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Patient education in the hospital-at-home care context

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Abstract

The objective of this study is to describe adult patients' and their family caregivers' experiences of patient education in the hospital-at-home care context. Methods included a cross-sectional descriptive study including three hospital-at-home units in Finland. Adult, non-palliative patients (n = 27) and their family caregivers (n = 18) were interviewed pairwise by telephone, and the data analyzed with inductive thematic content analysis. COREQ guidelines were used to plan and guide the study design. Results concluded both patients and family caregivers seemed to have quite similar knowledge expectations, which only differs slightly from findings in other in- or outpatient contexts. In the hospital-at-home context, there is an evident need for clinical coaching and guidance in relation to self-care activities and for future-oriented education about the services available after hospital-at-home care. Six themes describing patients' and family caregivers' experiences of patient education in the hospital-at-home care context emerged, from patient-centered, goal-oriented and empowering education to the bypassed education of both patients and family caregivers. We conclude that in the hospital-at-home care context, the patient is not alone in his/her illness but instead the patient and family caregiver together form a unit. Thus, the need exists for extended, iterative patient education in hospital-at-home care: need for clinical coaching, guidance and support in relation to self-care activities and for future-oriented education about the services available after HAH care. Such extended patient education, in which patients' family caregivers were included, strengthens the patient-family caregiver relationship, minimizes caregiver burden and the need for additional healthcare services.

Keywords

Patient education, family caregivers, hospital-at-home, person-centered care, pairwise interviews

Introduction

Economic constraints, demographic ageing, and the rising cost of healthcare services have led globally to the need for social- and healthcare reforms in many countries.¹ The trend toward caring for somatic, psychiatric and palliative care patients in their homes, when possible, has emerged in Northern Europe, North America and other parts of world during the past two decades. Hospital-at-home (HAH) care, through which patients of all ages and life situations receive care, requires systematic patient education. Patients' family caregivers should also be included in education, in accordance with the principle of patient-centered care.^{2,3} Patients' family caregivers are often included by professional HAH staff as informal coworkers in HAH care.⁴ Consequently, education should be provided to both patients⁵ and family caregivers prior to, during and after the HAH care period, for reasons of informed consent, shared decision-making and the clarification of responsibilities.

Hospital avoidance and early discharge are the aims of different health and nursing care reforms in Central Europe, the Nordic countries and the United Kingdom.^{6,7}

Even patients with complex temporary or chronic healthcare problems and advanced nursing care needs who do not need continuous observation⁸ are cared for at home when possible.⁹ Still, not all patients prefer to be cared for at home. Patients choose care at home if it facilitates flexibility in their individual schedules and/or time management¹⁰ and promotes their social relationships.^{11,12} Other reasons why outpatient care at home may be preferred over inpatient care in hospital include reasonable patient fees (compared to hospital care) and the desire for person-centered care, autonomy and dignity, all of which are associated with the home care context. In an interview study, patients chose HAH care if they had a spouse or housemate at home to support them and also received a pledge from care services that they would receive professional, good care at home.⁴

It is assumed that HAH patients' family caregivers will bear some responsibility for the care being given in the home context, and researchers have found that family caregivers can experience emotional, physical¹³ and cognitive burden¹⁴ from their new, sometimes demanding role.⁴ For many patients, family caregivers and even healthcare professionals, HAH as a service form still

seems to be unknown or unclear.¹⁵ Therefore it is important to develop information about this care alternative not only for patients but all of society.

Originally called hospital-based home healthcare, the HAH concept evolved in the 1990s. Today the terms advanced care at home, hospital-in-the-home (HITH) and person-centered medical home are used synonymously with HAH.^{16, 17, 18} The HAH care context is situated on the interface between hospital care and home care, and when patients and their family caregivers consent to HAH care the quality of the care being provided and eventual safety issues must be carefully considered.^{16, 19, 20} Through HAH care, the medical and advanced nursing care that is normally provided to hospital inpatients is provided in a home setting, overseen by a physician. HAH care is offered periodically to patients with significant somatic or mental healthcare needs or chronic illnesses, ill children or those in need of palliative care.²¹ HAH care is associated with person-centered principles, activities²² and outcomes.⁴ That is to say, it is associated with respect for the personal narratives that reflect a person's personal knowledge and the recognition of this respect through the safeguarding of a partnership through shared decision-making and meaningful activities in a personalized environment.^{23, 24} HAH care has been shown to lead to reductions in mortality and readmission rate¹⁷ and increases in patient and family caregiver satisfaction.¹¹

In Finland, HAH care can be administratively organized under primary healthcare, specialized healthcare, private healthcare, or a combination of these.²⁵ In Finland's Act on the Status and Rights of Patients (785/1992, section 5), "A patient shall be given information about his/her state of health, the significance of the treatment, various alternative forms of treatment and their effects and about other factors related to his/her treatment that are significant when decisions are made on the treatment given to him/her."²⁵ According to the Legal Dictionary²⁶ in reference to the topic of informed consent, it is noted that:

"Informed consent is the act of agreeing to allow something to happen, or to do something, with a full understanding of all the relevant facts, including risks, and available alternatives. It is only with a full comprehension of the risks and benefits of the decision, as well as an understanding of the possible alternatives, that any individual can consider whether an action would be in his best interests."

The goal of patient education is to empower patients – and their family caregivers – to engage in active participation in decision-making and self-care. Patient education can be defined as a goal-oriented, active nurse-patient dialog in which their physiological, psychological, social and other backgrounds are taking into account.²⁷ Through dialog, the nurse uses the patient's experiences and need for

understanding to guide the education provided, which creates possibilities for the nurse to reason and act in a way that the patient can follow. This, in turn, allows the nurse to *learn*.²⁸ In patient-centered education, the focus is shifted from the delivery of general *information* responding to patients' assumed learning needs to individually-tailored *education* that satisfies the patient's actual *knowledge expectations* in a specific situation.²⁹ Patient-centered education allows nurses to incorporate a focus on what patients themselves can do for their health and well-being in their everyday life prior to, during and after medical treatments³⁰ at home. Such advanced patient education does not solely include a focus on information but also coaching, guidance and support.³¹

In contrast to other forms of patient education, in which the information given is assumed to fit a certain situation, patient-centered education allows patients and family caregivers to reflect on and recognize whether their knowledge is adequate or inadequate to satisfy a goal in the situation they find themselves in at a specific point of time.³² Still, healthcare professionals always have an ethical obligation to provide obligatory information, e.g., about potential risks, if patients and/or family caregivers are unable or unwilling to formulate their knowledge expectations.²⁶ Once a nurse has understood what the patient's and family caregivers' knowledge expectations are, the next step is the nurse's response, which includes the coordination of the patient education process together in the interprofessional care team. It is vital to ensure that the patients and their family caregivers really understood the education, and therefore the assessment of their comprehension of the education is needed.³³

During our literature search, we found no published research with an explicit focus on patient education or family caregiver education in the HAH care context. We did find one study³⁴ in which HAH patients (n = 57) were pleased that their care could be arranged at home but nonetheless wished to receive more information about their care. These HAH patients were seen to be hesitant with regard to influencing the realization of their care, with about half (53 %) perceiving that they had been able to make decisions in their care.³⁴ The HAH patients in the aforementioned study did not perceive empowerment in their own care, and their knowledge expectations were not analyzed nor their comprehension assessed. The results seen there were similar to the results seen in other studies in other contexts on in- and outpatients' knowledge expectations and participation in decision-making with regard to care.^{35, 36}

Also family caregivers should be given the opportunity to participate in the decision-making related to a patient's admission into HAH care and receive tailored education about how HAH care can impact their everyday life, what their responsibilities will include, and how to engage in

care planning, changes and evaluations together with the patient and HAH staff.⁴ Using the validated Carer Support Needs Assessment Tool (CSNAT) instrument, Ewing et al.³ found that family caregivers in the HAH context have knowledge expectations about the patient's illness, symptom management, providing personal care, knowing who to contact when concerned, talking to the patient about his/her illness, and knowing what to expect in the future when caring for the patient. They need also support in relation to own well-being; financial, legal and work issues; in dealing with feelings, worries, beliefs and spiritual concerns; and practical help in the home. While a lot is known about family caregivers' expectations, even in the HAH context, there is very limited knowledge on their need for education in terms of coaching, guidance and support – even though patient education is a central professional competence for nurses and an important factor in safe, effective care.

The aim of this study was to describe adult patients' and their family caregivers' experiences of patient education in the HAH care context.

Methods

The data were obtained from a cross-sectional descriptive study including three HAH units in Finland in which adult, non-palliative patients' and their family caregivers' experiences of HAH care, in light of person-centeredness, were explored. In this paper, we focus on delineating patients' and family caregivers' experiences of patient education; other study results have been described in another paper.⁴

The strategic sample included two HAH units offering services during the day and evenings on weekdays and weekends (Units A and B, administratively under primary healthcare) and one unit offering services during the day, evenings and overnight on weekdays and weekends (Unit C, administratively under specialized health and nursing care).

After Ethical committee approval (Number R18179H), nurses at the included HAH units recruited voluntary adult

patients and their family caregivers for participation in the study. The included units' respective nurse managers contacted prospective participants by phone, providing information about the study and data collection procedure and asking for their preliminary interest to participate in an interview. Sample criteria included that participants were adult (>18) patients with a physical or mental health problem/problems but not in need of palliative terminal care, assisted by a family caregiver (spouse/partner, family member, other relative, close friend) and had received or were receiving HAH care. If preliminary interest was expressed, an HAH nurse gave the researcher-developed information sheet to the patient and his/her family caregiver during the next HAH care visit. This information sheet contained information about the aim of the study, data collection methods, participants' right to self-determination and aspects of confidentiality. Information about how and who to contact for additional information was also provided. To provide written informed consent, participants filled in and signed the lower portion of information sheet, which was collected by an HAH nurse and returned to the respective unit's nurse manager. Once collected, the nurse managers contacted the first researcher and provided the participants' contact information, after which the researcher called the participants and scheduled interviews. This three-stage process was planned to guarantee voluntariness and a true informed consent, i.e., to avoid coercion.

During spring 2019 (February 1 to April 31), structured pairwise telephone interviews of the participants were conducted, during which patients and their family caregivers were interviewed simultaneously to minimize any possible inconvenience related to in-home face-to-face interviews. The interviews were conducted by a researcher with long experience of nursing and qualitative research, and different interview methods.

The interview questions (Table 1) were developed from definitions of person-centeredness and the central attributes of the HAH context. Patient education was seen as an implicit part of the principles and activities inherent to person-centered care^{3, 4, 22} and subsequently no specifically patient-education-related questions were asked.

Table 1. Interview questions for pairwise telephone interviews

- | |
|---|
| <ul style="list-style-type: none"> - What do you think about nurses and, if applicable, physicians visiting you at home? - What do you think about your family caregiver helping you at home?/ you helping your family caregiver at home? - What do you think about the machinery/technical/virtual equipment, if any, used as part of the care in your home? - Can you describe a situation when HAH staff treated you in a person-centered way? - Can you describe a situation when HAH staff treated you in such a way that you felt dignity as a person? - How did you participate in the planning of the HAH care? - How did you participate in the evaluation of the HAH care? - How do you perceive HAH in comparison to traditional in-patient hospital care? |
|---|

Such reasoning was found to be valid: during the experiences in all questions. The order of the interview questions was flexible and related to the participants' replies.

The pilot testing of questions occurred during the first three interviews, including order of questions, and no need for modification was seen. The data derived from the pilot testing were included in the study. Background variables were sought at the beginning of each interview, including age, gender, acute or chronic health condition as reason for HAH care, and relationship with the patient.

The data emerged from interviews with 45 participants in total. Of these, 27 were patients (12 female, 15 male, age 20-87 years, mean 65 years) with an acute health problem (n = 20) such as urinary infection, pneumonia or erysipelas eczema presupposing IV antibiotics, or a chronic health problem (n = 7) such as colostomy and parenteral nutrition; 18 were family caregivers (11 female, 7 male, age 48-80 years, mean 69 years; 16 spouses and 2 housemates). The length of the HAH care period varied from three days to several months, mean five days. Of those providing informed consent, some patients did not have a family caregiver (n = 5) or their family caregivers declined to

participate (n = 4), stating that they were not affected by HAH care. These patients were nevertheless included in the study and interviewed, because of their explicit willingness to participate. Saturation was achieved after about 22 interviews, but we chose to continue with the remaining scheduled telephone interviews.

The data (13- to 53-minute long interviews) were tape-recorded and analyzed through inductive thematic content analysis.³⁷ During the preparation phase, we listened to the data with a focus on manifest content and used both sentences and parts of data that represented the idea underlying the whole as analysis units. During the organization phase, data answering the research question were written down, grouped according to similar content, and then coded, categorized and abstracted (Table 2). Throughout this process, we sought to be loyal to the participants' statements, and thus labelled the categories and themes to describe and highlight the differences between perceived *information* and perceived *education*. The main researcher conducted the data analysis while all authors confirmed the categorization, to verify trustworthiness.³⁷ Consolidated Criteria for Reporting Qualitative research (COREQ) guidelines enhancing the quality and transparency of health research for the

Table 2. Content analysis examples

Code	Subcategories	Category	Theme
I received some material about HAH to read, but nothing else	I only received information about HAH care	I only received diffuse information	FEELING CONFUSED: I RECEIVED FRAGMENTED PATIENT EDUCATION
To understand my situation I have seen my own x-rays and CT scan results, but nothing else	I only received some feedback on my clinical condition		
They only told me that I can always call HAH directly, if I have questions or problems, that I don't need to call the healthcare center first... But that was all...	I only received information about sources of further information		
I [will] now take cortisone medication for three weeks, and I suppose it helps me, but I don't know if it has any side effects... I had gestational diabetes but now I don't know if I have it anymore? The physician said this illness can recur, but I still don't know why and where I got it from...	I received some diffuse information		

Table 3. Subcategories, categories and themes

Subcategories	Categories	Theme
The staff instructed me and my family caregiver in my care I knew all the time what would happen	We both received tailored education about my care and felt in control	FEELING EMPOWERED: WE BOTH RECEIVED PERSONALIZED PATIENT EDUCATION
I have even received answers after home visits I received answers if I asked I received explanations when I felt like it	I received answers when it was convenient	FEELING SERVED: I EVENTUALLY RECEIVED ANSWERS TO MY QUESTIONS
I only received information about HAH care I only received some feedback on my clinical condition I only received information about sources of further information	I only received diffuse information	FEELING CONFUSED: I RECEIVED FRAGMENTED PATIENT EDUCATION
I need clear instructions for self-care I need to feel safe	Need for tailored self-care education to feel safe	FEELING INSECURE: WE WOULD NEED CLEAR SELF-CARE EDUCATION TO FEEL SAFE
I didn't receive any education and feel uncertain I would have needed information to make a correct choice Now, after the acute situation, we [understand that we] would have needed to know more	We still don't know enough and feel uncertain	FACING UNCERTAINTY: WE WOULD HAVE NEEDED TO KNOW MORE
I/we didn't get any patient education because of [my/the other's] background I tried to avoid asking questions because of time constraints	They took for granted that the other already knew I tried to avoid "causing trouble"	FEELING DISMISSED: BYPASSED PATIENT EDUCATION

reporting of studies using interviews were followed with regard to the study design (<https://www.equator-network.org/reporting-guidelines/coreq/>).

Results

Altogether six themes describing patients' and family caregivers' experiences of patient education in the HAH care context emerged (Table 3). The participants (n = 45)

from the three different HAH units had very similar experiences of patient education. We determined that separate patient-family caregiver content subcategories and categories were not needed, because nearly all of the categories that emerged were based on statements from both participant subgroups.

In the theme **Feeling empowered: we both received personalized patient education**, patients and family caregivers together described tailored, extended patient education. They used terms such as *instruction* and *explanation*, and revealed experiences of individual, contextual, goal-oriented and dialogic patient education that included coaching and support. In this theme, patient education was perceived to be highly personalized and correspondent to the actual clinical situation and circumstances seen during the HAH care period, e.g., specific advice related to medication, wound care or care plan. Patient education was also perceived to be comprehensive. It was considered to meet the participants' knowledge expectations, be understandable, increase patients' capacity for functional self-care, increase family caregivers' knowledge and skills as care assistants, and increase both patients' and family caregivers' sense of control.

The staff instructed us in the use of the vacuum bandage system and explained how it works (Patient and family caregiver C1)

We both received instructions about these specific medications and how to use them, and about this machine which arrived today, and very good instructions about hygiene in wound care (Patient and family caregiver B11)

They gave me my medication and took blood samples... and I got to know that they will come the next day again and take more samples ... I knew all the time what will happen (Patient B8)

In the theme **Feeling served: I eventually received answers to my questions**, patients or family caregivers separately expressed that they either received answers to their questions during or after a home visit or when they themselves felt ready to ask questions or receive answers. In this theme, while patients or family caregivers experienced that they received answers, goal-oriented patient education processes were not perceived to exist per se. This can be interpreted as that when patients or family caregivers expressed (some of) their knowledge expectations to staff, staff responded when possible – which can be viewed as a type of dialog. Furthermore, the patients or family caregivers perceived that staff followed their “pace” by respecting patients’/family caregivers’ experiences and readiness to receive education.

I have received an answer to the majority of my questions... those burdening me most... [If the staff] haven't had the answer right there, they have checked it out for the next day (Patient C2)

I always receive an answer to my questions, if [the staff] don't know they find out and call me afterwards (Family caregiver B5)

If I have had questions, [the staff] has answered them... If I have asked (Patient B9)

When I get new test results [the staff] explain them to me if I'm ready to listen... (Patient B12)

In the theme **Feeling confused: I received fragmented patient education**, while patients perceived patient education in certain areas, such as information about HAH care during admission to HAH care or further information about and feedback on their clinical condition, response to their actual knowledge expectations did not occur. While they mainly used the term *information* to describe their experiences, the terms *only*, *nothing else*, *that's all*, and *I (still) don't know* were seen in several statements and were interpreted as expressing perceptions of unsatisfactory, diffuse and fragmented patient education during and even after the HAH care period. See Table 1 for examples of the participant statements included in this theme.

In the theme **Feeling insecure: we would need clear self-care education to feel safe**, patients and family caregivers together mentioned insufficient education about self-care issues, such as possible illness- or treatment-related limitations. They often used the word *how* to express their need for practical coaching and guidance during the HAH care period. Also embedded in this theme was their need for support as part of patient education. We interpreted that they appeared to have experienced some patient education, but did not perceive it as being detailed enough to be empowering, perhaps because it was not based on their knowledge expectations, they did not express their expectations, or they acknowledged their knowledge expectations first after the HAH care period. They perceived that detailed patient education would have not only positively affected their functional self-care capacity but also their perceived safety – and avoidance of possible clinical complications and hospital admissions.

One should get more specific instructions about how to take care of oneself, so one can feel safe. Is it allowed to do the dishes with a cannula in the hand? Is it allowed to go the grocery with a cannula? (Family caregiver C6)

I didn't get a diagnosis, in fact, and just IV antibiotics... That's what they said... I didn't know how to take care of myself, what to do and what not to do... (Patient B6)

In the theme **Facing uncertainty: we would have needed to know more**, patients and family caregivers together related that they did not have any knowledge expectations about their possibilities or rights during the HAH care period – but that they acknowledged that during the interview. We found that because they did not

have any knowledge expectations during the care period, the HAH staff did not address such matters. Still, if the HAH staff had been familiar with earlier research on patients' and family caregivers' common knowledge expectations, a dialog about such could have been initiated. Patients and family caregivers together were uncertain about the choices they had made and the future that lay ahead, which can negatively affect both care satisfaction and future choices.

I didn't receive any education, and that I have noticed now afterwards... Where did the illness come from, can I get it again? (Patient C4)

I would have needed information about the fees... I still don't know how much [the HAH care] will cost, was this a right decision at all... (Patient B3)

Now, when the acute phase is over, I really would like to know about our situation... What is our situation, and how it will develop... What possibilities do we have, if I as caretaker get sick, or he becomes even more ill? Do we have a right to rehabilitation, for example? Both of us or only him? (Family caregiver C3)

In the theme **Feeling dismissed: bypassed patient education**, patients and family caregivers together experienced that their eventual knowledge expectations were dismissed when HAH staff members assumed that either the patient or his/her family caregiver already knew everything, e.g., because of prior care/illness experiences or even prior professional experience in care. The phrase *to get information* was often used, which can be seen as an indicator of own missing activity (reflecting on and expressing own knowledge expectations) or as an indicator of the tendency to wait passively until something happens. Some patients and family caregivers perceived that HAH staff were rushed during home visits, and therefore either did not ask anything so as to not "cause trouble" or asked questions but received very brief and superficial answers. We interpreted that because the time allocated for home visits was too short (or perceived as being too short), true dialog was inhibited, which in turn hindered the patient education process.

I received some information but [the staff] took a lot for granted, because I have nursing education from earlier, but they didn't check what I actually know and didn't know (Patient B5)

We have not received any education... My wife is a public health nurse and has [professional knowledge of] my illness (Patient B8)

I thought about [the staff's] schedule, they seemed to be in such a hurry... So I didn't ask anything (Patient B7)

Well, [the staff] do answer questions eventually but very briefly, [they] don't give any explanations... (Patient B1)

Discussion

We sought to describe adult patients' and their family caregivers' experiences of patient education in the HAH care context. Of 45 participants from three HAH units in Finland, the patients (n = 27) were mainly older (>65 years) male individuals (55.5%) with an acute infection (74%), while the family caregivers (n = 18) were older (mean 69 years), female (61%) spouses (89%) or partners (11%). This sample can be considered representative because it corresponds well to typical HAH samples in Finland.²⁵ and other countries.^{8, 9, 21} However, these results may not be able to be related to experiences of those HAH patients having a longer care period, or to family caregivers who are not spouses but sons, daughters, other relatives or neighbors.

From interviews with participants experiencing different phases of the HAH care process, we ascertained that patient education in the HAH context could be perceived in several different ways: from patient-centered, goal-oriented,²⁷ and empowering education to the bypassed education of both patients³⁴ and family caregivers. Both patients and family caregivers seemed to have quite similar knowledge and support expectations, which only differs slightly from findings in other in- or outpatient contexts.^{35, 36} It would appear that in the HAH context there is an evident need for clinical coaching, guidance and support in relation to self-care activities and for future-oriented education about the services available after HAH care. This is understandable if one considers the nature of HAH care as temporary care.⁹ Here, all of the themes except one were based on both patients' and family caregivers' perceptions. In the HAH care context, the patient is not alone in his/her illness but instead the patient and family caregiver together form a unit. Thus, the need exists for extended, iterative patient education in HAH care. One should remember that patients have the right to patient education and healthcare professionals have an obligation to provide such,⁵ whereby valid informed consent²⁶ and quality, safe care at home^{16, 19, 20} are ensured.

In this sample, some patients and family caregivers perceived that they received tailored, understandable education during the HAH care period, which made them feel in control. They felt empowered when they received patient education personalized to their actual knowledge expectations,^{32, 33} situation and circumstances: e.g., when they received information about specific medication or guidance³¹ in specific wound care instead of assumed information needs and routine education³³ Both patients and family caregivers perceived that they were therefore able to anticipate what would happen and when, and how to be prepared with regard to self-care. Such education can be considered the basis for a true informed consent,²⁶ shared decision-making and experiences of autonomy and dignity.⁴ We also found that such extended patient

education, in which patients' family caregivers were included, strengthened the patient-family caregiver relationship,^{2, 3, 11, 12} minimized caregiver burden^{4, 14, 30} and the need for additional healthcare services.

Some patients and family caregivers in this study perceived that they eventually received answers to their questions, which can also be interpreted as a response to their expressed knowledge expectations³³ and respect for their individual reflection processes, i.e., person-centeredness.^{23, 24} This also reveals HAH nurses' ability to follow their clients' "pace" by respecting clients' experiences and readiness to receive education, i.e., to learn from and about their clients.²⁸ However, one can question whether receiving answers is synonymous to the definition of patient education per se; does such encompass guidance, coaching and support,³¹ and is it a prerequisite for informed consent, i.e., "a full understanding of all the relevant facts, including risks, and available alternatives."²⁶ If patients or family caregivers do not ask questions or express knowledge expectations, like some participants in this sample, HAH staff should encourage them to reflect on and recognize their expectations³² and their actual comprehension should be checked. Here, the HAH staff should have initiated dialogs with the patients and family caregivers, as seen in earlier research in other contexts on patients' and family caregivers' common knowledge expectations. Engaging in such dialog for the purpose of iterative analysis of knowledge expectations does not need to be time consuming but can instead consist of discussion alongside other nursing activities and professional communication, with sufficient time remaining for other "tangible" nursing tasks.

The analysis of patients' and family caregivers' knowledge expectations should be conducted iteratively: during admission to HAH care, during the care process, after HAH care. Furthermore, with older people it is also vital that cognitive capacity is taken into account during such analysis, because of eventual age- or illness related factors.³³ Here the need for the iterative analysis of knowledge expectations was seen in the theme *Facing uncertainty: we would have needed to know more*. In that theme both patients and family caregivers acknowledged that even after the HAH care period they still did not have sufficient knowledge, and this negatively affected not only their life at present but also their future. We therefore question whether they perceived HAH care to be reliable and whether they would choose such care over hospital care in the future.

We saw that patients and family caregivers could perceive that they were dismissed, expressed as bypassed patient education, due to staff's assumptions that the patients or family caregivers already knew everything. We interpret also this as an absence of knowledge expectations analysis and comprehension but also as an inability to learn from

patients/family caregivers.²⁸ This was combined with the phenomenon of patients/family caregivers avoiding asking questions because of perceived time constraints or to avoid "causing trouble". While one can perhaps understand that at times the analysis of knowledge expectations does not occur – the number of HAH patients is increasing, but not the number of HAH staff³⁸ – this is nonetheless not acceptable in terms of professional conduct.

In this data, we understood HAH patients' and their family caregivers' perceptions of fragmented or unsatisfactory education with regard to self-care, prognosis, rights and possibilities to be connected a feeling of being unsafe, confusion and uncertainty, which may cause patients and family caregivers unnecessary suffering, negatively affect their participation in decision-making concerning own care, and may even increase their dependence on the healthcare system. Fragmented or unsatisfactory education can also result in misunderstandings, extra care visits or calls to healthcare staff, severe complications, rising healthcare service costs, or worse; all of which are contrary to the aims underlying social- and healthcare reforms.^{1, 7}

Conclusion

As seen in this study, patients' and family caregivers' perceptions varied from person-centered empowerment to bypassed non-existent patient education. HAH staff could be perceived to provide patient education that met patient's and family caregivers' actual knowledge expectations, but they were also perceived to provide fragmented or unsatisfactory education in which assumptions were made about clients' needs and dialog was lacking. No signs of comprehension checking as part of the informed consent process were seen in the data. Still, during home visits comprehension checking can be embedded into other discussions, so it is possible that the participants merely did not perceive or notice the occurrence of such.

One can question whether HAH, a clinically demanding care context, has developed advanced patient education structures and processes that ensure safe and person-centered care or whether focus has instead been placed on medical and clinical interventions and effectivity issues. In other studies, one sees that patient education in the hospital setting is very fragmented as well, therefore person-centered patient education structures, processes and inter-professional patient education responsibilities must be developed in both contexts if hospital avoidance and early discharge are to be further supported. As one participant noted, "I don't ask just to ask, these are really important things for me (Patient C4)."

Practice implications

This study was conducted at three HAH units in Finland and the results seen here cannot be generalized. It is possible that patient education was embedded in the HAH home visits to a greater extent than the participants here perceived, “hidden” among nursing activities and general interaction with patients and their family caregivers. Nevertheless, because patient education is a central nursing competency and an important factor in person-centered, safe, effective care, it cannot be disregarded in favor of medical and digital advances. Patient education should instead be made the systematic, explicit and visible core of advanced nursing care. We cannot learn from patients and family caregivers without dialog, and we should not allow the philosophy of person-centeredness to stagnate on the principle level.

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