

Experiences of COPD patients with a transmural Advance Care Planning trajectory

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Abstract

Title: Experiences of Chronic Obstructive Pulmonary Disease patients with a transmurial Advance Care Planning trajectory

Background: Chronic Obstructive Pulmonary Disease is the third leading cause of death worldwide. Professional care is in most of these cases aimed at improving quality of life and to prevent and relieve suffering, one approach is palliative care. A professional manner of supporting future care is Advance Care Planning. A top clinical hospital in the Netherlands developed a transmurial Advance Care Planning trajectory which consists of three components: 1) an information leaflet, 2) a group meeting, and 3) a personal conversation.

Aim: The aim of this study is to explore the experiences of Chronic Obstructive Pulmonary Disease patients with the transmurial Advance Care Planning trajectory.

Method: A generic qualitative study with nine semi-structured face-to-face and telephone interviews was conducted with Chronic Obstructive Pulmonary Disease patients. The interviews were conducted between February and April 2020. The interviews were assessed using a thematic analysis.

Results: The results of the data analysis show recurring main themes across all three components. The main themes have a different content per component of the trajectory. The main themes for the information leaflet are ambivalence and readiness. Main themes from the group meeting are ambivalence, readiness, atmosphere and familiarity with the information. The main themes of the personal conversation are ambivalence, readiness, and atmosphere.

Conclusion: This study offers healthcare professionals a series of patient experiences regarding opportunities for discussing future care in a way similar to Advance Care Planning. Important feelings of the patients were ambivalence, readiness and atmosphere. Patients are positive about continuing the Advance Care Planning trajectory. The findings and recommendations of this study can be helpful for evaluating the pilot trajectory.

Keywords

Advance Care Planning; Chronic Obstructive Pulmonary Disease; Experiences; Palliative care

Samenvatting

Titel: Ervaringen van patiënten met chronische obstructieve longziekte met een transmuraal toekomstig zorgplanningstraject

Achtergrond: Chronische obstructieve longziekte is wereldwijd een veel voorkomende doodsoorzaak. Professionele zorg richt zich op het verbeteren van de kwaliteit van leven en het voorkomen en verlichten van het lijden. Een manier van professionele zorg is palliatieve zorg. Een kenmerk van palliatieve zorg is communicatie en ondersteuning over toekomstige zorg, dit wordt ook wel toekomstige zorgplanning genoemd. Een topklinisch ziekenhuis in Nederland heeft een transmuraal toekomstig zorgplanningstraject ontwikkeld dat uit drie componenten bestaat; 1) een informatiefolder, 2) een groepsbijeenkomst, en 3) een persoonlijk gesprek.

Doel: Het doel van dit onderzoek is om de ervaringen van patiënten met chronische obstructieve longziekte met het transmuraal toekomstig zorgplanningstraject te onderzoeken.

Methode: Een generieke kwalitatieve studie met negen semigestructureerde interviews , face-to-face en telefonisch, met patiënten met chronische obstructieve longziekte werd uitgevoerd. De interviews vonden plaats tussen februari en april 2020. Een thematische analyse werd toegepast.

Resultaten: De resultaten van de data-analyse laten onder alle drie componenten terugkerende hoofdthema's zien. De hoofdthema's hebben per component een andere inhoud. De hoofdthema's voor de informatiefolder zijn ambivalentie en bereidwilligheid. Hoofdthema's die uit de groepsbijeenkomst naar voren kwamen zijn ambivalentie, bereidwilligheid, sfeer en bekendheid met de informatie. De hoofdthema's van het persoonlijke gesprek zijn ambivalentie, bereidwilligheid en sfeer.

Conclusie: Deze studie biedt zorgprofessionals een reeks aan patiëntervaringen met betrekking tot het bespreken van toekomstige zorg. Belangrijke gevoelens van patiënten waren ambivalentie, bereidwilligheid en sfeer. Patiënten zijn positief over het voortzetten van het toekomstige zorgplanningstraject. De bevindingen en aanbevelingen van deze studie kunnen behulpzaam zijn bij het evalueren van het pilottraject.

Trefwoorden

Toekomstige zorgplanning; Chronische obstructieve longziekte; Ervaringen; Palliatieve zorg

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a chronic progressive lung disease.¹ Worldwide, COPD is the third leading cause of death.^{2,3} The primary cause of COPD is tobacco smoke.⁴ In the Netherlands, approximately 600,000 people suffer from COPD.^{1,5} As the disease progresses, physical functions and quality of life gradually declines.⁵ Professional care is in most of these cases aimed at improving quality of life, both to prevent and relieve suffering.⁵

Palliative care is a professional approach, which can be defined as an approach that “improves the quality of life of patients and relatives who go through a life-threatening condition or vulnerability, by preventing and relieving suffering, through early identification and careful assessment and treatment of physical, psychological, social and spiritual problems. Palliative care’s main focus is to maintain autonomy and access to information and to inform decision-making.”⁶ Some characteristics of palliative care are communication and supporting future care by means of discussing life goals and choices of the patient and their relatives. Future medical care can be supported by Advance Care Planning (ACP).⁷⁻⁹ ACP is a continuous and dynamic process in which a patient, together with relatives and healthcare professionals, performs conversations aimed at clarifying life goals and choices.¹⁰

ACP is an important strategy to improve discussion about palliative care.⁷ It improves both patient satisfaction concerning communication with their physician and family satisfaction with palliative care.^{8,9,11-14} ACP increases frequency of out-of-hospital care, compliance with patients’ end-of-life wishes and satisfaction with care¹⁵ and contributes to reducing overtreatment and medical cost in palliative care.^{15,16}

Little is known about experiences of COPD patients with ACP. General barriers experienced by patients in relation to ACP are particularly focused on perceiving ACP as irrelevant, discussions with relatives and feelings of time constraints when consulting with healthcare professionals.¹⁷ Zwakman (2018) concluded that patients with life-threatening or life-limiting illness experience both positive and unpleasant feelings. Timing of the ACP and feeling comfortable about sharing personal information were found to be important factors in the ability to participate in ACP.⁷ Another study demonstrates the importance of a good connection with the healthcare professional, so the patients feel comfortable about asking questions and speaking openly.¹⁸ In 2012, Brown conducted research related to the experiences of patients with ACP. This is the only study focusing on ACP in COPD patients. It concluded that ACP was rarely discussed with COPD patients.¹⁹

Currently, ACP is not included in clinical paths. A top clinical hospital in the Netherlands identified this, and developed a transmural ACP trajectory for COPD patients. This trajectory is aimed at enhancing early discussions regarding the goals and choices of a patient, making it possible for healthcare professionals to provide personalized care.

The trajectory consists of three components that do not have to be fully completed or completed consecutively. It is a transmural trajectory, which means that it can be performed in the hospital and in primary care (by general practitioner or district (specialized) nurses in home care). The first component provides general information about ACP, supported by an information leaflet. The second component consists of a group meeting, which is held in the hospital. The third component relates to a personal conversation with a healthcare professional about treatment needs and life goals. These needs and life goals will be adopted in the patient's file.

Currently, it is unknown what the experiences of COPD patients are with this transmural ACP trajectory. To gain in-depth experiences of the COPD patients with this trajectory, the trajectory can be better adapted to the wishes and needs of the patients, and will improve discussion about palliative care.

Aim

The aim of the study is to explore the experiences of COPD patients with a transmural Advance Care Planning trajectory.

Method

Design. A generic qualitative study with semi-structured interviews was conducted. This method was chosen to gain an in-depth understanding of the experiences of COPD patients with the transmural ACP trajectory.²⁰

Population and domain. The study population consist of palliative COPD patients, who visit the top clinical hospital in the Netherlands or patients in primary care, and received at least one of the components of the trajectory: (a) received an information leaflet, and/or (b) attended the group meeting, and/or (c) had a personal conversation. A description of the trajectory is presented in Figure 1.

Participants were eligible for inclusion if they were eighteen years or older and could speak the Dutch language. Purposive sampling was used to aspire maximal variation²⁰, so there was a variety of perceptions of the different combinations of the components.

Figure 1 here.

Procedures. The study was conducted and reported in compliance with the Consolidated criteria for Reporting Qualitative Research (COREQ) checklist.²¹

The approach of the patients differs per component. Shortly after completion one of the components, patients were asked by their healthcare professional to participate in this study. With the patients' consent, the researcher was sent the contact details. Patients received the information letter regarding the study and were called by the researcher one week later. When patients had given their approval to participate in the study, the researcher arranged an appointment at the patients' preferred location.

Data collection. Data were collected between February and April 2020. Seven interviews took place face-to-face, and—due to the Covid-19 pandemic—two patients were interviewed by telephone.

Interviews were conducted by one researcher using a semi-structured interview guide. The interview guide emerged from existing literature and consisted of open questions about patients' experiences and in-depth feeling. The topics used in the interviews are: barriers¹⁷, feelings/emotions^{7,17}, ambivalence⁷, readiness^{7,22}, openness⁷ and maintaining a sense of control/trust.²² All interviews started with the main question: "Can you tell me your experiences about component 1 or/and 2 and/or 3?"

Prior to the interview, patients were asked to provide some demographic information.

The interview guide and demographic information was peer reviewed by four experienced members of the research team and was pilot tested.

All interviews were audio-recorded and fully transcribed by the researcher (MK) and durations varied between 32 and 90 minutes.

Data analysis. The data collection and data analysis were conducted in an iterative way; collection and analysis alternated back and forth.²³ A thematic data analysis was conducted using the method of Braun & Clarke²⁴ that includes six phases and is cyclically connected. This method was chosen for identifying, analysing and reporting themes.

After the first three interviews, the interview guide was discussed. The researcher first wanted to become familiar with the data and reread the data and noted initial ideas.

Subsequently, initial codes were generated. Each data item was coded in the entire data set

which was relevant to the research question. One interview was independently coded by another researcher (MU) to perform a validity check.²⁵ These codes were assessed for similarities and differences by the researcher. Themes were searched and collated by codes into potential themes. All relevant data to each potential theme was gathered and themes were discussed with another researcher (MU).

Potential themes and subthemes were reviewed for consistency with the codes and entire data to ensure they reflect the entire data. A thematic map of the analysis was constructed. Themes were defined and named. The essence of each theme was considered by the two researchers and illustrative quotes were selected. The data is presented descriptively and grouped by common themes. Interviews were fully transcribed and analysed in Atlas.ti (version 8).

Ethical issues. The study was approved by the Medical Ethics Review Board (METC) (ID: 2020-6121, Date 03.02.2020) of the Medical University of Arnhem-Nijmegen²⁶ and by the hospital's Local Feasibility Committee (LHC). Informed written consent was obtained from all patients prior to the interview.

Results

Demographic characteristics

Twenty-two participants were recruited after a component by the healthcare professional; nine patients agreed to participate in the study (response 41%). Four patients could not be reached by phone, three signed off after reading the information letter, three could not plan the interview in the near future, two patients could no longer remember the components and one patient was not able to be interviewed by phone because of hearing problems.

Interviews with nine patients were analysed, five of which were women; the average age was 68 (range: 55 - 81) (Table1).

Two patients received the information leaflet, four patients attended the group meeting and one patient had a personal conversation. One patient attended both the group meeting and a personal conversation and one patient completed all three components.

Table 1 here.

Main findings

The results of the data analysis show recurring main themes among all three components. The main themes have a different content per component, so the components are described independently. With all three components, patients experienced simultaneously positive and unpleasant feelings. The main theme was 'ambivalence'. Another recurring main theme of all

three components was 'readiness'. There were differences in patients' readiness to talk about ACP. The main theme 'atmosphere' arose from the group meetings and personal conversations. The theme 'familiarity with the information' refers to the group meeting. A thematic map was created; see Figure 2.

Figure 2 here.

Information leaflet

Ambivalence

Patients who received the information leaflet indicated that afterwards it was actually good that the healthcare professionals began to talk about ACP and distributed the information leaflet.

It's actually good they asked, because I cannot keep closing my eyes, but have to remain realistic – P.7

On the other hand, patients experienced a feeling that they were overwhelmed by the information leaflet. Patients indicated not being ready for it at the time and experienced a lack of clarity due to the information leaflet. Patients indicated they did not understand why they received the information leaflet, because they still felt well and wondered why they received the information leaflet at this point in time.

No, I am not shocked, I just think it's strange, the way I feel now that I have to talk about it. – P.4

Why now? What happened, do you see anything about me? Do you notice anything about me? What has changed? – P.7

A patient expressed lack of knowledge of what to do with recording wishes and needs.

No, just the only thing, if I get a breathlessness attack, what are they going to do? If I signed for that, will they give me a shot right away? – P.4

After receiving the information leaflet, patients had not discussed it with their relatives. One patient proceeded with other components of the trajectory, and had a discussion with his relatives afterwards. Other patients indicated that the information leaflet did not contribute to

discussing ACP with relatives, because patients felt there was no added value in thinking about problems that might arise in the future.

Readiness

Some patients who received the information leaflet indicated that thinking about the future was not necessary at that point in time. They stated that they would see what happened in the future, but at that time they were feeling too well.

This is about the future, and it is incredibly fun to worry about your future, but if you are in the future and it has not happened you have made it unfavourable for nothing... don't solve problems that aren't there. Well I don't have a problem yet, so I do not solve it either
– P.7

Group meeting

Ambivalence

Patients who attended the group meeting indicated that their attention to ACP had increased. Although the subject had a negative charge, the group meeting caused them to start thinking about the future.

Do I want to be resuscitated or not? How long do you want to be ventilated, yes of course you want to be ventilated until the end, but how tolerable is that? You are going to think about that – P.5

Well because it lives more. I have always said, if I become in vegetative state, if something happens to me and I become in vegetative state, I do not want to live any longer – P.6

Patients indicated that they appreciated the attention. They were happy that ACP could be discussed. They experienced it as a nice and pleasant meeting.

I just think that you should be realistic, I am very pleased about it, they offer it.... You don't have to leave these decisions to your kids – P.6

By way of contrast, patients indicated that they did not like the confrontation with their illness and some patients did not feel the urge at the moment to think about this matter.

There is something in me that I don't really want to know. I don't want to know that I have COPD. So I don't really want to be part of the group. On the other hand, I am also realistic, yes I just belong there – P.3

Readiness

Patients who attended the group meeting indicated different experiences in timing of ACP. Some patients do not feel the urge, other patients should have taken it place in an earlier stage of the disease.

For me it is 5 past 12, too late actually. I should have known 10 years earlier. Then I would like to see that graph (graph about live expectancies of patients with COPD) – P.5

A little bit in the back of my mind I think yes I have to do something with it, but I don't think it is urgent at the moment. Because you can still do everything - P.3

Atmosphere

The interviews showed that there was a pleasant atmosphere and there was an opportunity to ask questions during the group meeting.

That would not be a problem. and uh ... that was clear and understandable and uh how do you call that uh inviting – P.3

I noticed, it was an easy meeting. You can put it that way. Friendly – P.6

Patients felt a barrier because the group consisted of too many unknown persons. Patients indicated that because of the size of the group it was inappropriate to ask in-depth questions during the group meeting, and they did not feel the urge to share deep feelings and emotions during the meeting.

I found that more difficult. They are people you have never seen before. I perhaps like smaller groups, this was quite a large group – P.5

You know what happens, I mean things are mentioned, but you don't really talk about in-depth feelings... Well I prefer to just go into that depth. I mean, yes... despite all the emotions – P.9

Familiarity with the information

All patients experienced the group meeting as an informative meeting. Patients referred to the group meeting as complementing their own knowledge and clear and useful information was transferred.

Well, I think the meeting itself is, uh, I found it quite interesting. Yes, I found it mostly informative – P.3

I thought it was clearly, yes. For me it can be organized more often. Because you want to know – P.5

Almost all patients indicated that the information they received at the group meeting was known to them.

Well it was a good experience, but what I heard, I already knew a lot – P.1

I thought well, maybe I will get to hear some new things, because I do not often visit the doctor... But not really much immediately – P.3

Personal conversation

Ambivalence

The personal conversation was experienced on one hand as pleasant. Patients appreciated the recognition for their feelings and described it as a confrontational but clarifying experience.

You don't think about it that easily. Because you just get the question, do you want to be resuscitated? In what phase are we? But then you get used to that conversation again and then I quickly switch the button again. And then I think yes, it is just the way it is – P.8

That there is recognition for my feelings... That is a pleasant feeling for myself – P.9

Patients perceived the conversation as pleasant afterwards. They felt relieved when the conversation was over.

It is a bit of a liberation. Then you don't have to talk about it all the time. I mean, they know what I want. ... And start talking over and over again, yes I don't like that every day. I think about it every day, but in a completely different way. You have to talk about it. I'm not very good at that anyway – P.2

Afterwards, all patients indicated that they were happy that their wishes were recorded and clear to their relatives. They indicated that it gave peace and that the conversation provided a feeling of confidence that everything was recorded.

Yes, that's fine, we just talked about that, it also gives a feeling of trust. That's an okay feeling, shall I say. That is a pleasant feeling for myself – P.9

On the other hand, in spite of the pleasant feelings, unpleasant feelings also emerged. Patients indicated that talking about ACP evoked emotions and they experienced difficulties with recording wishes after the conversation. Patients preferred not to talk about ACP and indicated that all stages of grief were involved. A patient explained difficulties with recording his wishes and determining when the terminal phase would commence.

Yes to say definitively from this far I will go and I don't go any further. That was the worst... You feel yourself constantly deteriorating. But how far and how far can you still go? That is the worst – P.2

Another patient indicated difficulties with the formal and final recording of the wishes.

The moment it is recorded, I thought Help! So from then on it is very official I will say. But then it is a bit emotional ... Yeah, that touches your emotions – P.9

Readiness

It was indicated that deterioration of the disease requires clarity, and shortness of breath was a prerequisite for the urge toward a personal conversation.

If, for example, I had not been very breathless, well then it would not have been so bad for me, but this is just so bad on a given moment. That you just have to have clarity on both sides, at least also to the hospital, to the specialists and the care at home – P.8

Atmosphere

Patients described the importance of feeling comfortable and having an open atmosphere; these are preconditions for discussing ACP during a personal conversation. A patient explained the importance of having a good connection with the healthcare professional.

I think that has a lot to do with who is sitting in front of me and I have a connection with my nurse practitioner – P.9

Discussion

The results of this study show that the information leaflet does not lead to action on the part of the patient. Patients experienced a lot of uncertainty with regards to receiving the information leaflet. They did not know why they received the leaflet. The group meeting was generally perceived as pleasant. Patients indicated that they were encouraged to think about ACP, even though they indicated no new information was provided. They did, however, experience the group as being too large to create a safe place. The personal conversation was experienced as pleasant, or pleasant afterwards. Patients pointed out the importance of feeling comfortable with the healthcare professional. Patients indicated that it was difficult to express their wishes in a definitive manner.

Little is known about the experiences of COPD patients with ACP trajectories. There seems to be a difference in experiences between the three components. Literature shows that patients feel comfortable asking questions and speaking openly when they have a good connection with the healthcare professional.^{7,18} Patients in this study indicated that talking about ACP was easier when they had a good relationship with their healthcare professional. In the review of Zwakman (2018), patients simultaneously experienced ambivalent feelings, and these experiences emerged from the personal conversation in particular.⁷ This study showed that patients experienced discussion and establishing wishes definitively as unpleasant. Documentation is an important part of ACP and literature shows that patients may feel uncomfortable writing a document about their wishes.^{7,17} The timing of talking about ACP varies from patient to patient. This study shows that a few patients would have discussed it at an earlier stage. Other research shows that patients prefer to talk about it sooner rather than later.^{7,22}

Patients who received an information leaflet indicated that it did not lead to further actions. Evidence indicates that when an information leaflet alone is used as intervention, it may have a small beneficial effect on patient outcomes.^{27,28}

Strengths and limitations

The strengths of this study are that after the interview, a summary of the findings was member checked with the patients and the Consolidated criteria for Reporting Qualitative Research (COREQ) checklist²¹ was used to facilitate reporting the results.

While this study provides new insights into the experiences of COPD patients with the ACP trajectory, some limitations need to be acknowledged. First, due to the Covid-19 pandemic, the trajectory was stopped prematurely. As a result, it was not possible to interview a larger population and gain insight into their experiences. As a result, data saturation was not achieved. The quality of the research can be questioned by not achieving data saturation.²⁹⁻

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Second, the study focuses on a specific targeted trajectory developed by a top clinical hospital. Because the population comes from a specific area of the Netherlands, it cannot be generalized to groups in a different environment.

The last two patients were interviewed via telephone. The researcher was not able to observe the non-verbal attitudes of the patient, but research shows that there is no bias against telephone interviews. In fact, patients may feel more comfortable sharing their feelings by telephone.^{32,33}

Implications for clinical practice

The results show that there is confusion concerning the distribution of the information leaflet. Patients are not sure what to do with it. It would be helpful to give patients more context about receiving the leaflet and point out the importance of talking about ACP. It would benefit the group meetings if they were held with smaller groups. It could be beneficial for the information leaflet and group meeting to explain what patients can do themselves with ACP and what steps can be taken. Patients experienced the personal conversation as pleasant afterwards. This is valuable information for healthcare professionals, so they are nevertheless encouraged to have that conversation with patients about ACP, despite the fact that it was experienced as less pleasant that point in time.

Further research could focus on the perspectives of the experiences of healthcare professionals or relatives of COPD patients.

Conclusion

This study offers healthcare professionals a series of patient experiences regarding the opportunities to discussing future care in a way as ACP. The important feelings of patients were feelings of ambivalence, readiness and atmosphere. Patients indicated the group meeting did not lead to new knowledge. However, patients were positive about continuing

the ACP trajectory. Adjustments can be made within the trajectory, such as clarifying the goal and having the group meeting taken place in smaller groups. The findings of this study can be helpful for evaluating the pilot trajectory.

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Tables and figures

Table 1. Demographic background of the interviewed patients.

Demographic background	
Gender	56% female (5); 54% male (4)
Age in years	Mean = 68 (SD= 7,72, range: 55 - 81)
Component of trajectory	
Information leaflet	22% (2)
Group meeting	44% (4)
Personal conversation	11% (1)
Group meeting and personal conversation	11% (1)
Information leaflet, group meeting and personal conversation	11% (1)
Initiative to receive component	
Own	22% (2)
Healthcare professional	78% (7)

Figure 1. ACP trajectory

Components ACP trajectory	Content	Attended by
Information leaflet	Provision of general information to the COPD patient about ACP without any obligation	The leaflet is provided by a healthcare professional in hospital or primary care
Group meeting	Patients are informed and encouraged to discuss ACP with relatives and healthcare professionals	The group meeting is supervised by two healthcare professionals of the hospital
Personal conversation	A personal conversation about treatment needs and life goals. These needs and life goals will be adopted in the patient's file.	With a healthcare professional
The components of the trajectory did not have to be fully completed or completed consecutively.		

Figure 2. Thematic map of experiences of COPD patients.

	Main theme	Subordinate theme
All components	Ambivalence	Positive feelings
		Unpleasant feeling
All components	Readiness	Not being ready
		Being ready
Group meeting and personal conversation	Atmosphere	Pleasant atmosphere
		Difficulties
Group meeting	Familiarity with the information	Known information