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A qualitative study in Denmark**

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# BMJ Open Health professionals' perspectives of patients' and family members' needs in emergency departments and patient pathway improvement: a qualitative study in Denmark

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## ABSTRACT

**Objective** Besides working in a fast-paced environment, healthcare professionals (HCPs) in the emergency department (ED) are required to promptly respond to patients' needs and simultaneously achieve their organisational goals, which can be challenging. This study investigates how HCPs perceive and support the needs of patients discharged after a brief ED stay, as well as their family members.

**Design** The study used focus group discussions. The text material was analysed using systematic text condensation.

**Setting** Data were collected from two large EDs in Denmark.

**Participants** Sixteen HCPs were sampled purposively to participate in three focus group discussions.

**Results** Three main themes were condensed: (1) creating a trustful and reassuring relationship; (2) responding to family members: a bother or a benefit; and (3) working as an interdisciplinary team. The study indicated the need for increased interdisciplinary collaboration to reduce discrepancies in information dissemination, to meet patient and family needs and to deliver a holistic approach. A technical solution was suggested to facilitate collaborative teamwork.

**Conclusion** The study highlighted an existing gap between emergency HCPs' perceptions of patients' and family members' needs and the provision of the current patient and family support. Suggestions for future interventions include focusing on interdisciplinary teamwork, facilitated by a technical solution to support a person-centred and family-centred informative approach.

## INTRODUCTION

International guidelines have highlighted the need for an effective treatment plan within 4 hours to prevent overcrowding in emergency departments (EDs).<sup>1</sup> Healthcare professionals (HCPs) in EDs are aware of the importance of productivity, with high patient flow as a key element in the organisational structure.<sup>2</sup> Based on a British ethnographic

## Strengths and limitations of this study

- The qualitative approach allowed us to gather in-depth knowledge in an under-researched area within the domain of emergency care.
- The focus group discussions were thoroughly analysed to define the three overarching themes; quotations support the credibility of the findings.
- The limitation of this focus group study was that the participants were recruited from only two Danish hospitals, so the findings are contextual and reflect a Danish context.
- The methodology limits generalisation, although we obtained theme saturation and thoroughly described the context of the study.

study, HCPs believe that approaches to productivity should be patient centred; moreover, they are aware that the productivity line could be dehumanising, thus compromising patients' sensibilities.<sup>2</sup> An Australian qualitative study exploring HCP experiences during the implementation of the 4-hour rule in the ED<sup>1</sup> found a trade-off, namely, the reduction of HCP–patient communication because of an increased patient flow.<sup>1</sup> Therefore, HCPs need to balance patient interaction in the ED while striving to achieve organisational goals, create caring encounters and acknowledge patients' individual needs to improve care.<sup>3–5</sup> Furthermore, a prospective study conducted in an ED in Hong Kong underscored the need for HCPs to pay more attention in communicating with acute patients, as there is a higher risk of readmission if patients do not feel confident in the discharge plan.<sup>6,7</sup>

Research has highlighted patient and family perspectives and their needs and preferences when being discharged from the

ED,<sup>8,9</sup> particularly the need for clear communication in an ever-changing environment. The challenges within the ED and the many interruptions in patient encounters reduce patients' feelings of reassurance<sup>8</sup> and challenge their ability to understand discharge information.<sup>9–12</sup> A systematic review investigating discharge instructions showed that patients' communication with HCPs was principally performed in one-way conversations.<sup>9</sup> The medical discourse did not allow the possibility of asking questions, which did not promote the patients' confidence in being discharged and may lead to readmission.<sup>9</sup>

The involvement of family members in discharge information, such as medication and treatment adherence, has been acknowledged globally as a factor in improving patient outcomes.<sup>13,14</sup> Moreover, family inclusion and partnership in care strengthen patients' readiness for discharge.<sup>6</sup> This is particularly important for patients with brief hospital stays, in which there is little time for HCPs to prepare patients for discharge.<sup>10</sup> Family inclusion in care discussion has been found to improve patient outcomes in EDs by enhancing the understanding of information and symptom management at home, as well as helping with care-related matters while in the ED.<sup>10,15,16</sup> However, a recent study on patient and family needs highlighted that patients and families perceive HCP–patient interactions in the ED as fragmented and without family involvement, giving rise to feelings of insecurity at the time of discharge for both patients and family members.<sup>10</sup> Similarly, qualitative studies on patient/family involvement in the ED highlight that a culture supporting the inclusion of the voices of patients and families requires the organisation to move away from a hierarchical expert approach towards a person-centred and family-centred approach.<sup>17–19</sup> An in-depth understanding of current practices and barriers to a person and family-centred approach is needed to improve patient and family experience in EDs and meet their needs to reduce readmission.<sup>7,20</sup>

Therefore, this study aims to generate knowledge on addressing patients' and family members' needs during a brief ED stay (<24 hours of admission in an ED) from the perspective of HCPs and their suggestions for changes in practice.

## Objective

The aim of this study is twofold:

- ▶ To investigate how HCPs in the ED perceive the needs of patients and family members discharged within 24 hours.
- ▶ To explore how these can be supported in organising improved patient pathways.

## METHODS

### Study design

This research is part of the first phase of a three-phase participatory design study, with an overall aim to improve the experiences of patients and their family members discharged from the ED within 24 hours.<sup>21,22</sup> Participatory

design is a research methodology where the involvement of representatives of future end-users of the research field is a core element.<sup>22</sup> Phase 1 focuses on uncovering and understanding needs and practices,<sup>23,24</sup> whereas phases 2 and 3 focus on developing and testing a solution to cover the needs identified in phase 1. The principles of phenomenological investigation are traditionally used in the initial phase<sup>23,25</sup> and underpin the data generation in this study.

Phase 1 in this study aimed to gain knowledge on which needs and preferences exist in the ED from the perspectives of patients, family members and HCPs. We chose to publish two separate manuscripts because of the large amount of data. Data presenting knowledge of the patients' and family members' needs were gathered through participant observational studies and interviews.<sup>10</sup> The data in the present study were derived from focus groups with HCPs. Focus groups were chosen to produce a rich understanding of participants' experiences and beliefs and generate knowledge from the interactions between the participants.<sup>26</sup> The Consolidated Criteria for Reporting Qualitative Research was used as a checklist.<sup>27</sup>

### Settings

The HCPs who attended the focus groups were recruited from two EDs. The first is Odense University Hospital, a 1000-bed university hospital that provides care for a population of 230 000 adults living in the Region of Southern Denmark. Its ED has 69 000 annual attendees and 150 and 20 permanently employed nurses and physicians, respectively. The second is Hospital of Lillebaelt, which is a 320-bed hospital. Its ED has 50 000 annual attendees and 150 and 14 permanently employed nurses and physicians, respectively.

### Participants and recruitment

An email containing information about the study and the invitation to participate in the focus groups was sent by the management to the purposive group of HCPs. The first author discussed the focus group participants with the manager from each ED. The process of creating the focus groups included the idea of a heterogeneous group to ensure variation in age, qualifications<sup>26</sup> and personality to improve the discussions and outcomes.<sup>28</sup>

The eligibility criterion was nurses and physicians who have been employed at the ED for more than 6 months.

For the sample size, three focus groups of three to seven participants per group were formed.<sup>29</sup> Due to COVID-19 restrictions, participants from the two sites were not combined.

### Data collection

The research team was composed of a group of experienced qualitative researchers and clinicians. The first author was an experienced emergency clinician. The second and last authors had no recent experiences with emergency care.

The three focus group discussions were conducted in December 2020. The first author facilitated the focus groups. The second or last author observed, wrote field notes including group interactions and non-verbal language, and validated the content of the discussion. Each focus group discussion was split into two parts. Initially, the participants were asked to write three positive and negative thoughts on treating and caring for patients discharged from the ED within 24 hours. Then, they discussed their perspectives and the possible ways to optimise care. In the second part, the participants were introduced to quotes and findings from the study on patient and family member perspectives.<sup>10</sup> The patients and family members had highlighted the need for an increased understanding of their vulnerable state of mind during acute admission in the ED; moreover, they described a need for person-centred information with genuine involvement of family members.<sup>10</sup>

The discussions then commenced with the participants' thoughts on these findings. The following is an example of a quote by a patient that the HCP participants were asked to discuss: 'I need them to take the burden off my shoulders' (male patient in his 50s).

Using quotes from the patient/family study<sup>10</sup> encouraged discussions of how to address patients' and family members' needs, with a focus on possible differences and similarities in HCPs' perceptions of quality in treatment and care. The discussions lasted for 1–1.5 hours. One was held at the ED in Kolding and two in Odense. All focus groups were recorded and transcribed verbatim by the first author. Observer field notes were included as data in the analysis to provide context and improve reliability.<sup>30</sup>

### Patient and public involvement

The local patient and family member council have read the overall study protocol and gave proposals for improvements.

### Analysis

The data analysis was inspired by systematic text condensation.<sup>31</sup> The analysis was performed by the first author, who coded the data. The systematic condensation and interpretation of data supported by quotes from the focus groups were conducted continuously with the whole author group to reach a consensus. The process was conducted in four steps: (1) total impression: identifying themes; (2) identifying and sorting meaning units: themes to codes; (3) condensation: code to meaning; and (4) synthesis: condensation to descriptions and concepts of final categories.<sup>32</sup> Finally, patterns across data were identified and agreed on.

## RESULTS

### Participant descriptions

Three focus groups comprising 16 HCPs were conducted (table 1). According to the protocol of the overall study,<sup>21</sup> we planned four focus groups for the 20 participants.

**Table 1** Participants' demographic data

Demographics	Statistics
Gender and age, n	
Female	15
Male	1
Age (years)*, mean	8
Qualifications	
Registered nurse	14
Physician	2
Professional experience (years)†	
<5 years	7
>5 years	11
Experience in the ED (years), mean	3.5

\*Range: 25–59 years.

†Range: 2–25 years.

ED, emergency department.

Therefore, 20 HCPs were approached. However, two physicians were unable to attend due to their busy schedules and two nurses were off work due to sickness on the scheduled day of the focus group.

Three main themes with concomitant subthemes were derived from the patterns across the focus group discussions and supportive notes: creating a trustful and reassuring relationship, responding to family members: a bother or a benefit, and working as an interdisciplinary team.

### Creating a trustful and reassuring relationship

This theme was derived from consistent expressions by HCPs, of patients having a need to gain trust in HCPs from the very beginning of their stay in the ED. Trust was pronounced as fundamental in helping patients gain reassurance in acute and unpredictable situations. The factors involved in creating trust are prompt assessment, providing information and addressing patients' anxieties and fears.

### Prompt assessment

The HCPs argued that a trustful relationship often began through prompt assessment. Prompt assessment was defined by being assessed quickly upon arrival.

It is my impression that if patients feel they are trapped in uncertainty, for instance, if they are not assessed immediately upon their arrival, it might affect our ability to create a trustful and caring encounter. (nurse, focus group 1)

Prompt assessment aims to provide a preliminary evaluation of the patients' current conditions and plan their initial treatments and observational regimes.

In all focus groups, it was stated that it was essential for patient pathways to have a trustful beginning; otherwise, it could be difficult to gain a confident relationship

among patients and HCPs due to the shortness of time spent in the ED.

We have to get a good start. If the patients experience from the beginning of their stay that HCPs take responsibility, trust will be developed. If not, distrust is promoted, and from that point, the relationship might become difficult due to the brief time spent in the ED. (nurse, focus group 3)

However, the participants discussed that prompt assessment did not always seem to be an option due to the hectic and ever-changing nature of the ED. In several incidents, HCPs felt powerless, as the hectic environment affected how they provide person-centred care as part of a trustful relationship.

Undisturbed time is really important if we want to succeed in providing person-centred care. During most of my shifts, I get interrupted, for instance, by three phone calls, during patient conversations. The patients might think that I do not have a genuine interest in listening to their stories. (nurse, focus group 2)

#### Information

The patients' need for continuous information was highlighted by the HCPs. Most importantly, information should be consistent and accurate, as this also fosters trust and reassurance.

The patients are unaware of the severity of their illness. You, therefore, have to be explicit and clear about your thoughts, as this creates trust and eases their anxiety. (nurse, focus group 3)

For patients to be able to cognitively understand and perceive the information correctly, reassurance was mentioned as a key element.

If the patients do not feel calm and have faith in HCPs, it is difficult to understand any given information. (nurse, focus group 2)

#### Anxiety and fear addressed by HCPs

Several HCPs felt that patients' anxieties could be reduced by asking them questions concerning their thoughts or worries of becoming acutely ill if time and skills were available.

Talking about their worries and how they feel psychologically about the situation can create reassurance. (nurse, focus group 2)

Moreover, the HCPs argued that working in the ED demanded a technical approach to treatment and care more than psychological and social approaches. The technical approach was presumably dominant as the ED setting required HCPs to be able to act fast and work systematically in care and treatment due to critically ill

patients and a high and continuous flow of new incoming patients.

Our focus is often on physical issues, to begin treatment and to manage the patient flow. There might be a risk of overlooking what is most important for the patients. This could cause anxiety, I think. (physician, focus group 3)

#### Responding to family members: a bother or a benefit?

The HCPs agreed that family members play an important role both during the patients' ED stay and after their discharge. Family members were described to help with providing important information, understanding discharge information and preventing readmission. However, it was also perceived in some cases as time-consuming.

#### Providing important information

It was argued that family members often have a lot of information about the patient and are usually not in the same mental level of distress as the patients. They often help physicians clarify symptoms and find an accurate diagnosis.

Family members play a pivotal role because often, it is conversations with them that help us diagnose the patients accurately or even avoid unnecessary examinations. (physician, focus group 3)

#### Helping understand discharge information

Due to many encounters and the vast volume of information in the ED, the HCPs indicated that family members and patients might have difficulty remembering information given orally. Therefore, the use of written material concerning the treatment plan was suggested as part of the discharge conversation, even though it might be time-consuming. The HCPs believed this would support the inclusion of family members not present in the ED, as they would be able to read the discharge information and instructions as well.

When patients are re-admitted, I realize how little they were able to remember from the discharge instructions. It would be relevant to have the information in writing instead. This could be a way to empower the family as one unit. (nurse, focus group 2)

The HCPs noted that patients who spend only short stays in the ED are often labelled as having 'uncomplicated' conditions. They are, therefore, at risk of getting insufficient attention concerning their need for discharge information. Insufficient discharge information makes it challenging for the family to support the patient and affects both the patient and the family negatively.

Our core task is to maintain a high patient flow. In my experience, uncomplicated patients with low triage level and are able to self-care often suffer from that fact. (physician, focus group 3)

The HCPs suggested a discharge coordinator (technical or personal) in the ED to prevent fractional discharge information from being provided to patients, whether they have complex care issues or uncomplicated needs.

#### Preventing readmissions

The HCPs noted that not involving family members could increase the risk of readmission.

Involving the family might prevent re-admissions. We need to create a space for all voices to be heard. We need to take care of potential risks of re-admission, such as lack of pain control. (nurse, focus group 1)

It was discussed that family members often play a central role after discharge. Therefore, there was a need to empower them to handle the care and treatment plan. This empowerment was seen as essential because otherwise, family members might not feel confident in helping the patient manage possible recurring symptoms appropriately and may eventually urge them to call an ambulance.

We need to make sure the family members are able to handle the situation after discharge... Do they have the physical or/and cognitive resources to help the patient appropriately or do we need to do something, such as contact the primary home care for assistance? That we can only find out if we involve the family. (nurse, focus group 1)

#### Being time-consuming

Even though the HCPs found the involvement of the patient and their family members beneficial, it was discussed as problematic, especially in busy periods. In such instances, the HCPs mentioned the necessity of prioritising the patients and commencing the treatment to prevent overcrowding in the ED. Due to the short period of time that patients spend in the ED, many family members are not able to visit the department before patient discharge. Disagreements arose in the groups on whether involving family members needed to be prioritised or not.

I do not prioritize calling the family if the department is busy. This must be done by the patient. However, I am aware that it can be difficult for the patient to know the answers to all the questions raised by the family, which might affect whether the family member feels confident or not. (nurse, focus group 2)

#### Working as an interdisciplinary team

In all groups, the benefits of working as an interdisciplinary team were discussed, and suggestions towards its organisation were postulated.

#### Benefits of a close teamwork

The HCPs found it challenging to assemble all the information and knowledge regarding care, treatment and family. Subsequently, patient discharge conversations

would often become fragmented and confusing for the patients and their families.

Currently, we cannot ensure that everything is covered. We do what is expected from our point of view and send them home. I believe this may, in some cases, cause insecurity and distrust. (nurse, focus group 3)

They also found it difficult to identify possible obstacles to the patients adhering to the discharge plan or to detect how the patients would cope with their health situation in general. Interdisciplinary teamwork was presumed to have a positive effect on how the HCPs managed to accommodate patients' and family members' needs towards discharge.

To help our patients, we need short multi-disciplinary "brush ups". That way, the staff are kept on the right track because relevant information could be shared. (nurse, focus group 3)

In EDs, there is no tradition for interdisciplinary teamwork apart from the trauma rooms. The specific requirements to benefit from this collaborative approach were identified as follows: level of information and communication, involvement of social networks and collaboration with community nurses. This would ensure a discharge plan that accommodates patients' mental and psychological abilities, so they can manage as intended.

We have talked about reorganizing the workflow many times, but we found no optimal solutions. However, we have discussed all the benefits regarding improved collaboration. (nurse, focus group 3)

#### Suggestions towards improved teamwork

Suggestions regarding a joint discharge conversation protected from disruptions involving nurses, physicians and family members were initiated. A discharge conversation was viewed as a possible way to make a precise update on the plan, thus promoting collaboration with the community or family members not physically present in the ED. Notably, the HCPs also discussed the obstacles in having to wait for each other to enter a discharge conversation as a team. This approach could be a form in which information is given as a whole and not in fractional form.

If we all were gathered at the time of discharge, we would be able to summarize the treatment plan and care issues, but it could be difficult as it would affect the workflow. (physician, focus group 3)

The HCPs are aware that patients discharged after a few hours in the ED have potentially both given and received lots of information that could be difficult to understand and inconsistent in their stressed state of mind.

By the time of discharge, patients should have information in writing because they may not be able to



remember much after returning to their homes, considering their stressed state of mind. Currently, this is not implemented, but it may be relevant in the future. (nurse, focus group 3)

Health technical solutions were suggested as the 'discharge facilitator'. The technical solution should convey continuous and consistent information for patients and their family members during their stay in the ED. Likewise, the solution should enable the patient and family members to revisit the information at home and allow the HCPs to get a view of the patients' course of treatment in the ED.

If we had a system that facilitated the progress of ED activities and were available for the patients as well, the HCPs would be able to get a fast brush up on the next steps. It would increase the quality of the health-related discharge information we provide. (nurse, focus group 1)

## DISCUSSION

### Stronger interdisciplinary collaboration might improve patient pathways in the ED

Our findings highlighted that the ED organisational structure often provides short and fragmented encounters among HCPs, patients and family members due to a busy environment. This appears to be out of step with what the HCPs highlighted to be important from a person-centred and family-centred perspective where a trustful relationship should be the focus. A gap is present between what HCPs are 'forced' to handle to avoid situations with overcrowding and what they actually value and want to improve. This study identified that the HCPs stressed a need for patient flow in the ED and suggested a technical tool to improve engagement with patients and family members.

A Swedish qualitative study investigated the strategies used by HCPs in EDs and recommended that HCPs be given tools to handle hectic and stressful situations to enable quality care at all times regardless of the workload.<sup>5</sup> They highlighted a gap in the ED, where the HCPs are forced to contend with immense workloads and patient needs. Periods with high workloads create moral distress because time is spent on patient flow discussions rather than quality patient-HCP encounters. However, no specific tools were tested in the Swedish study.<sup>5</sup>

Clear communication was highlighted as the optimum way to develop therapeutic relationships with patients in the initial ED assessment in our study. Communication was also underlined as important to accommodate from the patient and family perspectives.<sup>10</sup> Clear HCP communication helped reduce patient burden, develop trust and increase reassurance.<sup>10</sup> Different models of communication strategies have been tested in support of creating improved discharge information.<sup>33 34</sup> In addition, the Calgary Cambridge model showed high reliability in a

person-centred communicative approach.<sup>35</sup> To meet patient and family needs in brief ED encounters, HCPs may find the 15-minute family interview framework useful, as it creates a clear structure for the conversation.<sup>36</sup>

The HCPs in our study argued that they were trained in a task-focused culture and a life-saving technical approach more than a person-centred approach. The Swedish study<sup>5</sup> also found that the HCPs possessed two strategies: a proactive strategy focusing on flow and a reactive strategy with the values of delivering person-centred communication.<sup>5</sup> Patients and families express that if HCPs do not provide person-centred communication, it causes feelings of being 'just another patient in a line', leading to insecurity, distrust and fear.<sup>10</sup> A prospective cohort study conducted by Body *et al*<sup>37</sup> found that HCPs in EDs are required to not only focus on physical symptoms and medications but also on easing suffering.<sup>37</sup> This includes managing emotional distress and developing therapeutic partnerships and tailored information in preparation for discharge.<sup>37</sup>

The HCPs in our study identified the need to balance an organisational structure that demands high patient flow with their awareness of the needs of patients and family members for trustful encounters and tailored information. To enable a balance of patient flow and person-centred and family-centred care, the HCPs recommended improved interdisciplinary teamwork. An organisational culture of interdisciplinary teamwork has been shown to enable mentoring and development of HCPs to achieve accurate and timely assessment and the delivery of person-centred and family-centred care.<sup>5</sup> Interdisciplinary teamwork was found to prevent misunderstandings and inconsistencies in the information given.<sup>5</sup> These findings are echoed by von Knorring *et al*<sup>38</sup> who found that 36% of ED patients experienced inconsistency of information.<sup>38</sup> Inconsistency was found to be a result of a lack of teamwork, and future research focusing on the impact of different types of teamwork was suggested.<sup>38</sup>

The HCPs in our study proposed the development of an unspecified health technical solution providing both in-hospital and follow-up discharge information. The solution was suggested as an integrated tool in the interdisciplinary teamwork to empower the patients with continuous information and clarity in their course of treatment despite busy periods in the ED. In a Korean pilot study by Kim *et al*,<sup>39</sup> it was found that an application-based service of personal mobile health records provided with patient-centred medical information improved the self-management of patients' health conditions and experiences in the ED.<sup>39</sup> The system required multiple steps in which the patients downloaded an application to their personal mobile phones and created an account to share ED data on their private mobile phones.<sup>39</sup> Previous research on promoting person-centred and family-centred outcomes has highlighted that patients' personal characteristics and preferences for information, as well as their specific disease, are influencing factors, but the impact of the environment is often overlooked when seeking

solutions.<sup>40 41</sup> The involvement of consumers as end-users in developing a technological solution to cover identified needs helps towards creating solutions to improve clinical practice.<sup>42 43</sup> However, barriers in the existing culture and its readiness to change must be identified to avoid resistance to change.<sup>44</sup>

### Can family involvement and ED care be matched?

In our study, the HCPs positively associated family involvement with improved care in the ED. Family support and understanding of the treatment and discharge plans were found to influence revisits to the ED. In a previous research, ED nurses found that working with families is either a bother or a benefit depending on whether the family members understand the healthcare system.<sup>14 45</sup> Furthermore, the HCPs discussed whether they were obligated to involve family members. The culture and attitudes influence how HCPs engage with families, and HCP training in communication skills is required to improve their relationship with families.<sup>16</sup> Based on our findings, future studies focusing on designing person-centred and family-centred strategies and how they can improve ED care are warranted. Our study suggests that it might be beneficial to apply technical solutions to integrate tailored information and therapeutic communication to reduce the existing gap between person-related needs and organisational needs of productivity and high patient flow.

### Limitations

This was a national study, limited by the fact that the Danish healthcare system is organised differently compared with that of other countries. Data were collected using qualitative methods, whereas a broader perspective could have been obtained through surveys. Due to their busy schedules, only two physicians were able to participate in the focus groups. Collecting data from the groups was difficult because they were either too homogeneous, suffering from an absence of interaction or too heterogeneous with the risk of larger disagreements.<sup>26</sup> The managers of the EDs participated in forming the groups to achieve the best balance among the HCPs.

### CONCLUSION

There is a gap between ED HCPs' perception of the needs of patients and family members and what is actually being delivered during short stays in the ED. The findings indicate that interdisciplinary teamwork could be the key to ensuring the development of customised patient-centred and family-centred information dissemination and goals within the ED. In the future, using technology to enable the delivery of tailored information to support person-centred and family-centred informative approaches during and after ED treatment should be considered. Technology enables patients and family members to revisit the information at home and the HCPs to view the patients' courses of treatment.

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**Contributors** CMJ, KBD, EC, ATL and CØ designed the study. CØ collected the data. CMJ, KBD and CØ performed the analyses. CØ took the lead in drafting the manuscript, while CMJ, KBD, EC, KØ and ATL provided feedback. All authors approved the final version of the manuscript. CØ is guarantor of the study.

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**Patient consent for publication** Not required.

**Ethics approval** This study involves human participants. In accordance with the Declaration of Helsinki and the Ethical Guidelines for Nursing Research, oral and written informed consent were obtained from all of the participants. The study did not require an ethical approval from the National Committee on Health Research Ethics (Ref. No. S-20192000-111). Ethics committee and IRB name: Committee on Health Research Ethics in the Region of Southern Denmark Committee No. 1 Ref. Professor Kirsten Kyvik. Reason for exemption: This study is an interview study without any intervention. The study was registered with the Record of Data Process of Registry of Southern Denmark (19/22672). Data were stored in SharePoint (Microsoft Corporation) and OPEN\_938.

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