

# Community nurses' perceptions on the use of advance care planning: a qualitative study

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Name Student	E.A Groenewegen
Student-number	6398839
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University	Utrecht University
Master	Clinical health science
Master program	Nursing Science, UMC Utrecht
Supervisors	I. van Doorne & M. van Rijn
Lecturer	J. van Dijk
Internship Institution	Amsterdam UMC
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## Abstract English

**Background:** In order to meet the needs of patients, it is important that healthcare professionals know what these needs are. Advance care planning (ACP) is a method for recording those needs and preferences with the patient. ACP could decrease uncomfortable life-sustaining treatment and care transitions in the palliative phase, reduce stress and anxiety and increase the chance of dying at the preferred place. The frequency of ACP conversations remains low and is often conducted late in the disease trajectory. Community nurses seem suitable to carry out ACP because of their patient population and holistic vision, but research of ACP in community care is lacking. Insight in perceptions of community nurses could create potential improvements which can contribute to the feasibility of ACP.

**Objective:** Explore perceptions of community nurses towards the use of ACP.

**Methods:** A qualitative descriptive exploratory research design, in which bachelor degree nurses participated, was conducted. Thematic analysis was used to identify themes.

**Results:** Fifteen community nurses from eight different home healthcare organisations were individually interviewed. Six themes were identified after analysis: nurses' own beliefs towards ACP, time to start ACP, prerequisites for the use of ACP, collaboration between involved professionals in ACP, carrying out ACP and ACP as part of usual community care.

**Conclusion:** Six themes regarding perceptions of community nurses on ACP were found: it is thought to be a tough topic, timing of ACP, the need for a trust-based therapeutic relationship, sufficient time, collaboration with other disciplines and too little awareness in home healthcare organisations with no available methods and tools.

Community nurses are suitable to conduct ACP because they have time to carry out ACP and the opportunity to build a trust-based relationship with patients. Training and tools are necessary to support community nurses in ACP.

**Keywords:** *Advance care planning, community nurses, qualitative research*

## Samenvatting Nederlands

**Achtergrond:** Om tegemoet te komen aan behoeften van patiënten, is het belangrijk dat zorgprofessionals deze behoeften kennen. Advance care planning (ACP) is een methode om die behoeften en voorkeuren van de patiënt vast te leggen. ACP zou stress, angst en in de palliatieve fase oncomfortabele levensverlengende behandelingen en opnames kunnen verminderen en de kans op overlijden op gewenste plaats kunnen vergroten. Maar de frequentie van ACP gesprekken blijft laag en wordt vaak/ laat in het ziekteverloop uitgevoerd. Wijkverpleegkundigen lijken geschikt om ACP te gebruiken vanwege hun patiëntenpopulatie en holistische visie, maar onderzoek ontbreekt hierin. Inzicht in de perceptie van wijkverpleegkundigen zou kunnen leiden tot mogelijke verbeteringen die kunnen bijdragen aan de uitvoerbaarheid van ACP.

**Doelstelling:** Onderzoeken van de percepties van wijkverpleegkundigen ten aanzien van het inzetten van ACP.

**Methode:** Een kwalitatief, beschrijvend en verkennend onderzoeksdesign werd gebruikt met een doelgerichte steekproef voor bachelor wijkverpleegkundigen. Thematische analyse is gebruikt bij het analyseren van de data.

**Resultaten:** Vijftien wijkverpleegkundigen, van acht verschillende thuiszorgorganisaties, zijn individueel geïnterviewd. Na analyse van de interviews werden zes thema's geïdentificeerd: eigen opvattingen van wijkverpleegkundigen ten aanzien van ACP, tijd om met ACP te starten, voorwaarden voor het gebruik van ACP, samenwerking tussen betrokken professionals bij ACP, uitvoeren van ACP en ACP als onderdeel van de gebruikelijke thuiszorg.

**Conclusie:** Zes thema's over de perceptie van het inzetten van ACP zijn gevonden: ACP wordt ervaren als zwaar onderwerp, timing van ACP, vertrouwensrelatie, voldoende tijd beschikbaar, samenwerking met andere disciplines en te weinig bewustzijn in thuiszorgorganisaties waarbij methoden en middelen onvoldoende beschikbaar zijn. Wijkverpleegkundigen zijn zeer geschikt voor ACP omdat ze tijd hebben om ACP uit te voeren en de mogelijkheid hebben om een vertrouwensrelatie op te bouwen met de patiënt. Training en hulpmiddelen zijn nodig om wijkverpleegkundigen te ondersteunen in ACP.

**Trefwoorden:** *advance care planning, wijkverpleegkundigen, kwalitatief onderzoek*

## Introduction

In The Netherlands more than 50% of the population suffers from one or more chronic diseases<sup>1</sup>. This number will increase due to the ageing population<sup>2-4</sup>. Disease progression may lead to a variety of symptoms which can substantially reduce quality of life<sup>5</sup>. Patients can face treatment decisions throughout the disease course<sup>5</sup>. To support patient to well-considered treatment decisions and focus care on quality of life, it is essential that healthcare professionals know what is important for patients before patients lose their ability to make decisions. A method for this is advance care planning (ACP)<sup>6</sup>. ACP enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences when appropriate<sup>6</sup>. ACP consists of physical, psychological, social and spiritual domains<sup>7</sup>. It potentially contributes to quality of life because it helps to decrease life-sustaining treatment and transition in the last months of life<sup>8</sup>. ACP can also reduce stress, anxiety and depression for the patient and family<sup>4,9</sup>. Moreover, it can increase the chance of dying at the place of the patient's choice<sup>4</sup>. A population where ACP can be used early and widely would be frail elderly living at home because of the risk of health deterioration and the increasing wish to die at home<sup>10</sup>.

Despite positive effects, the frequency of ACP conversations between patients and health care professionals remains low in clinical practice<sup>5,11-14</sup>. ACP is generally initiated late in the disease trajectory and is mainly carried out with patients diagnosed with cancer even though the goal of ACP is for conversations to be held before acute or life-threatening situations occur, irrespective of the type of illness<sup>15</sup>. Research into the use of ACP has mainly focussed on perceptions of general practices (GP), possibly because patients and healthcare professionals believe that the GP should have a prominent role in ACP<sup>16,17</sup>. Although involvement of a GP in the ACP process is indispensable, a purely physician-driven approach can lead to medically oriented ACP conversations that are often conducted late in the disease trajectory<sup>18</sup>. Wishes and goals of a non-medical nature should also be addressed in ACP<sup>19</sup>. Therefore, it can be meaningful that community nurses carry out ACP more frequently because of their holistic vision<sup>18,20</sup>. Furthermore, community nurses have expertise at establishing relationships with patients and their families which is the essence of good palliative care provision<sup>21,22</sup>.

However, little is known about the use of ACP by community nurses. Only two studies were found. Blackford & Street (2013) suggested that nurses did not feel competent and confident enough to initiate ACP and they were convinced that ACP conversations were the work of social workers or counsellors<sup>23</sup>. Seymour (2010) found that it is challenging to use ACP with the right timing, team work, policy focus and managing differences in patients' and families'

views<sup>24</sup>. Barriers to conducting ACP were lack of resources and public awareness about ACP and difficulties in talking about death by the nurses<sup>24</sup>. Both study samples were based on perspectives of specialist palliative care nurses<sup>23,24</sup>. Nurse specialists often only conduct consultations and specialist palliative care nurses are involved late, after a palliative diagnoses. Since regular non-specialized nurses deliver basic care where relationships will be established and are the first point of contact for patients, it is relevant to explore their perceptions of ACP. Moreover, the studies<sup>23,24</sup> cannot be generalized to The Netherlands because of differences in healthcare system per country.

To discuss needs and preferences with patients more frequently and earlier in the disease trajectory, insight in community nurses' perceptions of ACP is necessary. This could create insight in potential improvements which could contribute to the feasibility of ACP by community nurses.

### *Objective*

The objective is to explore the perceptions of the community nurses in The Netherlands towards the use of ACP to improve the feasibility of ACP in the community care.

# Method

## *Design*

A qualitative descriptive exploratory research design was used with semi structured interviews<sup>25</sup>. This design was deemed appropriate since the goal was to understand the context by factual responses to questions about feelings, perspectives, reasons and factors of the use of ACP<sup>26,27</sup>. The COREQ checklist was followed for transparent reporting of the study<sup>28</sup>.

## *Domain & population*

The domain of the study existed of general community nurses from The Netherlands. Community nurses who were (a) working at bachelor degree level, (b) non specialized and (c) working in a regular community care team were approached. The bachelor degree level meant they are responsible for the coordination and identification of care<sup>29</sup>. Bachelor degree nurses are involved in patient needs and are therefore more likely to handle conversations such as ACP than associate degree nurses. The non-specialized and regular care team characteristics of the population were important to understand the perspectives of nurses without specialization in order to create a sample that could be generalized to the current population of community nurses.

Nurses were recruited via the researcher's own network according to the network-method<sup>27</sup> with a purposeful sampling approach. Purposeful sampling was performed to create a heterogenic sample with variation based on different home healthcare organisations, variety in provinces and home care teams in urban and country areas. Sampling continued until no new themes emerged in the data analysis and two more interviews were performed to confirm datasaturation<sup>30</sup>.

## *Data collection & procedures*

Potential participants were approached by e-mail with information about the study and an invitation for an interview. Interviews were performed between February and April 2021. These one-to-one semi-structured interviews were guided by the topic list in Table 1. The topic list was based on previous literature about perceptions and practices of ACP in other health care settings<sup>24,31-34</sup>. A pilot interview was held to check the interview guide and the duration. Each interview was conducted by the main researcher and discussed afterwards with the research team for feedback. At the start of each interview, the study procedures as outlined in the e-mail were repeated, the participant was asked for permission to record the interview, and informed consent (IC) was obtained. The interviews were conducted online by video calling and were tape-recorded. Within three weeks after the interview, transcripts were

made and sent to participants for member verifications.

<Table 1>

### *Data analysis*

The data was analysed using the spiral of analysis of Boeije 2010 consisting of open coding (segmenting), axial coding (describing categories) and selective coding (reassembling)<sup>27</sup>.

The data analysis started during the data collection, so the interview guide could be adjusted in order to obtain appropriate data.

In the first phase of the analysis, the data was read carefully and divided into fragments. The fragments were compared with each other, grouped into categories that dealt with the same subject, and labelled with a code resulting in a coding scheme<sup>27</sup>. Coding was done openly by using MAXQDA, without having pre-determined themes. To ensure certain fragments were systematically assigned to the coded code, the first four interviews were independently coded by the supervisor and the main researcher to ensure inter-rater reliability<sup>27</sup>. Differences in coding were discussed after which consensus was reached. Subsequent interviews were coded by the main researcher only.

In the second phase, categories were linked<sup>27</sup>. In axial coding a distinction was made between categories that might fulfil an important role in the definitive findings and categories that were grouped around particular categories in order to determine which elements in the research were dominant and which were less important<sup>27</sup>. In the final phase, selective coding was fulfilled<sup>27</sup>. Connections between the categories were examined in order to make sense of what is happening in the field<sup>27</sup>. This phase was also conducted and discussed with the supervisor and consensus was reached about all the themes.

### *Ethical considerations*

This study has a non-WMO character and was conducted according to the principles of the Declaration of Helsinki (version October 2013). The METC was not requested because there were non sensitive topics or patients involved. IC was obtained verbally and saved on the tape and transcript. The transcripts were made anonymous by removing names. All data was treated confidentially.

## Results

In total 20 community nurses were personally invited to participate in the study. Two nurses did not respond, while the other nurses were all willing to participate. Data collection was completed after fifteen interviews since adequate data saturation had been reached and a varied sample was achieved. The final sample included fourteen woman and one man. Their age ranged from 23 to 63 years. Work experience at bachelor degree level varied from one to twenty years. The sample included eight different home healthcare organisations with a maximum of three nurses from one organisation. The community care teams were spread over seven different provinces of The Netherlands with a maximum of four in one province. There was an equal distribution between rural and urban work environments. The participants' characteristics are summarized in Table 2. The interviews lasted an average of 46 minutes, with a minimum duration of 28 minutes and a maximum of 57 minutes.

<Table 2 >

### *Themes*

Six major themes related to the perceptions of the use of ACP by community nurses were identified: nurses' own beliefs towards ACP, time to start ACP, prerequisites for the use of ACP, collaboration between involved professionals in ACP, performing ACP and ACP as part of usual community care.

### *Nurses' own beliefs towards ACP*

The participants' attitude to the concept of ACP was positive and they found it important to use. Participants' motivation was to create peace of mind for patients and families, meet patients' preferences and talk about the disease process and capabilities of the home healthcare team. Not every participant was familiar with the exact meaning of ACP. Some participants realized they had more experience than they previously thought. This was because they thought ACP had to be used in a certain way that was not available in their organisation.

The participants found ACP a tough topic to talk about and did not want to cause sadness or anxiety. Participants commented that it is sometimes difficult to find the right moment to discuss ACP while they generally felt competent enough to have ACP conversations and were not afraid to talk about death.

*P4: "So, how should I explain, it is not awkward but it feels like, like you are going to convey a sad mood when you do not want to."*



### *Time to start ACP*

Some participants said it was difficult to find the right time to initiate ACP. Cited starting signals were mentioned when the patients' health deteriorated, in crisis situations or in palliative or terminal care. However, some participants said that ACP conversations needed to start when quality of life became the focus of care. But mostly, when participants spoke about examples when they carried out ACP, it was in the terminal phase. Participants mentioned that they often conduct ACP discussions too late.

P6: *"But in the end it is just very nice for the client to have everything properly arranged, but um, I often ask questions towards the end than I do at an early stage."*

Participants suggested that more knowledge about timing of ACP could be helpful even if there is frequent contact with other healthcare disciplines to remind each other about ACP. On the other hand, they said it is often beyond their control if the GP involves the community nurse too late or the patient does not (yet) want help.

### *Prerequisites for the use of ACP*

All participants mentioned that it is important to establish a trust based therapeutic relationship and get to know the patient and their background to create insight in the patients' needs before talking about ACP. They explain that the relationship can be built by visiting the patient often.

P2: *"[...] That you know what network someone has and that you get to know someone's background and also someone's wishes, religion, culture before you really explicitly ask about it."*

Furthermore participants said it can be helpful to prepare the patient for an ACP conversation because patients and families can already have thought about ACP topics. However they said patients must be willing to discuss these topics with their nurse. The participants had various examples when patients did not, or not yet, wanted to talk about end of life.

Participants did not bring up ACP when patients were unaware of their palliative phase. Most participants think it is the GPs' or specialists' task to educate patients about their illness and create insight in their disease process.

P5: *"Sometimes the GP or the specialist does not clearly say that it is the end [...] and then I do not discuss it, then I wait until the doctor has discussed this with the patient."*

Both younger and older participants said that work and life experience is helpful when carrying out ACP. It was mentioned that juniors could benefit from training in palliative care. Participants suggested documenting ACP in the personal care plan rather than in the daily report to easier maintain overview.

### *Collaboration between involved professionals in ACP*

Several participants mentioned the importance of a rich professional network with frequent face-to-face contact, especially short communication lines with the GP, for the use of ACP. In addition, visiting a patient together with the GP was mentioned as very valuable. Participants found it difficult to say which profession is responsible for carrying out ACP. GPs, palliative nurses and community nurses were all appointed. Most participants thought that the GP is responsible for the clinical issues and the nurses for the other domains. GPs often start too late according to the participants because of their medical focus where they mainly see patients when health deteriorates rapidly. Participants also said it depends on the level of involvement of the discipline whom they consider responsible for ACP. But that lack of clarity about who is responsible for ACP can make things complex for patients, families and professionals.

P1: *"I think you should make good agreements about the care, who will carry out and who will discuss things with people. [...] That you are not all going to stand around the bed and that you are all going to ask the same things. Because well, hm, it is confrontational of course."*

Multidisciplinary consultations (MDC) can help to be informed earlier about patients who are entering their last phase of life according to the participants. Also the concept of monthly visits to oncology patients was mentioned to be suitable for ACP discussion.

Participants spoke about improvements to the handover between the hospital and the homecare teams. Most of the time, ACP was not mentioned in handovers while participants thought that drawing attention in the hospital could be useful for follow-up at home.

### *Carrying out ACP*

Participants found it essential that the patient is in control of ACP. They saw ACP as a process that needs to be discussed in multiple moments. Every participant said that it is possible to make time in their work schedule for ACP because of the importance of those conversations.

P9: *"Well, I make time. I mean I make indications of care myself [...] sometimes you can calculate in advance that a patient needs more care and include that in the indication. I think that as a nurse you should be creative with time."*

Two sides were mentioned about finding the right time for ACP conversations. Having an ACP conversation during care moments was said to be valuable because contact is already established which makes it easier to start talking about ACP. In addition, community nurses can discuss their own observations directly with the patient. On the other hand, it was suggested that it could be useful to make an appointment with a patient, and if requested family, because the patient is then prepared. The conversation feeling heavy was mentioned

as a disadvantage of this. Using a combination of both methods could be an advantage when carrying out ACP and contribute to multiple conversations according to the participants. They concluded that it is case dependant on what feels like the right moment to discuss ACP.

*P14: "So that is always a matter of feeling [...] I just ask a question in that direction and I notice from the response of the patient if there is room for it, but sometimes you just have to feel..."*

#### *ACP as part of usual community care*

The participants' overall opinion was that ACP has to become a more established part of community care. The lack of clear policy about ACP and too little awareness in their work organisations results in insufficient knowledge and use according to the participants. They explained that if they use ACP more frequently they get more comfortable. Participants said that it could be valuable to involve the whole team in ACP. They suggested that the First Responsible Caregiver (FRC) can play an important role because they often provide care to patients with whom they have an established relationship.

Participants are missing a method and a guide of ACP. They mentioned that it could be helpful to use a questionnaire listing all the important ACP topics. In addition, the questionnaire can be saved in a separate document and nurses get reminded of ACP when they see the document in the digital patient system.

*P15: "I think if there is a format, you might think more often about having that conversation with people."*

The guide needs to include information according to the participants about how to raise the topic of ACP with the patient, who is responsible for carrying out ACP, which topics need to be discussed and when nurses need to start with ACP. Finally, it was thought that training can contribute to their knowledge and skills in ACP.

## Discussion

This study explored the perception of community nurses towards the use of ACP and found: that nurses find ACP a tough topic to talk about, difficulties knowing the right time to start, the need for building a trust-based therapeutic relationship, that community nurses have enough time for ACP which should be discussed in multiple conversations, that nurses experience insufficient collaboration with other disciplines and that nurses experience too little awareness at team and organisational levels with no available method or tools for ACP.

### *Compared findings with literature*

The current study showed that community nurses can feel uncomfortable when carrying out ACP with patients. When this result was compared with available literature of patients perspectives, two perspectives were found. On the one hand, studies exist where patients in ACP conversations felt distressing due to the awareness of their illness and that end-of-life could occur<sup>35-38</sup>. On the other hand, some patients labelled the confrontation as positive because it had helped them cope with it<sup>39-42</sup>. Some participants in the current study suggested that you have to feel which moment is suitable for carrying out ACP and what might help patients to deal with these feelings.

The current study found difficulties in finding the right time to start ACP and participants felt they often started too late, for example in the terminal phase. Determining frailty can generally be a reason to start with ACP but difficulties for nurses in finding the right time is recognized<sup>19</sup>. Studies from perspective of patients show that they preferred ACP in an earlier stage of the disease trajectory but that it is often carried out too late<sup>43,44</sup>.

The need for a trust-based therapeutic relationship is also consistent with other literature<sup>43-45</sup>. Furthermore, empathic ACP discussions can contribute to a good relationship between patient and nurse<sup>19</sup>.

Having enough time for ACP is not found in previous studies. Reason for this could be lack of research of ACP in community care. Many studies about professionals in clinical settings or GPs showed difficulties in having enough time for ACP<sup>45-50</sup>. This could be a reason for insufficient collaboration with GPs and hospitals about ACP. In addition, lack of clarity about the role and responsibilities in ACP with other professional disciplines was found complex by participants and is also recognized in literature<sup>19</sup>. While nurses can contribute to collaboration around end-of-life care because of their mediating role<sup>51</sup>. This applies in particular to community nurse because of their pivotal role in the community<sup>52</sup>.

Too little awareness at team and organisational level and lacking tools for ACP has implications for clinical practice. Nurses may not be aware of the contribution they can make in this area and have limited opportunities to develop these skills<sup>53</sup>. Evidence is found that

training in ACP has positive effects on knowledge and skills<sup>54,55</sup> and improving the curriculum with palliative care education has been suggested<sup>19</sup>. This is consistent with the current study which found that juniors nurses benefit from palliative care training.

### *Strengths & limitations*

The current study contributes to the gap in knowledge about the use of ACP by community nurses and to the awareness of the important role that community nurses could fulfil in ACP. Trustworthy results are found because of the achievement of data saturation, the transparency of member check and the reliability of conducting all interviews by the same researcher. Data collection was conducted in the same time as data analysis which ensured the validity of the study since the topic list could be adjusted to relevant findings.

The findings may have been influenced by the sample. Mostly young community nurses with less work experience were included. This may affect the results because the study showed that young community nurses had more difficulties in providing ACP than senior community nurses. Besides, the participants were all motivated to participate which could suggest that they consider ACP an important topic. This could affect the outcome of having enough time because they could be more willing to make time for ACP than other community nurses.

### *Implications for clinical practice*

Both for research and clinical practice, awareness of the important role of community nurses and the care team in ACP is crucial. Tools and a clear policy are necessary to facilitate community care teams carrying out ACP. Participants suggested a questionnaire with main topics while carrying out ACP where they can save the answers in a separate document. In addition, community nurses need a guide with information about: how to talk about ACP with patients, who is responsible for ACP, which topics need to be discussed and when nurses needs to start with ACP. Furthermore, they think training is required to improve their knowledge and skills in ACP and junior community nurses could benefit most of the training. Further research is necessary to develop the questionnaire, guide and training.

### *Conclusion*

Found perceptions of community nurses towards ACP are a tough topic, difficulties in timing, the need of a trust-based relationship, sufficient time, insufficient collaboration and too little awareness. Community nurses are suitable to conduct ACP since they have time to carry out ACP and the opportunity to build a trust-based relationship with patients. However, training and tools are necessary to support community nurses in ACP.

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## Tables

Table 1. *Topic List*

View of ACP
Involved professional disciplines
Time to use ACP
Communication and documentation
Resource
Policy about ACP in organisation

Table 2. *Participants characteristics*

Characteristics	Interview participants (N=15)
Female	N=14
Age in years	Mean: 37.9, SD: 12.7
Years of work experience in healthcare	Mean: 14.3, SD: 9.6
Years of work experience at bachelor degree level of community nurse	Mean: 6.9, SD: 5.5
Characteristics community team, urban or rural (n= urban)	N=8