



**UNIVERSITY
OF TURKU**

This is a self-archived – parallel published version of an original article. This version may differ from the original in pagination and typographic details. When using please cite the original.

Wiley:

This is the peer reviewed version of the following article:

CITATION: Kuusisto, A., Santavirta, J., Saranto, K. and Haavisto, E. (2021), Healthcare professionals' perceptions of advance care planning in palliative care unit: a qualitative descriptive study. J Clin Nurs.

which has been published in final form at

DOI <https://doi.org/10.1111/jocn.15578>

This article may be used for non-commercial purposes in accordance with [Wiley Terms and Conditions for Use of Self-Archived Versions](#)."

Running head: PROFESSIONALS' PERCEPTIONS OF ACP

HEALTHCARE PROFESSIONALS' PERCEPTIONS OF ADVANCE CARE PLANNING IN PALLIATIVE CARE UNIT: A QUALITATIVE DESCRIPTIVE STUDY

Anne Kuusisto PhD, RN^{1,2} | Jenni Santavirta MHS, RN² | Kaija Saranto Professor of Health and Human Services Informatics³ | Elina Haavisto Professor of Nursing Science^{1,2}

¹Department of Nursing Science, University of Turku, Turku, Finland

²Satakunta Hospital District, Pori, Finland

³Department of Health and Social Management, University of Eastern Finland, Kuopio, Finland

Correspondence

Anne Kuusisto, Department of Nursing Science, University of Turku, Turku, Finland.

Email: anmakuu@utu.fi, tel. +358 44 707 9309

Email addresses of other authors

jenni.santavirta@satasairaala.fi, kaija.saranto@uef.fi, elina.haavisto@utu.fi

Acknowledgements

The authors want to thank the professionals involved in study, the contact persons who facilitated the data collection, the interviewers, and the language consultant for editing the English language.

Conflict of Interest Statement

No conflict of interest has been declared by the authors.

Funding information

The study was partly funded by Government research funding: Satakunta Hospital District (284/2019, 116/2020).

Author Contributions

Study concept and design: AK, EH

Data collection: AK, EH

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/JOCN.15578](#)

This article is protected by copyright. All rights reserved

Data analysis and interpretation: AK, JS, KS, EH

Drafting of the article: AK

Critical revision of the article: JS, KS, EH

All authors contributed to the final approval of the version to be submitted.

ORCID

Anne Kuusisto <https://orcid.org/0000-0002-9950-1985>

Kaija Saranto <https://orcid.org/0000-0002-3195-1955>

Elina Haavisto <https://orcid.org/0000-0002-9747-1428>

How to cite this article: Kuusisto A, Santavirta J, Saranto K, Haavisto E. Healthcare professionals' perceptions of advance care planning in palliative care unit: a qualitative descriptive study. *Journal of Clinical Nursing*

Printed by [Sanokunnu saranto@helsinki.fi - 213.186.228.126 - /doi/pdf/10.1111/jocn.15578] at [07/12/2020]

Accepted Article

This article is protected by copyright. All rights reserved

Accepted Article

DR. ANNE MARITTA KUUSISTO (Orcid ID : 0000-0002-9950-1985)

Article type : Original Article

Health

qualitative descriptive study

Abstract

Aims and objectives: To describe healthcare planning (ACP) in palliative care unit in hospital ward or outpatient clinic.

Background: Clinical guidelines recommend timely ACP as a central component of patient-centred palliative care. However, the ACP concept and terminology have been judged to be confusing and usage.

Design: Qualitative descriptive design

Methods: The study used purposive sampling. The data were collected through focus group interviews with registered nurses and practical nurses and individual or couple interviews with physicians and social workers. The data (n=33) were analysed by inductive content analysis. The study complied with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

This article is protected by copyright. All rights reserved

10.1111/jocn.15578

Accepted Article

Results: Three main categories emerged: Information content of ACP, coordination of care activities through ACP, content of ACP included assessment of need for patient care, preparing for changes in state of health and proactive medication. Coordination of care activities through ACP contained ACP care planning, cooperation and work practices between healthcare professionals. Support for p members and professionals and promoting patient self-care.

Conclusions: ACP is a useful and proactive tool for integrating patient-centred information, care and s activities can be coordinated through ACP in a multidisciplinary manner. ACP is significant and relev rk and patient care thro

Relevance to clinical practice: Results highlight the importance of proactive, concrete and holistic ACP. ACP should be up-to-awareness and implementing ACP into work processes are essential. Results can be utilised in planning and implementing interprofessional in-service training.

KEYWORDS

Advance care planning, palliative care, professional perspective, electronic health record, qualitative research

10.1111/jocn.15578

This article is protected by copyright. All rights reserved

What does this paper contribute to the wider global clinical community?

- Healthcare professionals need to know and use important information in the practical development of ACP and palliative care.
- In this study, ACP was seen to be a tool for service system development in palliative care. ACP may promote the quality of patient care and especially, care in unexpected situations and between places of care. ACP can be a way to shift emphasis from heavy services, e.g. the use of emergency services, to proactive and preventive work in palliative care.
- This paper identifies the content of work of nursing staff, care coordination, multidisciplinary collaboration and the importance of family members and their involvement in compiling ACP.
- Interprofessional education and in-service training for healthcare professionals concerning ACP is needed to enable a team-based approach to ACP in palliative care.

1 INTRODUCTION

Advance care planning (ACP), as a clinical process model (Hui & Bruera 2020, Rietjens et al. 2020) and central component of patient-centred palliative care (Institute of Medicine 2015, Rietjens et al. 2017), concerns many people. Every year, over 40 million people worldwide are in need of palliative care, which, if started early, reduces unnecessary hospital admissions and the use of healthcare services (World Health Organisation 2020.) ACP is the ability to enable individuals to define goals for future care, to discuss these goals with family members and healthcare providers, and to document and review these preferences, if appropriate (Rietjens et al. 2017). The main objective of ACP is to prepare patients and family members to participate with healthcare professionals in making the best possible decisions concerning end-of-life care (Sudore & Fried 2010).

The preparation of ACP is guided by legislation (Institute of Medicine 2015), ethical principles (e.g. American Nurses Association 2015, National Association of Social Workers 2020) and clinical guidelines (Institute of Medicine 2015, National Institute for Health and Care Excellence 2019). However, in practice, the ACP concept and terminology have been considered confusing (Boddy et al. 2013, Kermel-Schiffman & Werner 2017, Bar-Sela et al. 2020). Based

This article is protected by copyright. All rights reserved

on a systematic review, the absence of a clear definition of ACP may prevent the advancement and understanding of the topic (Kermel-Schiffman & Werner 2017). Previous studies report different types of ACP, such as communication about end-of-life care in general (Granek et al. 2013, Myers et al. 2018), or more specific types of ACP, like advance care wishes, such as advance directives (AD) (Zhou et al. 2010) and typically, living wills (Bar-Sela et al. 2020). Healthcare professionals' knowledge (Kermel-Schiffman & Werner 2017) and the facilitators of (Rietze & Stajduhar 2015, Rietjens et al. 2017) and barriers (De Vleminck et al. 2013, Toguri et al. 2020) to ACP have been studied especially in oncology (e.g. Zhou et al. 2010, Toguri et al. 2020). To our knowledge, previous research on the topic is mainly quantitative (Bar-Sela et al. 2020, Kuusisto et al. 2020), with the ACP definition (Sellars et al. 2015) limited to a specific diagnosis (Clark et al. 2017, Fritz et al. 2020), age (Detering et al. 2010, Li-Shan et al. 2015) or professional group (De Vleminck et al. 2013, Li-Shan et al. 2015) and to primary health care (Blackford & Street 2011, De Vleminck et al. 2013) or specialist care (Walling et al. 2017, Bar-Sela et al. 2020). The present study was undertaken to address this knowledge gap by a cross-sectional survey of healthcare professionals in a palliative care unit of a hospital ward or outpatient clinic.

2 BACKGROUND

Advance care planning (ACP) is part of person-centred care (Parse 2019) that allows patients to express their important personal wishes and values about life and dying that will help to guide their future care if they become unable to make their own decisions (Institute of Medicine 2015, Rietjens et al. 2017). ACP is one part of care planning (Walling et al. 2008), but it focuses more on patient preferences and values (Blackford & Street 2011). ACP can result in a documented plan regarding end-of-life care and the appointment of a substitute decision-maker in the event of loss of capacity (Seymour et al. 2010). Recently, core elements of ACP conversations were outlined. Most important is that ACP discussions are person-centred, and are flexible, depending on the circumstances at hand (Rietjens et al. 2020).

ACP is a joint responsibility of patients, family members and healthcare professionals (Rietjens et al. 2020) although it is controlled by physicians (Johnson et al. 2016). Involvement

This article is protected by copyright. All rights reserved

of family members in ACP is important (Kuusisto et al. 2020) if the and the patient is unable to participate in the ACP discussion (Kirsebom et al. 2017). Family members have been involved e.g. in discussion about hospital transfers (Shanley et al. 2011), palliative care options or when confirming treatment limitations (Kuusisto et al. 2020). ACP appears to be well supported, and nurses and other healthcare professionals report being comfortable and confident to take on the responsibility (Blackwood et al. 2019). Nurses have assessed ACP as an important opportunity to serve good nursing care (Seymour et al. 2010), are well positioned to engage in ACP discussions (Li-Shan et al. 2015) and have assisted patients and p al. 2010, Rietze & Stajduhar 2015). When ACP is used and expanded throughout the healthcare system (Walling et al. 2017) palliative care can be enhanced longitudinally through ACP (Hui & Bruera 2020).

Despite many benefits, e.g. improvement in end-of- mem , and reduction of anxiety, stress and depression in surviving members (Detering et al. 2010), ACP rarely occurs in practice (Kuusisto et al. 2020). Nurses were confused with ACP and day-to-day care planning, which they regarded as a key aspect of nursing (Seymour et al. 2010, Kuusisto et al. 2020), and acute care nurses did not know whether ACP was part of their work (Rietze & Stajduhar 2015). Professionals thought that having an ACP discussion was more important than paperwork, but if not documented, the content of the discussion was lost (Blackford & Street 2011). In critical statements, nurses believed that ADs alone (without discussion) were effective for commun care, the primary function of ACP being the documentation of treatment choices (Zhou et al. 2010) rather than being a communicative tool (Johnson et al. 2016), perhaps due to lack of in-depth knowledge of the legal issues concerning ACP (Kermel-Schiffman & Werner 2017).

Emotions like fear (Boddy et al. 2013, Bar-Sela et al. 2020) and anxiety or denial of terminal illness are connected with ACP use (Bernacki & Block 2014). Oncology staff mentioned communication difficulties between patients and family members as the main reasons for not completing ACP forms (Bar-Sela et al. 2020). Other barriers to ACP have been lack of education and time among nursing professionals (Blackwood et al. 2019). For general practitioners (GPs), the barriers to engaging in ACP have been lack of skills to deal with

This article is protected by copyright. All rights reserved

patient defining the right moment, fear and the attitude that it is the patient who should initiate ACP (De Vleminck et al. 2013).

Although physicians such as GPs who have known the patient for years (Mattes et al. 2015) are expected to initiate ACP (Mattes et al. 2015, Rietjens et al. 2020), end-of-life discussions are in practice often conducted by physicians who do not know the patient and do not routinely address their nonmedical goals. Palliative care experts tend to explore patients' nonmedical goals and to be more patient-centred in their discussions. (Bernacki & Block 2014.) A model that embedded a palliative nurse in oncology clinics resulted in increased ACP, but oncologists were concerned that nurses would discuss code status or hospice too early (Walling et al. 2017). Patients with cancer who named a nurse practitioner or social worker with whom they had had a discussion about end-of-life decisions were more likely to report having completed an AD than patients who did not name those providers (Clark et al. 2017).

3 AIM

The aim of this study is to describe healthcare professionals' perceptions of ACP in a palliative care unit hospital ward or outpatient clinic.

4 METHODS

The study was conducted using a qualitative descriptive study design. Qualitative descriptive approach is particularly suitable to obtaining straight answers to question(s) of specific data and uses low interpretation. (Sandelowski 2000.) The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines for qualitative research (Tong et al. 2007) were followed (See Supplementary File 1).

4.1 Study participants and data collection

The study used purposive sampling (Polit & Beck 2018) and data triangulation which may result in a broad understanding of the phenomenon of interest (Carter et al. 2014). The data were collected through four focus group interviews (Parahoo 2014) with registered nurses (n=18) and one focus group with practical nurses (n=5) and through individual or couple interviews with physicians (n=5) and social workers (n=5) in spring and autumn 2019 as part of a larger research

This article is protected by copyright. All rights reserved

project regarding evidence-based palliative care. A total of 33 healthcare professionals from palliative care units participated in the study (Table 1).

Interviews were conducted in three hospital districts (population 2.4 million) in five hospitals with five wards and one outpatient clinic. Interview was chosen as research method to find as new knowledge and perspectives on ACP (Tong et al. 2007, Parahoo 2014). A definition for ACP was not given in advance unlike in an earlier online survey (Sellars et al. 2015) as there was an interest to allow participants to describe their perceptions of ACP in their own words. The study question was kept as open and broad as was possible in view of the aim of the study (Parahoo 2014). To maximise the opportunity for nurses to participate and enable a wide range of opinions to be heard, focus group interviews were conducted as they allow efficient use of resources (Parahoo 2014). Individual interviews were conducted because no focus groups comprising physicians and social workers would otherwise have been achieved; at least this was the case with social workers, for no ward had more than one social worker. Instead of individual interviews, two couple interviews were conducted at the request of the interviewees.

Data collection was carefully planned and supported by clear instructions. Due to geographical distance, data were collected by four interviewers. The researchers announced the study initiation beforehand at the participating organisations. Focus groups were attended by nursing staff according to the work situation in the wards. The interviewees filled in a demographic questionnaire including age, education, palliative further education, title, work experience in health care and work experience in palliative care. The age of the participants ranged from 19 to 62 years (mean 46 years) and in palliative care, from less than one year to 19 years (mean 6 years). Twenty-two professionals (67%) had palliative in-service training. Interviews were conducted at a convenient time and place in the hospitals so that they could be conducted without interruptions (Polit & Beck 2018). Only interviewees and the interviewer were present. One individual interview was conducted outside the hospital in the study room of the city library and another by phone for logistical reasons. The interviews were audio-recorded with the permission of the participants. The mean duration of the interviews was 58 minutes.

This article is protected by copyright. All rights reserved

4.2 Data analysis

The data were analysed by inductive content analysis as an interdisciplinary entity with responses from different professional groups pooled together determined by the aim of the study because there was not enough previous knowledge about the topic (Elo & Kyngäs 2008). It is important that the data were as unstructured as possible (Elo et al. 2014). The description is also richer when the data includes a wide range of different professional groups. The purpose was also not to analyse and compare but to get the entry angle of the professionals. The data analysis process phases were preparation, organising and reporting (Elo et al. 2014). In the preparation phase, all the texts from the interviews were read many times to obtain an initial understanding of the data. All original expressions, i.e. words, sentences or sets of meanings corresponding to the study aim, were considered as a meaning unit and were tabulated. In the organising phase, categories were created from the raw data as a whole analysis unit. First, original expressions were simplified and simplifications with the same content were grouped into subcategories named after their contents. Through conceptualisation, subcategories were first merged into categories and then into main categories, while naming the categories and main categories corresponding with the contents. Original data was revisited several times to ensure correctness of the interpretation. Table 2 shows an example explaining the data analysis from meaning unit to category. The categories, which are externally heterogeneous cover all data, and no relevant information was omitted (Table 3). One researcher (AK) was responsible for the data analysis, but the research group discussed the analysis and the ambiguities were analysed together. The final step was carried out by reporting the analysis systematically and logically, presenting the views of the participants correctly, and emphasising the key results in the reflection (Elo et al. 2014). Accurate reporting and use of original expressions made it possible to verify that the results are based on data and not

4.3 Ethical considerations

The study followed the research ethics guidelines for good scientific practice (TENK 2019). Research permits were obtained from each organisation prior to data collection and ethical approval was granted (University Research Ethics Committee 15/2019). Important ethical principles in human research include informed research and consent, confidentiality, and privacy (Polit & Beck 2018). The right to self-determination was respected by emphasising the voluntary

This article is protected by copyright. All rights reserved

Accepted Article

nature of participation and possibility to interrupt the interview at any stage. The organisations were responsible for recruiting suitable and voluntary participants, meaning that the researchers did not influence the selection of participants. Thus no relationship between researchers and participants was established prior to the study. Study information was provided orally and in writing. The interviewers introduced themselves to the interviewees before the interviews. Each interviewee signed an informed consent form. Anonymity of the interviewees was carefully maintained at all stages of the study. A Register Report has been prepared on the preservation of research data.

5 RESULTS

Inductive content analysis resulted in three main categories: Information content of ACP, coordination of care activities through ACP, coping (Table 3).

5.1 Information content of ACP

The information content of ACP includes assessment of need for patient care, preparing for changes in state of health, and proactive medication. (Table 3).

5.1.1 Assessment of need for patient care

Assessment of need for patient care includes two subcategories (Table 3).

wishes

care.

determine ACP. In ACP, the patient expresses how he or she wants to be treated and it is agreed how to act in certain situations. ACP was combined with talking about the living will, but there was uncertainty as to whether ACP and living will mean the same thing.

People talk about living will; it may not be the same thing, but that is how I kind of understand it. (S5)

in ACP

preparedness for care and service needs and goals of care as part of palliative care. As soon as the patient enters the hospital, the goal is to map overall situation. Depending

This article is protected by copyright. All rights reserved

10.1111/jocn.15578

Accepted Article

patient current situation, it is assessed, for example, whether home care is still possible, what kind of services the patient might need, whether symptomatic care is appropriate, or if terminal care will soon be topical. The aim of ACP is to prepare for the future so that there will be no surprises.

Well there is the first impression, like how bad the situation is or whether there is hope in the sense that discharge may still be considered as an option, or does it look like the status of the person being treated is so poor that we will like instantly have a situation involving symptomatic mediation, and possibly palliative care very soon. (S4)

5.1.2 Preparing for changes in health status

Preparing for changes in health status includes two subcategories (Table 3).

Anticipation of symptoms in ACP means being prepared for possible symptoms and disor well-being, or unpredictable surprises like possibility of sudden bleeding or suffocation. Situations in palliative care change quickly and even small things in the require proactive measures from the nurses.

If there are urinary tract infections? But in a way also being proactive, they are small simple things, but for nurses they mean being proactive. (FGPN1)

Instructions for end-of-life care in ACP include symptom management and treatment limitations. Symptom management is based on a physician's symptom assessment, discussion with stakeholders, and documentation. Nurses find the existence of pre-defined care guidelines and orders very helpful in ACP in the case of a sudden deterioration in the patient's condition. Most importantly, they know what is done and what is not done. As planned, ACP includes instructions not only for nurses, but also for on-call physicians. Treatment limitations mean identified and determined policies concerning end-of-life care which are also guidelines for action. They concern aspects such as non-resuscitation, ventilator therapy, hydration, or transfers to emergency care at the end of life.

This article is protected by copyright. All rights reserved

10.1111/jocn.15578

Coordination of care activities through ACP includes ACP care planning, cooperation and work practices between healthcare professionals (Table 3).

5.2.1 ACP care planning

ACP care planning includes two subcategories (Table 3).

Documentation of ACP refers to data tool and data structure and was not a systematic and established activity. The data tool where ACP was recorded included both electronic health record and paper. According to practical nurses, ACP was sometimes recorded while at times, nothing was available. In some cases, ACP was just a piece of paper that neither the patient nor the family members were aware of. ACP documentation concerns a team-based approach, especially between nurses, physicians and different therapists such as physiotherapists. However, social workers did not recognise ACP as part of their work-related documentation. They considered it to be part of nursing when it comes to palliative care. In practice, very few patients had ACP. However, the development of ACP and, in particular, recording of ACP, was seen as a very important issue in the development of palliative care. Some physicians mentioned a specific template with a certain structure, i.e. subheadings which allow going through the contents of ACP. It was felt that such a model would facilitate ACP documentation and the need for more active use in palliative care was highlighted.

But it be what it is at times, sadly, just a piece of paper, and the patient or relatives don't know that one has been made. (FGN1)

We have an actual template for it, with subheadings; with the help of that, you can go through it and it makes it easier to record it in the patient journal. Maybe it should be taken into use more widely. (CIP1)

The locations and timing of ACP include the places where and the times when ACP was compiled. ACP was compiled at the health centre, in palliative outpatient clinics or hospital wards. If ACP was started in the palliative outpatient clinic, it could be utilised by the outpatient clinic between home hospital and hospital ward. When it was updated at every encounter, the advantage was that there was no need to complete it all at once. The timing of ACP varied. It could be started proactively, which was considered good, or done close to the time of death. For

This article is protected by copyright. All rights reserved

example, do not resuscitate (DNR) decisions could be made in advance. However, in practice, they were made at the stage when a fatal disease was diagnosed or at the last minute of life, although for chronic diseases, there is often time to prepare for death.

The care plan is then updated at every encounter. (P3)

Well there is time, but even so, they are only made at the last minute.
(FGPN1)

5.2.2 Cooperation and work practices between healthcare professionals

Cooperation and work practices between healthcare professionals include two subcategories (Table 3).

Securing continuity of care means that when responsibility for care shifts to another organisation, it is important that things are well-planned. Physicians said that within their own organisation, issues related to ACP may be clear, but as the patient moves elsewhere issues related to ACP are especially highlighted. Relational continuity of care, i.e. a relationship with the same physician, was seen as important for both patients and nurses. Nurses considered that it was safe and of high quality to have the patient seen by the same physician who had done the ACP. They knew the patient and the situation was thus easier for the nurses as well.

Nurses felt that it was important to develop ACP outside the hospital, especially in elderly patient with cancer care, to ensure continuity of pain medication. Mentoring nursing staff was seen as part of ACP. Nurses could visit nursing homes to provide counselling on symptom management and the death process.

I also see advance care planning in situations where we provide support to municipal elderly care and social services units, when nurses visit the units and inform staff of what may be coming. (FGN1)

Emergency load control means that ACP was a central aid and that there was no need to seek emergency care. Physicians were present in the ward only during office hours. With the help of ACP, the nursing staff in the ward was prepared until the next day and for weekends and were able to care for patients without the presence of a physician. During on-call time, with the

This article is protected by copyright. All rights reserved

use of ACP, nurses were able to care for the patient without contacting the physician on call by telephone, for example.

Advance planning is a key factor in that you don't have to go to ER.
(FGPN1)

So that we won't have to call ER. (FGN2)

5.3 S

patient, family members and professionals and promoting patient self-care (Table 3).

5.3.1 Communication between patient, family members and professionals

Communication between the patient, family members and professionals includes two subcategories (Table 3).

Medical knowledge in encounter facilitates patient education and interaction. Nurses said that when they know on a general level what is characteristic and typical of certain diseases such as cancers, they are able to educate patients on what might possibly be coming. Similarly, nurse made it easier to educate patients on issues that may arise in the future. A physician who had trained as a cancer physician considered encounters with patients with cancer to be easier than encounters with patients with other diseases such as Chronic Obstructive Pulmonary Disease (COPD) or Amyotrophic Lateral Sclerosis (ALS).

I guess more like, when you know in a way, on a general level, what certain cancers and illnesses involve and know something about what the average care pathway looks like as it were, well then you can perhaps give the patient some guidance on what may lie ahead. (FGN3)

End-of-life discussion in ACP means a conversation with the patient, family members and healthcare professionals on issues related to impending death such as the palliative care line and hospice. According to nurses, end-of-life discussion was assessed as heavy and was mainly a matter between the patient, family members and physician. The physician was responsible for

This article is protected by copyright. All rights reserved

treatment decisions and care lines, but nurses prepared the decisions with the patient and family members. Interviewees highlighted the need to information about the help that is available. The patients and family members need to know that preparations have been made and where the patient will be cared for. Patients' individuality and emotions were considered important in ACP because the degree of preparation for different things depends a lot on the patient. The future and the things to come should not be intimidating. Some people do not want to anticipate, and no one should be forced to do so. Some patients get anxious if things are brought up too early while others do not necessarily understand what a DNR decision means, for example. According to one physician, family members often feel that a resuscitation ban means neglect, and these misunderstandings were corrected. Physicians assessed that remaining life expectancy and time of death were difficult to estimate, but they considered that it was a good idea to tell patients if they had a few weeks or just a day left so that they could take care of their condition.

So that our professional expertise is utilised as it were, so that we assess, together with the patient, if there is a need to move on to some sort of treatment. (FGN2)

5.3.2 Promoting patient self-care

Promoting patient self-care includes two subcategories (Table 3).

Compiling ACP. ACP should be something that all those involved are committed to. According to physicians, patients and family members need to know that things have been prepared and where the patient is being cared for, but they do not always need to know every single medicine.

And it should be one that people are committed to, one that people have actually sat down to discuss, and where next of kin or other treatment units have also been involved. (CIP1)

With regard to self-care, ACP included information on where and how patient gets aid if needed or what to do if something happens, e.g. how to act if the patients' status deteriorates suddenly at

This article is protected by copyright. All rights reserved

home. Patients and family members must always know who to contact if something comes up; this gives a sense of security.

And it's also like a really important part of the patient and family members always knowing where to turn to if something comes up, that's like the crucial thing. It also brings a sense of security. (P2)

6 DISCUSSION

palliative care unit in hospital ward or outpatient clinic. According to this study, healthcare professionals perceived ACP in terms of both patient care and their own work. Their perceptions of ACP in palliative care unit consisted of information content of ACP, coordination of care activities through ACP, and

In this study, the information content of ACP was seen as a patient-centred and goal-oriented future care plan based on the assessment of need for patient care and compiled information for patient care. The information content of ACP presented by the healthcare professionals in this study mainly followed international guidelines (Institute of Medicine 2015, Rietjens et al. 2017) but was seen as much broader than in their study (Zhou et al. 2010) where only treatment choice documents were a central part of ACP. In this study, there was conceptual ambiguity and confusion between ACP, living will and even palliative care, possibly due to lack of knowledge and inconsistent practices. Previously, professionals could not distinguish between ACP and day-to-day care planning (Kuusisto et al. 2020). In their study Bar-Sela et al. (2020) described confusion between ADs and durable power of attorney, and that physicians talked more about ADs with patients than with nurses. Similarly, Kermel-Schiffman and Werner (2017) found that participants knew some aspects of ACP (such as ADs), but did not know others (such as the Patient Self-Determination Act). Boddy et al. (2013) reported that if professionals do not understand these issues they are not going to start bringing them up with patients if they do not know what they are talking about. Thus interventions such as education and training aimed at improving ACP knowledge among professionals are essential. Education should include e.g. ACP concept clarification and legislation. Compared to previous studies (Bar-Sela et al. 2020, Kuusisto et al. 2020, Toguri et al. 2020), the professionals in this study saw proactive medication

This article is protected by copyright. All rights reserved

Accepted Article

and n
 medication was prescribed beforehand rapid changes in
 responded to immediately without interruptions in patient care. In addition, resources for
 medication therapy should be taken care of both in their own unit as well as in nursing homes to
 ensure continuity of patients pain management. Previously, Kirsebom et al. (2017) found that
 medical consultants in nursing homes have found a lack of medical equipment, such as limited
 supply of medicines, impediments to patient safety.

In this study, coordination of care activities through ACP referred to ACP care planning
 being assessed by professionals to coordinate patient care; for example, professionals knew how
 to act in a particular situation, which broadened the perspective of ACP from a patient-centred
 process or document (Institute of Medicine 2015, Rietjens et al. 2017) to a tool for ACP care
 plann
 documentation was seen as a shared interprofessional responsibility between physicians and
 nurses, but surprisingly, social workers did not recognise their role in ACP compared to a
 previous study (Boddy et al. 2013) where social workers had a central role in ACP and were
 relied on by others for decision-making. In this study, social workers were perhaps not familiar
 with the ACP concept and they may have viewed it solely as a patient care plan. This may be due
 to the fact that there are often few social workers in the units and they may easily be left out of
 patient care. This gives rise to concern because different professional groups have different
 responsibilities in patient care and thus also in ACP. A fundamental aspect of social work is
 attention to environmental forces that address problems in living, for example (National
 Association of Social Workers 2020). Thus, social workers know the service system and the
 availability of services and they play a key role in e.g. preparation for patient discharge. In this
 study, physicians identified the benefits of structured documentation and the need for further
 development. Previously, nurses have said that a structured format could provide a guide for
 ACP
 seen as streamlining operations and care processes when there was no need to burden other
 professionals or units when ACP was available. This is an extremely important finding, because
 the current healthcare environment is characterised by a lack of coordination (Toguri et al. 2020).
 Our finding is supported by previous research. In their study, Shanley et al. (2011) indicated that

ment as extremely
 condition could be
 nical
 of ACI

10.1111/jocn.15578

This article is protected by copyright. All rights reserved

if ACP was not available, staff and family might be making decisions without preparation and would likely send the patient from nursing home to hospital.

In this study, through communication and support for patient self-care. According to professionals in this study, medical knowledge made patient encounters easier and facilitated patient education. Previously, the facilitators of ACP for nurses have included ACP-specific educational preparation, strategies to integrate ACP into daily patient care and confidence as well as frequency of ACP (Rietze & Stajduhar 2015). Disease-specific ACP programs, e.g. for patients with glioblastoma, have been used in daily clinical practice (Fritz et al. 2020), because there has been a lack of formal ACP-specific training (Sellars et al. 2015, Toguri et al. 2020). International guidelines support using trained non-physician facilitators to promote the ACP process (Rietjens et al. 2017). In this study, some nurses recognised their role in the preparation of ACP and prepared decisions with the patient based on their professional skills. Previously, Blackford and Street (2011) showed that even experienced palliative care staff have been reluctant to discuss end-of-life care, and many perceived ACP discussions as more difficult than symptom management or family support. However, according to the Finnish Current Care Guidelines on palliative care, ACP is prepared by the physician with a patient with advanced and fatal or life-threatening illness and, if necessary, with family members; the roles of e.g. nurses and social workers are thus not identified or recommended contrary to the ethical guidelines of their profession (American Nurses Association 2015, National Association of Social Workers 2020).

Today, there is a trend with an emphasis on primary health care and community home-based palliative care (World Health Organisation 2020). In this study, the involvement of family members in ACP was seen as necessary, and sometimes they asked for a meeting with professionals. A previous study shows that ACP done in collaboration with patients and family members facilitates future decisions on medical treatment and end-of-life care (Kirsebom et al. 2017). In Australia, ACP is most frequently initiated at the patient or family request (Sellars et al. 2015). Recently, Bar-Sela et al. (2020) stated that as disease progresses, the patient becomes less active and family members take a more central role in the communication. ACP lies within person-centred care guided by nursing theories such as self-care, goal attainment and empowerment through participating knowingly, which constitute the discipline of nursing (Parse

This article is protected by copyright. All rights reserved

1070771/011818/551100/1111101.mdb/000/-071827-981117 - untdononunans ununumms [A] 0000111

2019), aimed at promoting well-being and alleviating suffering of patients and family members (American Nurses Association 2015). Based on this study, ACP can enable patient coping e.g. at home and create a sense of security for patients and family members as they know that help is always available if needed.

Strengths and limitations

The findings from the study may be limited in the fact that the results may reflect perceptions because nurses are the largest professional group in the wards. However, due to geographical and organisational differences it can be assumed that the best representatives of physicians and social workers working in palliative care were included. There is no complete certainty of data saturation in all professional groups, which is difficult to evaluate in a qualitative study, especially when the scope of the study, like ACP, is broad and complex to investigate (Polit & Beck 2018). Instead of looking separately at the views of each professional group, a holistic picture study aim. It was challenging because different professional groups may have different perspectives. The transcripts were not returned to the participants for comments and/or correction, nor were the findings returned so that they could provide feedback. Despite the potential that participant checking has for enhancing credibility, it can lead to erroneous conclusions (Polit & Beck 2018). There are quite a many categories. They are, however, important, as they show the rich and diverse nature of the health ACP in palliative care.

7 CONCLUSIONS

This study revealed that healthcare professionals who were interviewed for the study assessed ACP to be a useful and proactive tool for integrating patient-centred information, care and forms of proactive healthcare which avoid ad hoc decisions. Palliative care activities can be coordinated in advance through ACP in a multidisciplinary manner, e.g., knowing how to act in a particular situation or not burdening other professionals or units

This article is protected by copyright. All rights reserved

managers. ACP is throughout the service system. Getting a broader picture of ACP requires taking into account the perspective of patients and family members in further research. The ultimate goal is to promote high-quality palliative care by producing information that can be of help in clarifying and developing ACP in palliative care.

8 RELEVANCE TO CLINICAL PRACTICE

The results of this study are important for clinical practice for developing evidence-based ACP practices for patients in palliative care. It is necessary that palliative care is coordinated, continuous and safe. Our results show the importance in palliative care of proactive, concrete and holistic ACP, not only recorded orders regarding life-sustaining treatment, for example. All patients in palliative care should have both ACP care planning and end-of-life discussion in place. ACP should be up to date and updated at wishes. R useful data tools is essential. Ignorance can lead to negative attitudes. Healthcare professionals need appropriate education and training to enable them to communicate and understand ACP. Knowledge among nursing management also needs to be raised in order to ensure resources enabling access to training. The results can be utilised in the planning and implementation of interprofessional in-service training. Healthcare professionals, especially nurses, around the world can compare the study findings with their own perceptions of ACP in palliative care.

This article is protected by copyright. All rights reserved

References

- American Nurses Association (ANA)** (2015). ANA Code of Ethics for Nurses. Retrieved from: <https://www.nursingworld.org/coe-view-only> (29.6.2020)
- Bar-Sella, G., Bagon, S., Mitnik, I., Baziliansky, S., Bar-Sella, A., Vornicova, O., & Tzuk-Shina, T.** (2020). The perception of Israeli oncology staff members regarding advance care planning. *Supportive Care in Cancer*, Jan 3. doi: 10.1007/s00520-019-05253-7. Online ahead of print
- Bernacki, R.E., & Block, S. D.** (2014). Communication about serious illness care goals. A review and synthesis of best practices. *JAMA Internal Medicine*, 174(12): 1994–2003
- Blackford, J., & Street, A.** (2011). Is an advance care planning model feasible in community palliative care? A multi-site action research approach. *Journal of Advanced Nursing*, 68(9): 2012–2033
- Blackwood, D. H, Walker, D., Mythen, M. G., Taylor, R. M., & Vindrola-Padros, C.** (2019). Barriers to Advance Care Planning With Patients as Perceived by Nurses and Other Healthcare Professionals: A Systematic Review. *Journal of Clinical Nursing*, 28(23):4276–4297. doi: 10.1111/jocn.15049. Epub 2019 Oct 3
- Boddy, J., Chenoweth, L, McLennan, V., & Daly, M.** (2013). It's just too hard! Australian health care practitioner perspectives on barriers to advance care planning. *Australian Journal of Primary Health*, 19(1):38–45. doi: 10.1071/PY11070
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J. & Neville, A. J.** (2014). The Use of Triangulation in Qualitative Research. *Oncology Nursing Forum*, 41(5): 545–547
- Clark, M. A., Ott, M., Rogers, M. L., Politi, M. C., Miller, S. C., Moynihan, L., Robison, A. & Dizon, D.** (2017). Advance care planning as a shared endeavor: completion of ACP documents in a multidisciplinary cancer program. *Psychooncology*, 26(1): 67–73
- Detering, K. M., Hancock, A. D., Reade, M. C. & Silvester, W.** (2010). The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial. *BMJ*, 23;340:c1345. doi: 10.1136/bmj.c1345

This article is protected by copyright. All rights reserved

- De Vleminck, A., Houttekier, D., Pardon, K., Deschepper, R., Van Audenhove, C., Vander Stichle, R., & Deliens, L. (2013).** Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. *Scandinavian Journal of Primary Health Care*, 31: 215–226
- Elo, S., & Kyngäs, H. (2008).** The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1): 107–115
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K. & Kyngäs, H. 2014.** Qualitative content analysis: a focus on trustworthiness. *SAGE Open* 4
- Fritz M. J. P. (2020).** Advance Care Planning in Glioblastoma Patients: Development of a Disease-Specific ACP Program). *Supportive Care in Cancer*, 28(3):1315–1324. doi: 10.1007/s00520-019-04916-9. Epub 2019 Jun 26
- Gran barriers to effective communication about end of life care. *Journal of Oncology Practice*, 9(4): e129–e135. doi: 10.1200/JOP.2012.000800**
- Henry, C. & Seymour, J. (2007).** Advance care planning: a guide for health and social care staff. London Department of Health
- Hui, D., & Bruera, E. (2020).** Models of palliative care delivery for patients with cancer. *Journal of Clinical Oncology*, 38(9): 852–865. DOI: 10.1200/JCO.18.02123
- Institute of Medicine (2015).** Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC, National Academies Press. Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK285681/> (10.5.2020)
- Johnson, S., Butow, P., Kerridge, I., & Tattersall, M. (2016).** Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. *Psychooncology*, 25(4):362–386
- Kennel-Schiffman, I., & Werner, P. (2017).** Knowledge regarding advance care planning: A systematic review. *Archives of Gerontology and Geriatrics*, 73, 133–142

This article is protected by copyright. All rights reserved

- Kirsebom, M., Hedström, M., Pöder, U., & Wadensten, B. (2017). General Practitioners' Experiences as Nursing Home Medical Consultants. *Scandinavian Journal of Caring Sciences*, 31(1): 37–44. doi: 10.1111/scs.12310. Epub 2016 Apr 4
- Kuusisto, A., Santavirta, J., Saranto, K., Korhonen, P., & Haavisto, E. (2020). Advance care planning for patients with cancer in palliative care: A scoping review from a professional perspective. *Journal of Clinical Nursing*, 29(13–14): 2069–2082. doi: 10.1111/jocn.15216
- Li-Shan, K., Huang, X., O'Connor, M., & Lee, S. (2015). Nurses' Views Regarding Implementing Advance Care Planning for Older People: A Systematic Review and Synthesis of Qualitative Studies. *Journal of Clinical Nursing*, 24(15–16): 2057–2073. doi: 10.1111/jocn.12853. Epub 2015 May 4
- Mattes, M.D., Tung, K., Baum, R., Parikh, K., & Ashamalla, H. (2015). Understanding the views of those who care for patients with cancer on advance care planning and end-of-life care. *American Journal of Hospice & Palliative Care*, 32(8):802-9. doi: 10.1177/1049909114540035. Epub 2014 Jun 16
- Myers, J., Cosby, R., Gzik, D., Harle, I., Harrold, D., Incardona, N., & Walton, T. (2018). Provider Tools for Advance Care Planning and Goals of Care Discussions: A Systematic Review. *American Journal of Hospice & Palliative Care*, 35(8):1123–1132. doi:10.1177/1049909118760303
- National Association of Social Workers (NASW) (2020). Code of Ethics. Retrieved from: <https://www.socialworkers.org/about/ethics/code-of-ethics> (5.7.2020)
- National Institute for Health and Care Excellence (NICE) (2019). End of life care for adults: service delivery. Guidance. Retrieved from: <https://www.nice.org.uk/guidance/ng142> (28.6.2020)
- Parahoo, K. (2014). *Nursing Research. Principles, process and issues*. Third edition. Palgrave MacMillan. New York

This article is protected by copyright. All rights reserved

- Parse, R. R. (2019). Nurses and Person-Centered Care. *Editorial. Nursing Science Quarterly*, 32(4):265. doi: 10.1177/0894318419864335
- Polit, D.F., & Beck, C.T. (2018). *Essentials of nursing research. Appraising evidence for nursing practice*. Ninth edition. Wolters Kluwer. Philadelphia
- Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, Definition and recommendations for
an international consensus supported by the European Association for Palliative Care. *Lancet Oncology*, 18, e543–551
- Rietjens, J., Korfage, I., & Taubert, M. (2020). Advance care planning: The future. *BMJ Supportive & Palliative Care*. doi: 10.1136/bmjspcare-2020-002304
- Rietze, L., & integrative review. *International Journal of Palliative Nursing*, 21(10): 495–503
- Sandelowski, M. (2000). Focus on research methods whatever happened to qualitative description? *Research in Nursing & Health*, 23, 334–340
- Sellers, M., Silvester, W., Masso, M., & Johnson, C. E. (2015). Advance care planning in palliative care: a national survey of health professionals and service managers. *Australian Health Review*, 39(2):146–153
- Seymour, J., Almack, K., & Kennedy, S. (2010). Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliative Care*, 8;9:4. doi: 10.1186/1472-684X-9-4
- Shanley, C., Whitmore, E., Conforti, D., Masso, J., Jayasinghe, S. & Griffiths, R. (2011). Decisions about transferring nursing home residents to hospital: Highlighting the roles of advance care planning and support from local hospital and community health services. *Journal of Clinical Nursing*, 20 (19-20): 2897–2906 doi: 10.1111/j.1365-2702.2010.03635.x. Epub 2011 May 4
- Sudo preparing for end-of-life decision making. *Annals of Internal Medicine*, 15 (4): 256–261

This article is protected by copyright. All rights reserved

- TENK** (2019). The ethical principles of research with human participants and ethical review in the human sciences in Finland. Finnish National Board on Research Integrity TENK guidelines 2019. Retrieved from: https://www.tenk.fi/sites/tenk.fi/files/Ihmistieteiden_eettisen_ennakkoarviointin_ohje_2019.pdf (11.7.2020)
- Toguri, J., Grant-Nunn, L., & Urquhart, R.** (2020). Views of cancer patients, families, and providers on initiating and engaging in Advance Care Planning: A Qualitative study. *BMC Palliative Care* doi:10.21203/rs.3.rs-33395/v1
- Tong, A., Sainsbury, P., & Craig, J.** (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6): 349–357
- Walling, A., Lorenz, K. A., Dy, S. M., Naeim, A., Sanati, H., Asch, S. M. & Wenger, N. S.** (2008). Evidence-based Recommendations for Information and Care Planning in Cancer Care. *Journal of Clinical Oncology*, 26(23):3896-902. doi: 10.1200/JCO.2007.15.9509
- Wall**
practitioner in an oncology clinic. *Journal of Oncology Practice*, 13(9): e792-e799. doi: 10.1200/JOP.2017.020990
- World Health Organisation** (2020). Palliative care. Retrieved from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care> (11.7.2020)
- Zhou, G., Stoltzfus, J. C., Houldin, A. D., Parks, S. M., & Swan, B. A.** (2010). Knowledge, attitudes, and practice behaviors of oncology advanced practice nurses regarding advanced care planning for patients with cancer. *Oncology Nursing Forum*, 37(6):E400-10. doi: 10.1188/10.ONF.E400-E410

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

This article is protected by copyright. All rights reserved

Table 1. Description of data collection and study participants (n=33)

Interview type	Professional(s) involved	Number of participants
Focus group FGN1	Registered nurse	6
Focus group FGN2	Registered nurse	4
Focus group FGN3	Registered nurse	3
Focus group FGN4	Registered nurse	3
Focus group FGPN1	Practical nurse	5
Couple interview CIN1	Registered nurse	2
Couple interview CIP1	Physician	2
Individual interview P1 P3	Physician	3
Individual interview S1 S5	Social worker	5

This article is protected by copyright. All rights reserved

Accepted Article

Table 3.

Main category	Category	Subcategory
Information content of ACP	Assessment of need for patient care	
		care
	Preparing for changes in patient's state of health	Anticipation of symptoms
		Instructions for end-of-life care
	Proactive medication	Symptomatic medication
		Resources for medication therapy
Coordination of care activities through ACP	ACP care planning	Documentation of ACP
		Locations and timing of ACP
	Cooperation and work practices between healthcare professionals	Securing continuity of care
		Emergency load control
Support for patient coping	Communication between patient, family members and professionals	Medical knowledge in encounter
		End-of-life discussion
	Promoting patient self-care	commitment to care

10.1111/jocn.15578

This article is protected by copyright. All rights reserved

