RESEARCH ARTICLE

Accessibility of information on patients' and family members' end-of-life wishes in advance care planning

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Abstract

Aim: To describe healthcare professionals' accessibility and transfer of patients' and family members' end-of-life wishes in ACP to the palliative care unit.

Design: The study used a qualitative descriptive study design.

Methods: Purposive sampling was used. The data ($N = 33$) were collected through interviews with physicians, registered nurses, practical nurses and social workers. The data were analysed by inductive content analysis.

Results: Two main categories emerged. Patients' and family members' end-of-life wishes documentation in relation to changing information needs was described in relation to patients' condition and care context. Transfer of patients' and family members' end-of-life wishes to palliative care unit included written and verbal communication. Results showed lack of implementation of ACP early, lack of implementation about the holistic interpretation of ACP into medical notes and lack of transferability of ACP into documenting systems impacting on accessibility and realization for the patient and family members at the end-of-life.

KEYWORDS
advance care planning, advance directives, electronic health records, palliative care, patient preference, qualitative research

1 | INTRODUCTION

Advance care planning (ACP) and patients' end-of-life wishes are important in information transfer in palliative care (PC; Kiely et al., 2013). Professionals should document care plans and share them with patients, family and team members (NICE, 2017). ACP is a patient-centred information tool that should reflect patients' current wishes and enable their future healthcare planning (Rietjens et al., 2017; Kuusisto et al., 2020; Kuusisto et al., 2021; Rietjens et al., 2021). ACP is linked to its context. For example, in some healthcare systems its emphasis is placed upon medical decisions such as orders about life-sustaining treatment (Kuusisto et al., 2020) reflecting health costs and insurance systems (Medicare, 2021), whereas the

use of Personal Health Record (PHR) for ACP is more national than universal (Kanta, 2021; Scottish Government, 2018).

ACP documentation practices and location in Information Technology (IT) systems vary between continents and countries. In the USA, clinicians reported that documentation ranged from making notes in electronic health record (EHR) to completing forms (Hooper et al., 2020). Primary care providers often considered that ACP was accessible whereas specialists more often did not (Dillon et al., 2017). Receiving PC services was associated with having accessible ACP (Tai-Seale et al., 2018). PC clinicians considered that it was easy to assess the presence or absence, but not the content of ACP (Lamas et al., 2018). Most ACPs that were not easily accessible were free-text progress notes (Walker et al., 2018). In Europe, professionals working in PC

usually had personal contact (Engel et al., 2020), a paper or a digital form (Engel et al., 2020; Mertens et al., 2021), but medical, nursing and psychosocial records were separate (Mertens et al., 2021). Patient's prior visit to palliative outpatient clinic (POC) was connected with more comprehensive ACP information (Hirvonen et al., 2018).

Advance directives (ADs), also called living wills (Docker, 1996; Kanta, 2021), are components of ACP (Hooper et al., 2020). They are advisory or formal statutory documents concerning patients' end-of-life wishes based on professional ethics (American Medical Association, 2021). ADs can promote communication and reduce distrust (Johnson et al., 2015). In the USA, although needed, ADs never appeared in home healthcare admissions (Sockolow et al., 2020). In Europe, ADs have mainly been restrictive, mostly Do Not Resuscitate (DNR) orders (Walker et al., 2018; Andreasen et al., 2019).

Efforts to honour patients' wishes and improve access include standardized workflows (Walker et al., 2018), national registries for ACP information (Arnett et al., 2017; Lamas et al., 2018) and patient portals (Kanta, 2021; Lamas et al., 2018). PHR includes data patients enter themselves (Marin, 2007). In the National Data Repository for PHRs, individuals can save their ADs (Burris & Sevier, 2020; Kanta, 2021), completed by one in three US adults (Yadav et al., 2017). Despite advanced digital services (Burris & Sevier, 2020; Kanta, 2021), its usefulness still depends on patient or family members keeping and delivering the documents (Standing et al., 2020). In Australia, concordance between elderly self-reported completion of ACP and its presence in EHR was only fair (Detering et al., 2021). In the USA, ACP was not available when needed (Grudzen et al., 2016; Turner et al., 2018; Hooper et al., 2020). Typical locations were filing cabinets or purses. Digital forms were files stored on memory sticks and computers. The challenges included keeping the information up-to-date and general procrastination. (Turner et al., 2018.) Family members have been patients' voices (Anderson et al., 2019), but patients' family information—if included—mostly consists of a short note about patient being single, married or having children (Flink et al., 2015). Patients' end-of-life care was inconsistent with their wishes (Khandelwal et al., 2017). Lack of patients' ability to express themselves has been linked to absence of AD (Andreasen et al., 2019).

Taken together, the literature reveals gaps in the documentation and delivery of dying patients' personal goals and wishes. Whilst ACP is advocated in the policy worldwide (Andreasen et al., 2017; Rietjens et al., 2017; Sudore et al., 2017), the application of the definition (clinical care experience versus lived and living experience), the systems and policies to implement the documentation and hence accessibility is not standardized. The aim of this study is to describe healthcare professionals' accessibility and transfer of patients' and family members' end-of-life wishes in ACP to the palliative care unit. The research questions are:

1. How has information on patients' and family members' end-of-life wishes in ACP been documented in previous care setting in relation to changing information needs?

2. How is information on patients' and family members' end-of-life wishes in ACP transferred to palliative care unit from previous care setting?

2 | METHODS

2.1 | Study design

The study used a qualitative descriptive study design which is well suited for researchers wishing to use a low level of interpretation (Vaismoradi et al., 2013).

2.2 | Study context

In Finland, PC is organized with a mode which divides PC services into a basic level and specialized levels. The ACP is written by a physician in collaboration with the patient and, if necessary, with the family members. There is no specific format for an AD, but it can be created in the My Kanta Pages. It is a citizens' own online service where they can browse their own health records and their medication recorded by healthcare services. The service is accessed through the Kanta Services website. (Finnish Institute for Health & Welfare, 2021.) There are five large EHR brands used in public hospitals and three in public health centres (Kaipio et al., 2020). EHRs are integrated with the national centralized patient data repository ("Kanta") (Kanta, 2021).

2.3 | Study participants and data collection

The aim of the qualitative study is to describe the topic in an in-depth and holistic fashion, through the collection of rich narrative materials (Polit & Beck, 2017). Therefore, purposive sampling was used (Parahoo, 2014) and informants were asked for the study in a multidisciplinary manner on the basis of previous scoping review (Kuusisto et al., 2020). The data were collected through focus group interviews with registered nurses and practical nurses and through individual interviews with social workers and physicians. They were eligible to participate if they were working in direct patient care in the inpatient or outpatient palliative care unit. Individual interviews were conducted because no focus groups comprising social workers and physicians would otherwise have been achieved. Two couple interviews were conducted at the request of the interviewees instead of individual interviews. A total of 33 professionals aged 19–62 years (mean age 46 years) participated. (Table 1) The range of participants' work experience in healthcare was 1–37 years (mean 17 years) and in PC 0–19 years (mean 6 years).

This study was conducted in five hospitals with five wards and one outpatient clinic in three hospital districts (population 2.4 million) in spring and fall 2019 as part of a larger research project about evidence-based PC. A piloted interview guide was used. As part of

TABLE 1 Description of data collection and professionals involved (N = 33)

Interview type	Professional group	Number of professionals
Individual interview P1–P3	Physician	3
Individual interview S1–S5	Social worker	5
Couple interview CIN1	Registered nurse	2
Couple interview CIP1	Physician	2
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

Abbreviation: "P3", Telephone interview.

the ACP theme, the interviewees were asked whether the patients' and family members' end-of-life wishes were reflected in the care plan for the patient coming to the palliative care unit.

The study initiation was announced beforehand at the participating organizations. Interviews were conducted by professional group face-to-face meetings in the hospitals, one in the study room of the city library and another by telephone (Table 1). Only the researcher and participants were present. Interviews were audio-recorded with the participants' permission. The interviews lasted between 29–173 min (mean 58 min).

2.4 | Data analysis

The data were analysed following the steps of inductive content analysis (preparation, organizing and reporting). First, the data were read several times to outline the overall picture. Original expressions corresponding to the research questions were extracted from the data and simplified. Patients' or family members' end-of-life wishes were used as a code, and colours were used for coding purposes. This yielded a total of 77 simplifications. Next, simplifications with the same content were combined into descriptive subcategories. The subcategories were merged into categories, named according to their content. Finally, the categories were merged into a main category. (Parahoo, 2014; Vaismoradi et al., 2013).

2.5 | Ethical considerations

The study was conducted in accordance with good scientific practice (World Medical Association, 2021) with research permits from organizations and ethical approval (University Research Ethics Committee 15/2019). The organizations recruited suitable and voluntary participants. Thus, no relationship between interviewees and interviewers was established prior to the study. The study information was provided in writing and orally. The researchers introduced themselves to the participants before the interviews.

2.6 | Trustworthiness

To ensure the quality of the results, the Guba and Lincoln criteria were applied (Guba & Lincoln, 1994). The credibility of the research process has been enhanced by the collaboration of a multidisciplinary team of researchers familiar with the topic and the multidisciplinarity of the interviewees. The researchers were outsiders in relation to the PC unit, suggesting that they have not influenced, through their preconceptions, the descriptions produced by healthcare professionals. Credibility is demonstrated with authentic quotations from the data which describe the results obtained. Confirmability was verified by asking clarifications when needed. Transferability is strengthened by the facts that during the data collection and analysis process, some of the responses (especially for nurses) began to recur, which can be considered as a sign of partial saturation of the data. The study provided information about the participants, interview process and the research context that was as accurate as possible. Qualitative research is context-specific, allowing the reader to assess the possible transferability of the results to another context. (Polit & Beck, 2017.)

3 | RESULTS

3.1 | Patients' and family members' end-of-life wishes documentation in relation to changing information needs

Patients' and family members' end-of-life wishes documentation in relation to changing information needs includes two categories (Table 2).

TABLE 2 Patients' and family members' end-of-life wishes documentation in relation to changing information needs

Main category	Category	Subcategory
Patients' and family members' end-of-life wishes documentation in relation to changing information needs	End-of-life wishes documentation in relation to patients' condition	End-of-life wishes documentation in sudden change in patient's state of health
		End-of-life wishes documentation in predictable course of disease
	End-of-life wishes documentation in relation to care context	End-of-life wishes documentation inside the hospital
		End-of-life wishes documentation outside the hospital

3.1.1 | End-of-life wishes documentation in relation to patients' condition

End-of-life wishes documentation in the event of sudden change in patient's state of health means that patient's wishes could not be taken into account. Such situations included sudden brain disaster or acute events in surgical wards. Patients could no longer be asked anything. They were unable to express themselves and their wishes.

> When they come into the PC unit the time span is very short, I mean their condition has really deteriorated quickly.
>
> (S5)

> You can no longer ask the patient anything and they are not able to express themselves at that stage, like wishes concerning care or similar.
>
> (CIP1)

End-of-life wishes documentation in predictable course of disease, such as patients with cancer or memory disorders, were noticed better compared to patients with sudden changes in health. However, at times a patient entering the ward was almost in the terminal phase. Professionals realized that ACP should occur early in the disease trajectory to ensure patients and family members are prepared and key benefits of ACP are attained. One physician pointed out that everyone should make a living will well in advance.

> At times we state that this is now more or less the terminal phase.
>
> (S4)

> People should more often make a living will. Generally speaking, we should all do it quite early.
>
> (P2)

3.1.2 | End-of-life wishes documentation in relation to care context

End-of-life wishes documentation inside the hospital varied. Professionals said that they were well known in cancer care units and especially POCs. There, professionals work in close connection with patients and family members, and for example, DNR is discussed and documented. On the other hand, the plan for PC may be made in a specialist care ward just before the patient enters the PC unit. In that case, patient and family members are not prepared and issues related to PC may come as a surprise to the patient, even if they have been discussed. If the patient is in poor condition, entering a PC ward may be a shock.

> To some extent it is seen more then because they have sort of done palliative nursing, or PC with them at the outpatient clinic.
>
> (FGN4)

> [...] have sometimes visited the palliative outpatient clinic, there they have...
>
> (CIP1)

> [The patient] is in poor condition and is transferred to the municipal side and comes to our ward; the elevator lobby where it says "PC ward"; going through that door, that has been a real shock for many.
>
> (FGN1)

End-of-life wishes documentation outside the hospital was described as variable, with the exception of home-based end-of-life care. Coordinators had documented wishes on their own documenting platform. They had also taken into account family members. Patients' wishes were thus very visible. Professionals reported that, for example, patient's preferred care setting for end-of-life had often been discussed. With patients in home care, there was also a care plan for the family.

> When they have done this home-based end-of-life care mapping visit it is really visible, but when they come to the ward for the first time, when we're talking about a patient like that, these things are in really good order.
>
> (CIP1)

> In addition, they come to our ward for symptomatic treatment, and we have plans for families.
>
> (FGPN1)

3.2 | Transfer of patients' and family members' end-of-life wishes to palliative care unit

Transfer of patients' and family members' end-of-life wishes documentation to the PC unit includes two categories (Table 3).

3.2.1 | Written communication

Transfer of patients' and family members' end-of-life wishes through Electronic Health Record was not well-established. Documenting systems did not enable documenting the full elements of holistic ACP. There was no one place for such information to be documented. Interviewees pointed out that therapeutic goals had probably been drawn up, but they were rarely documented. Family members' wishes were not usually documented in EHR since it was considered to be the patient's record. If family members' wishes were documented, they were mainly related to the desired care setting and whether they could be contacted 24/7. Family members hoped that the patient would no longer be transferred and could be in the same place for the rest of their life.

TABLE 3 Transfer of patients' and family members' end-of-life wishes to palliative care unit

Main category	Category	Subcategory
Transfer of patients' and family members' end-of-life wishes to palliative care unit	Written communication	Transfer of patients' and family members' end-of-life wishes through Electronic Health Record (EHR)
		Transfer of patients' and family members' end-of-life wishes through Patient Health Record (PHR)
	Verbal communication	Interaction between patient, family members and healthcare professionals
		Interaction between healthcare professionals

Usually there's nothing documented in the medical case summaries.

(CIP1)

Well, pretty seldom. But no... like in nursing daily care plans, not there... it's text that is written quite fast, almost in real time, very succinctly, you don't really elaborate that the patient would now like to expresses wishes concerning end of life or something.

(S1)

But like, goals for care, objectives, that have been set together with the patient's family. I'm sure some have been made, but they are rarely visible in the care plan.

(CIN1)

Transfer of patients' and family members' end-of-life wishes through Patient Health Record was described as a good thing, but Information Technology (IT) systems did not enable holistic ACP to be documented, made accessible. Interviewees described unavailability and inadequacy of information as problems with access to living will. They were not necessarily accessible although the patient had stored it in the National Data Repository for personal health records (Kanta, 2021). They could be found in EHR as separate, scanned files, or were kept at home and not available when needed despite the fact that professionals had Kanta services in use.

Like if you have made one and entered it in the Kanta [data repository].

(FGPN1)

In our files they are often separate scanned files.

(S2)

The will is probably kept at home. Or somewhere else... at that stage, it cannot be in the hospital files.

(S4)

ACP was not just about medical decisions. There was also an individual element, and both of these need to be considered. Living wills included end-of-life care desires (avoidance of pain, prolonged treatments, nutrition, additional examinations and preferred end-of-life care setting), but also very small, apparently very important wishes (favourite food and drink). Nurses said that refusal of any treatment may have been documented on a general level. Physicians stated that a living will without contents provided scant information about the patient's wishes.

Sometimes there are very small wishes, but you can tell right away that this is something that is very important for this person.

(S4)

In general, the wishes are quite modest. Usually they have to do with food and drink and particular times of the day.

(FGPN1)

It may only say that there is one, but there is nothing about the content, so it really doesn't give a good idea of the patient's wishes.

(CIP1)

3.2.2 | Verbal communication

Interaction between patient, family members and healthcare professionals means that patient's wishes were met through discussion. Given the lack of systematic initiation, documenting and accessibility of ACP, healthcare professionals had to reply proxy voice of family members. This raises questions with regards the fidelity of ACP documentations and decisions. Sometimes, a family member conveyed information, for example about living will. Nurses pointed out that family members thought that "terminal care unit" was a chilling name for the care setting if the patient was still scheduled for discharge.

I interview the patient personally about the significant things, so I don't even expect them to be stated quite clearly.

(S3)

Of course, information may then be given by a family member.

(CIP1)

Sometimes family members may bring up that this person has a living will.

(S4)

The family may say that you can tell that the name sounds chilling, especially as the patient is still going home. They come in for symptomatic treatment and go back home, that is the plan, so that sort of gives rise to feelings like that.

(FGN1)

Interaction between healthcare professionals means that professionals exchanged information about patients' wishes between different care settings by phone. In information transfer, telephone conversations were either considered to work well or not.

They call and say I've been working on this, and the wish here is such and such, and this is how we go from here. I think it works quite well, it's a really good way of transferring it further along the way for the good of the person being cared for.

(S4)

Sometimes you get this feeling that it's like a report you get on the phone.

(FGN2)

4 | DISCUSSION

The aim of this study was to describe healthcare professionals' accessibility and transfer of patients' and family members' end-of-life wishes in ACP to the palliative care unit. Two main categories emerged: *patients' and family members' end-of-life wishes documentation in relation to changing information needs* and *transfer of patients' and family members' end-of-life wishes to palliative care unit*. The key results showed lack of implementation of ACP early in the disease trajectory, lack of implementation about the holistic interpretation of ACP into medical notes and lack of transferability of ACP into healthcare documenting systems impacting on accessibility and realization for the patient and family members at the end-of-life.

In this study, *patients' and family members' end-of-life wishes documentation in relation to changing information needs* was described in relation to *patients' condition* and *care context*. Professionals working in PC unit presented lack of implementation of ACP early in the disease trajectory and highlighted the relevance of early ACP for everyone. Some patients came to PC unit almost in the

terminal phase. This could have been prevented if the patient had been previously identified, for example by means of features in IT systems (Lamas et al., 2018; Andreasen et al., 2019). On the other hand, in the case of patients transferring from specialist care ward to PC unit, the ACP discussion could have taken place very recently. The patient and family members may thus not yet have had time to internalize the PC policy; for example, this confirms the previous findings that ACP mostly occurred late (Kuusisto et al., 2020) and few chronically ill patients had an ACP (Dillon et al., 2017; Tai-Seale et al., 2018; Walker et al., 2018). ADs made beforehand could have promoted communication of patients' preferences (Johnson et al., 2015). ACP should start very early as a discussion forum around patients' and family members' wishes and choices (Kuusisto et al., 2020) based on the readiness of the individual (Rietjens et al., 2017). Motivating people to make an ACP is important (Yadav et al., 2017). The COVID-19 pandemic has shown the importance of ACP. Anyone can encounter a sudden, unexpected change in state of health. To our knowledge, this is the first study to show the role of the family care plan in PC. EHR is for documenting patient care, but even though family members and surrogate healthcare decision-makers play a big role, the guidelines do not address their role (NICE, 2017).

In this study, *transfer of patients' and family members' end-of-life wishes to PC unit* was described in relation to *written* and *verbal communication*. Transfer of written communication was viewed through both professionally generated (EHR) and patient-generated (PHR) records. According to the professionals in this study, patients' and family members' end-of-life wishes did not transfer particularly well to the PC unit through the EHR; family members' wishes even more poorly than patients' wishes. Professionals told lack of implementation about the holistic interpretation of ACP into medical notes. Besides medical decisions, there were also individual issues such as personal private wishes. According to guidelines, both of these should be considered (Rietjens et al., 2017). Previous scoping review showed that internationally nursing professionals had a central role in the preparation of ACP (Kuusisto et al., 2020) although Finnish guidelines do not address their role in ACP documentation (Finnish Institute for Health & Welfare, 2021). If the contents of ACP are not documented clearly and comprehensibly, it conveys poorly the wishes in relation to changing information needs. That is why the IT systems need to be reorganized to enable holistic ACP to documented, made accessible.

In this study, the lack transferability of ACP into healthcare documenting systems impacted on accessibility and realization for the patient and family members at the end-of-life. The finding is supported by previous research. In their study, Khandelwal et al. (2017) showed that the wishes of patients and families were not always met. On the other hand, in their study Walker et al. (2018) found that the ACPs that were not easily accessible were free-text progress notes. Lack of standardization of ACP documentation was common, and changes in the patients' care preferences were not easily accessible in the EHR. This study showed that national services such as Kanta in Finland (Kanta, 2021) with reservation

could be the new solutions linking patients' wishes with the care they receive that have been called for in the USA (Burris & Sevier, 2020). First, to increase the use of patient-generated living wills, for example My Anticipatory Care Plan (Scottish Government, 2018), the user-friendliness of the forms should be improved (Hooper et al., 2020; Turner et al., 2018) to increase the use. Second, solutions related to the integration of healthcare IT systems need standardization better interoperability to enabling ACP access (Walker et al., 2018).

In this study, professionals emphasized the importance of verbal information exchange alongside written information exchange. For example, end-of-life care discussions might have taken place even though they did not appear in the EHR. Access to information still depends on the patient and family members. For example, family members could convey information about the patient's living will to the PC unit. Previously, ACP has not been available in emergency department (Grudzen et al., 2016 Turner et al., 2018; Hooper et al., 2020). This can lead to an ethical dilemma: is information from pre-filled forms or family members reliable? On the other hand, unless the patient has discussed ACP, such as having AD in a desk drawer, with a family member (Detering et al., 2021), the information goes unnoticed. In this study, professionals pointed out that alongside electronic information exchange, there is still a need for verbal information exchange and discussion. Sometimes, phone consultations between professionals work well.

4.1 | Strengths and limitations

This study has some limitations. First, the data focus on nursing professionals and there is a relatively small number of physicians and social workers. This is understandable, when in terms of quantity, the majority of healthcare professionals are nurses. Another limitation may be that no secondary analysis of patient records was done. It would have provided an opportunity for a quantitative screening of the data. The strengths of this study lie in purposive sampling (Polit & Beck, 2017). Professionals involved in this study were PC clinical practice experts with an average of six years of work experience in PC. They were willing to share their views and experiences. It is to be assumed that they have the best knowledge concerning the research topic. This study relies on their reflections, not on a recent case. The broad population base of the study areas, which covers almost half of Finland's population base, is a strength of the study.

5 | CONCLUSIONS

This study focussed on an under researched area the documenting and accessibility of ACP documentation for healthcare professionals. It also highlights the need for a greater integration and seamless provision of services to ensure information can be accessed and enabled end-of-life wishes to be upheld.

5.1 | Relevance to nursing practice

This article is of interest to members of the education research community. Patients' and family members' end-of-life wishes may change even during the treatment situation. Jointly agreed wishes must be documented and, if necessary, updated in the ACP. Nursing staff and coordinators played a key role in documenting end-of-life wishes of patients and family members in holistic ACP. They need education to highlight their important role in ACP documentation. Moreover, it must be taken to ensure that information is passed on to patient, family members and all involved. Doing so, wishes could be taken into account and affect the implementation itself. In this study, family members' end-of-life wishes were not usually documented in EHR since it was considered to be patient's record. Professionals need education and support how to do this. Standardizing the design of ACP is important. Next, in order to improve access to ACP, in particular the development of a POC and family care plans should be continued. Especially documenting of family members' wishes must be instructed and documentation guidelines developed. Future research should examine how nursing professionals can promote ACP documentation to ensure continuity of care.

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