ORIGINAL ARTICLE

Quality of information transferred to palliative care

Anne Kuusisto PhD, RN, Postdoctoral Researcher[1,2] | **Kaija Saranto PhD, RN, Professor**[3] | **Päivi Korhonen PhD, MD, Professor**[4] | **Elina Haavisto PhD, RN, Professor**[1,2,5]

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

[2]Satakunta Hospital District, Pori, Finland

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

[4]University of Turku, Department of General Practice, Turku University Hospital, University of Turku, Turku, Finland

[5]Tampere University, The Health Sciences Unit of the Faculty of Social Sciences, Tampere, Finland

Correspondence
Anne Kuusisto, University of Turku, Department of Nursing Science, Medisiina B, FI-20014 Turku, Finland.
Email: anmakuu@utu.fi

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Abstract

Aims and objectives: To describe the quality of information coming from previous care units to palliative care.

Background: Information quality is an interconnected concept that includes different dimensions and can be viewed from different perspectives. More knowledge is needed from a multi-professional perspective on the information quality coming to palliative care.

Design: Descriptive qualitative study.

Methods: Altogether 33 registered nurses, practical nurses, social workers and physicians working in palliative care were purposively selected to participate in thematic interviews. The research was carried out in six palliative care units in three hospital districts. The data were analysed by using deductive and inductive content analysis. The COREQ checklist was used.

Results: Three main categories with thirteen categories were identified in connection with the deductive analysis based on the Clinical Information Quality framework: (1). Informativeness of information coming from previous care units to palliative care included accuracy, completeness, interpretability, plausibility, provenance and relevance. (2). Availability of information coming from previous care units to palliative care included accessibility, portability, security and timeliness. (3). Usability of information coming from previous care units to palliative care included conformance, consistency and maintainability. Each category is divided into sub-categories followed by narratives of their content.

Conclusions: This study provides new knowledge on the quality of information coming to palliative care from a multi-professional perspective. Professionals working in palliative care units highlight issues describing good information quality, but also point out quality issues and areas for improvement.

Relevance to clinical practice: The results can guide the development of documentation practices and Health Information System development as well as be used in the generation of a new audit instrument of information quality.

1 | INTRODUCTION

Palliative care relies on the success of the continuity of care with high information quality (IQ) received from the previous care unit. According to International Palliative Care Guidelines, end-of-life records should be accurate, clear, standardised and include a goal of care statement (Olsson et al., 2021). Previous studies have shown that incorrect and incomplete data (Wang et al., 2011) may lead to gaps in the continuity of care (Gott et al., 2011; Guo et al., 2022; Izumi et al., 2020), such as patient's feelings of uncertainty in a new palliative care unit (Guo et al., 2022) or risk of patient safety incidents such as medical errors (Izumi et al., 2020). The World Health Organization (2007) has launched international guidelines to support healthcare professionals in documentation that demonstrates professional obligation, accountability and legal requirements. Recently, the usage of standardised terminology has been highlighted (Johnson et al., 2018; Olsson et al., 2021; Sjöberg et al., 2021; Vuokko et al., 2017). In the palliative care context, communication guidelines may vary in different countries due to different positions of healthcare professionals, national laws and regulations (Olsson et al., 2021). IQ is a complex concept (DeLone & McLean, 2003; Fadahunsi et al., 2021; Ojo, 2017) and more knowledge is needed from a multi-professional perspective on the IQ coming from previous care settings to palliative care.

2 | BACKGROUND

Information quality (IQ) has to do with matters related to the content of care and the characteristics of Health Information Systems (HIS). IQ impacts both user's satisfaction with HIS and the purpose of using HIS that influence the extent to which the HIS can bring advantages for the individual and organisation (DeLone & McLean, 2003). IQ has been operationalised, for example, in terms of correctness, usefulness and timeliness of the information generated by the HIS. IQ has significantly influenced HIS use and user satisfaction. (Ojo, 2017).

In this study, IQ is viewed from the perspective of Clinical Information Quality (CLIQ) frameworks for digital health in palliative care. Based on systematic review, the CLIQ framework consists of three main categories of information: *informativeness*, *availability* and *usability*. *Informativeness* covers the benefits of digital information for clinical purposes. *Availability* considers the functionality of the HIS for maintaining clinical information. *Usability* concerns the ease of use of clinical information. Each main category includes categories which have been measured by determining whether a wanted (true positive) or unwanted attribute (quality problems) is there or missing. (Fadahunsi et al., 2021) (Table 1).

> **What does this paper contribute to the wider global community?**
>
> - This study recognises that the quality of information (IQ) transferred to palliative care unit is a multidimensional concept and consists of informativeness, availability and usability of information.
> - The study produced usable information that can support the development of palliative care from a multidisciplinary perspective. The results help to draw attention to the issues through which IQ can be developed by preventing potential patient safety problems.
> - Results show that from the healthcare professionals' perspective, both Health Information Systems and data production, in particular recording practices, should be harmonised to improve the IQ transferred to palliative care. Every single healthcare professional has an important role and responsibility to play in providing quality information. It is important that each professional commits to following commonly agreed guidelines, so that the content and meaning of information always remain the same regardless of who records the information.

From the perspective of informativeness of information, documents sent between palliative care settings have been nonspecific and general, not always providing important information such as patients' end-of-life (Brownstein et al., 2021; Kuusisto et al., 2022; Sjöberg et al., 2021) or spiritual care wishes (Baetz-Dougan et al., 2021). In transitions from hospital to hospice, lack of information on end-of-life and everyday care and medication was found (Izumi et al., 2020). On admission to palliative care unit, nurses identified a shortage of information on patients' home conditions (Mertens et al., 2021). Document analyses showed that in the USA, the quality of pain documentation in a cancer centre was below the highest level (Song et al., 2015), whereas in Sweden, documentation in specialised palliative care units was task-oriented, mostly related to medication interventions (Sjöberg et al., 2021).

From the point of view of availability of information, end-of-life care documents should be accessible to healthcare professionals when necessary (Olsson et al., 2021). In Canada, a newly developed paper-based transfer form between hospital and long-term care was found useful. However, phone calls and discharge summaries were still needed for conveying descriptive information in order to build a coordinated scheme for end-of-life care. (Baetz-Dougan et al., 2021).

TABLE 1 Clinical information quality framework for digital health (Fadahunsi et al., 2021)

Main category	Category	Definition
Informativeness	Accuracy	The extent to which information is true.
	Completeness	The extent to which no required information is missing.
	Interpretability	The extent to which information can be understood.
	Plausibility	The extent to which information makes sense based on common knowledge.
	Provenance	The extent to which the source of information is trustworthy.
	Relevance	The extent to which information is useful for the intended task.
Availability	Accessibility	The extent to which existing information is easily obtainable.
	Portability	The extent to which information is accessible in different systems.
	Security	The extent to which information is protected from unauthorised access and corruption.
	Timeliness	The extent to which current information is available on time.
Usability	Conformance	The extent to which information is presented in the desired format.
	Consistency	The extent to which information is presented in the same format.
	Maintainability	The extent to which information can be preserved.

In Europe, the use of electronic nursing discharge summary reduced patients' responsibility for data transfer (Kuusisto et al., 2009). In India, the participation of family members in end-of-life care was seen as important, but professionals did not always have their up-to-date contact details (Salins et al., 2017). A digital platform is needed to enable timely, comprehensive and high-quality transfer of information between different care settings and professionals (Mertens et al., 2021).

From the viewpoint of usability of information, document analyses have provided information on the quality of the documentation in palliative care (e.g. Brownstein et al. 2021; Sjöberg et al., 2021; Song et al., 2015). Care plans and discharge reports have been inconsistent, depending on the palliative care unit and the professional (Mertens et al., 2021). A systematic review showed that consistency and completeness of patient data in HIS have been better with structured documentation (Vuokko et al., 2017). However, nurses working in hospital or home care did not use the same care plan models, which posed a challenge for collaboration (Lundereng et al., 2020).

Taken together, IQ is an interconnected concept that includes different dimensions and can be viewed from different perspectives (DeLone & McLean, 2003; Fadahunsi et al., 2021; Ojo, 2017). However, there is no consensus on the definition of IQ for the clinical purposes of digital health information (Fadahunsi et al., 2021). This would be very important for the continuity of care, also considering palliative care.

3 | AIM

The aim of this study is to describe the IQ coming from previous care units to palliative care. This study is part of a larger study with extensive data which has been collected from various healthcare professionals, but also from patients and family members. The purpose of the wider study is to describe the evidence-based practices of advance care planning (ACP) in palliative care in terms of data content, data structure and data quality, aiming to ensure the continuity of care for a patient with cancer, in order to improve the quality of care and patient safety by promoting the flow of information and preventing unnecessary emergency visits.

4 | METHODS

4.1 | Study context (setting)

In Finland, health services consist of primary healthcare and specialised medical care. Primary healthcare services are provided at communal health centres. Specialised medical care is carried out in hospitals, but it is also provided as consultations to primary healthcare. In addition, there are private services providers. (Ministry of Social Affairs and Health, 2022).

Palliative care is provided by public and private service providers. Public services are provided in nursing homes and long-term

care wards in health centres. Specialised palliative care is provided in a hospital, hospice or, if a hospital-at-home is available, at home or in a housing service unit. The organisation of palliative care is changing in connection with the reform of the social and healthcare service system that still is and was under way in Finland at the time of the study. (Finnish Institute for Health and Welfare, 2021).

4.2 | Design

This study employed qualitative methodology and used thematic interviews as data collection method. Qualitative description is a suitable design when the aim is to represent experiences where little is known about the theme under research (Doyle et al., 2020). Guidelines for reporting qualitative research (Tong et al., 2007) (Data S1) were followed.

4.3 | Sample

Purposeful sampling was used to obtain diverse multi-professional perspectives, which are especially helpful in qualitative description in healthcare (Doyle et al., 2020). Each of the six research units had a contact person who recruited interviewees, distributed consent forms and acted as a liaison for researchers. The inclusion criteria were registered nurse, practical nurse, physician and social worker, voluntary participation and working in direct patient care in a palliative care unit in Finland.

4.4 | Data collection

The data were collected from spring to autumn 2019 in three hospital districts with five departments and one outpatient department. Registered and practical nurses participated in focus groups. Social workers and physicians were interviewed individually because no focus groups covering social workers and physicians would have been achieved incidentally. Based on the subjects' preference, two couple interviews were carried out instead of individual interviews. Altogether 33 healthcare professionals were interviewed. (Table 2).

The interviews were performed with occupational group-specific face-to-face sessions in the workplace, one by telephone and another in a private place suggested by the interviewee without disturbance from other persons. The interviews, recorded with the permission of the interviewees (Kyngäs et al., 2020), lasted between 29 and 173 min (mean 58 min). An interview guide based on literature was used as an aid to the thematic interview, which is a method of data collection where data are gathered by interviewing participants about issues relating to the aim of study. The themes for the interview were derived from theoretical concepts that were related to the aim of the study. (Åstedt-Kurki & Heikkinen, 1994). In May 2019, a pilot study with a nurse focus

TABLE 2 Description of data collection and the healthcare professionals involved (n = 33)

Interview type	Professional group	Number of professionals	Code
Individual interview	Social worker	5	S1–S5
Individual interview	Physician	3	P1–P3[a]
Focus group	Practical nurse	5	FGPN1
Focus group	Registered nurse	6	FGN1
Focus group	Registered nurse	4	FGN2
Focus group	Registered nurse	3	FGN3
Focus group	Registered nurse	3	FGN4
Couple interview	Registered nurse	2	CIN1
Couple interview	Physician	2	CIP1

[a]'P3' = Telephone interview.

group in one unit was done to test the themes and to identify potential problems (Kyngäs et al., 2020). Based on the feedback, the questions were re-formulated in a language used and understood by the interviewees. The pilot interview was not included in the data. Two themes emerged: the quality of the information and usability of the information. The interviewees were asked to assess (when a new patient comes to their unit) the quality of information coming from the previous treatment setting (usability in their own unit for patient care).

4.5 | Ethics

The study followed academic scientific practice (World Medical Association, 2021). It received ethical approval (University Research Ethics Committee 15/2019) and research permits from the organisations. The participants were informed about the practices involved the study. After that, they gave their consent to participate. The interviewees were told that participation was confidential and voluntary, and they could withdraw from the study at any time. The researchers were from outside the palliative care unit and no relationship with the participants was established prior to study commencement.

4.6 | Data analysis

Deductive-inductive content analysis was used to analyse the data (Elo & Kyngäs, 2008; Kyngäs et al., 2020). The theory with the Clinical Information Quality framework (CLIQ) was used to guide

the deductive analysis from the outset and served as a classification framework for the analysis. The CLIQ framework has been prepared on the basis of a systematic literature review and contains three main categories: Informativeness, Availability and Usability, which can be used to assess the extent to which digital health information is suitable for clinical purposes. The CLIQ framework was chosen as the deductive framework for this study because it was considered suitable for reviewing the IQ of the clinical data transferred to palliative care in the context of digital health technology for the treatment of patients for preventive or therapeutic purposes in the healthcare context (Fadahunsi et al., 2021).

The data were first organised according to the three main categories of CLIQ framework. Initially, the data were searched for original expressions suitable for each main category of CLIQ framework. The data were then analysed inductively (Elo & Kyngäs, 2008; Kyngäs et al., 2020) within the main categories ($n = 3$) and categories ($n = 13$) of the CLIQ framework: Informativeness (accuracy, completeness, interpretability, plausibility, provenance, relevance), Availability (accessibility, portability, security, timeliness) and Usability (conformance, consistency, maintainability) (Fadahunsi et al., 2021). The unit of analysis was a part of a sentence or a combination of words. The original expressions were simplified, after which the simplifications with the same meaning were grouped into subcategories and named according to their content describing the desired information attributes or quality problems in each category (Figure 1). The authors only had a three-partition as a deductive analysis framework. New categories would have been formed if the data had not 'sat in place in the framework during the analysis phase'.

4.7 | Rigour

Trustworthiness is assessed by addressing credibility, confirmability and transferability. Credibility means that the research results correspond to the interviewees' perception of the phenomenon being studied (Kyngäs et al., 2020). In this study, interview was chosen as the best method for obtaining profound information on the participants' perspectives (Elo & Kyngäs, 2008). Qualitative data helped to understand how professionals working in palliative care units deal with the quality of information. Purposive sampling enabled the use of the informants with the best knowledge in the study. The participants in the study represented different healthcare professional groups, which confirms credibility. Credibility was enhanced by a multidisciplinary team of researchers in the research process. In deductive analysis, an analysis matrix is important because it can have a large influence on the study analysis. In this study, a highly structured CLIQ matrix was used to guide the analysis process with the aim of the study, which improved the credibility of the study. Inductive content analysis was first performed by one researcher. After that, the research group went through the results together, discussed and accepted them. Confirmability means that the data represent the information provided by the participants. To strengthen authenticity, at least one original citation was provided for each named category. The careful reporting of results enhanced confirmability. Confirmability of the results is increased by similarities with previous research evidence (Kyngäs et al., 2020). The results describe the experiences of the interviewees on the topic, but they can be extended to other similar palliative units, with some reservations.
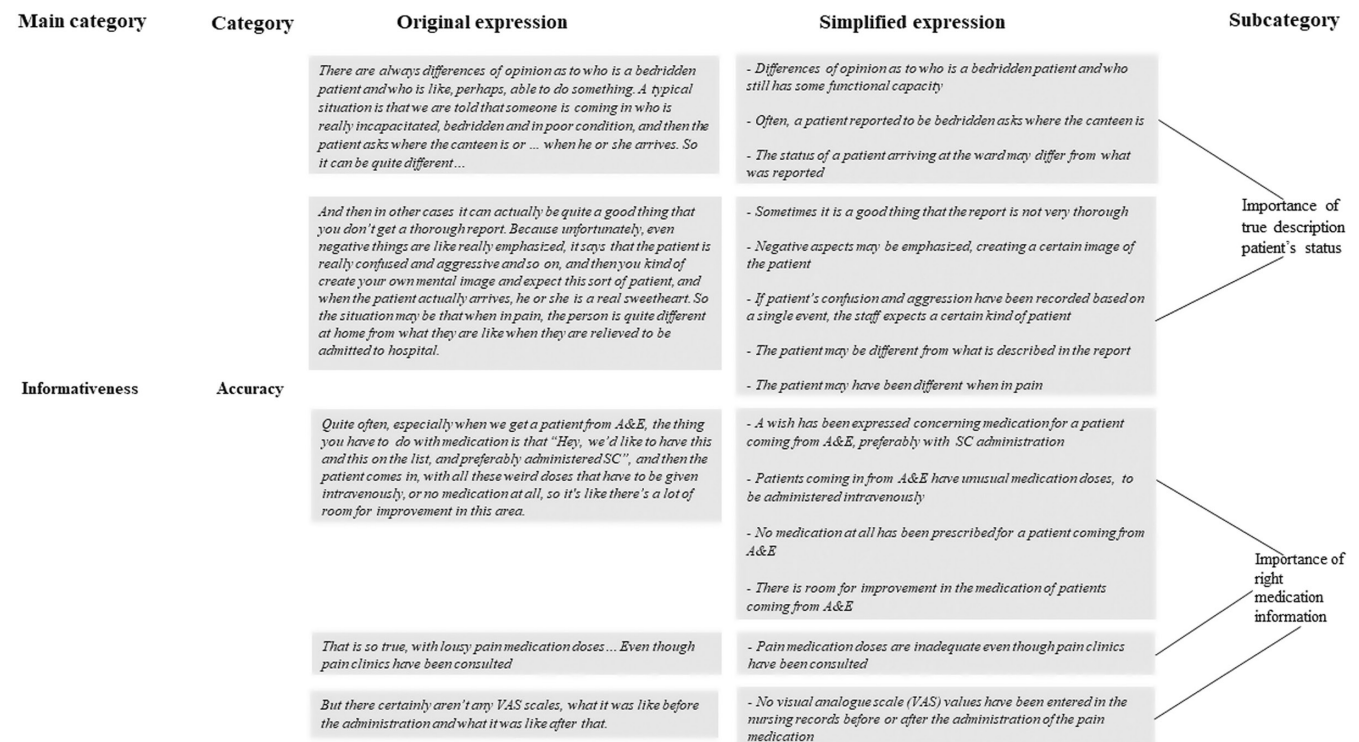

FIGURE 1 Example of formation of categories of informativeness (accuracy)

5 | RESULTS

The participants in the study were aged 19 to 62 years (mean age 46 years). They had worked in healthcare from less than two to 37 years (mean 17 years) and in palliative care, from less than 1 year to 19 years (mean 6 years) (Table 2).

The findings are presented based on the three CLIQ framework main categories and their thirteen categories (Fadahunsi et al., 2021). Each category is divided into sub-categories followed by the narratives of their content (Figure 2).

5.1 | Informativeness of information coming from previous care units to palliative care

5.1.1 | Accuracy of information

Importance of true description of patient's status was evident as the information received did not always describe the patient's condition. Indeed, a patient reported as being incapacitated may actually have been able to walk. On the contrary, sometimes, it was pointed out as a good thing that the information obtained was not too thorough. Negative things might have been emphasised, which could have created a certain image of the patient. If a patient's confusion and aggression, for example, was recorded on the basis of a single event, the nurses were prepared for a specific type of patient. Another example illustrated conflicting information obtained about a patient who, based on records, had suffered from pain and been anxious at home but whose pain had been relieved by the time of entering the palliative care unit.

Importance of right medication information was highlighted. There was room for improvement in the medication information and pain assessment of patients coming to the palliative care unit. The quality of medication information transferred to palliative care being correct and precise was considered noteworthy. For patients arriving at the palliative care unit through the emergency department, the palliative care unit had in advance expressed wishes about certain drugs and routes of medication administration. In practice, however, the prescriptions and routes of medication administration received did not meet expectations. At times, no medication had been prescribed, the route of medication administration was different from that desired, or painkillers were inadequate although the pain clinic had been consulted. In addition, in some cases, there were no visual analogue scale (VAS) values in the nursing records before or after the administration of the pain medication.

> A typical situation is that we are told that someone is coming in who is really incapacitated, bedridden and in poor condition, and then the patient asks where the canteen is or … when he or she arrives. (FGN2)

> That is so true, with lousy pain medication doses… Even though pain clinics have been consulted. (FGN3)

5.1.2 | Completeness of information

Sufficient end-of-life care information meant that receiving all the necessary and appropriate information for end-of-life care was vital, but it was not always received on arrival. In practice, especially care instructions were described as being incomplete. For example, treatment guidelines and do not resuscitate (DNR) decisions were generally pending on arrival. Only few patients had a DNR decision on arrival to the palliative care unit; at times, patients were described to come to the palliative care unit as if to prepare them. Even at the end of life, not enough information about the patient's emotions was always obtained through the health records.

Sufficient functional ability and social information were needed to provide an overall picture of patient performance. Documentation of patient's functionality or the amount of assistance needed were seen as very important. However, there were no documentations in nursing reports of whether the patient visited the toilet independently or assisted, for example. Assessing a patient's performance was perceived as challenging; as an example, patients with cancer may endeavour to look better than they are actually feeling during the palliative outpatient visit. Regarding discharge, social information and descriptions of patient's housing and survival at home were considered essential, but they were inadequate or not found in the electronic health record (EHR). That is why professionals working in palliative care units had to find out this information by themselves.

> It would be good if there were clearly more notes on the patient's functional capacity on any page, regardless of whether they are written by a doctor or a nurse. (P2)

> We kind of chart the patient's living arrangements, it's not as if I could find that information anywhere. (P2)

5.1.3 | Interpretability of information

End-of-life care concepts not unambiguous pointed out that they were not understood in the same way. That is because the use of palliative care and end-of-life care concepts was not established. Even physicians who regularly treated palliative care and end-of-life care patients could confuse those concepts. As an example, a patient might have been registered with an end-of-life care decision and transferred to the palliative care unit, but what the end-of-life care decision meant could only be ascertained in the ward. The end-of-life care decision did not necessary specify what to do and what not to do. Patients in the end-of-life care phase could be in a very different situation depending on when the decision was made.

The concepts of service housing not unambiguous meant that they were not clear to the various healthcare professions when their meaning was not always the same even for social workers who were in regular contact with those concepts. In practice, it
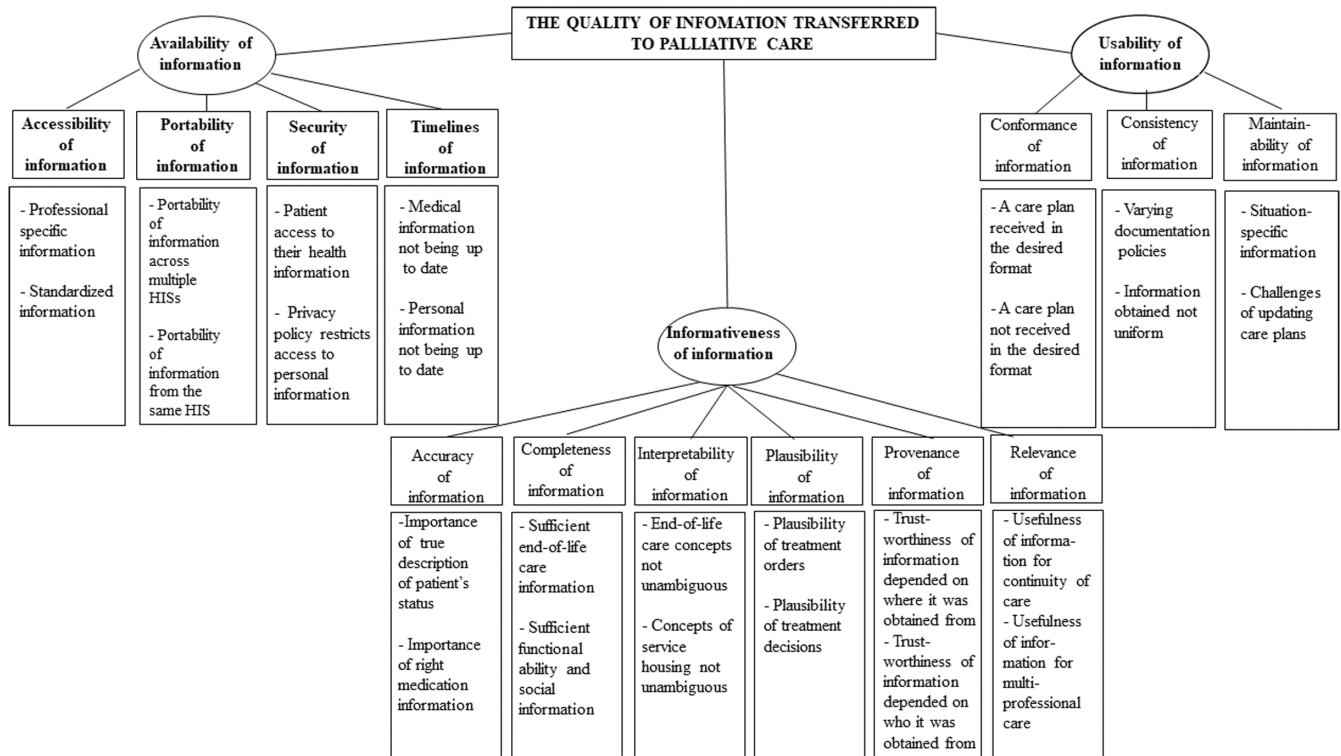
FIGURE 2 Quality of information transferred to palliative care

was not always clear from the records where the patients lived and what their housing conditions were. The name of the service apartment did not necessary indicate the number of services available, for example. Even though the information received indicates that a patient lives in a nursing home, expected to have regular service and care, they may actually have their own apartment there and get some home services not regularly, but only at pre-specified times.

> Palliative care and end-of-life care are frequently confused; there are even doctors who deal with these patients all the time who can get them mixed up. (FGN1)

> And the terminology related to service housing is not too clear to other professionals, and not necessarily to the social worker, either. (S2)

5.1.4 | Plausibility of information

Plausibility of treatment orders signified that especially treatment orders or treatment decisions obtained were not always considered credible. Healthcare professionals working in the palliative care unit explained that it was sometimes left to the recipient of the information to assess the value of this information in palliative care use. The information obtained from different places, such as primary healthcare, was not always seen as reasonable and probable. As an example, red blood cell transfusion was recommended if a patient's

haemoglobin level was below 85 g/L and he or she required daily transfusions.

Plausibility of treatment decisions meant that at times, it was the responsibility of the recipient of the information to assess whether it was sensible to act on the basis of the treatment decisions received. For example, there had been a misunderstanding in primary care that the patient or family member did not accept the DNR decision, which is why the patient had been transferred to a palliative unit. In these cases, treatment decisions remained the responsibility of the recipient of the information.

> It says: 'Red blood cell transfusions are given if hemoglobin level is 85, and then given daily for a week", you have to sort of assess whether it makes any sense. I mean the information.' (P1)

> In most cases, if they here come from outside, the patients, I mean like from a health centre, there is some misconception that the patient or their next of kin will not accept something like a DNR decision. (P1)

5.1.5 | Provenance of information

Trustworthiness of the information received depending on where it was obtained from meant that the place of origin and the professional responsible for the information had an influence on IQ. According to the interviewees, IQ varied depending on where patients came

from, and documentations in the sending unit should be made in the same way as in the receiving unit. In this case, in a transfer situation, besides an oral telephone report, the information should be recorded in the EHR where the information can be checked if necessary.

Trustworthiness of information received depending on who it was obtained from indicated that the healthcare professional responsible for the information had an influence on IQ. In other words, the IQ obtained also depended on the nurse or physician who provided it and on how they interpreted things. For example, a telephone report did not appear convincing because the nurse who gave it had not necessarily seen or cared for the patient. According to the nurses, the clarity of the treatment instructions received depended on the physician in the sending unit.

> So if you have not actually even nursed and do not know the patient, that may sometimes cause the report not to be quite truthful. (FGN2)

> What is written in the records depends on the doctor who has seen the patient; sometimes there is a clear policy, sometimes not. (FGN1)

5.1.6 | Relevance of information

Usefulness of information for continuity of care was seen as very important, especially if a patient with cancer had been treated for a long time. In practice, the information recorded in the previous care setting and received by the palliative care unit provided additional information. If the patient's symptoms have been recorded at home, professionals in the palliative care unit can compare whether the symptoms have increased. Small crumbs of information, such as information on whether the patient is a home care client, were considered helpful. Even though a care plan developed in a previous care setting provided guidance, it was not seen as suitable as a plan in the new setting. For the continuity of care, the visibility of the request for palliative care expert consultation, even just one sentence, was seen as the most important piece of information received. *Usefulness of information for multi-professional care* appeared differently to different occupational groups. Physicians saw information about the planned nursing interventions as useful for advance care planning (ACP). On the contrary, they felt that nursing documentation was task-focused, focusing mainly on medication delivery documentation, while information on the evaluation of care outcomes was limited. For nurses, medical case summaries appeared to be of a general nature. Social workers felt that these issues concerned mainly nursing care so they could not comment on the content issues.

> Like symptoms have kind of been charted, what they were like at home when it was done, so when the

patient comes to the ward we can compare whether a particular symptom has increased more. (FGN4)
>
> Maybe good usability, if you consider prognostication, well you can find it right there in the nursing record on the left-hand side, in the tips and plans sections .... that's where. (P2)

5.2 | Availability of information coming from previous care units to palliative care

5.2.1 | Accessibility of information

Professional-specific information was related to the quality of being able to access digital information from the HIS in palliative care. Documentations for each professional group were professional-specific records located on their own pages in the HIS. Besides medical records, nursing care plans and daily progress notes with individual patients' everyday life matters were located in the nursing records. Nursing-specific as well as medication information was seen as accessible because all of it was found in its own place in the HIS.

Standardised information meant that the content of documentations was structured and standardised in the HIS. Subheadings had been used to structure the texts. However, they were still mainly per-day and per-visit entries. Standardised recording was assessed to facilitate the accessibility of information in the palliative care unit. For example, prescriptions or physicians' comments related to medication were easily found when subheadings had been used to structure the text.

> That the SOS pages are there, and we can see the notes made by physiotherapists and nurses and physicians, and they can see our notes as well. (S4)

> Of course, subheadings are used and it's easy to find physicians' prescriptions or comments related to medication, for example. (CIP1)

5.2.2 | Portability of information

Portability of information across multiple HISs implied that the data recorded in the other organisation were separate from the patient data in their own organisation. In other words, the ability to access information from previous care units required the use of multiple HISs. In practice, professionals working in the palliative care unit found information by searching it from several different HISs. Professionals saw outpatient records through a separate HIS, but daily progress notes, for example, could be found in their own nursing records. The use of many different HISs hampered easy access to information from previous care units.

Portability of information from the same HIS was seen as a goal. Professionals waited for the implementation of the same HIS for all units. They trusted that information from previous care units would be better accessible in palliative care once the same HIS was in use by all.

> In social work we also see the Client Information System notes, or outpatient notes as it were. (S4)

> And once we are all in the same system it will be easier to look it up. (P1)

5.2.3 | Security of information

Patients' access to their health information included both authorised and unauthorised access to HIS, and they were issues related to information security. Patients had the opportunity to review their own data. Patients' legal right to inspect their own data referred to their right to their own healthcare data. Professionals explained that patients could read their own patient data in the My Kanta service. It is a national online service where citizens can view the data entered by healthcare professionals. In terms of data security and data protection, patients can also check the My Kanta service to see where their healthcare data have been processed and shared.

Privacy policy restricts access to personal information meant that privacy prevented access to family members' information. There were restrictions in the processing of personal data due to the protection of privacy. In practice, it meant that the contact information of patients' relatives was not always accessible in the palliative care unit. In particular, in the case of a patient still living at home, the next-of-kin data could not be updated from the national Digital and Population Data Services Agency to the EHR in use. For example, demographic data of unmarried partners were not necessarily up to date, or the patient might have a spouse but did not live at the same address.

> Of course, the patient can look up and check his or her own patient information in the Kanta [national data repository] system. (S1)

> Or if they live at home, well naturally, it's not as if the actual network of family and friends can always be obtained from the population data services or something. (S2)

5.2.4 | Timeliness of information

Medical information not being up to date concerned especially medical case summaries and referrals. Professionals were unhappy with the timeliness of the information delivery, because the information transferred to the palliative care unit was not available on time.

Medical documents received from the patient's previous care unit might be out of date. Professionals said that the medical case summary was not up to date when the patient arrived at the palliative care unit. The referral may also have been written a few days before the discharge and a lot might already have changed.

Personal information not being up to date suggested that if a patient's personal information was out of date, perhaps from more than 10 years ago, it might not be of any value in the current situation. For example, a patient's spouse might have died or a patient reported to be single might in fact have a cohabiting partner.

> The text is something that was written on Friday, and there have been two long days during which all kinds of things may have happened. (FGN2)

> There may also be information that is incorrect or outdated. (S2)

5.3 | Usability of information coming from the previous care units to palliative care

5.3.1 | Conformance of information

A care plan received in the desired format meant that it was very well prepared, met expectations and included useful information and was obtained from certain care units. Conformance of information transferred from previous care unit was viewed through legal requirements or guidelines of documentation. For example, a patient referred by a physician who had provided medical care in the patient's home could have a clear and ready-made care plan.

A care plan not received in the desired format meant that the IQ did not always meet the legal requirements of documentation guidelines. The care plans received from previous care unit did not meet the expectations, were not in the desired format and not all patients coming to unit had a care plan. Most patients had proactive care plans of some kind, but from some places, patients arrived with incomplete information and more limited plans, or even without any plan at all. Patients from surgical units, for example, arrived with quite vague information and plans.

> Well like from some places you get plans for the long term that are really good and carefully considered. (P3)

> In principle, we never get what you might call a ready-made care plan for them. (FGPN1)

5.3.2 | Consistency of information

Varying documentation policies came up in it that the IQ received in palliative care unit varied depending on the sending unit. Deficiencies in

uniform operational policies appeared in the variation in the records received. The operating methods of the different units were not identical. The same things were recorded in different places in HIS in different municipalities. The common documentation practices agreed in the quality manual were thus not always put into practice.

Information obtained not uniform meant very differently structured care plans received in the palliative care unit. Naturally, they varied according to the patient, but also depending on the stage of treatment. Sometimes there could be a very detailed plan while sometimes there was no plan at all.

> Every municipality records the same things on slightly different pages. (P2)

> It varies a lot. Ranging from practically nothing to very detailed information. (CIN1)

5.3.3 | Maintainability of information

Situation-specific information indicated that IQ was related to a specific time or situation in one's own unit. For example, receiving usable care instructions was challenging during on-call time. The challenges of data transfer were highlighted especially on weekend nights. During office hours, the ward physician would be able to contact the physician in the referring unit and influence decisions before the patient was transferred. The information received also depended on the situation in the unit during the phone report, such as whether there was a lot of noise during the report or whether there was a possibility to listen in peace and ask questions.

Challenges of updating care plans were reflected in that some of the care plans received were not up to date. The need to allow continuity of care required information maintenance in information transfer. Nurses believed that a patient should be able to be treated according to a care plan. However, it was challenging if the plan was not up to date. In palliative care, situations change rapidly. There are many difficulties in updating care plans, and it might even be forgotten.

> What the situation is like when you are on the phone at this end - is it really noisy or something, are you able to listen undisturbed and ask about those things. (FGN4)

> Updating the nursing plan may be what is most often forgotten, so yes, there are a lot of problems with that. (FGN2)

6 | DISCUSSION

This study describes IQ coming from previous care units to palliative care in the main categories of information: *informativeness*, *availability* and *usability* based on the CLIQ framework (Fadahunsi et al., 2021). Healthcare professionals working in palliative care units highlight issues describing good IQ, but also quality issues and areas for improvement.

Informativeness of information received from previous care units means the extent to which it is useful for clinical purposes in palliative care units (Fadahunsi et al., 2021). In this study, a holistic palliative view of the patient is not conveyed as the information on patients' physical or mental condition and functional ability as well as housing arrangements appeared to be inadequate in the documents received in the palliative care unit. Correspondingly, in a previous study, at hospice admission, nurses did not receive sufficient information on the patient's living arrangements and everyday care from the hospital, which delayed care (Izumi et al., 2020). These inadequacies may also hinder early discharge, continuity of care and impair the quality of care received by the patient. A previous study (Kuusisto et al., 2009) showed that the patient's condition in the transfer phase is the most important thing for the new care setting.

In this study, the information on prescriptions received on admission to palliative care unit is not seen as appropriate for proper symptom management. Similarly, in their study, Brownstein et al. (2021) described the pain medication orders for long-term patients entering acute hospital for the last days of their lives as inaccurate. In another study, in the case of patient transfer, deficient prescriptions from the hospital caused additional work for nurses working in hospice. In addition to incomplete medical information, the inadequate information on pain assessment highlighted in this study is an important observation as palliative care aims to alleviate suffering (Olsson et al., 2021). In contrast to this study, a review of patient records showed that the use of pain assessment measures was well reflected in the care plans of end-of-life patients although other symptom assessment measures were rarely used (Sjöberg et al., 2021). Another document analysis at one cancer centre in the USA showed that documentation of pain re-assessment was inadequate and routine-based and did not include enough information of variations in the severity, location or nature of the pain (Song et al., 2015). Previously in their study, Gott et al. (2011) showed that lack of a structured approach to palliative care transition hindered effective transition between secondary and primary care in the United Kingdom.

This study reveals the inconsistency of the use of concepts related to palliative and end-of-life care even among professionals who constantly use them. The findings of incompleteness or even complete absence of treatment guidelines and treatment decisions such as DNR for end-of-life care patients are worrying and may be reflected in the continuity of care and the treatment patients receive. This may be because a joint end-of-life discussion has not yet taken place (Kuusisto et al., 2022). Previous studies have shown that patients were not told their prognosis in hospital, and this may be a barrier to preparing them for palliative care (Gott et al., 2011; Izumi et al., 2020). In the study by Gott et al. (2011), the patients were not told about the palliative care line and they were discharged from acute hospital without being of aware of being in the terminal phase, and thus with a false hope of recovery. Palliative care

guidelines recommended that patient's preferences, medical decisions and treatment limitations should be included in the end-of-life care documents (Olsson et al., 2021). Earlier studies have shown, however, that ACP records were rare at the end-of-life stage (Brownstein et al., 2021; Izumi et al., 2020; Kuusisto et al., 2022; Sjöberg et al., 2021) and there was a lack of prognostication documentation, such as updating the patient's prognosis in the care plans (Gott et al., 2011).

The healthcare professionals in this study link the IQ to the source of the data on the basis of their professional experience. They value uniform documenting practices and express a wish that they should be uniform across units. For the informational continuity of care, it is important that (end-of-life care) concepts are understood and used in a consistent manner. A systematic review showed that structural recording and the use of standardised terminologies is needed to achieve high IQ (Vuokko et al., 2017).

The relevance of information can be seen through its benefits. In this study, previous data provided more information and made it possible to compare symptoms or revealed a need for palliative specialist consultation, for example. A recent scoping review (Olsson et al., 2021) verified the finding of this study that consulting is one of the key elements of palliative care. In this study, the value of the nursing care plan was seen through multi-professional benefits. The planned nursing interventions in the nursing care plans were seen as useful for the medical professionals as well. This is a significant finding as previously the benefits of nursing documents have mainly been reported for nursing professionals (Kuusisto et al., 2009).

Availability of information coming from previous care units shows how practical the HIS is for maintaining clinical information (Fadahunsi et al., 2021). Interestingly, unlike in a previous study, in this study professional-specific records in HIS were not seen as a barrier for information access. In Belgium, similarly to this study, professionals used discrete professional-specific records, and a lack of shared HIS hindered inter-professional collaboration between treatment settings in palliative care (Mertens et al., 2021). Instead, in this study, structured nursing data content promoted information access and supported the expansion of its use. Internationally, the use of standardised nursing terminologies is not a norm, but integration is seen as necessary (Johnson et al., 2018; Vuokko et al., 2017), also in palliative care, improving cooperation and reducing misunderstandings (Olsson et al., 2021).

In this study, the portability of data required that it be searched in separate HISs because patients' information is located in different registers of various organisations. It is thus believed that the new upcoming shared HIS will improve the portability of information. The finding is supported by several studies showing that despite different stages of digitalisation in different countries, the ability of documents to be easily carried or moved between care settings is seen as a cornerstone of successful palliative care (Baetz-Dougan et al., 2021; Mertens et al., 2021; Olsson et al., 2021).

Based on this study, a national information portal such as Kanta [national data repository] in Finland (Kanta, 2022) could provide solutions for data transfer with shared care plans in palliative care. This study provides evidence of its benefits to patients. The professionals in this study recognised that nowadays, patients are empowered and can check their own patient data, such as nursing discharge summary in 'Kanta' (Kanta, 2022). Health data are highly sensitive and should be protected from outside access. According to the General Data Protection Regulation [EU] and international documentation guidelines, healthcare professionals have the duty to protect patient confidentiality (World Health Organization, 2007). In this study, professionals working in palliative care unit reported that they did not always receive up-to-date information about incoming patients and that family members' contact information was sometimes outdated, similarly as in the study by Salins et al. (2017). Correspondingly, in the study of Mertens et al. (2021), there was variability in the time of arrival of medical case summaries from hospital to primary care. Receiving information late could entail a risk of adverse effects on the quality of care (Izumi et al., 2020; Kuusisto et al., 2009). Moreover, without up-to-date contact information, it is challenging for palliative care units to reach patient's relatives if necessary when the patient's condition deteriorates rapidly, for example. Already in 2009, one study (Kuusisto et al., 2009) showed that electronic nursing discharge summary, nowadays accessible from 'Kanta' (Kanta, 2022), enabled real-time transmission if carefully done and if complemented by a short report and medical case summary.

Usability of information coming from the previous care units concerns the fluency of use of clinical information (Fadahunsi et al., 2021). In this study, the desired format of the care plan was that it was clear and as highly planned as possible. However, non-compliance of the information received with the information needed hampers the exchange of information in palliative care. Similarly, in previous studies, professionals valued clear information exchange (Guo et al., 2022), but additional information had to be obtained from the patient or family members, for example (Mertens et al., 2021). On the contrary, electronic nursing discharge summary has reduced the patient's responsibility for communicating information in hospital transfers (Kuusisto et al., 2009).

In this study, conformity with World Health Organization (2007) guidelines is not always seen in the documentation. Instead, there is high variability in the information received from patient's previous care setting, from almost nothing to a well-designed detailed care plan in the study of Mertens et al. (2021). In Australia, in the study by Brownstein et al. (2021), less than half of those long-term patients who moved to hospital had a confirmed ACP. More consistent information has been achieved with the use of standardised documentation (Vuokko et al., 2017) although its use is not uniform (Johnson et al., 2018). In this study, the challenges of maintaining the information obtained concern in particular instructions and care plans during on-call time. From the patients' perspective, continuing medication is important in transfer situations (Guo et al., 2022). It is important that those who continue with the palliative care have information about the medications that have worked for the patient

in question (Izumi et al., 2020). Based on international palliative care guidelines, end-of-life care documentation should be regularly updated (Olsson et al., 2021). In the study of Gott et al. (2011), patients and family members were unaware of the care plan. In the case of palliative patients, it is especially important to take into account patients' own up-to-date wishes (Brownstein et al., 2021; Kuusisto et al., 2022).

6.1 | Strengths and limitations

The usefulness of qualitative research is the insight into 'the life world of the participants' as a key benefit of this study (Doyle et al., 2020). This study relies on subjective measures, in other words, on the perspectives of the information users. The data were collected through thematic interviews with healthcare professionals with an average of six years of work experience in palliative care. There is no absolute certainty that the data were saturated (Kyngäs et al., 2020) as they were collected by four interviewers at different times in three different geographical areas. The researcher team spent a lot of time on the data to increase the understanding of the research topic. The CLIQ framework guided the analysis. As presented earlier, some of the categories of the CLIQ could fit into more than one category (Fadahunsi et al., 2021); however, in this study, they were located based on the common view shared by the researchers.

7 | CONCLUSION

This study provides new knowledge on the IQ, in other words, the informativeness, availability and usability of information coming from previous care units to palliative care from a multi-professional perspective. Healthcare professionals working in palliative care units highlight issues describing good information quality, but also point out quality issues and areas for improvement.

8 | RELEVANCE TO CLINICAL PRACTICE

Informed decisions require quality information transfer. The information transferred is irrelevant unless it is of good quality. According to this study, every single healthcare professional has an important role and responsibility in providing quality information. It is important that the content and meaning of information always remain the same regardless of who records the information. Thus, healthcare professionals should be encouraged to produce quality information. The results of this study can be used to improve IQ and continuity of care in the palliative care setting. They can guide the development of documentation practices, for example by peer review methods and Health Information System development, as well as be used in the generation of a new audit instrument of information quality. By unifying the recording of a multi-disciplinary care plan, palliative care can be developed. In our next study, we will address this issue.

ORCID
Anne Kuusisto https://orcid.org/0000-0002-9950-1985
Kaija Saranto https://orcid.org/0000-0002-3195-1955
Päivi Korhonen https://orcid.org/0000-0002-0244-4890
Elina Haavisto https://orcid.org/0000-0002-9747-1428

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SUPPORTING INFORMATION

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