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Feeling worried and powerless: A qualitative interview study of relatives' experiences of the collaboration with patients and nurses during COVID-19 visiting restrictions in Denmark

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Abstract

Relatives are an important resource to hospitalised patients and hence to nursing. During the COVID-19 pandemic, visiting restriction policies were implemented in healthcare settings globally, unwillingly excluding relatives from visiting the bedsides of their loved ones. The aim of the present study was to explore how the visiting restrictions influenced relatives' relationships with patients and collaboration with registered nurses at non-pandemic hospital wards. In total, 13 relatives were interviewed. The study was reported following the COREQ guidelines and checklist. Content analysis led to three themes: 1) being excluded from providing care and support; 2) being excluded from conveying person-centred and situational relevant knowledge to registered nurses; and 3) being excluded from assessing the health status of the hospitalised loved one. Together they describe relatives feeling worried and powerless regarding the health of their hospitalised loved one and the performed nursing care. Findings from studies such as this are pivotal to any future national or global health crisis, where visiting restriction policies are implemented.

Keywords

content analysis, COVID-19 pandemic, nursing, qualitative research, relatives

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Background

Relatives provide emotional support for hospitalised patients,^{1,2} advocate for the patient,^{1,3} help patients understand information and make decisions,⁴ which support the work of healthcare professionals, thereby contributing to efficiency of healthcare.^{2,5} Thus, relatives are an important resource for hospitalised patients⁵ and for nursing care. However, from March 2020, the COVID-19 pandemic caused worldwide changes in task conditions of healthcare systems due to the highly contagious nature of the disease.⁶ To prevent the virus from spreading in society and inside hospital settings, recommendations related to hygiene and socialising were implemented during the first wave of the COVID-19 pandemic in Denmark. This influenced the relationship between registered nurses (RNs), patients and relatives as the presence of patients' relatives in hospitals was restricted to a minimum.⁷

A recent study by Jørgensen et al. described how the changed conditions at Danish hospitals and the exclusion of relatives in non-COVID-19 hospital wards affected nursing care as it expanded RNs' area of responsibility, resulting in an increased workload.⁸ Patients described how collaboration

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with relatives and RNs was extensively affected due to the imposed distancing from RNs unless contact was related to instrumental care. Patients felt lonely and vulnerable, and the exclusion of relatives affected their sense of dignity and respect.⁹

When a patient is admitted to the hospital, it affects the psychosocial aspects of relatives' daily life and entails emotional changes such as sadness, worry and despair.^{10,11} Relatives typically give priority to the welfare of the person close to them and often forget to care for themselves.¹² The needs of relatives are found to include social, emotional and practical needs. Hence, to assist relatives sufficiently during admission to a hospital of a loved one, the healthcare team should take those aspects into account in the care of involved relatives.^{13,14} Furthermore, relatives report a need for accurate and comprehensible information from the healthcare professionals to be able to provide qualified care and support to their admitted loved one.¹²⁻¹⁴ Research, however, shows that the provision of information is not always sufficient to meet the needs of the relatives,^{11,14} as caregivers tend to underestimate these needs, thereby not prioritising them. Verhaeghe et al. emphasise the importance of RNs being able to prioritise and initiate meeting the needs of family members.¹²

Relatives, being physically and emotionally distressed, express a need for closeness with the ill loved one, understood as being physically close to the patient.¹⁴ Thus, visiting restrictions during pandemics have been found to affect relatives negatively,¹⁵ and being deprived of direct contact with the patient increases relatives' worries about the well-being of their loved one.¹⁶ As demonstrated, existing research underlines the importance of the RNs prioritising the needs of the relatives as they may provide physical closeness as well as social and emotional support to the patient during hospitalisation. However, there is a lack of knowledge of how relatives to patients at non-COVID-19 wards experience their opportunity to care for their hospitalised loved ones in collaboration with RNs. During the first wave of the COVID-19 pandemic, specific COVID-19 wards were established at Danish hospitals. These wards handled patients with COVID-19 and were staffed with healthcare professionals from other hospital wards. In this study, we focused on the setting of non-COVID-19 wards, understood as all other wards than those specifically established to manage patients with COVID-19. This study focusses on relatives' experiences of the collaboration with patients and nurses in non-COVID-19 hospital wards during the first wave of the COVID-19 pandemic where visiting restriction policies were first implemented. The knowledge gained from this study can help inform future times of health crisis involving the implementation of visiting restriction policies.

Aim

The aim of the present study was to explore how COVID-19 visiting restrictions influenced relatives' relationship with patients and collaboration with RNs at non-pandemic hospital wards.

Methods

Design

The study was designed as a qualitative interview study and reported following the COREQ guidelines and checklist.¹⁷

Study setting

The study was conducted in a university hospital in the North Denmark Region during the first wave of the COVID-19 pandemic (March to June 2020). During this time, visiting restriction policies were enforced at all Danish hospitals, excluding most relatives from entering the hospitals.

Participants and recruitment

In this study, eligible participants were relatives of outpatients or hospitalised patients during the first wave of the COVID-19 pandemic in Denmark with no prior relationship to the researchers. We utilised a convenience sampling strategy,¹⁸ and participants were invited through the university hospital's Facebook site, where they were instructed to contact the primary investigator if they were interested in participating in the study. In total, 13 relatives (10 women; age range = 34–58 years) reacted to the Facebook announcement, and all were included in the study. The participants roles as relatives included being spouses, children and parents to patients who had been in contact with non-COVID-19 wards at the university hospital. The 13 participants were relatives to patients whose hospital contacts included planned visits such as health examinations during pregnancy, dialysis or follow-up due to chronic illness, and acute visits due to sudden health issues or accidents. These hospital contacts included both outpatient consultations ($n = 3$) and admissions to inpatient wards ($n = 10$).

Interviews

The interviews were based on a semi-structured interview guide¹⁹ that contained themes on how COVID-19 visiting restrictions influenced relatives' relationship with patients and collaboration with nurses at non-COVID-19 hospital wards. The interviews were initiated with the opening question: 'Please elaborate on how you experienced hospital contact during the pandemic' followed by questions such as 'How did you experience being helped as a relative?' In addition, the interview guide contained specific and probing questions. The interview guide was pilot tested, which led to minor adjustments, and the pilot test interview was included in the data.

The interviews took place between June and August 2020 and were conducted by four female healthcare PhD-educated researchers (HHT, CBT, KB, SJ) employed at the university hospital, who informed each participant about the research interest and study aims and employment at the interview. Only the interviewer and researcher were present. The interviews took place in offices at the university hospital and lasted 20–71 min. They were digitally recorded and transcribed

verbatim. One participant was unable to participate in an interview, but provided a written case-story, describing the experiences of being a relative during the COVID-19 pandemic. This case-story was included alongside the interviews as data.

Ethics

The regional research administration Data Protection Agency was notified about the study (ID 2020-0272) and ethical guidelines as well as regulations regarding data management were followed. According to Danish legislation, the study needed no further ethical approval. Ethical considerations involved applying the Declaration of Helsinki as reported by the World Medical Association.

The participants received both written and verbal information about the study and provided informed, written consent when they agreed to participate and were informed of their rights also to withdraw the consent at any point. Data were collected and stored according to GDPR regulations and confidentiality was also maintained as the participant names were replaced with ID numbers.

Analysis

An inductive, latent content analysis was performed to create condensed meaning of the interviews.²⁰ Latent content analysis is understood as interpreting what is hidden at a deeper level within the text and to discover the implied meaning in participants' experiences. First, the interview transcripts were read and re-read to familiarise with the text and get an overall sense of the entire data material. Subsequently, the text was coded and abstracted into themes and subthemes by three authors (HHT, CBT, BL), who discussed data saturation and the themes also using coding 3 as a support tool until consensus was reached. Next, the themes were discussed with all authors. This process intended to prevent premature disclosure of the analysis.²⁰ NVivo 10 was used as a data management tool to structure the data and support the analytical process.²¹ The transcripts were not returned to participants.

Findings

Visiting restriction policies excluded most relatives from being physically present at the hospital and affected the participating relatives' everyday life due to limited possibilities to interact with and care for the hospitalised person close to them. Furthermore, relatives expressed concern about how visiting restrictions affected their possibilities to collaborate with RNs, as they were unable to interact and communicate face-to-face.

The findings described different aspects of the relatives feeling worried and powerless regarding the health of their hospitalised loved one and the performed nursing care. These aspects were elaborated in the following three themes: 1) being excluded from providing care and support; 2) being excluded from conveying person-centred and situational relevant knowledge to RNs; and 3) being excluded from assessing the health status of the hospitalised loved one.

Being excluded from providing care and support

The relatives described how visiting restrictions profoundly affected the support and care they were able to provide to their hospitalised loved ones during hospitalisation and after discharge. Some expressed that it differed from the support and care they would have provided if they had been able to be present bedside. The contact to the patient was primarily by telephone, which was described as problematic:

'I think always it's difficult not being able to sit together as there are so many things that you miss out on in facial expressions (mimic) and such things, as yes, we have a habit of joking with each other, but we're able to see if there is something that is bothering underneath. So that has been very hard. We have tried it before, when I stayed a period abroad, but in this case, it's different, as it's kind of serious it's difficult not to be able to sit in the same room. I really would have liked to be there without being forced only to have contact over the phone.' (Informant 8)

In this way, being excluded from entering the hospital and from being face-to-face with their hospitalised loved ones was difficult, as the relatives felt that their habits with specific forms of interactions were disrupted, and they missed out on important aspects of communication leaving them unable to provide the care and support they would normally have provided.

Communication about the patient's health situation and treatment was a care task described by most relatives. It was perceived not only in terms of information and understanding of the situation but comprised care and support. One participant explained:

'But well, it's, it's the whole thing about that you lose control, and it's one of yours, one of your dearests, that are thrown out into this, and it's hard not to be able to be there with them, comfort them and be there for them and that kind of things, right?' (Informant 10)

Being excluded from the hospital to some meant losing control of the situation as they were unable to influence the terms for physical presence. This was experienced as burdensome, difficult and frustrating, as the relatives felt excluded from providing care and support to people who were dear to them. To some, previous experiences with similar situations became a reference point to the ongoing situation. One said:

'It's that extra set of ears to hear, that is it. Last year, when I got operated twice in my chest and my husband participated in everything and it has been so valuable to me that he also was there. We sat at home before and talked about what questions we had, and then if I didn't, you know, when it's for real one can get emotional and so, and then he could take over and support, right? And so, help in that way.' (Informant 5)

In these cases, the relatives could be very explicit about what it meant to be excluded from supporting their loved one. In this specific case, the relative regretted not being able

to support her husband in the same way he had supported her. This emphasises that the dynamics of reciprocity and mutual commitment in the relationship between patient and relative are at stake and that this not only refers to the actual hospitalisation or outpatient event but is closely connected to previous shared life events.

The care and support provided by relatives was not limited to the time where their loved ones were hospitalised, but it also included the time after discharge. Here, the family played a central role and being excluded from entering the hospital challenged the relatives' possibilities to assess the need for support and care after discharge and the planning of it. One participant said:

'So, not being able to have a contact to the team of healthcare professionals has been frustrating. That the information that I needed to be able to make MY plan for the time after discharge that was really not ideal. And there might also have been some issues that I would have questioned and asked about regarding what medication she should take and other things also.' (Informant 8)

Not being able to prepare properly caused additional uncertainty. As illustrated here, the participants described how this was related to not having access to the healthcare team, hence lacking information they needed to plan the time after discharge. In this way, being excluded from bedside visits compromised not only the support and care that relatives can provide directly in the hospital, but also their possibilities for assessment and planning of care and support after discharge.

Being excluded from conveying person-specific and situational relevant knowledge to RNs

Collaborating with RNs when being excluded from entering the hospital obliged the participating relatives to interpret the RNs' information and assessments of the situation. This was an uncertain task as the relatives were unable to know if person-specific knowledge was included in care. One relative explained:

'But it was frustrating. It was frustrating to feel that they had no control of him. And we were not allowed to be there to see how he was really doing. To help by saying "this behaviour that is not really him, that is not how he normally is". They actually thought that he normally was that poor. I really wonder if they did the right things in there.' (Informant 1)

Not being able to contribute with knowledge on habitual behaviours and conditions of their hospitalised loved one left the relatives frustrated and unsure of the quality of care and concerned regarding the integration of person specific knowledge on symptoms and habitual condition, personally and cognitive. This demonstrates that person-specific and situational care by relatives is perceived as an important aspect that is a prerequisite and an essential foundation for quality in nursing care. Some relatives wondered why the knowledge that they could contribute with was not considered in treatment and care:

'I kind of wondered as it's a cerebral disease, as I could hear afterwards that some of the questions, he was asked on genetics and family conditions the first days, there he answered totally wrong. Because he was so confused and afterwards, he was really chocked that he had given so wrong answers on such vital information. And I do wonder why nobody checked with us.' (Informant 1)

The relatives believed that they held important information about their loved one and being excluded from contributing this knowledge left the relative questioning the quality of care and treatment and generated feelings of uncertainty. Some relatives reported that they wanted to contribute to also give an understanding of the patient's symptoms from an everyday life perspective. However, they were excluded from contributing, as no one from the hospital reached out to them. One said:

'During his hospitalisations, I have not been contacted to get information at all, the staff has not reached out to get information on how the symptoms materialise here at home.' (Informant 11)

To these relatives, important knowledge was not included in the care and treatment provided at the hospital, and they worried that it would impact the care provided for their loved one at the hospital.

Collaboration with RNs and communication between relatives and RNs primarily took place by telephone, without face-to-face contact. A relative described the experience:

'But I mean, how is the professional responsibility, how it goes, I mean it was us that had to call on the phone all the time and sometimes several times a day, and sometimes you got to talk to someone who really didn't know much and had to look at the computer and read in order to tell us how things were.' (Informant 4)

In this way, communication with RNs was experienced as a rather unsystematised, uncertain and unclear practice. Not being able to reach a RN, who was aware of the current situation of their loved one, only increased the feelings of being unwillingly excluded from contributing to care and support. Not being able to follow the progression of the health of their loved one only added to the uncertainty that relatives felt about the health state of their loved one and whether the provided care and treatment was sufficient.

Some relatives experienced a lack of communication between themselves and RNs during hospitalisation and described it as having implications after discharge, as one reported here:

'I ask him on FaceTime and texts at the hospital, and when he comes home, he just doesn't remember anything at all. And I said: "Ok, what then? Are you going to rehab by a physiotherapist or occupational therapist or dietician?" And he simply didn't know. He had this written discharge note, but it was very short.' (Informant 5)

Some relatives tried to get information from hospital websites, but these only addressed broader matters and did not provide person-centred knowledge:

'We did not receive any information at all. And all that we have been able to find was at the Internet homepage, and it was only on that the patient had to come alone, and things on cancellations. So, we have not been offered any alternative information, nothing has been sent to us from anywhere. We have had to search it for ourselves.' (Informant 13)

Such information-seeking strategies emphasised the relatives' need to be informed, specifically regarding the patient's actual situation. Such information is needed when relatives navigate how they can provide care and support.

Being excluded from assessing the health status of the hospitalised loved one

Besides a complicated collaboration and communication with the RNs and limited possibilities for provision of care and support to the patient, visiting restrictions complicated assessment of the patient's health status, which further comprises the qualities of profound knowledge of the patient and his or her way of expressing feelings, symptoms and disease. A participant described how exclusion from physical presence at the hospital was experienced:

'I really think that it was so totally weird to be standing outside looking in, in some way. It was that feeling that was so extremely uncomfortable.' (Informant 1)

To this relative, it was very uncomfortable to be obliged to have an outside position as she was not able to be present physically at the hospital. Participating relatives expressed how they felt a loss of control over the situation and experienced feelings of powerlessness because they could not assess the health status of their hospitalised loved ones. One relative explained:

'So, I had that period; it was, it was really like crazy long time, I mean, because you are afraid, right? And worried, and I think that it really is all about that you have this feeling that you have no control now, you are totally in the hands of others.' (Informant 10)

Not being able to access information about the current health status of their hospitalised loved one left the relatives feeling unsure and worried about what was going on, implying that they had to rely on the professionals. Not knowing about the initiated treatment and care added to these worries and feeling of powerlessness.

The participating relatives described how the COVID-19 visitation restrictions had direct negative influence on their possibilities for assessing the health status of their loved one, as they had to rely on reports and information from the RNs. This would require a trust, which was not always present, as expressed here:

'It was frustrating to have to interpret what the nurses said. And maybe not quite have that confidence that they had had sufficient time to be around him, so they could make a real and realistic assessment of how he was really doing.' (Informant 2)

The uncertainty about assessment of the patient's health status was experienced as a problem, as such an assessment constituted the basic understanding of how the present health status differed from habitual status. A relative said:

'Is this normal or abnormal – I mean, have we experienced it before, and could they in that case perhaps try to do this? So, it was quite a lot, but still it was through their eyes that I saw my father and not with my own eyes.' (Informant 3)

This aspect was demonstrated in a more extreme form, when it was impossible to communicate with the patient and the only possible communication related to the health status was with healthcare professionals. One participant said:

'And they really didn't know what was wrong with him and he was unconscious so we couldn't get into contact with him in any way whatsoever as it was not possible. So, it was only based on the dialogue we had with nurses and doctors that we kind of had to sense how he was doing.' (Informant 3)

This theme emphasises that relatives have a need to assess the patient's actual situation and health status to generate an understanding based on the patient's uniqueness.

Discussion

The aim of the present study was to explore how COVID-19 visiting restrictions influenced relatives' relationships with patients and collaboration with nurses at non-pandemic hospital wards. Key findings describe how the visiting restriction policies implemented at non-COVID-19 wards left the relatives feeling worried and powerless regarding the health of their hospitalised loved one and the provided nursing care. This meant that by being unwillingly excluded from the hospital, the relatives were unable to assess the health status of their hospitalised loved one and to provide the support and care that they would otherwise have provided – both during admission and after discharge. These experiences became a source to frustration, uncertainty and worry.

The no-access visiting policies that were implemented in many hospitals during the first wave of the COVID-19 pandemic have been described as a barrier to fulfilling relatives' psychosocial needs, as impacting negatively on their psychosocial well-being, as leaving them feeling anxious and provoking feelings of guilt when not being able to visit the hospitalised loved one.^{15,22} Similarly, the negative emotional impact of visiting restriction policies, such as relatives worrying about the patient's condition and possible ways for relatives to provide care to hospitalised loved ones have been the focus of healthcare research since the first wave of COVID-19.²³ Several of these previous studies have focused on relatives of patients with severe COVID-19,^{24,25} relatives of severely ill patients at intensive care units (ICUs)^{15,22,26} and bereaved

relatives who lost a loved one during the COVID-19 pandemic.²⁷ The present study focused on the experiences of relatives of patients at non-COVID-19 wards and in this way, our study provides additional insights into how COVID-19 and the related emergency response impacted not only on the wards directly involved in managing COVID-19 infections, but also resonated throughout the hospital wards. More specifically, the findings reported here contribute with insights into how the negative emotional impact experienced by relatives of hospitalised patients is not limited to the relatives of seriously ill patients or patients at ICUs. Rather, the visiting restriction policies implemented at the time seem to have affected relatives of hospitalised patients more broadly.

A key finding from our research is related to relatives' experiences of being unable to convey person-specific and – in their opinion – relevant knowledge about their loved one to RNs during the time of the visiting restriction policies. This left them feeling worried and powerless, facilitating uncertainty about what was going on at the hospital. Another side to this was the relatives' descriptions of not being able to reach RNs by telephone to get information about the status of their loved one. This only added to their worries. For several years, taking a person-centred approach has been regarded as essential for providing high-quality patient care at all hospitals.^{28,29} An important principle of person-centred care is the involvement and support of relatives and other carers.³⁰ As part of this care principle, healthcare professionals need to acknowledge the importance of relatives and other carers for the well-being of the patient.³¹ In light of our findings, it seems that during the first wave of the COVID-19 pandemic, these important aspects of person-centred care were disregarded. Reaching out to involve relatives of hospitalised patients in the care and treatment of their loved one was not prioritised by RNs in non-COVID-19 wards. Considering the intentions to practice healthcare in a person-centred manner that is reported across contemporary healthcare settings,^{28,29} it seems there is still a great gap between actually practising a person-centred approach in hospital settings and the descriptions of practices presented by relatives in this study. It seems that even though person-centred care represents an approach to care that can seem obvious, it may be difficult to practice in everyday work.^{31,32} Even though empirical research stresses that recognising, listening to and respecting the needs of relatives is important, this aspect of person-centred practice is one that both patients and healthcare professionals may regard as less important.³¹ This underlines the need for a continued focus on and active engagement in incorporating involvement of relatives into everyday care practices.

Involving relatives should not only take place when convenient to RNs. Ideally, involvement of relatives should build on the needs and preferences of all involved parties.³¹ Relatives who were not being present at the bedside experienced this as minimising their ability to be involved in the patient's course of illness and diminishing the patient's access to emotional support from them. Considering the positive effects attributed to person-centredness in healthcare,^{28,31} it is important to address the lack of involvement of relatives in similar healthcare crisis in the future, as not establishing contact or collaboration with relatives to patients could

potentially affect quality of care, continuity and patient outcomes negatively.²⁹

Our findings display that the emotional impact of relatives being unable to provide strong-felt caring responsibilities should not be underestimated. Even though visiting restrictions can cause ethical dilemmas for healthcare professionals in balancing the protection of the public and the well-being of patients and their family members,³³ some studies suggest that developing local compromises as an alternative to the no-access policies should be considered in the future. In future situations, healthcare professionals should be aware of potential negative effects of visiting restrictions on patients and families in recognition of the value of social contact between patients and their families.²³

Strengths and limitations

This research was conducted during the first wave of the COVID-19 pandemic employing a pragmatic recruitment strategy. Using social media to recruit volunteer participants may have favoured some participants over others. Volunteering for research is often motivated by some level of altruism and the wish to help others by participating. Furthermore, individuals may choose to volunteer based on their interest in the topic in question, it is relevant and important, and feeling they have important insights to contribute.^{34,35} Several of these aspects may have been strengthened by the research topic being related to the consequences of the COVID-19 visiting restrictions policies, and the study taking place during the first wave of the pandemic. Many people were affected by the situation and may have been motivated to volunteer, seeking an opportunity to share their experience. Disclosing potential volunteer bias as the ones mentioned above, and reporting on participant characteristics, may improve the reader's ability to assess potential for transferability of the study findings to similar contexts or populations.³⁶

The research process of this study was characterised by researcher triangulation – from planning the study, conducting the interviews, and through the process of analysis and dissemination of findings. This increases the credibility and validity of research and may help overcome fundamental biases, which may stem from using one single research method.³⁷ Researcher triangulation contributes to different perspectives on the topic being studied and can confirm findings.³⁷ In this way, triangulation contributed to the richness and clarity of our study.³⁸ However, triangulation also increases the complexity of research, adding to the time spent on the process and raising the demand for the analyst skills among the researchers involved.^{39,40} Involving skilled qualitative researchers in our process offered a strength in meeting such demands.

Conclusion

The visiting restriction policies implemented at non-COVID-19 hospital wards left the participating relatives feeling worried and powerless regarding the health of their hospitalised loved one and the provided nursing care. This study emphasises the importance that relatives ascribe to their admitted loved one receiving situational person-centred nursing care that

considers the uniqueness of each person. Furthermore, the study shows that these relatives find it important to be able to contribute with knowledge to RNs about the specific patient. This constitutes an important aspect of delivering adequate care and support.

Even though many countries, at the time of writing, are in the phase of managing the post-COVID challenges, e.g. by distributing vaccines to vulnerable groups in society, findings from studies such as the one reported here are pivotal to any future national or global health crisis, where visiting restriction policies are implemented. An implication to consider in future health crises is related to how relatives can be included when they are restricted from accompanying their loved ones in any appointment at the hospital. Out of sight should not mean out of mind and healthcare professionals need to take on the responsibility of involving relatives to the extent of the patients' wishes.

Author contributions

HHT, CBT, KB, BL, MG, KHK, LJ, BP, SLV, BL, MGN, SJ and MTA were responsible for the conceptualisation, methodology, investigation, resources and supervision. HHT, CBT and BL were responsible for the formal analysis and validation. HHT and BL were responsible for the data curation, writing the original draft and visualisation. HHT was responsible for project administration. All authors were responsible for reviewing and editing the manuscript.







Conflict of interest

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