrated again the importance of ACP to find out what the person thinks or which questions he has about the end of life and every training reminds me again to do more ACP conversations."*

> *GP: "Every time, new angles concerning interview techniques are passed on to us that are very useful and the training was very interesting but I cannot say that it has had a significant influence on my way of communication. I do not have enough ACP conversations to implement the information that is given at the training."*

Patients and caregivers

Nobody knew the concept of ACP so it was the first acquaintance with this subject. One patient thought she already knew ACP but she confused it with euthanasia. The ACP conversation went very well, according to all patients and caregivers. They were very content that the GP had brought up the subject with them, except for one patient. She did not like to talk about her wishes concerning future medical care because it was an unpleasant subject so she would not do it again. The other patients and caregivers unanimously considered a conversation about ACP very useful. The GPs answered all the patients' curiosities. Discussions with the family were very difficult but after the GP showed the initiative, they appreciated the courage to break up the taboo, which made it easier for them to talk about it.

> *Patient: "People do not talk about it and now, in the presence of the doctor, everything is discussed. I would never talk about my death with my daughter, I find it so strange. Now she knows what I want."*

They also declared that they would have done it earlier, if they knew that ACP existed. One caregiver noticed that it was a lot of information and she easily forgot things. Nevertheless, she was very positive because she had the feeling that both she as her mother were more prepared to what would happen in the future.

> *Caregiver: "It is better to know what you are going to do in advance. And what may happen by the time there is something going on, you are a little bit prepared."*

One patient also described an ACP conversation as a grip or a hold. She was reassured after the AD had been discussed and her wishes were written down.

Perception on education concerning advance care planning for GPs

General practitioners

1. Education about ACP for GPs

Every participating GP emphasized the importance of ACP in general practice since every physician is confronted with patients who have reached the final phase of their life at some point.

> *GP: "Family medicine is very comprehensive, but all your patients die once. Hence, ACP is a subject you can use for every patient."*

When the question 'Which elements about ACP should be discussed in the education of future physicians?' was asked, they all agreed that students should get adequate and sufficient information about ACP with reference to a guideline since none of them had received any form of education about ACP during their medical training. Moreover, education about communication is indispensable. Medical students must be taught how to communicate appropriately with patients with regards to ACP. How can they initiate ACP to patients without worrying them? How do they take care of patients with a low or high educational level? How do students handle resistance? Every GP declared that when they started to talk about ACP, patients were often reluctant to talk.

> *GP: "Which approach do you need to reassure patients? These are communication techniques. I did not receive this kind of information during my training. I think this is important because, as you have seen it yourself, some patients agree immediately to have a talk about ACP but other patients refuse easily. Especially with patients whose health is deteriorating. When I sometimes start to talk about ACP, patients panic and ask me if they are going to die (every GP nods). Sometimes these conversations are very difficult."*

In addition, it is essential to put theory into practise. Students could practise this by doing conversations about ACP in small groups based on a role play. Another suggestion was giving students the opportunity to practise an ACP conversation during their internship in a hospital, for example at the geriatric department. A third idea consisted of presenting cases about ACP from daily practice. By evaluating and discussing these cases, they would learn how to perform ACP with patients.

> *GP: "I think that ACP can be part of an internship of medical students in a hospital. At the geriatric department, you have nurses who asks patients about what they think that is important at the end of life. I think medical students should so do this. You memorise better when you can do things yourself, I think."*

Another suggestion was to incorporate ACP into seminars, which are mandatory for GPs- in- training. They could devote at least one seminar to this subject, preferably not in the first year. This way, junior- doctors have time to do a number of ACP conversations on which they can reflect in group afterwards.

Repetition is essential. Physicians are not confronted with ACP every day, but this is a reason why they need enough practice in advance. For this reason, the participating GPs proposed sufficient attention for ACP during their training in general. On the one hand, this could be achieved by formal trainings, such as a symposium which focuses on ACP. On the other hand, they also emphasized the importance of peer groups. During this kind of meetings, physicians are given the opportunity to exchange and discuss their experiences. Each and every physician agreed that this form of training could be very educational.

> *GP: "ACP is something I do not do every day and I know from experience that I need repetition. That is the reason why I think that a peer group really contributes to memorise the process of ACP. It is also a place where you can discuss certain things with your colleagues. You can hear their opinion. It really works for me."*

Phasing of ACP was an important element that the GP's repeated a couple of times during the interview. From their current experiences, they noticed less resistance and refusal by their patients. In this way, patients get the chance to become acquainted with the concept of ACP gradually. This method is already being used in nursing homes by nurses who are specialised in ACP.

> *GP: "If you start immediately with this conversation about ACP, they take a step back. First, you need to say that ACP exist. After two visits, I repeat the subject, I show them the papers and leave this behind. Then I say: read the papers when you have some time. Next time, we talk about it if you want."*

Therefore, in this approach of phasing ACP, it was suggested during the interview to involve nurses, who are in closer contact with the patient. In this way, they can gauge the attitude of the patients towards ACP and subsequently introduce it gradually to them. Hence, according to the physicians, nurses and GPs could achieve much more together instead of passing on all the information at once and thereby increasing the possibility of resistance and incomprehension.

> *GP: "Like my colleague says, nurses know which patients are accessible to discuss ACP with and which patients are not. If they drop the subject occasionally, then they can gain their confidence gradually. This way, you achieve much more."*

A second idea was to involve junior residents in the hospital. In this way, they can introduce the ACP to the patient. Another suggestion was to appoint a nurse who discusses ACP with the patient and his family or environment, analogous to the method used in the hospital of Sint-Truiden. One GP also proposed to apply to the ambulant palliative support team. They could be helpful in initiating and talking about ACP in the home setting. The participating physicians believed that primary health care workers must be sufficiently aware of ACP. The organisation of courses about this subject would contribute their knowledge about ACP. They also ought it to be important that patients are sensitised about this topic. This can be achieved, for example, by information evenings organized locally. However, only a part of the patient population is interested, but one GP believed that patients often feel more comfortable and safe when participating in a larger group.

2. Outcome of education about ACP

According to each of the four GPs, education about ACP has an effect on the following factors: relationship between the GP and his patient, GPs confidence, quality of the end-of-life conversations, quality of the ACP interview.

Every GP emphasised the positive effect of education about ACP on their relationship with the patient. They also unanimously believed that courses about ACP would increase their confidence and that they would be able to initiate a conversation more easily.

> *GP: "You feel that the other GPs have the same problem. You know that you are not the only one who feels a little uncomfortable with the subject. "*

According to the participating GPs, education could also increase the quality of life when patients have reached the end of life.

> *GP: "I also think that it can be time-saving, if you know the preferences of the patient in advance. Now, we are actually losing time sometimes to make sure that everyone agree."*

Last, they were also convinced that education about ACP would increase the quality of the interview between the GP and the patient.

Patient and caregivers

Both patients as well as caregivers considered education about ACP of GPs important and valuable. In this way, physicians could provide accurate information about ACP through which the patient and his family understand the meaning of ACP. Secondly, attention to communication skills during education was also pivotal.

> *Patient: "It would be very good if the doctors would follow a training about ACP."*
> *Patient: "I think education is important. If you have a question, they can help and answer you better."*

1. Education about ACP for GPs
   a. Knowledge

According to all patients and caregivers, sufficient knowledge about ACP is indispensable in trainings about ACP. GPs must receive adequate information about ACP during education about ACP and they must be able to give appropriate advice to the patient and their families. Therefore, knowledge is the cornerstone. Also, physicians must be capable of guiding patients and their families by providing information about what might happen in the future. Mutual conversation between physicians would also have a beneficial influence on their knowledge.

Patient: "He must know what he is talking about. Doctors must be able to inform you well."

b. Communication skills

All interviewees put emphasis on the communication skills that every physician must acquire. All patients and caregivers considered the physician's empathetic capacity of essential importance. A GP must give the patient his full attention during the conversation and he must be able to actually listen to the patient. The patient's preferences and wishes must be taken into account and they also expect that their physician will execute their decisions when necessary.

> *Patient: "A doctor must be able to listen to his patient. It is difficult to explain. But as a doctor, you maybe think you are important. If you come here, I will listen to you and you have to listen to me. It is true. You are a doctor. But the patient can also tell his opinion, no? It is not about what the doctor wants. It is about what the patients wants. And that is what is it about, right?"*

The character of a person should also be taken into account. Which information can be shared with this patient? Both patients and caregivers indicated that it was important involving their family during the conversation because they are often in close contact with the patient and also often prefer to be informed.

> *Patient: "He did that conversation with me and my daughter was involved with everything he said. I thought that was good. C. was involved the entire conversation, including what he asked for. I have no one but her."*

The physician must provide sufficient time and information must be given in a way that it is comprehensible for the patient.

> *Caregiver: "Every doctor should take his time. It doesn't have to take three hours. But when he leaves and you know everything and you also know that they took their time to give you all this information, it is all right."*

Both patients as well as their caregivers expected their GP to be genuinely honest and they also wanted to be able to rely on their doctor if they have questions.

2. Outcome of education about ACP

The effects of education about ACP of GPs were also discussed during the semi-structured interviews with patients and their caregivers. Four subjects were reviewed: relationship between the GP and his patient, GPs confidence, quality of the end-of-life conversations, quality of the ACP interview. Both patients as well as the caregivers agreed that education about ACP has a positive effect on their relation with their GP.

> *Caregiver: "I do think so. Before, the doctor didn't know my mother's wishes. Now he knows what my mother wants. So, our understanding with our GP also improves. Though, it takes a lot of time and not all GPs have that amount of time."*

The quality of the ACP conversation would also improve if their GP would follow a training about ACP. Two patients considered that education about ACP would increase the quality of life at the end of life. One caregiver believed that education would have a positive effect on the confidence of a GP.

Comparison between patients, caregivers and GPs

Experience about ACP conversation

GPs described ACP as an intensive process because patients often react anxious and prefer not to talk about it initially. Sometimes too much information is provided which can result in adverse effects on patients and therefore, an introduction is preferred to get patients acquainted with ACP. The training they attended was very useful. New insights were provided at each training and it reminded them to reinitiate ACP with patients regularly. However, because of the developed routine and the workload they are faced with every day, they realised that too little ACP conversations are executed through which they easily forget all the gathered information. This is the reason why the training about ACP did not have a significant influence on their way of communicate about ACP with patients. On the contrary, almost all patients and caregivers were satisfied with the conversation. One caregiver stated that the GP had answered all her questions but that the amount of

information was a little bit too much. The conversation gave them the feeling being more prepared to what might happen in the future and also having something to hold on to.

Perception on education about ACP for GPs

Both patients, caregivers and GPs stated that education about ACP for GPs is a necessity. In particular knowledge and communication skills were indispensable. According to all interviewees, GPs must get adequate information about ACP in order to give sufficient information to patients and their caregivers. Communication skills were also of high importance for all respondents. However the content of the communication skills differed slightly between the patients, caregivers and physicians. According to patients and caregivers, doctors must possess empathic capacity. They also have to involve caregivers and family and their information must be in comprehensible language. From their experience in the past, training in communication skills must focus especially on communicating ACP to various types of patients. Because all physicians had experienced resistance when initiating or discussing ACP, they wanted to learn tools to cope with this resistance. All respondents were convinced that education about ACP would have a positive effect on the relationship between the GP and the patient, the quality at the end of life, GP's confidence about ACP and the quality of the ACP conversation. In general, comparison between patients, caregivers and physicians results in good correspondence concerning elements that must be present in the training of ACP for physicians.

Summary key findings
✓ All patients and caregivers experienced the advance care planning conversation as extremely useful.
✓ Although trainings are very educational because of lack of routine, information is often forgotten by which the influence on conversations about advance care planning is rather limited.
✓ Education about advance care planning is of great importance according to general practitioners, patients and caregivers.
✓ Education about advance care planning must provide adequate knowledge and information to improve communication skills.
✓ Involving other health care professionals (e.g. nurses) might positively influence the advance care process in primary care.
✓ Education about advance care planning has a positive effect on the quality of the advance care planning conversation, quality at the end of life, general practitioners' confidence and relationship between general practitioner and the patient.

Discussion

In this qualitative improvement intervention study, we investigated the perception of GPs, patients and caregivers on education ACP among physicians. A GP stated that despite educational level of training concerning ACP, lack of routine in daily practise is often the cause of forgetting all the acquired information. This results in a rather limited effect of education on the ACP process. Several studies confirmed that a lack of time was one the barriers to undertake ACP conversations in general practice.[1, 18-21] Collaboration with other primary HCP and secondary care might contribute to reducing the workload and time pressure concerning ACP executed by physicians was suggested by De Vleminck *et al.* (2014).[21] In general, both patients as caregivers experienced the conversation as agreeable. In the presence of their GP, patients found it easier to talk about their end-of-life treatment. One patient preferred not to talk about het medical wishes anymore because she felt uncomfortable. A study from Schubart *et al.* (2018) showed that ACP conversations had a beneficial influence on the communication about end-of-life treatment wishes between patients and their caregivers. Discomfort about the topic was one of the barriers.[22]

According to all participating GPs, ACP is very important in general practice. Each of the four GPs did not receive any education about ACP as a student and they feel a need of training since discussing treatment at the end of life with their patients is not without difficulties. Improvement of knowledge and communication skills concerning ACP were the main topics. They suggested assessing ACP conversations (during an internship in a hospital) and a role play in small groups to improve their communication capacities. This suggestion was

investigated by Lum *et al.* (2017). They evaluated the implementation of an ACP educational session to teach third-year medical students a value-based ACP process in small groups. More than 90% of the students declared that the session was very educational and useful. They felt also better prepared to discuss ACP with patients.[23] Internal medicine residents felt more confident to initiate ACP conversations after they had followed a novel curriculum about ACP which focused on didactics, a simulated patient communication session and a demonstration of skills. They reported an increased use of the communication skills they were taught during the curriculum.[24] Apart from specific trainings concerning ACP, reflecting and exchanging their experiences with peers was an important element in the education about ACP among GPs. They agreed that hearing other colleagues' experiences and attitudes made a significant contribution to their own knowledge about ACP. These findings are supported by another qualitative study, conducted by Glaudemans *et al.* (2019).[25] Moreover, research showed that personal experience of taking care for someone who reached the end of life, had a positive effect on communication skills and the quality of care. These results support the idea that educational interventions concerning ACP must involve reflection and communication about ACP. The authors also emphasized the importance of incorporating ACP in the education of medical students.[26]

Patients and caregivers preferred a holistic approach of care. They stated that the level of their physicians' knowledge is essential. Exchanging experiences with colleagues has a positive effect on their knowledge. In addition, physicians must possess sufficient communication skills. They have to be able to listen to the patient and his family and give comprehensible information. Involving family, taking the patient's character into account, respecting his or her preferences and open and honest communication were also important. These data were confirmed by findings from literature. Patients and caregivers prefer not only empathic, candid and open lines of communication but also a well-informed physician that focuses of the patient with regard to his wishes and preferences. Involvement of their GP was also primordial.[27-30]

Both GPs as well as patients and caregivers believed that training about ACP would likely have a beneficial influence on GPs confidence, as showed earlier (cfr. introduction).[13-15] The relationship between GPs and patients would also improve. Research showed that end-of-life discussions are associated with a greater trust in their physician. Additionally, ACP would enhance family relationships and would help resolving conflicts between families and HCPs. However, they noticed that ACP could take the family's attention away from patient care.[31-32] Training would also have a positive effect on the quality of the ACP conversation and thereby also increasing quality of life at the end-of-life stage. These findings are confirmed by systematic reviews and meta-analyses. The results showed that interventions focused on end-of-life communication, improved the concordance between delivered care and preferred care at the end of life.[2, 33] So far, no research is done that explored the effect of education about ACP on the relation between GPs and patients.

Multiple suggestions for improving ACP in primary health care according to GPs were introduced. Phasing the ACP process was recommended to allow patients to meet with ACP. Sudore *et al.* showed that applying this method significantly changed the participant's attitude towards ACP.[34] Thereby, nurses should be involved to facilitate this process, which is confirmed by The Federation palliative care of Flanders.[1] The European Association for Palliative Care recommends a trained facilitator (who is not a physician) but supports the patient.[35] Research showed that nurses could play an important role in the ACP process by eliciting care preferences and facilitating communication between family members.[36] Moreover, they were also well positioned to raise awareness among individuals and facilitate the ACP process.[37] However, as described above, nurses' knowledge and confidence regarding ACP often is inadequate. This implicates more education about ACP in education programs for nursing students regarding practical advice about communication and documentation. Research about which methods significantly improves nurses' knowledge and confidence is necessary.[9, 36, 38] Besides helping patients with their AD, nurses could also play a role in facilitating ACP in the environment, such as training according to Boot *et al.* (2016).[39] Subsequently, they suggested also to involve the palliative care team and a role for junior residents in hospitals in the initiation of ACP. A qualitative study conducted by physicians, nurses and social workers showed the benefits and importance of an interprofessional teamwork. By working as a team, different opinions by members of each profession will come together by which improves quality of care.[40] Sensibilising patients, physicians and also nurses and other care providers is essential to raise awareness. As described above, knowledge about ACP is rather low in general among physicians and nurses.[6, 7, 9, 10] GPs also have different views on ACP (cfr. introduction). [4] In asking if they were aware of the concept of ACP, all patients and caregivers responded that it was the first time they heard of it. The Federation of Palliative Care of Flanders and European Association for Palliative Care recommend raising public awareness among patients according to their specific needs.[1, 35]

There were several limitations in this qualitative improvement intervention study. Although data saturation was achieved, the sample size was quite small so results may be incomplete. This was due to several factors. Only four GPs were included who were responsible for recruiting patients and caregivers. After the ACP conversations, two patients and one caregiver preferred not to participate to the semi-structured interviews. Reasons for their abstention included a lack of time to participate and not wanted to discuss their AD. It was also difficult for the participating GPs to include patients and caregivers who met the inclusion criteria, who were willing to do ACP conversations and who wanted to participate to the semi-structured interview afterwards. Next, there was an unequal distribution among patients, caregivers and GPs concerning age and gender. The female gender outnumbered the males in the subpopulation 'patients and caregivers'. Thereby, almost all patients had the age of 70 or more. Just one patient was aged below 70 years. Only two general practices were included in this improvement intervention study. Moreover, these practices are also located in a rural region, so no comparison with a general practice located in an urbanized region was possible. Due to difficult communication during the semi-structured interviews, it is possible that the questions had lost their neutral intonation. Nurses and social workers and specialists were not involved in this qualitative improvement intervention study. Consequently, all these factors can contribute to biasing the results. Thereby, further research with a larger sample size of patients, caregivers, GPs and other HCP including nurses, social workers and specialists is necessary to obtain representable results and to verify these outcomes.

Nonetheless, this intervention study has also several strengths. This is – to the best of our knowledge- one of the first qualitative improvement intervention studies that examines the perception on education among GPs of both GPs as well as patient and caregivers. Multiple subpopulations who are directly and indirectly involved in the ACP process were interrogated. In this way, it was possible to compare the findings from different perspectives. This cleared the road for getting valuable feedback from patients and caregivers concerning the ACP conversation and topics that are of importance for this group. Moreover, these findings can be taken in account to future education programs developed for primary HCPs.

Conclusion

In conclusion, trainings about ACP are very educational but because of the lack of routine, this information is often forgotten by which the influence on discussing ACP is rather limited. Patients and caregivers were very pleased with the way the ACP conversation was executed by their GP, even though the concept was unknown. Education about ACP is necessary in order to improve ACP in general practice. Especially knowledge and communication skills are of essential importance. Knowledge about ACP is the foundation according to GPs. Training about communication skills are also indispensable because every GP experienced difficulties during conversations about end- of- life treatment preferences. Additionally, patients and caregiver emphasized the empathic capabilities that physicians must possess. GP's perspectives concerning training for both medical students, doctors-in-training and GPs were identified and clarified. All participants believed education about ACP would have a positive influence on the interpersonal relationship between the GP and the patient, the quality at the end of life, the quality of the ACP conversation and GP's confidence. Other primary health care workers can play a supporting role in the ACP process and optimizing applied training is necessary. Further research with a larger sample size of all surveyed groups as well as other HCP (e.g. nurses, social workers, specialists) is necessary in order to verify these outcomes.

References

1. Van Mechelen W, Piers R, Van den Eynde J, & De Lepeleire J. Richtlijn Vroegtijdige Zorgplanning. Vilvoorde, Federatie Palliatieve Zorg Vlaanderen vzw. Richtlijnen Palliatieve Zorg. 5-2015. www.pallialine.be.
2. Brinkman-Stoppelenburg, A., Rietjens, J.A., Van der Heide A., The effects of advance care planning on end - of-life care: a systematic review, Palliat Med. 2014; 28: 1000-1025.
3. Conroy S, Fade P, Fraser A, Schiff R., 'Advance care planning: concise evidence-based guidelines.' Clin Med 2009 Feb; 9(1):76-9.
4. De Vleminck, A., Pardon, K., Beernaert, K. Houttekier, D., Vander Stichele, R., Deliens, L., How Do General Practitioners Conceptualise Advance Care Planning in Their Practice? A Qualitative Study, Plos One, 2016, 12pages.
5. Gorman TE, Ahern SP, Wiseman J, Skrobik Y., 'Residents' end-of-life decision making with adult hospitalized patients: a review of the literature.' Acad Med 2005 Jul; 80(7):622-33.
6. Flores, T., Mato, S., Rivero, P., Galan, A., Knowledge and attitudes about advance directives on physicians and nurses, Aten Primaria. 2013 Oct; 45(8):404-8.
7. Champer Blasco, A., Carit Monfort, F., Marquet Palomer, R., Conocimientos y actitudes de los profesionales de los equipos de atencio´n primaria sobre el documento de voluntades anticipadas, Aten Primaria. 2010; 42(9):463–469.
8. Cartwright C., Montgomery J., Rhee, J., Zwar, N., Banbury, A., Medical practioners' knowledge and self-reported practices of substitute decision making and implementation of advance care plans, Internal Medicine Journal, 2014, 44:234-239.
9. Jezewski, M. A., Feng, J. F., Emergency nurses' knowledge, attitudes, and experiential survey on advance directives, Elsevier, Volume 20, Issue 3, August 2007, Pages 132-139.
10. Silva, E., Neves, M., Silva, D., Nurses' perceptions of advance directives, Aten Primaria. 2014; 46(Espec Cong 1):145-149.
11. Wang, C., W., Chan, C., L., W., Chow, A., Y., M., Social workers' involvement in advance care planning: a systematic narrative review, BMC Palliat Care. 2017 Jul 10; 17(1):5.
12. Fulmer, T.; Escobedo, M.; Berman, A.; Koren, M.J.; Hernandez, S.; Hult, A., Physicians' Views on Advance Care Planning and End-of-Life Care Conversations, J Am Geriatr Soc. 2018 Jul;66(6):1201-1205.
13. Walczak, A. , Butow, P.A.,, Bu, S., Clayton, J.M., A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work?, Patient Education and Counseling 99 (2016) 3–16.
14. Detering K, Silvester W, Corke C, Milnes S, Fullam R, Lewis V, et al. Teaching general practitioners and doctors-in-training to discuss advance care planning: evaluation of a brief multimodality education programme. BMJ Support Palliat Care 2014 May 20.
15. Clayton JM, Butow PM, Waters A, et al. Evaluation of a novel individualised communication-skills training intervention to improve doctors' confidence and skills in end-of-life communication. Palliat Med 2013; 3: 585–91.
16. Gutheil IA, Heyman JC. A social work perspective: attitudes toward end-oflife planning. Soc Work Health Care. 2011; 50(10):763–74.
17. Sherwood J. The preparation of advance directives in skilled nursing facilities: social service workers' knowledge and attitudes. Long Beach: California State University; 2012.
18. Fletcher, S., Sinclair, C., Rhee, J., Goh, D., Auret, K., Rural health professionals' experiences in implementing advance care planning: a focus group study, Australian Journal of Primary Health; Collingwood Vol. 22, Iss. 5, (Oct 2016): 423-427.
19. Sharp, T., Malvon, A., Barclay, S., GPs' perceptions of advance care planning with frail and older people: a qualitative study, Br J Gen Pract. 2018 Jan; 68(666): e44–e53.
20. Tilburgs, B., Vernooij-Dassen, M., Koopmans, R., van Gennip, H., Engels, Y., Perry, M., Barriers and facilitators for GPs in dementia advance care planning: A systematic integrative review, PLoS One. 2018 Jun 20;13(6):e0198535.
21. De Vleminck, A., Houttekier, D., Pardon, K., Deschepper, R., Van Audenhove, C., Vander Stichele, R., Deliens, L., Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review, Scand J Prim Health Care. 2013 Dec;31(4):215-26.
22. Schubar, J.,R., Reading, J., M., Penrod, J., Stewart, R.R., Sampath, R., Lehmann, L., S., Levi, B., H., Green, M., J., Family Caregivers' Characterization of Conversations Following an ACP Event, Am J Hosp Palliat Care. 2018 Sep;35(9):1161-1167.

23. Lum, H.D., Dukes, J., Church, S., Abbott, J., Youngwerth, J.M., Teaching medical students about 'The conversation': an interactive value-based advance care planning session, Am J Hosp Palliat Care. 2018 Feb;35(2):324-329.
24. Berns, S.H., Camargo, M., Meier, D.E., Yuen, J.K, Goals of care ambulatory resident education: training residents in advance care planning conversations in the outpatient setting, Journal of Palliative Medicine, 01 December 2017, Vol. 20(12), pp.1345-1351.
25. Glaudemans, J., de Jong, A., Onwuteaka Philipsen, B.D., Wind, J., Willems, D.L., How do Dutch primary care providers overcome barriers to advance care planning with older people? A qualitative study, Family Practice, 2019, Vol. 36, No. 2, 219–224.
26. Wallace, C.L., Cruz-Oliver, D.M., Ohs, J.E., Hinyard, L., Connecting Personal Experiences of Loss and Professional Practices in Advance Care Planning and End-of-Life Care: A Survey of Providers, American Journal of Hospice & Palliative Medicine, 2018, Vol. 35(11) 1369-1376.
27. Davison, S.N., Facilitating Advance Care Planning for Patients with EndStage Renal Disease: The Patient Perspective, Clin J Am Soc Nephrol 1: 1023–1028, 2006.
28. Parker, S.M., Clayton, J.M., Hancock, K., Walder, S., Butow, P.N., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagert, R., Tattersall, M.H., A systematic review of prognostic/end-of-life communication with adults in the advanced stagesof a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information, J Pain Symptom Manage. 2007 Jul;34(1):81-93. Epub 2007 May 25.
29. Johnson, C.E., McVey, P., Rhee, J.J., Senior, H., Monterosso, L., Williams, B., Fallon-Ferguson, J., Grant, M., Nwachukwu, H., Aubin, M., Yates, P., Mitchell, G., General practice palliative care: patient and carer expectations, advance care plans and place of death-a systematic review, BMJ Support Palliat Care. 2018 Jul 25, pii: bmjspcare-2018-001549.
30. Murray, C.D., McDonald, C., Atkin, H., The communication experiences of patients with palliative care needs: A systematic review and metasynthesis of qualitative findings, Palliative and Supportive Care (2015), 13, 369–383.
31. Keary, S., Moorman, S.M., Patient-Physician End-of-Life Discussions in the Routine Care of Medicare Beneficiaries, J Aging Health. 2015 Sep; 27(6):983-1002.
32. Rhee, J.J., Zwar, N.A., Kemp, L.A., Advance care planning and interpersonal relationships: a two-way street, Fam Pract. 2013 Apr; 30(2):219-26.
33. Houben, C.H.M., Spruit, M.A., Groenen, M.T.J., Wouters, E.F.M., Janssen, D.J.A., Efficacy of Advance Care Planning: A Systematic Review and Meta-Analysis, Journal of the American Medical Directors Association, Volume 15, Issue 7, July 2014, Pages 477-489.
34. Sudore, R.L., Schickedanz, A.D., Landefeld, S., Williams, B.A., Lindquist, K., Pantilat, S.Z., Schillinger, D.? Engagement in Multiple Steps of the Advance Care Planning Process: A Descriptive Study Among Diverse Older Adults, J Am Geriatr Soc. 2008 June; 56(6): 1006–1013.
35. Rietjens, J.A., Sudore, R.L., Connolly, M., van Delden, J.J., Drickamer, M.A., Droger, M., van der Heide, A., Heyland, D.K., Houttekier, D., Janssen, D.J.A., Orsi, L., Payne, S., Seymour, J., Jox, R.J., Korfage, I.J., Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care, Lancet Oncol 2017; 18: e543–51.
36. Seymour J, Almack K, Kennedy S (2010) Implementing advance care planning: a qualitative study of community nurses' views and experiences. BMC Palliative Care 9.
37. Splendore, E., Grant, C., A nurse practitioner–led community workshop: Increasing adult participation in advance care planning, Journal of the American Association of Nurse Practitioners, September 2017, Volume29, Issue9, Pages 535-54.
38. Miller, B., Nurses Preparation for Advanced Directives: An Integrative Review, J Prof Nurs. 2018 Sep - Oct; 34(5):369-377.
39. Boot, M., Exploring the district nurse role in facilitating individualised advance care planning, Br J Community Nurs. 2016 Mar;21(3):144-7.
40. Lakin, J.R., Benotti, E., Paladino, J., Henrich, N.n Sanders, J., Interprofessional Work in Serious Illness Communication in Primary Care: A Qualitative Study, J Palliat Med. 2019 Jan 28.
41. Mortelmans, D., Handboek kwalitatieve onderzoeksmethoden, vierde herziene druk, 563 pagina's.
42. Mortelmans, D., Kwalitatieve analyse met Nvivo, tweede herwerkte druk, 2017, 319 pagina's.
43. Tong, A., Sainsbury, P., Craig, J., Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, International Journal for Quality in Health Care; 2007, Volume 19, Number 6: pp. 349–357.

Appendix

Codebook Nvivo 12 Pro

Codebook Nvivo 12 Pro

Perception on education about advance care planning among/for general practitioners: a qualitative intervention improvement study

- Effect educatie rond VZP
    - Arts- patiënt relatie
    - Kwaliteit VZP gesprek
    - Laatste levensfase
    - Zelfvertrouwen arts
- Ervaring VZP gesprek
    - Artsen
        - Aftakelingsproces/taboeonderwerp
        - Cultuur
        - Intensief proces
            - initiëren onderwerp (herhaaldelijk)
            - Tijdsbelastend
            - Veel informatie in een gesprek
        - VZP= onbekend bij een patiënt en mantelzorger
            - Mondelinge bespreking VZP
            - Verwarring wilsverklaring en euthanasie
    - Patiënt en mantelzorger
        - Inhoud VZP gesprek
            - Veel informatie in VZP gesprek
        - Verloop VZP gesprek
        - VZP als houvast
- Implementatie van VZP eerste lijn verbeteren door samenwerking eerste lijn zorgverleners
    - Rol van (thuis)verpleegkundigen
    - Rol van palliatief support team
- Opinie educatie VZP
    - Artsen
        - Ervaring eigen opleiding VZP
        - Opinie educatie VZP
    - Patiënte en mantelzorgers
- Opleiding VZP in eerste lijn
    - Opleiding andere eerste lijn zorgverleners
    - Opleiding artsen
        - Volgens artsen
            - Communicatie in opleiding VZP van artsen
            - Navorming huisartsen
            - Bijscholingen
            - Opleidingen
            - Opleiding ASO's
            - Opleiding basisarts
            - Opleiding HAIO's
            - Overleg tussen artsen onderling
            - Sensibilisering huisartsen
            - VZP formulieren

        - Volgens patiënten en mantelzorgers
            - Communicatievaardigheden
                - Aandacht voor patiënt en omgeving
                - Empathisch vermogen arts
                - Belang van betrekken omgeving
                - Belang van tijd in VZP gesprek
                - Open communicatie naar patiënt omtrent VZP
                - Uitleg op maat van patiënt en mantelzorger
                - Vertrouwensrelatie tussen arts en patiënt
            - Kennis
                - Inhoud VZP
                - Onderling overleg artsen
    - Opleiding patiënten
        - Sensibilisering algemene bevolking

Approval protocol

GROEP BIOMEDISCHE WETENSCHAPPEN
HERESTRAAT 49, O&N II – BUS 700
BE-3000 LEUVEN

English version below.

Ons kenmerk: MP004921
Uw kenmerk: Masterproef studie: Vroegtijdige zorgplanning
Leuven, 19-03-2018

DEFINITIEF GUNSTIG ADVIES

Geachte Geert Goderis
Geachte Lisa Vanbrabant

De Onderwijs-Begeleidings-Commissie voor Medische Ethiek (OBC) heeft in delegatie van het Ethisch Comité voor Onderzoek van de Universitaire Ziekenhuizen KU Leuven (EC) het vermeld protocol onderzocht en besproken op haar vergadering van 19-03-2018

De Commissie heeft geen bezwaar tegen het project mits vertrouwelijke behandeling van de gegevens en naleving van de Belgische wetgeving omtrent privacy.

De Commissie is van oordeel dat er vanuit ethisch standpunt geen bezwaren zijn bij de voorgestelde studie, zoals ze werd beschreven in het protocol. Ze verleent dan ook een gunstig advies over deze studie.

Dit gunstig advies van de Commissie houdt niet in dat zij de verantwoordelijkheid voor de geplande studie op zich neemt. U blijft hiervoor dus zelf verantwoordelijk. 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.

U wordt eraan herinnerd dat bij klinische studies iedere door u waargenomen ernstige verwikkeling onmiddellijk zowel aan de opdrachtgever (desgevallend de producent) als aan het Ethisch Comité moet worden gemeld, ook al is het oorzakelijke verband met de studie onduidelijk.

Dit gunstig advies betreft de indiening van 06-03-2018 en wordt gegeven voor de duur van de Masterproef van de betrokken student(en).

Elke wijziging aan het protocol doet dit gunstig advies vervallen. U dient in dat geval een amendement voor advies voor te leggen aan de commissie die eerder uw dossier goedkeurde.

Met vriendelijke groet,

Prof. Pascal Borry
Voorzitter
Onderwijs-Begeleidings-Commissie voor Medische Ethiek KU Leuven

Aandachtspunten (indien van toepassing)

Het Ethisch Comité wenst de hoofdonderzoeker/promotor van de studie te wijzen op zijn/haar verantwoordelijkheid betreft de privacy van de persoons-/patiëntgegevens bij contact met de patiënt en/of inzage in het elektronisch medisch dossier, inclusief de correcte implementatie hiervan door medewerkers en studenten. Het EC verwijst naar de richtlijnen van ICH/GCP hierover op de website, en benadrukt dat een GCP-opleiding van elke hoofdonderzoeker verwacht wordt. Het EC verwijst tevens naar de Belgische wetgeving (Wet van 8/12/1992 ter bescherming van de persoonlijke levenssfeer en Wet van 22/8/2002 betreffende de rechten van de patiënt).

Bij gebruik van elektronisch medische gegevens is een formeel akkoord van de dienstraad vereist. De opdrachtgever is verantwoordelijk voor de conformiteit van de anderstalige documenten met de Nederlandstalige documenten.

Onderzoek op embryo's in vitro valt onder de wet van 11 mei 2003. Voor dergelijk onderzoek is er naast een positief advies van het Ethisch Comité ook een goedkeuring van de Federale Commissie voor medisch en wetenschappelijk onderzoek op embryo's in vitro noodzakelijk vooraleer dit onderzoeksproject kan doorgaan.

Vooraleer u dierexperimenten mag opstarten is een goedkeuring vereist van de Ethische Commissie Dierproeven (ECD). U dient zich bijgevolg aan te melden bij deze commissie voor het onderdeel met dierproeven en hun adviezen te volgen. Gelieve te noteren dat u het onderzoek pas mag starten nadat u een definitief gunstig advies van deze commissie heeft verkregen.

Onderzoek op humane cadavers vereist een goedkeuring van het Ethisch Comité voor Zorg en Begeleiding. U dient zich bijgevolg aan te melden bij deze commissie en hun adviezen te volgen. Gelieve te noteren dat u het onderzoek pas mag starten nadat u een definitief gunstig advies van deze commissie heeft verkregen.

Over de commissie

De Onderwijs-Begeleidings-Commissie voor Medische Ethiek is een subcommissie van het Ethisch Comité voor onderzoek van de Universitaire Ziekenhuizen KU Leuven.

De Commissie bevestigt dat, in geval van belangenconflict, de betrokken leden niet deelnemen aan de besluitvorming omtrent de studie.

Our reference: MP004921
Your reference: Master's thesis study: Vroegtijdige zorgplanning
Leuven, 19-03-2018

DEFINITIVE FAVOURABLE RECOMMENDATION

Dear Geert Goderis

Dear Lisa Vanbrabant

The Educational Supervisory Committee on Medical Ethics (OBC) has, by delegation of the UZ (University Hospitals) KU Leuven's Research Ethics Committee, (EC) examined and discussed the specified protocol at its meeting of 19-03-2018

The Committee has no objection to the project provided the data is treated confidentially and there

is compliance with Belgian privacy law.

The Committee is of the opinion that from an ethical perspective there are no objections with regard to the proposed study, as described in the protocol. Therefore it also issues a favourable recommendation for this study.

This favourable recommendation issued by the Committee does not mean that it actually assumes responsibility for the planned study. Responsibility for the study remains with the student concerned. Moreover, you must ensure that your opinion as the researcher involved is represented in publications, government reports etc. that are the result of this study.

You are reminded that during clinical studies, you must immediately inform the client (and where appropriate the manufacturer), as well as the Ethics Committee of any serious complications observed, even if the causal link with the study is unclear.

This favourable recommendation relates to the submission on 06-03-2018 and is valid for the duration of the master's thesis of the student or students concerned.

Any change to the protocol cancels this recommendation. In this case you must present

an amendment for recommendation to the committee that previously approved your

file. Kind regards,

Prof. Pascal Borry
Chair
Educational Supervisory Committee on Medical Ethics KU Leuven

---

Points of concern (if applicable)

The Ethics Committee wishes to point out to the principle researcher/supervisor of the study his or her responsibility regarding the privacy of personal/patient data in contacts with the patient and/or consultation of the electronic medical file, including the correct implementation thereof by staff and students. The EC refers to the guidelines for ICH/GCP related to this matter on the website, and emphasises that a GCP training course is expected from each principal researcher. The EC also refers to the Belgian Privacy Law (Law of 8/12/1992 on the protection of privacy and the Law of 22/8/2002 regarding patient rights).

Formal Faculty Council agreement is required for the use of electronic medical data. The client is responsible for ensuring that documents in other languages comply with the Dutch documents.

Embryo in vitro research is subject to the Law of 11 May 2003. In addition to a favourable recommendation by the Ethics Committee, approval by the Federal Commission for Medical and Scientific Research on embryos in vitro is required for this type of research before the research project can proceed.

Before animal experiments may begin approval is required from the Animal Ethics Committee (ECD). Therefore you must register with this committee for the component involving animal experimentation and comply with its recommendations. Please note that you may only begin the study once you have received a definitive favourable recommendation from this committee.

Human cadavers research requires approval from the Ethics Committee for Care and Support.

Therefore you must register with this committee and comply with its recommendations. Please note that you may only begin the study once you have received a definitive favourable recommendation from this committee.

About the committee

The Educational Supervisory Committee on Medical Ethics is a subcommittee of the UZ KU Leuven's Research Ethics Committee.

The Committee confirms that in the event of any conflicts of interest, the members concerned will not participate in the decision-making process related to the study.

Approved protocol

MASTERPAPER PROTOCOL: PROSPECTIVE STUDY

1. APPLICANTS

Protocol - full title	Het effect van educatie van huisartsen op vroegtijdige zorgplanning: een kwaliteitsverbeterend project
Version 1: Date submission	Date:6/03/2018
Version 2: Date resubmission	(to add in case of resubmission) Date:Click here to enter a date.
Version 3: Date third submission	(to add in case of third submission) Date:Click here to enter a date.
Principal Investigator – Promoter	Name: prof. Dr. Geert Goderis
	Telephone: 016/37.72.80; 016/34.14.38
	E-mail: geert.goderis@kuleuven.be
The principal investigator is a health professional according to the Law of 10 May 2015. YES x NO □	
Co-Investigator – Co-Promoter	Name: dr. Theo Raskin
	Telephone: 011 48 59 32
	E-mail: raskin.theo@telenet.be
The co- investigator is a health professional according to the Law of 10 May 2015. YES x NO □	
Sub-investigator – Student(s)	Name: Lisa Vanbrabant
	Student number: r0469289
	Telephone: 0474/24.79.38
	E-mail: lisa.vanbrabant92@gmail.com

2. Background and rationale

Vroegtijdige zorgplanning (VZP) is een continu proces van reflectie en interactie tussen de arts en patiënt inzake voorkeuren en wensen voor toekomstige zorg, wanneer de patiënt niet meer in staat is om zijn wil te uiten. Het is een zeer dynamisch proces waarin zorgnoden en zorgdoelen worden opgenomen in een zorgplan met als doel kwaliteitsvolle zorg te voorzien, aangepast aan de wil van de patiënt. (1)

De voorbije 2 decennia is VZP meer en meer onder de aandacht gekomen. Er zijn tal van studies gepubliceerd met betrekking tot verschillende aspecten van VZP. Tot op heden is er veel onderzoek gebeurd naar interventies die zorgen voor een verbeterde implementatie van VZP. Tamayo- Vela'zquez *et al.* (2008) hebben in een meta-analyse zeven systematic literature reviews onderzocht om na te gaan wat de meest succesvolle interventie is om wilsverklaring te vervolledigen. Het resultaat was dat een combinatie van informatief materiaal en herhaalde gesprekken verspreid over meerdere contact de meest efficiënte methode was om wilsverklaringen te vervolledigen. (2)

Als er wordt gekeken naar educatie van hulpverleners en naar de invloed hiervan op VZP, is de informatie uit de literatuur eerder beperkt. In de richtlijn ' Vroegtijdige zorgplanning', die ontwikkeld is door De Federatie Palliatieve Zorg Vlaanderen, wordt aanbevolen dat hulpverleners zouden moeten opgeleid worden. Tevens wordt erin weergegeven welke elementen een opleiding zou moeten bevatten. (3) In de eerste plaats zouden artsen geëduceerd moeten worden. Zij zijn immers de persoon van wie verwacht wordt dat zij het VZP-proces initiëren. Een arts staat er echter niet alleen voor. Ook verpleegkundigen en andere welzijnswerkers nemen een belangrijke plaats in het proces rond VZP, aangezien ze vaak ook in de persoonlijke levenssfeer van de patiënt betrokken zijn en het VZP-proces kunnen ondersteunen en vergemakkelijken. (1, 4)
In een meta-analyse van Gorman T. et al. (2005) werd o.a. gekeken naar 1) kennis inzake palliatieve zorg en VZP en 2) invloed van educatie op vaardigheden en kennis omtrent palliatieve zorg en VZP bij residenten in het ziekenhuis.(5) Daaruit bleek dat residenten zich vaak onvoorbereid voelden bij het nemen van beslissingen omtrent het levenseinde. Schartz et al. (2003) onderzocht bij 55 afstuderende huisartsen training en begeleiding inzake terminale patiënten. 37% rapporteerde weinig of geen begeleiding en ondersteuning gehad te hebben met betrekking tot zorg bij het levenseinde. (6)
Cartwright *et al.* (2013) onderzocht door middel van een vragenlijst de kennis van huisartsen en specialisten in New South Wales in Australië inzake vroegtijdige zorgplanning. Tevens werd er ook gekeken naar de manier waarop zij deze kennis omzetten naar de praktijk. In Australië is de wetgeving omtrent VZP in iedere staat anders opgesteld. Dit leidt dus tot verschillende begrippen en documentatie. Enerzijds had de meerderheid van artsen hadden al gehoord van de verschillende opties van VZP. Anderzijds varieerde de kennis sterk omtrent de verschillende mogelijkheden van VZP tussen respondenten.
De Vleminck *et al.* (2016) onderzocht door middel van een kwalitatieve studie hoe huisartsen VZP conceptualiseerden, gebaseerd op hun ervaring in de praktijk. Huisartsen onderling hadden zeer uiteenlopende ideeën/ opvattingen omtrent vroegtijdige zorgplanning. De onderzoekers stelden dat een gedeeld akkoord omtrent doelstellingen van VZP noodzakelijk is om een succesvolle uitvoering te garanderen. (8)
Detering *et al.* (2014) onderzocht het effect van een kort multimodaal opleidingsprogramma bij 148 artsen, zowel huisartsen en specialisten in Australië. Het programma bestond uit vooral documentatie doorlezen, het bekijken van een DVD, een interactieve e-simulatie met een patiënt, een workshop en een trainingshandleiding inzake VZP. De artsen hadden na het opleidingsprogramma meer zelfvertrouwen gewonnen om gesprekken rond VZP aan te gaan bij patiënten alsook hun aanpak was verbeterd na de e-simulatie. (9)
Daarnaast zijn er ook een aantal studies uitgevoerd waarbij vooral gekeken werd naar communicatievaardigheden en hoe deze verbeterd konden worden. Clayton *et al.* (2013) ontwierpen voor 22 junior artsen een geïndividualiseerd trainingsprogramma met betrekking tot communicatievaardigheden over het levenseinde. Nadat ze het programma volledig doorlopen was, werd er onder andere gekeken wat het effect was van de training op hun zelfvertrouwen en communicatievaardigheden met betrekking tot gesprekken over het levenseinde. Iedere deelnemer rapporteerde het educatieprogramma als nuttig in hun communicatie naar patiënten toe. (10) Een driedaagse training met specifieke focus op communicatie skills voor palliatieve artsen werd ontworpen om hun communicatievaardigheden te verbeteren. Ook in deze studie werd de training als zeer nuttig beschouwd en had de training een positief effect op het zelfvertrouwen van de artsen. (11)

3. Study objectives

In dit kwaliteitsverbeterend project wil ik onderzoeken wat het effect is van educatie op de kwaliteit van vroegtijdige zorgplanning. Hoe ervaren huisartsen, patiënten en mantelzorgers een gesprek rond vroegtijdige zorgplanning nadat de huisarts een opleiding omtrent vroegtijdige zorgplanning heeft gevolgd?

4. Research Method

Een eerste stap is onderzoeken bij welke patiënten vroegtijdige zorgplanning is uitgevoerd en bij welke patiënten vroegtijdige zorgplanning nuttig zou kunnen zijn. Dit gebeurd aan de hand van een literatuurstudie. Vervolgens wordt ook met de deelnemende huisartsen besproken welke patiënten in aanmerking komen voor deelname aan deze kwalitatieve studie.
Vervolgens volgen de deelnemende huisartsen een opleiding die een dag duurt. Zij nemen deel aan het Symposium Palliatieve zorg – Zorg in verbinding, dat plaatsvindt op 21 april te Sint-Truiden. Hier komt Vroegtijdige zorgplanning uitgebreid aan bod.
De derde stap is door middel van semigestructureerde interviews afnemen bij de deelnemende huisartsen, patiënten en mantelzorgers tot saturatie van data wordt verworven. De semigestructureerde interviews zullen worden afgenomen aan de hand van topiclijsten, opgesteld voor de desbetreffende groepen. (12)
Demografische gegevens zullen genoteerd worden met respect voor de anonimiteit van alle deelnemers (zie ook rubriek ‘ Data storage and management’)

5. Selection and withdrawal of participants

5.1 Inclusion and exclusion criteria

- Inclusie criteria met betrekking tot de artsen
    - Praktijk waar ik mijn huisartsen opleiding zal doen en voltooien
    - Andere praktijken in de omgeving die geïnteresseerd zijn om deel te nemen aan deze kwalitatieve studie
    - Ondertekend informed consent formulier
- Inclusie criteria: patiënten
    - Deelnemende patiënten die het informed consent formulier hebben ondertekend
    - Leeftijd: afhankelijk van resultaten uit de literatuurstudie ‘ Bij welke populatie wordt VZP best uitgevoerd?’
    - Zowel mannen als vrouwen
    - Thuiswonend
    - Wilsbekwaam
- Inclusie criteria: mantelzorger
    - Een persoon uit de naaste sociale omgeving die zorgt voor ondersteuning voor een patiënt met een concrete zorgnood
- Exclusie criteria: artsen
    - Indien informed consent formulier niet wordt ingevuld
    - Indien arts de opleiding om een of andere reden niet kan volgen
- Exclusie criteria: patiënten
    - Wilsonbekwaam
    - Woonzorgcentrum
    - Dementie

5.2 Expected duration

De verwachte duur van dit kwaliteitsverbeterend project is acht maanden met een maximumduur van tien maanden. In deze tijdsspanne wordt zowel de opleiding gevolgd door de deelnemende huisartsen

en worden de semigestructureerde interviews afgenomen bij zowel de deelnemende artsen, geselecteerde patiënten en mantelzorgers.

5.3 Recruitment

In overleg met de deelnemende huisartsen en rekening houdend met de resultaten uit de literatuur omtrent bij welke patiënten vroegtijdige zorgplanning nuttig zou kunnen zijn, zullen geschikte patiënten gecontacteerd worden. Iedere huisarts zal een twee tot viertal patiënten selecteren, afhankelijk van hoe snel saturatie van data zal bereikt worden.
Vervolgens zullen zij door mij (de onderzoeker) indien mogelijk telefonisch en/ of door een bezoek gecontacteerd worden met informatie over het onderzoek. Indien de patiënt wenst deel te nemen, zal tevens een informed consent formulier worden ingevuld.

6. Analysis

Describe the measures taken to avoid, or at least minimize, biases. Give the number of participants to be enrolled, together with the rationale for the sample size. Describe also methods for data analysis.

Het exacte aantal interviews dat zal worden afgenomen is op dit moment nog niet gekend. Er wordt geschat dat per iedere arts die deelneemt, een twee- tot viertal interviews nodig zullen zijn om tot saturatie van de data te komen. Er wordt een schatting gemaakt rond zestien tot twintig interviews.
De analyse van de data zal worden uitgevoerd volgens het QUAGOL principe waarbij iedere stap zal worden doorlopen. (13) Tevens zullen de data ook door een tweede lezer geanalyseerd worden om te vermijden dat de antwoorden teveel genuanceerd worden.

7. Data handling and management

7.1 Data storage and management

In dit kwaliteitsverbeterend project zullen kwalitatieve data verzameld worden. De data zullen geanonimiseerd worden zodat de identiteit niet kan worden achterhaald. De data die verzameld wordt door middel van opname door gebruik van een recorder, zullen via het … principe verwerkt worden. Dit betekent dat de gegevens op een computer gecodeerd en verzameld worden. Deze computer is beveiligd met een wachtwoord zodat toegang door andere gebruikers dan mezelf niet mogelijk zal zijn. De opnames en eventuele papieren nota's die tijdens het coderingsproces mogelijks zullen worden gemaakt, worden na afronding van de studie vernietigd.

7.2 Declaration of Confidentiality and Careful Management of Information and Personal Data

In the framework of his / her Master's thesis, the student(s) will have access to all kinds of data, information, results and documents, including personal data which is not exclusively limited to patient data (the "Information"). In order to ensure the confidentiality of this Information and the privacy of those involved, within the framework of his / her Master's thesis the student(s) should always deal with the Information with the greatest care and discretion.

Data collected in the framework of a Master's thesis, in particular research related to patients and including the collection and analysis of personal data, requires the utmost of care and discretion. Therefore, at all times the student must observe complete confidentiality with respect to the Information he / she has collected during the course of his / her Master's thesis.

In performing this research, the student(s) commit(s) him/herself to the following confidentiality obligations:

- *He / she accepts, during and after the completion of the Master's thesis, the obligation to strictly observe the confidentiality of the Information he / she has collected and the activities to which he / she has participated, and regarding the patients, healthy volunteers and the staff members with whom he / she comes into contact;*
- *He / she will only process and collect data that is relevant and necessary for his / her Master's thesis;*
- *He / she will not share information with persons not directly involved within the framework of his / her research;*

- *He / she will take all necessary steps to protect the confidentiality of Information and the privacy of those involved;*
- *He / she will handle with care and responsibility the Information and the access granted to him/her to information systems and digital media.*

All investigators shall treat all information and data relating to the study as confidential and shall not disclose such information to third parties or use such information for any purpose other than the performance of the study. The collection, processing and disclosure of personal data, such as participants' health and medical information, is subject to compliance with applicable personal data protection legislation.

8. Assessment of RISKS and Safety

Er zijn geen gezondheidsrisico's verbonden aan deze kwalitatieve studie.

9. Approval

Hereby we confirm that data collection is performed with approval of the head of the respective unit(s) or department(s) where data collecting is taking place.

10. Publication Policy

Publications will be coordinated by the Principal Investigator. Authorship to publications will be determined in accordance with the requirements published by the International Committee of Medical Journal Editors and in accordance with the requirements of the respective journal.

11. Direct access to source data and documents

The investigator(s) and the institution(s) will permit study-related monitoring, audits, ethical review and regulatory inspections (where appropriate) by providing direct access to source data.

12. References

1. Van Mechelen W, Piers R, Van den Eynde J, & De Lepeleire J. Richtlijn Vroegtijdige Zorgplanning. Vilvoorde, Federatie Palliatieve Zorg Vlaanderen vzw. Richtlijnen Palliatieve Zorg. 5-2015. www.pallialine.be.
2. Tamayo- Vela'zquez, M., I., Simo'n- Lorda, P., Villegas- Portero, R., Higueras- Callejo'n, C., Garcı´a-Gutie´ rrez, J.,F., Martı´nez-Pecino, F., Barrio-Cantalejo, I., M., 'Interventions to promote the use of advance directives: An overview of systematic reviews', Patient Education and Counseling 80 (2010) 10–20.
3. Harle I, Johnston J, MacKay J, Mayer C, Russell S, Zwaal C. Advance care planning with cancer patients: guideline recommendations (Evidence-based series; no. 19-1). Toronto (ON): Cancer Care Ontario (CCO); 2008 Jan 28.
4. Conroy S, Fade P, Fraser A, Schiff R., 'Advance care planning: concise evidence-based guidelines.' Clin Med 2009 Feb; 9(1):76-9.
5. Gorman TE, Ahern SP, Wiseman J, Skrobik Y., 'Residents' end-of-life decision making with adult hospitalized patients: a review of the literature.' Acad Med 2005 Jul; 80(7):622-33.
6. Schwartz CE, Goulet JL, Gorski V, Selwyn PA.Medical residents' perceptions of EOL training in a large urban teaching hospital. J Palliat Med. 2003; 6:37–44.
7. Cartwright C., Montgomery J., Rhee, J., Zwar, N., Banbury, A., Medical practioners' knowledge and self-reported practices of substitute decision making and implementation of advance care plans, Internal Medicine Journal, 2014, 44:234-239.

8. De Vleminck, A., Pardon, K., Beernaert, K. Houttekier, D., Vander Stichele, R., Deliens, L., How Do General Practitioners Conceptualise Advance Care Planning in Their Practice? A Qualitative Study, Plos One, 2016, 12pages.
9. Detering K, Silvester W, Corke C, Milnes S, Fullam R, Lewis V, et al. Teaching general practitioners and doctors-in-training to discuss advance care planning: evaluation of a brief multimodality education programme. BMJ Support Palliat Care 2014 May 20.
10. Clayton JM, Butow PM, Waters A, et al. Evaluation of a novel individualised communication-skills training intervention to improve doctors' confidence and skills in end-of-life communication. Palliat Med 2013;3:585–91.
11. Clayton JM, Adler JL, O'Callaghan A, et al. Intensive communication skills teaching for specialist training in palliative medicine: development and evaluation of an experiential workshop. J Palliat Med 2012;15:585–91.
12. Mortelmans, D., Handboek kwalitatieve onderzoeksmethoden, Acco, 2013, 563 pagina's.
13. Dierckxde CasterleB, GastmansC, Bryon E, Denier Y. QUAGOL: a guide for qualitative data analysis. IntJ NursStud. 2012;49(3):360-71.

13. Annexes

INFORMATIEFORMULIER

'HET EFFECT VAN EDUCATIE VAN HUISARTSEN OP VROEGTIJDIGE ZORGPLANNING: EEN KWALITEITSVERBETEREND PROJECT'

Promotor:
Prof. Dr. Geert Goderis
KU Leuven - ACHG
UZ Leuven - MIR
Kapucijnenvoer 33 Blok J
Bus 7001
3000 Leuven

Co-promotor:
Dr. Theo Raskin
Sint-Jansberg 4
3800 Engelmanshoven

Onderzoeker:
Lisa Vanbrabant
Huisarts-in-opleiding
Katholieke Universiteit van Leuven

Achtergrond en doel van de studie

Vroegtijdige zorgplanning is een continu proces van reflectie en interactie tussen de arts en patiënt inzake voorkeuren en wensen voor toekomstige zorg, wanneer de patiënt niet meer in staat is om zijn wil te uiten. Het is een zeer dynamisch proces waarin zorgnoden en zorgdoelen worden opgenomen in een zorgplan met als doel kwaliteitsvolle zorg te voorzien, aangepast aan de wil van de patiënt.
De voorbije 2 decennia is vroegtijdige zorgplanning meer en meer onder de aandacht gekomen. Er is tot op heden reeds veel onderzoek uitgevoerd om vroegtijdige zorgplanning te verbeteren. Zo is uit onderzoek gebleken dat gesprekken met betrekking tot vroegtijdige zorgplanning best over meerdere contactmomenten worden verspreid en mondelinge conversaties best worden ondersteund door middel van informatief materiaal onder de vorm van brochures etc.
Daarnaast hebben onderzoekers ook het effect van opleiding van zowel artsen als patiënten omtrent vroegtijdige zorgplanning bestudeerd. In de richtlijn ' Vroegtijdige zorgplanning' van De Federatie Palliatieve Zorg Vlaanderen, wordt opleiding van hulpverleners aanbevolen. In de eerste plaats is training van artsen van belang, aangezien zij de persoon zijn die het proces rond vroegtijdige zorgplanning vaak initiëren.
Echter heeft onderzoek aangetoond dat enerzijds artsen zich vaak onvoorbereid voelen in het nemen van beslissingen rond het levenseinde. Ook hebben de artsen vaak weinig of geen opleiding gehad wanneer het gaat over zorg rond en bij het levenseinde. Daarnaast hebben artsen niet altijd hetzelfde

idee over vroegtijdige zorgplanning en meestal vloeit dit voort uit eigen ervaring. Anderzijds blijkt uit onderzoek dat als artsen een opleidingsprogramma volgen, dit een positief effect heeft op zowel het zelfvertrouwen van de arts om een gesprek over het levenseinde te beginnen alsook een gunstig effect op hun communicatievaardigheden.

In dit kwaliteitsverbeterend project wil ik kijken wat het effect is van educatie op de kwaliteit van vroegtijdige zorgplanning. Hoe ervaren zowel huisartsen, patiënten en mantelzorgers een gesprek rond vroegtijdige zorgplanning nadat de huisarts een opleiding omtrent vroegtijdige zorgplanning heeft gevolgd?

.

Implicaties voor de deelnemer

De artsen dienen een opleiding te volgen omtrent vroegtijdige zorgplanning. Daarna zal iedere deelnemende arts met een aantal patiënten een gesprek rond vroegtijdige zorgplanning voeren. Vervolgens neem ik bij zowel artsen, patiënten en mantelzorgers een interview af om na te gaan hoe zij het gesprek ervaren hebben, wat hun indrukken zijn etc. Dit zal ongeveer een uur in beslag nemen. Indien u, nadat u akkoord bent gegaan om deel te nemen aan de studie, toch niet wenst deel te nemen, is dit geen probleem. De gegevens zullen anoniem verwerkt worden.

Indien er nog bijkomende vragen zouden zijn, kan u mij altijd contacteren.

FACULTEIT GENEESKUNDE

Vakgroep Academisch Centrum voor Huisartsengeneeskunde

Onderzoeker Lisa Vanbrabant

INFORMED CONSENT

Ik, ondergetekende, …….. verklaar hierbij dat ik, als deelnemende huisarts bij dit kwaliteitsverbeterend project omtrent het effect van educatie op vroegtijdige zorgplanning

(1) de uitleg over de aard van het onderzoek en de vragen die tijdens dit onderzoek zullen worden aangeboden heb gekregen en dat mij de mogelijkheid werd geboden om bijkomende informatie te verkrijgen

(2) geheel uit vrije wil deelneem aan het onderzoek

(3) de toestemming geef aan de onderzoeker om mijn gegevens en resultaten op anonieme en vertrouwelijke wijze te bewaren, te verwerken en te rapporteren

(4) op de hoogte ben van de mogelijkheid om mijn deelname aan het onderzoek op ieder moment stop te zetten en dit zonder opgave van reden

(5) ervan op de hoogte ben dat ik op aanvraag een samenvatting van de onderzoeksbevindingen ter beschikking kan krijgen

Gelezen en goedgekeurd op …….. (datum),

Handtekening deelnemende huisarts

FACULTEIT GENEESKUNDE

Vakgroep Academisch Centrum voor Huisartsengeneeskunde

Onderzoeker Lisa Vanbrabant

INFORMED CONSENT

Ik, ondergetekende, …….. verklaar hierbij dat ik, als deelnemende patiënt bij dit kwaliteitsverbeterend project omtrent het effect van educatie op vroegtijdige zorgplanning

(1) de uitleg over de aard van het onderzoek en de vragen die tijdens dit onderzoek zullen worden aangeboden heb gekregen en dat mij de mogelijkheid werd geboden om bijkomende informatie te verkrijgen

(2) geheel uit vrije wil participeer aan het onderzoek

(3) de toestemming geef aan de onderzoeker om mijn gegevens en resultaten op anonieme en vertrouwelijke wijze te bewaren, te verwerken en te rapporteren

(4) op de hoogte ben van de mogelijkheid om mijn deelname aan het onderzoek op ieder moment stop te zetten en dit zonder opgave van reden

(5) ervan op de hoogte ben dat ik op aanvraag een samenvatting van de onderzoeksbevindingen ter beschikking kan krijgen

Gelezen en goedgekeurd op …….. (datum),

Handtekening deelnemende patiënt

FACULTEIT GENEESKUNDE

Vakgroep Academisch Centrum voor Huisartsengeneeskunde

Onderzoeker Lisa Vanbrabant

INFORMED CONSENT

Ik, ondergetekende, …….. verklaar hierbij dat ik, als deelnemende mantelzorger bij dit kwaliteitsverbeterend project omtrent het effect van educatie op vroegtijdige zorgplanning

(1) de uitleg over de aard van het onderzoek en de vragen die tijdens dit onderzoek zullen worden aangeboden heb gekregen en dat mij de mogelijkheid werd geboden om bijkomende informatie te verkrijgen

(2) geheel uit vrije wil deelneem aan het onderzoek

(3) de toestemming geef aan de onderzoeker om mijn gegevens en resultaten op anonieme en vertrouwelijke wijze te bewaren, te verwerken en te rapporteren

(4) op de hoogte ben van de mogelijkheid om mijn deelname aan het onderzoek op ieder moment stop te zetten en dit zonder opgave van reden

(5) ervan op de hoogte ben dat ik op aanvraag een samenvatting van de onderzoeksbevindingen ter beschikking kan krijgen

Gelezen en goedgekeurd op …….. (datum),

Handtekening deelnemende mantelzorger

FACULTEIT GENEESKUNDE

Vakgroep Academisch Centrum voor Huisartsengeneeskunde

Onderzoeker Lisa Vanbrabant

INFORMED CONSENT

Ik, ondergetekende, Lisa Vanbrabant verklaar hierbij dat ik, als onderzoeker van dit kwaliteitsverbeterend project mondeling de nodige informatie heb gegeven over dit kwaliteitsverbeterend project, dat ik een kopie heb gegeven van de informatie- en toestemmingsfolder die door de verschillende partijen werd ondertekend, dat ik bereid ben om zo nodig alle aanvullende vragen te beantwoorden en dat ik geen druk op de patiënt uitgeoefend heb om aan de studie deel te nemen. Ik verklaar dat ik werk volgens de ethische principes die worden beschreven in de Verklaring van Helsinki en de Belgische wet van 7/5/2004 over proeven op mensen.

Handtekening onderzoeker

Het effect van educatie van huisartsen op vroegtijdige zorgplanning: een kwaliteitsverbeterend project

Vragenlijst semigestructureerd interview

Huisartsen

Drop- off: algemene gegevens

1. Geslacht:
   □ Man □ Vrouw
2. Leeftijd:
   □ 25-30 jaar □ 30- 35 jaar □ 35- 40 jaar □ 40- 50 jaar □ 50- 60 jaar □ > 60 jaar
3. hoe lang werkzaam als huisarts:
   □ < 5 jaar □ 5-10 jaar □ 10- 15 jaar □ 15- 20 jaar □ > 20 jaar

Topiclijst

Thema 1: Ervaring met vroegtijdige zorgplanning (VZP)

- Wat is uw ervaring met VZP tot nu toe?
- Heeft u het gevoel dat u voldoende kennis hebt omtrent VZP om een goed VZP-gesprek te voeren?

Thema 2: Educatie omtrent vroegtijdige zorgplanning

- Heeft u tijdens je opleiding tot huisarts geïnformeerd geweest over vroegtijdige zorgplanning?
- Heeft u tijdens de praktijkvoering bijscholingen gevolgd omtrent vroegtijdige zorgplanning?

Thema 3: Effect van educatie op vroegtijdig zorgplanningsgesprek

- Heeft het volgen van de opleiding een invloed op het voeren van een vroegtijdig zorgplanningsgesprek?
    - Effect op zelfvertrouwen met betrekking tot vroegtijdige zorgplanning
    - Effect op communicatie met betrekking tot vroegtijdige zorgplanning

Thema 4: Implicatie van opleiding vroegtijdige zorgplanning

- Denkt u dat educatie met betrekking tot vroegtijdige zorgplanning kan bijdragen tot een betere kwaliteit van vroegtijdige zorgplanning?

Vragenlijst semigestructureerd interview

Patiënten

Drop- off: algemene gegevens

1. Geslacht:
   □ Man □ Vrouw
2. Leeftijd:
   □ 25-30 jaar □ 30- 35 jaar □ 35- 40 jaar □ 40- 50 jaar □ 50- 60 jaar □ > 60 jaar

Topiclijst

Thema 1: Ervaring met vroegtijdige zorgplanning (VZP)

- Wat is uw ervaring met VZP tot nu toe?

Thema 2: Educatie omtrent vroegtijdige zorgplanning

- Heeft u ooit al informatie gekregen over vroegtijdige zorgplanning?

Thema 3: Effect van educatie op vroegtijdig zorgplanningsgesprek

- Denkt u dat het volgen van de opleiding een invloed op het voeren van een vroegtijdig zorgplanningsgesprek?
  - Effect op zelfvertrouwen met betrekking tot vroegtijdige zorgplanning
  - Effect op communicatie met betrekking tot vroegtijdige zorgplanning

Thema 4: Implicatie van opleiding vroegtijdige zorgplanning

- Denkt u dat educatie met betrekking tot vroegtijdige zorgplanning kan bijdragen tot een betere kwaliteit van vroegtijdige zorgplanning?

Vragenlijst semigestructureerd interview

Mantelzorger

Drop- off: algemene gegevens

3. Geslacht:
   □ Man □ Vrouw
4. Leeftijd:
   □ 25-30 jaar □ 30- 35 jaar □ 35- 40 jaar □ 40- 50 jaar □ 50- 60 jaar □ > 60 jaar

Topiclijst

Thema 1: Ervaring met vroegtijdige zorgplanning (VZP)

- Wat is uw ervaring met VZP tot nu toe?

Thema 2: Educatie omtrent vroegtijdige zorgplanning

- Heeft u ooit al informatie gekregen over vroegtijdige zorgplanning?

Thema 3: Effect van educatie op vroegtijdig zorgplanningsgesprek

- Denkt u dat het volgen van de opleiding een invloed op het voeren van een vroegtijdig zorgplanningsgesprek?
  - Effect op zelfvertrouwen met betrekking tot vroegtijdige zorgplanning
  - Effect op communicatie met betrekking tot vroegtijdige zorgplanning

Thema 4: Implicatie van opleiding vroegtijdige zorgplanning

- Denkt u dat educatie met betrekking tot vroegtijdige zorgplanning kan bijdragen tot een betere kwaliteit van vroegtijdige zorgplanning?