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ORIGINAL ARTICLE

Who cares?—The unrecognised contribution of homecare nurses to care trajectories

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Abstract

Background: Organisation of patients' trajectories is a critical element of nursing practice. However, nursing practice is mainly expressed in terms of direct patient care, while the practices through which care is organised have received little attention, are poorly acknowledged and lack formal recognition.

Aim: To examine the management of care trajectories as provided by homecare nurses.

Design: We conducted focus group interviews with 29 Danish homecare nurses. The analysis drew on the evidence based and theoretically informed framework care trajectory management. Care trajectory management is conceptualised as comprising of three organisational components: (1) Trajectory awareness, (2) Trajectory working knowledge and (3) Trajectory articulation.

Findings: The organising work of homecare nursing is both complex and unpredictable requiring advanced organisational, collaborative and clinical competences to secure concerted actions in alignment with the needs of the individual patient. Without having any formal obligation homecare nurses took on the responsibility for the coordination of the different activities of the professional actors, and for securing concerted actions. Care trajectory management as provided by homecare nurses reflected a high degree of commitment for patients and illustrated that this type of organising work was driven by the values of the humanistic ethos of nursing.

Conclusion: The study highlights the strength of the invisible and ongoing organising work of homecare nurses. Care trajectory management in homecare reflects the moral foundation of nursing. Consequently, the professional logic of nursing reflected as direct patient care alone is too narrow. We need to acknowledge the organising work of patients' trajectories as a core task equal to direct patient care.

Our study highlights the need for articulating the organising work of homecare nurses and for presenting problematic organisational structures to policymakers and managers. If not, the important organisational work of homecare nurses is at the risk of remaining invisible.

KEYWORDS
care trajectories, community nursing, homecare nursing, indirect patient care, organisational structure, organisational work

BACKGROUND

Nursing work has mainly been expressed in terms of caregiving to individual patients, while the practice through which care is organised has received little attention. This is curious, since nursing has always involved organisational aspects of care. Indeed, Florence Nightingale acknowledged this as early as 1860 in her book *Notes on Nursing* [1]. She argued that the responsibility of nursing entailed creating of an environment that fostered the patient's healing and health. This entailed enhancing sanitary conditions, a qualified and efficient staff as well as attending directly to the well-being and comfort of patients [1]. This account translates easily into modern day nursing terms such as organisation and coordination of care, keeping an overview of the patient's situation, and involving relevant staff. Accordingly, organisation and coordination of patients' care was and still is an important part of nurses' work. These vital element nevertheless seem to be taken for granted or forgotten in current nursing theories whose focus mainly addresses the nurse–patient relationship in relation to direct patient care [e.g. ref. 2–4].

However, nurses make an important contribution to the coordination and organisation of patient care but the work of organisation and coordination has received little attention by nurses themselves and lacks recognition in existing management systems [5, 6]. This is problematic, because organising work affects the quality and safety of trajectories [7] especially of elderly patients [8–10]. Further, some estimate that the organising work of nurses counts for about 70 per cent of the work nurses do [7]. Thus, there is a need for highlighting the aspects of nursing practice dealing with the coordination and organisation of patient care. Particularly in a community setting [11]. Here, a growing number of fragile elderly people live with long-term illnesses in their own homes [12, 13] as policy demands have called for a move of care delivery from secondary to primary care due to demographic changes [11, 12].

As a consequence of this development recent studies in the Nordic countries show that homecare nursing has become increasingly diverse and comprehensive as older patients in particular often leave the hospital with ongoing care needs [10, 12]. Several studies stress that homecare nursing plays an important role in patient care delivery, as it involves assessing the patient's needs, following up with advanced medical care and last but not least of coordinating work across different healthcare organisations [8–10, 12, 13]. A study into Danish homecare nurses' provision of follow-up plans after patients' discharge, showed that homecare nurses took on a huge responsibility to ensure patients' care and safety, which required compensating shortcomings of existing organising structures [12]. Thus, homecare nurses' care and organisation of care actions are essential for these patients.

Researchers have argued, that homecare services are based on New Public Management ideologies, which have led to rigid organisational systems and a fragmented operational delivery of health care services [14]. This is problematic as homecare nurses work in teams, who create a series of activities that are relational, flexible and creative in nature [15, 16]. This complexity underlines the fact that homecare nursing is much more than an operational delivery of health care services and that these activities are part of a collective effort requiring increased coordination and organisation.

Over the last two decades, the nurse researcher Davina Allen has highlighted the complex and largely invisible contribution hospital nurses make to the coordination and organisation of patient care [e.g. ref. 5, 7, 17, 18]. Allen conceptualises this work as care trajectory management by drawing on the scholarship of the sociologist Anselm Strauss [7, 17]. Care trajectory refers to the '*unfolding of a patient's health, welfare and social care needs, the total organisation of work associated with meeting those needs' [...]* [17, p. 5]. Hence, care trajectory refers to an activity system as the basic unit of analysis consisting of interrelated practices and artefacts oriented towards a shared goal, i.d. the patient [7, p. 20]. In other words, the practices through which patients' trajectories are organised. This type of care often remains invisible in nursing practice; it typically comes to light when problems occur [12–14].

Consequently, there is a need for illuminating the practices through which patients' trajectories are organised by homecare nurses. Accordingly, the aim of this paper was to examine the management of care trajectories as provided by homecare nurses.

METHOD

The study has a hermeneutic stance and takes it departure in a takes a qualitative design. We conducted five focus group interviews with 29 homecare nurses representing four Danish municipalities.

Context and participants

In Denmark, the delivery of primary healthcare services is free of charge and provided by 98 municipalities who are also responsible for homecare delivery services. This concerns primarily homecare services to support those living with long-term physical and psychological conditions, the growing number of older people as well as follow-up care plans after patients' discharge. As the 98 municipalities vary in size and population, the districts of the homecare nurses vary across the municipalities. 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 as they agreed to inform the homecare nurses about the study. Homecare nurses interested in participating in the study were asked to contact the researchers to make an appointment. Twenty-nine homecare nurses responded and were included in the study.

The included participants were trained as registered nurses and represented a wide range of differences in terms of experiences within the field of nursing, job experience as homecare nurses (between 1 and 27 years), and age (between 26 and 57 years).

Data collection

The number of participants in the five focus groups ranged from four to seven. We developed a semi-structured interview guide based on open questions to stimulate the discussion between participants [19]. To allow the participants to discuss what really mattered to them in the provision of care and follow-up plans after patients' discharge the interviews started: "Please describe key challenges faced in relation to patients' transition from hospital to home". As the interview progressed, the moderator asked specific questions to deepen the nurses' descriptions of the homecare nurses' roles and practices related to organisational elements of their work in the hospital to home transitions. Acknowledging the social dynamics of the interview, the moderator ensured that all participants had the opportunity to speak [19].

The interviews were conducted by AN and BM and lasted about 90 min. The interviewers had no former relationship with the participants. Two interviews took place at the local university and three at the homecare nurses' workplace. All interviews were audio recorded and transcribed verbatim. The transcribed interviews consisted of 261 pages in Danish language.

Theoretical framework

To explore the homecare nurses' management of care trajectories, the analysis drew on the care trajectory framework developed by Davina Allen [5, 7, 17, 18, 20] as this theory provides a theoretical and conceptual foundation of the organising work of nurses [5, 7, 17, 18, 20]. The theory arises from Allen's ethnographic studies of the organisational elements of the nursing role [7] and is further developed into a translational mobilisation theory (TMT) in which Allen combines different sources such as sociological theory and Actor Network Theory [5, 18, 20]. Allen argues that TMT is a new paradigm for understanding the organisational elements of nursing work as *it brings into view nurses' agency and its consequences for patients, the organisation and the profession* [5, p. 41]. Accordingly, TMT focuses on the concrete activities of the everyday reality of nursing practice through which organisational life is accomplished [5].

Deploying TMT and a body of studies focusing on trajectory, Allen [17] has developed the conceptual framework care trajectory management to systematically examine and explicate the organisational components of patient care. Allen conceptualises care trajectory management in three organisational components:

1. Trajectory awareness, that is practices that refers to the work of maintaining overview of trajectories of care as they evolve in time and space, such as *'Knowing exactly what is going on everywhere'* [17, p. 6]. Trajectory awareness is typically initiated when patients are admitted to a service and a precondition for the second component of the framework: trajectory working knowledge.
2. Trajectory working knowledge, that is the translational work that supports information sharing to make progress of care as illustrated in the following quote: *'we are the link; they tell us and then we tell everyone else'* [17, p. 7]. This work includes how multiple interests are accommodated to enable concerted action within a care trajectory [17].
3. Trajectory articulation which covers the collective practices through which trajectory elements are organised to ensure all elements necessary to meet patients' needs such as expertise, materials, information are aligned in time and space [17]. Illustrated as: '*Nurses run the place. [...] that requires anticipating people's needs and constantly being two steps ahead'* [17, p. 7].

Allen's conceptual framework further entails a list of factors that influence the complexity of

trajectory management such as diagnostic ambiguity and co-morbidities that may challenge standardised care pathways. Conflicts between team members, the number of actors involved as well as psychosocial factors of patients and relatives also contribute to complexity.

Accordingly, the care trajectory management framework provides evidence-based concepts and theories through which to describe, analyse, and reflect on the organising work of nursing practice systematically. Although Allen's theory is developed in a hospital context, she encourages researchers to use the theory as a foundation for further research in a community context [7, p. 16].

Data analysis

To explore the organisational components provided by homecare nurses, we constructed the analytical questions below to guide the analysis.

1. What characterises the homecare nurses' trajectory awareness, that is their work of maintaining overview of trajectories of care as they evolve in time and space [17]. 2. What characterises the homecare nurses' trajectory working knowledge, that is translational work that supports information sharing to make progress of care, and how do homecare nurses ensure that multiple interests are accommodated to enable concerted action within a care trajectory [17]. 3. What characterises the homecare nurses' trajectory articulation, that is what collective practices do homecare nurses initiate to ensure that all elements necessary to meet patients' needs are aligned in the right place and at the right time [17].

Guided by these questions, we looked at data from all focus group interviews to identify similarities and discrepancies to describe nuances and variations in the data. During this process, the authors continuously discussed the emerging findings until a comprehensive understanding emerged.

Ethical considerations

Ethical considerations followed the basic principles for research given in the *Helsinki Declaration* [21] and the Data Protection Regulation [22]. The participants received verbal and written information about the purpose of the study, the right to withdraw, and the confidentiality of the data given. Additionally, no personal information of participants was taped. Further, the study was approved by the Danish Data Protection Agency [ID no: 2016–051-000001].

FINDINGS

Initiating plans: Creating order and making sense

Homecare nurses struggled to get an overview of the patients' trajectory of care when patients were transferred from hospital to home and they often had very little time to prepare the first visit after the patient's return from hospital. The formal responsibility for initiating patients' care trajectory in homecare was unclear; however, homecare nurses' collaborators expected homecare nurses to have the full overview of the patients' trajectory.

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

> 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.

The homecare nurses were not asked if they had the necessary competencies or resources to take care of a given patient, which contributed to complexity of trajectory from hospital to home. Further, decisions taken in hospital could be out of step with the reality of the homecare context. For instance, patients could be prescribed medicine that was incompatible with their economic conditions. In these cases, it was up to the homecare nurse to get the prescription changed. Also, part of the procedures that homecare nurses had to follow was anchored in hospital wards with whom the homecare nurses had no natural collaboration. For instance dialyses had to be conducted in accordance with the recommendations used in the responsible ward or pointed out by the responsible physician. For the homecare nurses, this meant following different procedures for the same treatment which contributed to the complexity of a patient's care trajectory.

Building on their professional knowledge, homecare nurses did their best to gather all relevant information, for example from hospital staff, general practitioners and patients' relatives.

> It is not like you are reluctant to call the hospital ward and ask them and normally they can answer your question. It is worthwhile to give them a buzz if you are in doubt or if you have questions concerning the medication. Most of the communication tends to be written communication, which is fine... but still

> there may be questions when you update the medication of patients so oral communication is important too...

With reference to Weick [23], Allen [17] describes this work of creating order from different sources as 'sensemaking'. Our material shows that for this complicated work there is no manual. Hence, the creation of a care trajectory to a great extent depends on the individual homecare nurse's knowledge, commitment and professional network. Written artefacts such as discharge reports played a significant role as an information source that could answer some of the unanswered questions of the homecare nurses. However, access to information sources could be an obstacle race in which the homecare nurse had to spend hours to get in contact with the right healthcare professionals. Often their success depended on the goodwill of other professionals.

> It would have been nice to speak directly to the relevant professional to clarify certain aspects ... in those situations you have to call the hospital only to learn that the nurse in charge of the patient is no longer on duty...

The difficulties in getting information access were experienced by the homecare nurses as unnecessarily time consuming and preventing them from doing their best for the patients. After succeeding in getting access to information sources the homecare nurses carefully selected all information relevant for the patient's trajectory.

Accommodating contradictory objectives to enable concerted actions

The organisation and coordination of care to make progress of patients' trajectory and enabling alignment the professional actors involved was a highly complex task Homecare nurses drew on their organisational knowledge, for example about chain of command and norms, that is a situated knowledge developed over time.

As the work of homecare takes place in patients' private homes, the professionals involved are largely working alone when making decisions. The homecare nurses took on the role as managers to make ongoing care trajectories proceed.

> It is very difficult to pinpoint exactly what I'm doing as a homecare nurse because I do almost everything... I take care of managing almost everything related to patients' health.

Homecare nurses drew on their knowledge of trajectories to act in consistence with procedures defined by the organisation. Although they sometimes questioned the rationality behind organisational procedures, they were loyal to them. However, in some situations, homecare nurses were willing to bend organisational rules to create concerted actions. For example homecare nurses occasionally went to the pharmacy to collect medicine for a patient if this was the only possible way to secure a patient's prescribed new medication although this constituted a formal reason for being dismissed.

If necessary, homecare nurses might also be willing to overstep their authority to make a patient trajectory proceed. For example home care nurses were not allowed to check for urine infection without prescription. Sometimes they did and called the patient's GP afterwards to fast-forward a prescription. Home care nurses legitimised this overstep of authority when it could be rationally substantiated as doing the best possible for patient.

> I bent the rules somewhat to keep the ball rolling and all that ... sometimes you automatically just follow routines ... and there is also the time pressure to consider...

When organising a care trajectory, a high degree of the homecare nurses' work related to the categorisation of the patient's physical condition as stable or unstable. Due to organisational procedures this categorisation defined the educational level of the professional actors involved. Patients categorised as stable should be handed over to homecare assistants. This procedure complicated the organising work of the homecare nurses through its fragmentation of care. To stick to the procedures defined by the organisation, homecare nurses often had to hand over patients categorised as stable to homecare assistants with less professional education although the homecare nurses risked to miss out on potentially important observations of the patient's physical condition. To compensate for a potential lack of information homecare nurses carefully provided homecare assistants or close relatives with information about the kind of follow-up observations they needed to potentially reorganise a patient's trajectory.

> It is important to educate the healthcare assistants to observe what you want them to observe. It takes an awful lot of time, and they have no sufficient training in observing patient's trajectory.

Accordingly, the homecare nurses drew on their professional and relational knowledge to enable concerted actions among the people involved, for example related to patient observation. In terms of patient safety, however, homecare nurses could feel uncomfortable when having to hand over

observation tasks to trajectory actors less qualified themselves and consequently being unable to reorganise the patient's trajectory in time.

Distributing goals: Liaising between multiple actors

Homecare nurses drew on their situated organisational knowledge developed over time to align trajectory elements in time and space. Acting on this knowledge was twofold. One the one-hand homecare nurses were sticking to clinical procedures given by the organisation or the hospital. On the other hand, home care nurses were acting on procedures defined at organisational level; especially concerning the classification of tasks to be performed by homecare nurses and which by homecare assistants.

> We (homecare nurses) are moving further and further away from the patients and others (homecare assistants) must observe the patients for us.

Further, supporting actions and decision making were complicated by the fact that it was difficult for the homecare nurses to get an overview of the patients. Since all patients are in their homes, they are 'invisible' which made it difficult to assess the necessary needs each patient required on any particular day. An unexpected worsening of a patient's condition might spoil the time schedule.

> (...) many of these aspects are related to time and resources. We do not have the time to look up references ... we do not have the time to look for supplementary knowledge. We have been cut to the bone.

According to Allen [17] trajectory articulation includes decisions about what should be done, by whom, when, where, using which materials. Our study shows, however, that homecare nursing contains an additional element not included in Allen's framework as homecare nurses also need to consider 'in what way'. This element was highly complex as it could potentially challenge homecare nurses' individual competences concerning patients with highly complex care needs requiring specialist knowledge. The complexity increased in relation to trajectories in which a number of different professional actors were involved such as GPs, specialist nurses, occupational therapists, physiotherapists, homecare assistants and as well as patients and relatives. The actors involved thus have different levels of education, different types of education, and different foci in the trajectory.

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

In this multitude of professional communication, homecare nurses were to pinpoint which type of information was relevant for the purpose at hand. Drawing on their overview of the patients' trajectory, the home care nurses took on the responsibility for calling in the right professionals at the right time, for the coordination of the different activities of the professional actors, and for securing concerted actions.

Homecare nurses identified and addressed potential lack of alignment of decisions among the professional actors. For example homecare nurses did check-ups after patients' discharge to control that medication was given at the right time and in the right order.

> When discharged from hospital patients receive assorted medication. On several occasions, I have observed that medication has been left unwrapped or that patients have not received the medication prescribed when homecare assistants have been in charge. Often patients have left over medication from before they were being hospitalised; homecare assistants might overlook this and may be unaware that the hospital have changed the patients' medication.

To distribute and coordinate the activities of various care providers thus required in-depth knowledge of organisational processes and of the professional actors involved.

DISCUSSION

Our analysis of homecare nurses' management of care trajectories highlights the strength of the invisible and ongoing organising work of homecare nurses. This organising work stretches over different phases of the care trajectory and includes highly diverse managing activities, ranging from care trajectory awareness to trajectory working knowledge to trajectory articulation. The findings emphasise that this organising work is framed by an underlying level of complexity. Similar to findings in other studies this complexity was caused by patients living in their own homes, by the number of individual healthcare professionals who mainly work alone and by the involvement of different organisational settings such as out-patient clinics, hospitals and the patients' general practitioner [12, 13,

15, 16]. Consequently, the activities embedded in homecare nurses' management of care trajectories are both unpredictable and highly complex requiring homecare nurses to bring together information from different parties to create order through sensemaking. This demanded in-depth contextual knowledge such as thorough professional knowledge, positive relations with others, often less skilled care providers, and included the coordination of multiple and pragmatic interests in circumstances of organisational complexity. Homecare nurses were loyal to institutional procedures while at the same time rebelling against them if the procedures obstructed the ongoing concerted actions of the organisation of care. Likewise, other studies found that homecare nurses were disobedient and manipulated organisational structure to ensure the best possible care for patient [12, 14].

Despite, our findings highlight that organisational work related to care trajectory in home care is a key component of care to individual patients this organising work it is poorly acknowledged both within healthcare systems and by nurses themselves [6, 24]. For example organising work does not feature in job descriptions [24] and therefore remains invisible to managers. Worse, nurses themselves often refer to organising work in terms that carry negative connotations such as a taken-for-granted work at the expense of individual relational work [11] or 'as the dirty work of the profession and a distraction from nurses' 'real work' with patients' [7, p. 148]. This reflects a professional logic that sees direct patient care as superior to the organisational work of patients' trajectories. This professional logic is also implicit in the work of nurse theorists who stress the moral commitment and the caring relationship with patients [e.g. ref. 2–4]. Our findings highlight, however, that the care trajectory management of home care nurses is not in opposition to values embedded in nursing theories. Rather our findings reflect that the point of departure for homecare nurses' organising work is strongly influenced by the fundamental values embedded by nurse theorists emphasising the specific needs of specifics individuals in specific situations [e.g. ref. 2, 3, 4].

Although often implicit, the underlying value of homecare nurses' organising work illustrated a high degree of commitment to patients driven by an underlying desire to mobilise action in the interests of the individual patient. The findings showed that in the interests of patients, homecare nurses were even willing to bend rules and overstep their authority to compensate for problematic organisational structures. This finding reflects the unique professional competences of home care nurses to integrate clinical work and organising work thereby acting on the basis of the professions' moral foundation [25]. Thus, our findings clearly illustrate that the indirect care in terms of organising work of homecare nurses is driven by the values of the humanistic ethos has guided nursing practice through decades [25]. This argument can be substantiated by Strandås et al. [14], as they stress that homecare nurses were 'gaming the system' to perform their profession in accordance with their own professional ideals (p. 10).

Consequently, we argue that the dichotomy between direct patient care and organising work is a false one in modern homecare nursing. Today's homecare consists of increasing specialisation and the rise of chronic illness and multi-morbidity highlights the need for managing care trajectories [12, 26, 27]. Accordingly, the organisational work in homecare has to be considered in its own right as part of 'real nursing'. A plethora of coordination initiatives suggests this as a new skill requiring new functions [24, 28] and new competences [13, 16]. These aspects were also reflected in our findings highlighting that today's care trajectory management to a high degree consisted of ad hoc tasks and ad hoc solutions.

A recurring aspect in the findings concerns the tendency of some organisational procedures were experienced as counter-productive and led homecare nurses to overstep administrative rules to compensate for the constraints of organisational structures. Ironically, this compensation of counter-productive organisational structures means that organisational problems remain invisible. This stresses the need for articulating the practices through which care is organised and supply this information to policymakers and managers.

Strengths and limitations

We drew on Lincoln's and Gubas' [29] generic criteria for trustworthiness. Authors AN and BM led the analysis. To establish credibility they engaged in peer debriefing, and the discussion of potential discrepancies in interpretations before reaching consensus [28]. Further, the authors maintained an audit trail of the analysis process to establish dependability and confirmability [29]. To enhance transferability, all authors considered potential differences between the rural and urban contexts and found no noticeable differences in homecare nurses' descriptions. However, the study was conducted in Denmark where healthcare is mainly tax financed. Thus, transferability of findings will be possible to countries with a comparable approach to health care.

On the one hand, using the care trajectory framework provided us with a language with which to explicate the organisational components of patient care. On the other hand, however, using a theoretical framework for analysis always implies a risk to overlook certain aspects of the phenomenon under investigation. We were

continuously attentive to this risk of a potential dominance of the framework applied and ready to supplement Allen's theory if necessary to cover the voice of participants.

CONCLUSION

Our study highlights that care trajectory management is a critical element of homecare nursing requiring advanced organisational, collaborative, and clinical competences to be in alignment with the needs of the individual patient. The care trajectory management provided by homecare nurses reflects a high degree of commitment for the patient. Accordingly, this organising work is not in opposition to direct patient care but reflects the moral foundation of nursing. Consequently, the professional logic of nursing reflected as direct patient care alone is too narrow in modern nursing practice. We need to acknowledge the organising work of patients' trajectories as a core task equal to direct patient care.

Our study highlights not only the need for articulating the organising work of homecare nurses but also for presenting problematic organisational structures to policymakers and managers. If not, the important organisational work of homecare nurses is at the risk of remaining invisible.

AUTHOR CONTRIBUTION

All authors contributed to the study design. ALN, and BM did data collection and analysis; the manuscript preparation was done by ALN and all authors agreed on the final version.

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CONFLICT OF INTEREST

The authors declare there are no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data are available on request due to privacy/ethical restrictions.

ETHICAL APPROVAL

According to Danish law, formal ethical approval of the study was not required and ethical considerations followed the basic principles for research given in the (Helsinki Declaration World Medical Association, 2013). The participants received verbal and written information about the purpose of the study, the right to withdraw, and the confidentiality of the data given. Further, the study was approved by the Danish Data Protection Agency [ID no: 2016–051-000001].

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