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Hospital and home care nurses' experiences and perspectives on collaborative discharge planning when cancer patients receiving palliative care are discharged home from hospitals

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Hospital and home care nurses' experiences and perspectives on collaborative discharge planning when cancer patients receiving palliative care are discharged home from hospitals

Short Title: Discharge collaboration in palliative care

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ABSTRACT

Aims and objectives: To explore nurses' experiences and perspectives on discharge collaboration when cancer patients receiving palliative care are sent home from hospitals.

Background: Cancer patients receiving palliative care experience multiple transitions between the hospital and their home. Poor discharge collaboration is a major cause of preventable hospital readmissions. Better collaborative discharge planning could improve the management and care for these patients outside the hospital setting. Previous research has mostly been conducted in non-cancer populations. Further research regarding both home care nurses' and hospital nurses' perspectives on the collaboration is required.

Design: A qualitative study with descriptive and explorative design.

Methods: Data were collected through 10 individual, semi-structured interviews of nurses working at two oncology wards at a university hospital and home care services in four different municipalities within the hospital's catchment area. Data were analyzed using systematic text condensation. COREQ-guidelines were adhered to in the reporting of this study.

Results: Three categories emerged from the data analysis: lack of familiarity and different perceptions lead to distrust; inefficient communication creates a need for informal collaboration; and delayed discharge planning challenges optimal collaboration.

Conclusions: The nurses lacked an understanding of each other's work-situation, which created a collaboration characterized by distrust, misunderstandings and misconceptions regarding each other's abilities to care for the patient. This led to inefficient communication, relying on individual knowledge, informal communication and personal networking. In turn, this created delays in the discharge planning, resulting in poorly prepared discharges often lacking necessary equipment and documentation.

Relevance to clinical practice: To improve the care of cancer patients receiving palliative care outside the hospital setting, better communication is a key factor to promote confidence and understanding between nurses working in different levels of healthcare.

Keywords: Neoplasm, Palliative Care, Patient Discharge, Patient Transfer, Home Care Services, Hospitalization, Documentation, Information Technology, Qualitative Research.

SAMMENDRAG

nivåer av helsevesenet.

Tittel: Sykepleieres erfaringer og perspektiver på samhandlingen mellom sykehuset og hjemmetjenesten når palliative kreftpasienter skrives ut til hjemmet.

Bakgrunn for studien: Palliative kreftpasienter opplever mange overganger mellom sykehus og hjemmet i løpet av deres sykdomsperiode. Manglende samhandling mellom tjenestenivåene forårsaker mange unødvendige sykehusinnleggelser. Bedret samhandling mellom første- og andrelinjetjenesten kan bidra til bedre ivaretakelse av pasientene utenfor sykehusene og kan bidra til å redusere samfunnskostnadene som følge av unødvendige sykehusinnleggelser. Tidligere forskning har hovedsakelig vært gjennomført i andre populasjoner enn kreftpasienter, eller har utelukkende undersøkt sykepleieres perspektiver fra enten hjemmetjeneste- eller sykehuskontekst.

Hensikt: Hensikten med denne studien var å utforske sykepleieres perspektiver på samhandlingen mellom sykehuset og hjemmetjenesten når palliative kreftpasienter skrives ut fra sykehus til hjemmet.

Metodologi: En kvalitativ studie med beskrivende og utforskende design. Data ble samlet gjennom 10, semistrukturerte individuelle intervjuer med fem sykepleiere fra to onkologiske sengeposter i sykehus og fem sykepleiere fra hjemmetjenesten i fire forskjellige bydeler i sykehusets nedslagsfelt. Intervjudataene ble analysert gjennom systematisk tekstkondensering. COREQ-retningslinjer har blitt fulgt i rapporteringen av denne studien. Resultater: Tre kategorier oppsto gjennom analyseprosessen: Manglende kjennskap og ulike oppfatninger skapte mistillit; ineffektiv, formell samhandling skapte behov for uformell kommunikasjon; og forsinket utskrivelsesplanlegging utfordret optimal samhandling. Konklusjon: Sykepleierne manglet forståelse for hverandres ansvarsområde, som skapte en samhandling preget av mistillit, misforståelser og ulike oppfatninger av hverandres ferdigheter og pasientens behov. Dette førte til lite effektiv kommunikasjon, ofte avhengig av individuelle kunnskaper, hvilket førte til dårlig planlagte utskrivelser preget av manglende utstyr og dokumentasjon. For å bedre omsorgen for palliative kreftpasienter utenfor sykehuset må kommunikasjonen bedres for å fremme forståelse og tillitt mellom sykepleiere fra ulike

Nøkkelord: Samhandling, Palliativ omsorg, Pasientutskrivelser, Hjemmetjenesten, Spesialisthelsetjenesten

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INTRODUCTION

Life expectancy is increasing worldwide (WHO, 2018). Due to the aging population, the cancer incidence is projected to increase by 62 % by the year 2040 (Aunan, Cho, & Soreide, 2017; Cancer Research, 2018). Many of these patients will develop a need for palliative care, which is an approach that aims to improve the quality of life of patients facing life threatening illness by providing relief from pain and other distressing symptoms. Palliative care is applicable early in the course of illness, in conjunction with treatment that intend to prolong life (WHO, 2019). While the concept of palliative care has long had strong associations with end-of-life care, today's advances in medical and surgical treatment indicate that many cancer patients receiving palliative care can expect to live longer with their disease (Kaasa et al., 2018). Most cancer patients would prefer to spend more time at home (Skorstengaard et al., 2017), but are often hospitalized for advanced treatment for symptoms such as dyspnea, pain, nausea and other physical impairments (Numico et al., 2015; O'Brien & Jack, 2010). Consequently, cancer patients experience multiple transitions between hospitals and their home during their illness trajectories, with nurses having pivotal roles as the healthcare professionals closest to the patients both in hospital and in the home care setting (Aamodt, Lie, & Helleso, 2013)

Cancer patients receiving palliative care often have lifelong nursing and caring needs with considerable symptom burdens that require long lasting care and longer follow-up time (Yates, 2017). In order to reduce the societal costs due to the expected increase in the number of cancer patients, effective collaboration has become a top priority for healthcare systems to aid in switching from predominantly acute, hospital-oriented palliative care towards community-based palliative care (Helleso & Fagermoen, 2010). The goal is to manage the long-term cancer patients preferably outside of the hospital setting, with home-based palliative care proving to be more cost-effective than hospital care (Kaasa et al., 2018). However, poor co-ordination between hospitals and home care services is recognized as a key factor in costly and preventable hospital readmissions (Ventura, Burney, Brooker, Fletcher, & Ricciardelli, 2013). To address these challenges, there is an increased need for knowledge regarding nurses' perception of todays' collaboration between hospitals and home care services when cancer patients with palliative care needs are discharged home from hospitals.

BACKGROUND

Fragmentation of healthcare services is present, especially when provided by professionals from different organizations (Karam, Brault, Van Durme, & Macq, 2018). Many cancer patients experience cancer care as fragmented, the treatment trajectory unpredictable, and complaints about uncoordinated care is common. These shortcomings lead to frustration and distress for patients and their families, already in a difficult situation with advanced disease (Mack et al., 2017). Nurses experience that reduced length of hospital-stay and rapid patient turnover may result in discharges characterized by time-constraints (Nosbusch, Weiss, & Bobay, 2011). Moreover, home care nurses experience that vital information, medication or equipment often are not part of the transition (O'Brien & Jack, 2010), and experience uncertainty regarding what they are supposed to do for the patient (Groene, Orrego, Sunol, Barach, & Groene, 2012).

Hospital nurses may lack sufficient knowledge about the care requirements after discharge (Danielsen, Sand, Rosland, & Forland, 2018), and consequently recommend institutional care because they consider the homecare setting unsuitable for advanced palliative care (Aamodt et al., 2013). The decision to discharge cancer patients to their homes can be based on the intention to facilitate home-death with the discharge planning being initiated when death is imminent, forcing nurses to resolve multiple tasks within short timeframes (Tan & Blackford, 2015). The absence of standardized and predictable discharge frameworks often makes discharge-planning dependent on the individual nurses' knowledge and experience with discharge processes (Nosbusch et al., 2011).

The introduction of electronic communication between care levels seems to have a positive effect on nurses' efficiency and reflection regarding the informational needs of others (Melby, Brattheim, & Helleso, 2015). However, nurses' information exchange is still challenged by time constraints, stressful workload, lack of confidence in other nurses' competence, lack of resources, discontinuity of staff and lack of suitable routines and policies (Olsen, Ostnor, Enmarker, & Hellzen, 2013). Successful collaboration is also challenged by the diverse care objectives, and the perceptions and cultures that exist between different organizational levels of healthcare (Petersen, Foged, & Norholm, 2019), including power struggles and lack of trust (Tonnesen, Kassah, & Tingvoll, 2016). Organizational trust is defined by familiarity and confidence in cooperative, organizational systems and individuals (Luhmann, 2000). It is recognized as a key factor related to collaboration (Helleso, Sorensen, & Lorensen, 2005). Sources of nurses' distrust may involve doubt about other healthcare professionals'

motivation in providing care, feeling threatened by other nurses' involvement and lack of confidence in other nurses' skills (Karam et al., 2018). Challenging transitions appear to undermine trust between nurses from different organizational levels of healthcare (Tew Jr., 2012).

Challenges with inter-organizational collaboration are well described in the literature (Karam et al., 2018; Melby et al., 2015; Petersen et al., 2019; Radhakrishnan, Jones, Weems, Knight, & Rice, 2018). However, studies regarding collaboration between hospitals and home care services have mostly been conducted in non-cancer populations (Groene et al., 2012; Helleso & Fagermoen, 2010; Orvik, Nordhus, Axelsson, & Axelsson, 2016; Petersen et al., 2019), or have focused on terminally ill cancer patients discharged for end of life care at home (O'Brien & Jack, 2010; Tan & Blackford, 2015). Current research studies have predominantly investigated the home care services' perspective (Danielsen et al., 2018; Tonnesen et al., 2016) or perspectives at the hospital level (Aamodt et al., 2013; Nosbusch et al., 2011). With the expected increase of cancer patients receiving palliative care, there is a need to acquire a deeper understanding regarding nurses' perspectives on collaboration between healthcare professionals on the primary and secondary levels of care upon discharge home. The aim of this study was to explore hospital and home care nurses' experiences and perspectives regarding collaborative discharge planning when cancer patients receiving palliative care are discharged home from hospitals.

METHODS

Design

A qualitative method with descriptive and explorative design using individual semi-structured interviews of nurses in the hospital and the home care setting was chosen. This design is suitable to describe and understand nurses' experiences with collaboration between the hospital and the home care services (Polit & Beck, 2017). The data collection method has the potential to attend to the complexity of the research topic and allow for considerable reciprocity and engagement between the participant and the master's student. In turn, this enables the master's student to probe the participants' responses for clarification and achieve in depth empirical descriptions of the participants' accounts as compared with group interviews (Galletta, 2013).

Participants and recruitment

The participants were recruited from two oncology wards at a university hospital in the Southeast region of Norway, and home care services from four different municipalities within the hospital's catchment area. The head nurses at both oncology wards and the home care services' managers were responsible for recruitment of the participants. Purposive sampling was employed using the following inclusion criteria: registered nurses or specialist nurses in oncology, palliative care or another relevant specialty; minimum two years of experience from either the oncology ward or the home care service; and experience with and responsibility for coordination and planning of discharge processes for cancer patients receiving palliative care being discharged home from hospitals. Through purposive sampling, the master's student created a sample not representative of the population, but rather a sample that could provide rich descriptions about the phenomenon being studied (Polit & Beck, 2017). Eleven nurses were approached, but one from the home care services withdrew after receiving further information about the study. Ten nurses, five from home care services and five from the oncology wards participated. All but one nurse in the hospital group worked full-time, one nurse had no specialty and one had another specialty than oncology or palliative care. All nurses in the home care nursing group worked full-time. Three of the home care nurses worked as cancer coordinators. The sample is further described in Table 1. (Insert Table 1 here)

Data collection

Data were collected through individual semi-structured interviews between December 2018 and March 2019. The interviews were conducted at the participants' work place and lasted between 20 to 50 minutes. A semi-structured interview guide with open-ended questions was used to facilitate reflection and conversation. The interview guide was developed based on previous research and was pilot tested. Following the pilot interview, certain questions in the interview guide were re-phrased to be more open-ended or removed entirely. Furthermore, new follow-up questions were added. Due to changes in the interview guide, the pilot interview was not included in the material. The guide covered the following topics: nurses' experience with the discharge of cancer patients with palliative care needs, experience of discharge collaboration, routines and procedures for discharge, experience with collaboration meetings, use of communication tools, the involvement of the patient and their family and experience related to contacting the hospital or home care services. The interviews were audio

recorded and transcribed verbatim by the master's student. Field notes were taken to supplement the recordings.

Data analysis

The data material was analyzed by the master's student using systematic text condensation (STC). STC offers researchers a reflexive and feasible procedure to analyze qualitative data, while maintaining a reasonable level of methodological rigor. STC consist of four steps: 1) total impression - from chaos to themes; 2) identifying and sorting meaning units - from themes to codes; 3) condensation - from code to meaning; 4) synthesizing - from condensation to descriptions and concepts (Malterud, 2012). Guided by the aim of the study and the STC method, preliminary themes were identified through open-minded reading of the material and the field notes. Eight preliminary themes emerged, and the data material was carefully re-read to identify meaning units that were sorted in preliminary themes. The preliminary themes were then renamed, merged or deleted to form three code groups, into which the meaning units were allocated. The empirical data for each code group was analyzed further, and two or three sub-groups for each category were constructed. The meaning units for each sub-group were condensed into artificial quotes, representing the original terms used by the participants. The condensed excerpts were then synthesized and abstracted to develop descriptions, concepts and credible stories grounded in the empirical data that explain or answer the study aim. As a final step, the interview transcripts were re-read to secure that the interpretation was a valid representation of the original interview transcripts. Examples of the analysis process are provided in Table 2. NVIVO (Version 12) was used to organize and analyze the data.

(Insert Table 2 here)

Trustworthiness

To ensure the credibility of the findings the nurses were recruited from a large university hospital with several oncology in-patient units and home care services in that hospital's catchment area. This ensured that the nurses were providing data regarding the same collaboration practices, routines and agreements, and that discharge planning was common. The data was obtained from four different home care districts with differences in demographics and economy. This provided different nuances, experiences and challenges related to collaboration, further enhancing the transferability of the findings (Lincoln & Guba, 1985). Iterative questioning methods that ensure clarification and honesty from the participants were applied (Polit & Beck, 2017). The rich use of quotations enhance

trustworthiness and conformability of the results by demonstrating that the interpretation accurately represents the participants' voices and are not invented by the inquirer (Elo et al., 2014). The master's student has a postgraduate degree in oncology nursing, has experience from home care services and is currently working at a palliative unit in a hospital. This familiarity with the participating organizations was essential to create a purposive sample, develop and adjust the interview guide and in the collection of data. To maintain reflexivity, discussions were conducted between the master's student and the two supervisors who have different academic and professional backgrounds. The discussions provided competing interpretations that helped overcome biases and preconceptions (Graneheim & Lundman, 2004). The discussions were conducted in the development of the interview guide, in the recruitment of nurses and in the data analysis. Consolidated criteria for reporting qualitative research (COREQ) guidelines were followed. COREQ-checklist is provided in Supplementary file 1.

Ethical considerations

The study was approved by the Norwegian Social Science Data Services (NSSDS) (reference number: 61526), the hospital's research leader and head nurses, and managers in the home care services. All participants received written information about the project prior to consenting and informed written consent was obtained from the participants prior to the interviews. The participants were assured that the interview data would be treated confidentially and were guaranteed anonymity in the presentation of findings. The data material was stored securely and separately in accordance to the guidelines set forth by the NSSDS.

RESULTS

Three categories emerged from the data analysis: Lack of familiarity and different perceptions lead to distrust; inefficient communication creates a need for informal collaboration; and delayed discharge planning challenges optimal collaboration.

Lack of familiarity and different perceptions lead to distrust

The collaboration was characterized by nurses lacking knowledge and understanding of each other's situation across the hospital and home care services. Hospital nurses were concerned about the level of knowledge and ability of the home care services to handle medical devices such as intravenous equipment or drains. They also experienced inconsistencies regarding what type of equipment home care services could handle. Home care nurses expressed that

they were unfamiliar with the regular rounds and decision-making processes within hospitals. Moreover, they did not understand why hospital nurses sometimes were delayed in the collaboration process. The nurses' knowledge regarding each other, however, were often based on preconceptions, assumptions or former patients' testimonies rather than actual experiences, which they admitted often negatively influenced their impressions. All this led to a collaboration characterized by misunderstandings, assumptions and distrust due to an absence of contact between the different levels of healthcare, as illustrated by one hospital nurse:

We don't understand each other's situation well enough [...] I don't feel very close to the home care teams, we rarely see them, we don't know who they are, we don't know what they can and what they can't do, and it varies from district to district what they know about procedures and such. (Hospital nurse 3)

Even though both groups of nurses expressed genuine concerns for the patients, the collaboration between them was characterized by different perceptions regarding the patients' needs. Hospital nurses were often determined that patients with palliative care needs required institutional care. Home care nurses, however, often wanted the patients discharged home, as they considered themselves well capable of meetings the patients' needs. This caused frustration and distrust towards each other's motives regarding the collaboration, further inhibiting a communication based on a willingness to resolve their different perceptions. The nurses' preconceptions led to discussions regarding where the patient should be discharged rather than the nurses providing sincere descriptions of what the patient required help with. Furthermore, the nurses did not trust each other's assessments as described by one home care nurse:

Sometimes I think that the hospital exaggerates the patients' needs a little. Of course, they are ill, but the attitude seems to be that 'You are very ill, you need to go to a nursing home to get better'. We become the villains because we don't want them placed in a nursing home. But we know the patients will be better off at home. (Home care nurse 5)

Personal relations between the different levels of healthcare increased the nurses' trust in each other's abilities and assessments as this enabled them to create a collaboration environment characterized by a willingness and flexibility to solve difficult situations. This was considered especially important among nurses working in the home care services. Personal knowledge of someone working in the hospital environment enabled them to get help and assistance faster and more efficiently than nurses trying to communicate through official channels. If possible,

the nurses preferred to collaborate with nurses they were familiar with, as illustrated by one home care nurse:

We talk about it, "Oh, he's been admitted to this or that unit, how nice, then we can talk to this or that person working there". Knowing each other individually is definitely an asset. (Home care nurse 4)

Inefficient communication creates a need for informal collaboration

The nurses communicated with each other through electronic messages, telephone calls, discharge meetings and through the patients. They were mainly encouraged to communicate through electronic messages, as this enabled a third party to understand what agreements were made regarding the discharge or the follow-up care of the patient. The nurses expressed a positive attitude towards electronic messaging. However, they considered it insufficient in cases where the patients had comprehensive needs, burdensome symptoms or regarding topics perceived as sensitive, such as patients' inability to care for children. Oral communication was considered less time-consuming than electronic communication. Electronic correspondence often led to the dialogue bouncing back and forth with follow-up questions and additional information. Nurses were often unsure regarding what kind of information they were supposed to share. In addition, several nurses expressed a lack of trust in the electronic messaging system. They felt the need to call and double-check that the recipient had read and understood the messages they had sent electronically, as illustrated by one hospital nurse:

I like to call the home care services in the more complicated cases where there are a lot of things that need to be arranged and several loose ends. Just to verify that they have received my messages and are prepared to receive the patient on the agreed date, even though I've sent the exact same information electronically. (Hospital nurse 2)

Discharge meetings between hospital nurses, home care nurses and hospital doctors prior to the discharge were considered useful to ensure good and safe transitions for patients. This was especially the case for patients who required comprehensive home care, had severe disabilities such as paralysis or in need of complicated medical equipment such as analgesia or nutritional pumps. These meetings enabled nurses to talk freely about what they were expected to do regarding the discharge and made disagreements regarding the patient less likely. Face-to-face collaboration made it easier to remember everything the patient would need at home. However, the discharge meetings were considered time-consuming and, in some cases, redundant. This was especially the case when home care services already knew the patient well or there were not any major changes in the patient's condition. Home care nurses also

experienced that hospital nurses were sometimes poorly prepared or had insufficient knowledge regarding the patient, as illustrated by one home care nurse:

It is beneficial that the nurse conducting the meeting knows the patient well, because a lot of times they don't, and then I feel like I just don't get anything out of it. It's a long way for me to the hospital, and it is a waste of time if we're just going to sit there and drink coffee. (Home care nurse 1)

Delays or deficits in the delivery of discharge papers to home care services often required that patients conveyed important medical information between the different levels of healthcare. This was frustrating to the home care nurses since the information from the patients often was wrong or inconclusive. Moreover, documents sent between the different levels of healthcare often lacked essential information such as diagnosis, treatment, nursing problems and nursing interventions. Hospital nurses were often unsure as to how much information they were supposed to convey to home care nurses as they experienced that their informational needs were inconsistent. The collaboration challenges seemed to be exacerbated by the fact that home care services and hospital nurses used different scales and models for assessing and describing the patients, as illustrated by one hospital nurse:

We can't see everything from the scores used by the home care services, and the messages we receive hardly make any sense to us since they have a completely different way of assessing the patient. So even when they send us their plan with "category five this, category three that" it doesn't make any sense to us. (Hospital nurse 4)

Delayed discharge planning challenges optimal collaboration

Nurses agreed that early discharge planning was essential for optimal collaboration and successful patient discharge. However, the discharge collaboration was challenged by factors outside of the nurses' control as hospital doctors had the final say in discharging the patient. Hospital nurses perceived doctors as reluctant to discuss early discharge planning because they considered it premature. Consequently, the discharge planning was often initiated shortly before the patient was expected to be discharged. Moreover, the nurses experienced that doctors were indecisive regarding the discharge date and often ordered new blood samples or additional examinations that prolonged the hospital stay, as described by one hospital nurse:

It is so dependent on the doctors, because sometimes they suddenly want to try again and don't stand by their decision to discharge the patient. Sometimes they suddenly want to insert a stent or a drain and the discharge gets delayed. It ends up going back and forth like, what are we doing now? (Hospital nurse 4)

The lack of early discharge planning led to time-constraints with a collaboration characterized by a sense of urgency, especially in cases where the patient's condition deteriorated rapidly. Since discharge collaboration was initiated late during the hospital stay, hospital nurses were often forced to convey large amounts of information to home care services in a short time frame. The discharge collaboration was further exacerbated by hospital nurses' insecurity as to acquiring the necessary equipment and medication. Also, the nurses faced challenges with early planning because they often worked with several problems regarding the patient such as pain and nausea treatment leading to not prioritizing discharge planning until the patient was ready to be discharged, as illustrated by one hospital nurse:

Sometimes it gets so busy here, which to me is the biggest problem. We are doing so many things for the patient that we just 'forget' about the discharge planning, because that's not what's essential now. Instead it is pain relief, nausea treatment, all that other stuff. (Hospital nurse 1)

Delayed discharge planning made home care nurses experience that crucial elements regarding medication and equipment provision got overlooked and deficiencies were considered difficult to correct due to a lack of out-of-hours services. Home care nurses felt a need to stress this repeatedly to hospital nurses because they experienced that hospital nurses underestimated the difficulties faced by home care services in acquiring missing equipment. Moreover, the home care nurses faced challenges with time-critical and complex collaboration as they were often on the road or in between out-patient consultations, limiting their ability to adequately source the patients' needs. The home care nurses described that they sometimes conducted discharge meetings the same day the patient was discharged, and were often given limited time to resolve several challenges regarding the discharge, as illustrated by one home care nurse:

If something should be improved, it should be earlier discharge planning. Quite often, they call us on a Thursday and tell us that the patient is coming home on Friday. That gives us pretty limited time to get everything in place. (Home care nurse 3)

DISCUSSION

This study has explored hospital and home care nurses' experiences and perspectives on the discharge collaboration when cancer patients receiving palliative care are discharged home from hospitals. Three categories were presented: Lack of familiarity and different perceptions lead to distrust; inefficient communication creates a need for informal collaboration; and delayed discharge planning challenges optimal collaboration.

The nurses in the present study experienced a sense of unfamiliarity with each other's work-situation and responsibilities regarding the patients. This appeared to inhibit mutual trust and create challenges with communication and collaboration between nurses in the hospital and the home care services. Organizational trust is defined by familiarity and confidence in cooperative, organizational systems and individuals (Luhmann, 2000) and is being recognized as a key factor related to collaboration (Karam et al., 2018). However, challenging transitions appear to undermine trust between different levels of healthcare (Tew Jr., 2012). Nurses in the present study seemed to achieve trust more easily when they collaborated with nurses they were acquainted with. This could be explained by trust being built up over time and through mutual acquaintanceship (Karam et al., 2018). Differences between cultures and nursing policies that exist in different nursing settings may also contribute to unfamiliarity and distrust between the different levels of healthcare (Helleso et al., 2005).

In Norway, a Coordination Reform was implemented in 2012 that involved the encouragement of practices with earlier discharges (Orvik et al., 2016). The changes in the organization of healthcare systems may explain the nurses' lack of mutual trust, as trust is considered best achieved in a familiar world, and changes may negatively impact the perception of trust by those participating in it (Luhmann, 2000). Moreover, nurses in the present study seemed to lack trust in each other's assessments regarding the patient, which seemed to be connected to power struggles that could appear in the relationship between healthcare professionals across organizational boundaries (Tonnesen et al., 2016). Furthermore, hospital nurses expressed frustration about home care nurses' apparent intention to discharge patients receiving palliative care to their homes rather than an institution. This may indicate that hospital nurses have preconceptions regarding palliative care being administered within institutions, as indicated in a previous study (Aamodt et al., 2013).

Communication is a key element of collaboration to obtain trust, balance power and clarify professional roles between healthcare professionals (Karam et al., 2018). A key factor for successful collaboration is good informational flow between each level of organizational systems, and advances in information technologies aspire to enhance collaboration by creating digital bridges (Melby et al., 2015). Research indicates, however, that use of information technology does not always meet healthcare professionals' needs, creating a need for oral communication (Karam et al., 2018). In the present study, nurses valued electronic messaging as this enabled them to document agreements made between the different levels of healthcare. However, the nurses seemed to lack trust in the electronic messaging systems as they often

resorted to other means of communication when the information was considered important or time-critical. The lack of trust in the electronic messaging systems seemed to be related to unsystematic ways of communicating and different ways of assessing the patients. This seemed to cause insecurity among the nurses regarding what information they were supposed to convey electronically. Oral communication, however, may also be a challenge as nurses struggle to acquire the right telephone numbers and getting hold of the right person to collaborate with (Lyngstad, Grimsmo, Hofoss, & Helleso, 2014). Research indicates that nurses find it difficult to send the 'right' information due to a lack of insight into the working practices and informational needs of others (Helleso & Fagermoen, 2010).

Utilization of information technology may negatively influence the trust obtained through collaboration as it encourages practices with less face-to-face collaboration (Marcotte, Kirtane, Lynn, & McKethan, 2015). Face-to-face collaboration through meetings was considered useful by the nurses in the present study. However, the meetings were sometimes perceived as redundant due to a lack of a predictable and systemized meeting schedule. In addition, nurses' inexperience with conducting and managing meetings and meetings being considered time-consuming were perceived as barriers to efficient discharge meetings. The arbitrary and inconsistent information exchange between nurses often made them rely on patients to transfer information between different levels of healthcare. This was perceived as problematic as nurses often experienced that the information patients conveyed was either wrong or inconclusive. This is supported by research that indicates that patients forget 40–80 % of the medical information they receive, and that nearly half of the information they do remember is wrong (Kessels, 2003).

Nurses in the present study considered early discharge planning essential for optimized collaboration and communication, but described it as strenuous and time-consuming work, often characterized by time-constraints. Research indicates that discharge planning should be initiated as early as possible, preferable on admission (Pellett, 2016). However, time constraints are considered key factors in delayed discharge planning (Atwal & Caldwell, 2006; Pirani, 2010). Furthermore, the present study suggests that individual difficulties regarding how hospital units and home care services were organized may be barriers to early discharge planning rather than challenges with the collaboration itself. Hospital nurses attributed delays in discharge planning to lack of priority, heavy work load and doctors' reluctance to discuss early discharge planning. Research indicates that different perceptions and conflicting views about discharge planning between nurses and doctors are factors that

lead to inefficient discharge planning (Connolly et al., 2010). Home care nurses struggled with collaboration and discharge planning as these tasks typically were conducted in between visits to other patients, making it a challenge to acquire the necessary information regarding the patients' needs. Challenges with organizational structures and available workforce may limit the involvement of home care nurses in the decision-making processes (Tonnesen et al., 2016). This could indicate that characteristics of the nurses' work environment may impede successful execution of complex discharge collaboration characterized by mutual trust and confidence in collaborative partners. It could seem as collaboration with unfamiliar professionals with structural and cultural differences overburden systems that already lack the necessary resources and workforce to handle their current demand (Karam et al., 2018).

Study limitations

A limitation of this study may amount to the small sample size and the few nurses recruited from each setting. However, based on the narrow study aim, the participants' experiences with discharge collaborations and their willingness to share their experiences, a sample of ten participants were considered to provide sufficient informational power. In qualitative research, sufficient information power is considered more important than a high number of participants to capture rich descriptions and variations in the data material (Malterud, Siersma, & Guassora, 2016). None of the nurses from the hospital group were specialized in palliative care nursing and were slightly younger and less experienced than the nurses from the home care group. The organization, delivery and availability of palliative care services are not consistent across Norway and therefore nurses working in other urban or rural locations might have other experiences. Due to these limitations, there may be experiences and nuances of experiences we were not able to identify.

CONCLUSION

Discharge collaboration between nurses working in hospitals and home care services is characterized by poor knowledge about each other's working environment, inefficient and unsystematic communication, and discharge planning characterized by time constraints and delayed processes. Lack of mutual acquaintanceship seems to create a distrust which further inhibits efficient and high-quality collaboration. The nurses seem to lack trust in each other's professional judgement, leading to arguments and discussions regarding placement of care post-hospitalization. Also, the lack of trust seems to be connected to different nursing terminologies and tools used in patient assessments between the primary and secondary level of care. Challenges in communication often make nurses resort to informal communication, as

they seem to lack trust in the electronic messaging systems. If health authorities aspire to tackle the challenges of managing long-term cancer patients with palliative care needs outside of the hospital setting, measures should be made to increase the organizational trust and familiarity between primary and secondary levels of care. More research is required to identify how trust is best achieved between different organizational levels of healthcare.

RELEVANCE TO CLINICAL PRACTICE

- Collaboration between nurses working in home care services and oncology wards in hospitals is challenged by a lack of trust and knowledge between different levels of healthcare.
- The lack of trust between the different healthcare levels have adverse implications on how nurses perceive each other, how they communicate and how they collaborate when planning to discharge cancer patients home with palliative care needs.
- If governments aspire to tackle the challenge of managing long-term cancer patients with palliative care needs outside of the hospital setting trust between primary and secondary care levels should be reinforced.

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APPENDICES

Table 1: Description of participants

	Hospital nurses	Home care nurses
N=10	5	5
Female	5	4
Age range (mean)	28-45 (32.8)	35-59 (40.6)
Years employed at current position (mean)	2.5-13 (5.9)	5-10 (6.6)
Nurses with oncology specialty degree	3	3
Nurses with palliative specialty degree	0	2
Nurses with a different specialty	1	0

Table 2: Example of stepwise analysis from meaning units to categories using STC

1. Unit of meaning	2. Sub-group	3. Category
We assume the patient can't be sent home (Hospital nurse 2) We don't know how much help the patients can get (Hospital nurse 3) We don't always understand how decisions are made by the hospitals (Home care nurse 3)	Lack of understanding of each other's situation	
The home care service often disagrees and thinks the patient can be cared for at home (Hospital nurse 1) The hospital assumes that the patient requires much more than they actually do (Home care nurse 4) Hospitals think the patient can't be sent home, but we know he'll be perfectly safe at home (Home care nurse 5)	Different perceptions regarding the patients' needs	Lack of familiarity and different perceptions lead to distrust
I am often asked to contact the hospital, because I know people working there (Home care nurse 1) It is easier to trust someone you have met before (Hospital nurse 5) Having acquaintances working at the hospital makes it easier to reach out and get help (Home care nurse 3)	Personal networking enables trust	_
To avoid that time-consuming back-and-forth messaging, I prefer to use the telephone (Hospital nurse 2) Sometimes electronic messages work fine, other times you have to call and nag the home care nurses a little (Hospital nurse 3) I often have to use the telephone to get clarification and catch up on the discharge planning (Home care nurse 2)	Challenging electronic communication	
Meetings are helpful to ensure that we agree. We must talk to each other (Home care nurse 1) It depends on the nurse working that day, often it's a little random which nurse conducts the meeting (Hospital nurse 3) I've experienced that the hospital nurse conducting the meeting doesn't know the patient (Home care nurse 10)	Benefits and challenges with discharge meetings	Inefficient communication creates need for informal collaboration
A lot of the information must be provided by the patient, such as what treatment they got (Hospital nurse 2) Often, I must ask the patient, but they don't remember what kind of treatment they received (Home care nurse 5) Sometimes when I ask the patient, they aren't even aware that their cancer has metastasized (Home care nurse 4)	Patient as messenger of information	
We are doing so many things for the patient that we just 'forget' about the discharge planning (Hospital nurse 1) It depends on the doctors. Suddenly they want to try again, and don't stand by their decision to discharge the patient (Hospital nurse 4) Early communication is important. Sending a message to us on a Thursday with discharge on Friday is not okay (Home care nurse 3)	Challenging and delayed discharge planning	Delayed discharge planning
It's a challenge if the patient requires a lot of equipment, it depends on who's at work and if they are good at it or not (Hospital nurse 3) If the patient is sent home before the equipment arrives it becomes a bad experience for the patient (Home care nurse 1) Bad collaboration is when the hospital doesn't provide the necessary medication and equipment (Home care nurse 4)	Medication and equipment provision	challenges optimal collaboration

Supplementary File 1. COREQ (Consolidated criteria for Reporting Qualitative research) Checklist

,	Item	Guide Question/Description	Reported
	no.		on page no.
Domain 1: Research tea	m and r	reflexivity	110.
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	8
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Title page
Occupation	3	What was their occupation at the time of the study?	9
Gender	4	Was the researcher male or female?	Male, title page
Experience and training	5	What experience or training did the researcher have?	9
Relationship with particip	oants		
Relationship established	6	Was a relationship established prior to study commencement	No
Participants knowledge of the interviewer	7	What did the participants know about the researcher? E.g. personal goals, reasons for doing the research	N/A
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? E.g. Bias, assumptions, reasons and interests in the research topic	9
Domain 2: Study design	1	•	
Theoretical framework			
Methodological orientation and theory	9	What methodological orientation was stated to underpin the study? E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7
Participants selection			
Sampling	10	How were participants selected? E.g. purposive, convenience, consecutive, snowball	7-8
Method of approach	11	How were participants approached? E.g. face-to-face, telephone, mail, email	7-8
Sample size	12	How many participants were in the study?	8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	8
Setting			
Setting of data collection	14	Where was the data collected? E.g. home, clinic, workplace	8
Presence of non- participants	15	Was anyone else present besides the participants and researchers?	8
Description of sample	16	What are important characteristics of the sample? E.g. demographic data, date	8, Table 1

Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	8
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	8
Field notes	20	Were field notes made during and/or after the interview or focus group?	8
Duration	21	What was the duration of the interviews or focus groups?	8
Data saturation	22	Was data saturation discussed?	17
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and	finding	S	
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	8, Table 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	9
Software	27	What software, if applicable, was used to manage the data?	9
Participant checking	28	Did participants provide feedback on the findings?	No
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each question identified? E.g. participant number	10-14
Data and findings consistent	30	Was there consistency between the data presented and the findings?	10-14
Clarity of major themes	31	Were major themes clearly presented in the findings?	10-14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	14-17

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