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Published in:
British Journal of Community Nursing

DOI:
[10.12968/bjcn.2020.25.1.10](https://doi.org/10.12968/bjcn.2020.25.1.10)

Publication date:
2020

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Norlyk, A., Deleuran, C. L., & Martinsen, B. (2020). Struggles with infrastructures of information concerning hospital-to-home transitions. *British Journal of Community Nursing*, 25(1), 10-15.
<https://doi.org/10.12968/bjcn.2020.25.1.10>

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Struggles with infrastructures of information concerning hospital-to-home transitions

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Across the globe, policy demands have called for a move of care delivery from secondary to primary care due to demographic changes and an increase in the number of older people with multiple comorbidities (Violan et al, 2014; Martinsen et al, 2018). Accordingly, health systems undergo reorganisation, with a specific focus on short in-patient stay, specialised treatment and very early discharge. However, several studies stress that homecare nurses are facing many challenges due to the increased demand of supporting patients with more complex medical conditions and health needs (Martinsen et al, 2018; Phelan et al, 2018).

Studies have shown that transitional care of older people from hospital to homecare nursing is complex. Often, these individuals have medical, cognitive, physical and social problems that must be taken into account in relation to

discharge and follow-up care plans (Greysen et al, 2014; Martinsen et al, 2015). Further, transitional care has been recognised as a high-risk area due to evidence indicating a correlation between patient hand overs and adverse events (Laugaland et al, 2012). Consequently, homecare nurses have a unique role in providing follow-up care after discharge and preventing readmissions (De Vlieghe et al, 2014).

Studies have indicated many challenges in relation to cooperation and communication between health providers in communities and hospitals. These include difficulties in understanding each other's perspectives and roles in the transition process (Kirsebom et al, 2013; Høgsgaard, 2018; Petersen et al, 2019). Petersen et al (2019) investigated how hospital nurses and homecare nurses talk about and experience cross-sectoral collaboration in a Danish context. They highlighted that lack of knowledge of each party's working conditions negatively affected communication and collaboration about care transition. Similarly, Høgsgaard (2018) illustrated how tensions, dilemmas and paradoxes influenced cross-sector cooperation negatively, as the patient discharge process became a battleground for healthcare professionals due to the control mechanisms of new public management.

Further, research has stressed that the use of different information and communication technology across sectors does not support the necessary exchange of information (Melby et al, 2015; Foged et al, 2018). Deficits in communication and a lack of coordination in the discharge process can cause serious breakdowns in the continuity of care. This may potentially harm the patient and increase the risk of poor medical outcomes (Laugaland et al, 2012; Olsen et al, 2013; Phelan et al, 2018). A review from Ireland indicated a high prevalence of missed care and inadequate systems in the offering of homecare (Phelan et al, 2018). Another review (Åhsberg, 2019) on Swedish patients indicated that half of the patients considered as fragile were readmitted to hospital within 30 days of discharge.

ABSTRACT

Homecare nurses play a unique role in providing care during the follow-up after hospital discharge and in preventing readmission. The aim of this study was to explore the key challenges faced by homecare nurses in relation to caring for discharged patients. Data were collected through five focus group interviews with 29 Danish homecare nurses and subjected to inductive content analyses. The key challenges faced by homecare nurses fell into three themes: struggling to see the bigger picture, caring for patients from a distance, and compromising on professionalism. The findings demonstrated a paradox between the need for information and the struggle to access this information due to complicated infrastructures of information-sharing. Homecare nurses took on a substantial responsibility in providing the best possible care despite having limited information. Ironically, by taking on this responsibility, they implicitly contribute to covering up the problems of organisational and professional information flow.

KEY WORDS

- ◆ Homecare nursing
- ◆ Community nursing
- ◆ Transitional care
- ◆ Hospital-to-home transition
- ◆ Information and communication

Thus, poor cross-sectorial cooperation and communication of information regarding discharge are of concern, particularly as future homecare nurses face a higher degree of complex care situations given the changing demographics, the increased number of patients with comorbidities and the preferred transfer of care delivery from secondary to primary care. Examining 17 systematic reviews to provide a broad overview of the care transitions literature, Kansagara et al (2015) found that the vast majority of this literature was hospital focused, and literature examining the role of primary care teams during transitions of care was sparse. As primary care teams and homecare nurses, in particular, play a key role in the provision of care and follow-up plans after discharge, the aim of the present study was to explore the key challenges faced by homecare nurses in relation to caring for discharged patients.

Methods

Data were collected via focus group interviews with Danish homecare nurses. The methodological orientation for this study was a content analysis approach, as described by Graneheim and Lundman (2004) and Graneheim et al (2017).

Context and participants

In Denmark, municipalities are responsible for the delivery of primary health services, all of which are free of charge. As the 98 Danish municipalities vary in size and population, homecare nurses' districts differ considerably. To reflect this variation, participants were recruited from two rural and two urban municipalities. Information about the study was sent to the head nurses in each of the municipalities. Homecare nurses interested in participating in the study contacted the researchers to make an appointment. Some 29 homecare nurses responded and were included in the study.

All included participants were registered nurses with widely varying experiences within the field of nursing, job duration as homecare nurses (1–27 years) and age (26–57 years).

Interviews

The three authors conducted five focus group interviews. The number of participants in each group ranged from four to seven. An open, semi-structured interview guide was developed to ensure that the questions stimulated discussion (Halkier, 2016). To allow the participants to talk about what really matters to them in transitional care, the interviews started with the statement: 'Please describe important challenges faced in relation to patients' transitions from hospital to home.' This question was followed by questions such as: 'Please describe your experiences of the cooperation between hospital nurses and homecare nurses', 'Can you please describe your experiences of the cooperation with patients and relatives?' and 'Please describe your experiences with the internal relationships in the community concerning hospital-to-home transitions'.

As the interview progressed, the moderator asked specific questions to elicit more detailed descriptions.

Acknowledging the social dynamics of the interview, the moderator ensured that all participants had the opportunity to speak. The interviews took place in a quiet meeting room in the different communities. They lasted about 90 minutes and were audio recorded and transcribed verbatim. There were no former relationships between the interviewers and the interviewees.

Data analysis

Data were analysed by using the inductive content analysis approach as described by Graneheim and Lundman (2004) and Graneheim et al (2017). First, all interviews were analysed at the manifest and descriptive levels asking 'what the text says' to cover the obvious content. This was followed by answering the question of 'what the text talks about', which involved an interpretation of the underlying meaning of the text (Graneheim and Lundman, 2004; Graneheim et al, 2017).

Initially, all transcriptions were read several times to get an overall picture of the nurses' experiences. Subsequently, each of the transcriptions was divided into meaning units. The meaning units were condensed while still preserving the core content and then labelled with a code at a level of higher abstraction to answer 'what the text says'. The codes were organised according to their similarities and differences concerning the challenges faced by homecare nurses. Subsequently, the codes enabled the researchers to structure the text into categories and sub-categories that reflected the shared commonality of the content.

The next stage consisted of an expression of the latent and interpretive content of the text. This stage was supported by the question 'what the text talks about' and directed towards identifying themes that spanned the categories. The researchers then interpreted the identified meanings and described a new whole. All three authors discussed the emergent patterns to eventually identify themes that best covered the homecare nurses' experiences.

Ethics considerations

The basic principles for research given in the Helsinki Declaration were followed, and the study was approved by the Danish Data Protection Agency [ID no: 2016-051-000001]. The participants received verbal and written information about the purpose of the study, the right to withdraw and the confidentiality of their data.

Findings

In relation to early discharge of older patients, homecare nurses described the challenges as being multifaceted in nature. Although patients were medically fit for discharge, they were not in a good physical state due to early discharge. Together with the high number of patients with comorbidities, this caused a higher degree of complexity in patients' care needs.

The nurses' responses revealed three major themes: struggling to see the bigger picture, caring for patients from the distance, and compromising on professionalism. A series of subthemes also emerged, related to the different aspects

of the homecare nurses' role, for example, taking on the responsibility for lack of information, acting as the patients' assistants and the complexity of working a field directed by different guidelines.

Struggling to see the bigger picture

The high degree of complexity of patients' care needs means that homecare nurses need detailed information about the patients' treatment at the hospital, including, for example, laboratory test results, reasons for catheterisation, changes in medication and, last but not least, information about follow-up care plans after discharge. Homecare nurses considered this information vital to qualify their observations of the patient. For instance, information about a patient's C-reactive protein (CRP) levels would guide them on whether or not to monitor the patient's temperature and signs of infection.

For homecare nurses, seeing the bigger picture of the individual patient is essential to be able to provide good care and to follow up adequately after discharge. The overall challenge the homecare nurses reported facing was in getting access to this information. The lack of information carried with it a huge responsibility, as they were concerned about making mistakes. The struggle in obtaining the relevant information was very time-consuming, and the nurses reported that they often spent more time on this than was allocated in their schedule.

Much of my day is spent on retrieving the information or documents following the patient's discharge. This is estimated to take half an hour, but it often takes me three-quarters of an hour or a full hour.

Yes, we must know the full story. Well, well ... you have been given that type of medication as well? Then, we phone the hospital to learn more and so on. Phoning for information is very time-consuming.

Although GPs automatically get information about the patient's treatment at hospital, homecare nurses have limited access to this information. It is not directly available to them without getting in touch with the GPs, and they described how they often struggle to contact the GP as they have no direct line, or need to hold the line, as patients do. This is particularly a problem in situations where critical changes related to the patients' illness occur. Difficulties in contacting GPs or hospitals mean the nurses are forced to act quickly and get the approval needed later.

When we need a doctor, it's hard to get hold of one. Especially GPs. Our only option is to join the telephone queue and wait our turn.

Further, due to the structure of the transition from hospital to home, homecare nurses do not have a direct communication line with hospital nurses. They are handed written information for the patient, but this information was not always relevant. Consequently, the homecare nurses reported that they often had to rely on their own professional intuition to monitor their patients after discharge.

You must pick up bits and pieces from the patient's files.

Yes, we need to see the bigger picture immediately while also considering the unpredictability of the situation.

Sub-theme: taking on the responsibility for lack of information

Homecare nurses felt obliged to take on the responsibility of ensuring the accuracy of patients' medication. Due to possible changes to ongoing medication or a new prescription being recommended after discharge, the nurses sometimes even had to bend or break the rules to ensure patients got the right medication; they considered themselves to be the patients' last chance to get the medication they needed.

Further, because of comorbidities and the complexity of their treatment and care needs, patients usually had appointed check-ups at different outpatient clinics or hospitals. However, neither the patient, their spouse or close relative nor the GP had a full overview of the patient's situation. As it was unclear who was responsible for this information flow, the homecare nurses assumed this responsibility, and they described how they struggled to see the bigger picture of the patient's situation due to lack of information.

Caring for patients from a distance

Due to organisational structure, homecare nurses do not meet patients before discharge. Further, they do not always meet newly discharged patients on a daily basis, as this task is often assigned to healthcare assistants, who have less medical education and training than nurses. Hence, the nurses have to rely on the observations of the healthcare assistants to make care decisions. Homecare nurses reported that they took on the responsibility of teaching healthcare assistants about what to observe or measure, to ensure that the healthcare assistants were alert and responded promptly to what the homecare nurses regarded as critical changes.

The fact that homecare nurses are unable to base their care on personal observations creates a stressful information paradox. On the one hand, they have the overall responsibility for patients' care. On the other, they are forced to hand over complex tasks to healthcare assistants, which results in a stressful work environment with unclear definitions of responsibility. For the homecare nurses, it was frustrating that the care needs of the patients were getting increasingly complex, but more tasks had to be handed over to healthcare assistants.

That's why it is important to educate the healthcare assistants to observe what we want them to observe. It takes an awful lot of time, and they have no sufficient training in observing. We (homecare nurses) are moving further and further away from the patients, and others must observe the patients for us.

Sub-theme: assuming the role of the patient's assistant

Homecare nurses perform a multifaceted role, as the patient's coordinator, facilitator, sparring partner, as well as the manager of the patient's care pathway. These tasks require a high degree of communication with patients, their relatives and other health professionals at different hospitals as well as at outpatients' clinics. This is naturally very time-consuming. However, these essential tasks remain invisible, as it is not possible to document them or the associated communication.

I'm responsible for a project in which I am both coordinator and project manager. I'm responsible for the communication with the hospital and the patient's GP, and, at the same time, I have to make sure that the nursing assistants know what they have to observe.

Compromising on professionalism

To ensure appropriate follow-up after discharge, homecare nurses often have to rely on information from patients themselves or their relatives. Often, both patients and their spouses have difficulties in remembering the information provided at the hospital, for example, about blood test results, treatment, follow-up treatment and hospital visits. Further, when homecare nurses had to deliver care, lack of information about treatment initiated at the hospital meant that homecare nurses often appeared as poorly prepared. This could create awkward situations, leading to homecare nurses feeling they were being perceived as professionally incompetent.

You feel a bit stupid when you ask the patient: "so you have been hospitalised. What was wrong with you, what have they done to you?" And the patient asks, "Well, didn't you read my hospital records?"

Yes, and then we come across as somewhat unprepared and slightly dim.

According to policy, hospital nurses contact the local medical officer when patients are ready for discharge and provide the medical officer with information about the patient. However, local medical officers are not always trained nurses and may not be able to judge the complexity of the nursing tasks following discharge. Although the medical officers play a key role in information exchange, they are not always able to gauge what information is relevant for homecare nurses to help them provide care. This lack of direct contact with hospital nurses results in complex communications pathways, in which important information can be lost.

Today, I was sent to a patient who had just been discharged. I was thinking, okay, there are many tasks involved here: tracheotomy, nutrition probe, and it's a psychiatric patient. These three aspects don't always mix well. If you are a bit hesitant or insecure, the patient may feel uncomfortable. I

wonder why our medical officer agreed to let us take care of this patient when we have not been trained to handle these complex situations

The unclear work environment of homecare nurses can push them beyond the limit of their competencies. They are expected to be experts in all fields, yet they have to struggle to get the necessary information about specialised tasks and patient-related matters. Often, patients' care needs are urgent, so homecare nurses must take immediate action despite being unsure. The homecare nurses in this study reported that they used different strategies to handle such situations, ranging from trusting their gut feeling, asking colleagues who admitted the patient or using alternative information sources, such as Google.

You try asking your colleagues, or phone the hospital to get advice

Yes, and we also google

Or try YouTube, ha ha

Sub-theme: complexity of working with inconsistent guidelines

The data revealed a subtheme of homecare nurses needing to navigate patient care in a field with different guidelines. Often, guidelines provided different advice for the same treatment, both across hospitals and between hospitals and the community (e.g. how to change the dressing for a central venous catheter). However, patients felt insecure if the procedures and guidelines of the homecare nurse differed from those they had experienced at the hospital, and this would lead them to believe that homecare nurses are less qualified or competent than hospital nurses.

The patients get nervous if our guidelines differ from hospital guidelines; for the patients, what the hospital does is right. The nurse in the hospital said so and so, and no way am I going to change that—even if we (the homecare nurses) follow our guidelines

Further, patients expect the homecare nurse to rely on the information they claim was provided at the hospital. Therefore, if the homecare nurses were unsure how to act in a given situation, they were sometimes intimidated by patients and forced to act against their professional intuition. In the example described in the quote below, a nurse terminated the administration of chemotherapy, as she felt pushed by the patient and had no one from whom to seek advice.

I had a patient who took his chemo as pills. He wanted me to crush the pills in order to get his medication into his nutrition probe. My gut reaction was to refuse, I didn't want to do it, but this patient insisted that he had been allowed to do so in the hospital and it was okay. There you are (sighs). I didn't want to say no, so I did it. Afterwards, I called the hospital to ask if this was okay. Of course, it

wasn't, but we (homecare nurses) are on our own with no colleagues to ask.

Discussion

The findings of the present study showed that discharged patients have an urgent need for highly complex care and treatment, but homecare nurses find it very difficult to obtain the relevant information for them to continue care at home after discharge. Thus, the key challenge faced by homecare nurses revealed a paradox between the need for information and the struggle to get access to this information. This paradox was mainly caused by the complicated infrastructures of information in the hospital-to-home transition. These infrastructures had built-in barriers, such as long communications paths, rules about limited access to patients' hospital records, rules about limited access to discharge summaries and procedures concerning information exchange between hospital nurses and homecare nurses. These findings are supported by those of Olsen et al (2013), who highlighted that information exchange is often complicated and problematic in transitional care, due to barriers associated with processes between hospital nurses and homecare nurses.

Further, barriers associated with the organisation structure were reported in this study, and these are aspects over which the homecare nurses felt they had little power (Olsen et al, 2013). Our findings further stressed that homecare nurses often struggled to get in touch with patients' GPs and were not able to discuss issues with colleagues as they worked alone. This lack of information influenced the nurse-patient relationship negatively and thus compromised the homecare nurses' professionalism.

Our findings of homecare nurses' struggle to achieve the information needed are supported by other studies as well (Olsen et al, 2013; Petersen et al, 2019). Smith and Alexander (2012) identified a list of information gaps in transitional care, such as medication reconciliation, wound care and discharge summaries from caregivers. Additionally, Romagnoli et al (2013) identified that homecare nurses faced a variety of unmet information needs during the first 30 days in the immediate post-hospitalisation period, which potentially led to readmission. In a systematic review investigating discharge practices for older patients, Laugaland et al (2012) found that health personnel outside the hospital reported information inconsistencies, such as missing information about medicine regimens, laboratory test results, follow-up care plans and medication list. Our study findings complement these reports by illustrating the complex infrastructures of information and by showing that the homecare nurses take on a huge responsibility with regard to missing information. The homecare nurses interviewed in the present study wanted to improve patients' health and wellbeing. To do so, they struggled to get an overview of the patients' status due to the paucity of information.

Drawing on philosophy and empirical studies, Sørensen and Hall (2011) elaborated on the nature of the phenomenon of seeing the big picture. The authors found that clinicians'

ability to see the big picture influences the health of the patient and is related to issues of security and accountability. Sørensen and Hall (2011) argued that seeing the big picture is good nursing practice, as it indicates a desire and an attempt to achieve excellence in practice. Thus, seeing the big picture is a sign of professional pride. Our study supports these findings and further illustrates that seeing the big picture reflects a holistic approach to patient care that is unique and essential in nursing, as it is related to the ethos of nursing (Bishop and Scudder, 1990).

Ensuring safe medication administration after discharge was just one of the many tasks of homecare nurses. Several recent studies have focused on lack of information in relation to medication administration (e.g. Foged et al, 2018; Kollerup et al, 2018; Patterson et al, 2019). These studies concluded that reducing medication discrepancies in the transition from hospital to home requires improved communication, through access to electronic medical records or standardised transfer forms. Our findings show that providing accurate medication management is not only simply a matter of safe transition. For the homecare nurses in this study, medication management could not be reduced to sticking to procedures. Other important concerns for homecare nurses were fear of compromising professional responsibility by not being able to adopt a holistic approach to patient care and having to rely on information from less qualified healthcare assistants. Some homecare nurses even bypassed rules as they took on this professional responsibility.

Interestingly, although the homecare nurses in this study were recruited from both rural and urban municipalities, they reported identical challenges related to the hospital-to-home transition. Thus, the homogeneity of the focus groups provide in-depth knowledge of the challenges faced by homecare nurses in relation to this transition.

Limitations

The present study is limited by the fact that the findings relate to a Danish context, in which homecare is predominantly free. Thus, the experiences of homecare nurses reported here may differ from those of homecare nurses from other cultural backgrounds and contexts. Accordingly, the generalisability of the findings would depend on the specific context.

Conclusion

The key challenges faced by homecare nurses were related to the paradox between the need for information and the struggle to get access to this information due to complicated pathways of information exchange. Homecare nurses took on a huge responsibility with regard to missing information, and went beyond their remit to ensure this did not adversely affect patient care. Ironically, by taking on this responsibility, they are complicit in covering up the problems with organisational and professional information flow. **BJCN**

Accepted for publication: December 2019

Conflicts of interest: none

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KEY POINTS

- ◆ Homecare nurses have a unique role in providing care after discharge and prevent readmissions
- ◆ The key challenges faced by homecare nurses are related to the need for information and the struggle to get access to this information
- ◆ Homecare nurses also find it frustrating that the cases of patients with complex care needs are often handed over to healthcare assistants
- ◆ The complex and unclear work environment of homecare nurses tends to push them to the limits of their competencies

CPD REFLECTIVE QUESTIONS

- ◆ What can be done to facilitate homecare nurses' access to information in hospital-to-home transitions?
- ◆ How may it be possible to improve the cooperation between homecare nurses and GPs?
- ◆ What will be the most challenging issue in hospital-to-home transition for homecare nurses in future?

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