
Caring from a distance: how a COVID-19 visitor ban affects relatives when a loved one is admitted to a neurological or neurosurgical ward

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Abstract

Background: Neurological patients often suffer physical, cognitive, communicative, behavioural or psychosocial limitations. This may weaken the preconditions for participating in decisions about their treatment, rehabilitation and future. These impairments often cause relatives to care and advocate for the patient. This practice was gravely interrupted by the COVID-19 visitor ban.

Aims: This study aims to investigate how relatives of neurological patients experienced the visitor ban and to identify potential areas for improvement.

Methods: Twelve semi-structured interviews with relatives of neurological patients were conducted. Data were analysed by performing a thematic analysis inspired by Braun and Clark.

Results: The following six themes emerged: Visitor ban as a necessary evil, Losing control and feeling checkmate, Mending the information gap, Waiting by the phone, Empathy and compassion as the core of a good relationship and Caring for a loved one from a distance.

Conclusions: Having a loved one admitted to a neurological ward during the COVID-19 visitor ban greatly restrains relatives and affects the relationship with their loved one and the hospital

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healthcare staff. Healthcare staff need to take responsibility and reach out, while simultaneously exploring new ways of communicating.

Keywords

COVID-19, neurology, patients, qualitative research, relatives, thematic analysis

Introduction

The year 2020 became one that we will forever remember. The unpredicted COVID-19 virus rapidly overtook the international agenda, as the media intensely covered the rising infection and death rates (Su et al., 2021). A plethora of topics related to the pandemic was described (Ng and Tan, 2021). It became increasingly evident that this health crisis would gravely impact the circumstances of our healthcare systems and countless aspects of our daily lives (Keller et al., 2020; UN, 2020). Public health and social measures are continuously adjusted to reduce transmission, as this appears to be an effective preventive tool. However, it seems to simultaneously affect our physical, mental, psychosocial, and economic health and well-being in ways we cannot yet completely fathom (WHO, 2020). The health crisis urgently calls for the need to explore how these restrictions affect vulnerable populations and address actions to facilitate support (Day et al., 2020; Galea et al., 2020).

Depending on the severity of a neurological disease (herein used to collectively refer to neurology and neurosurgery) or brain injury, patients may suffer from various disabilities, including paralysis in one side of the body, speech problems (aphasia), poor balance, swallowing problems, fatigue, difficulty remembering, thinking, and solving problems and altered personality (Langhorne et al., 2011). The complexity of neurological disease means that patients may endure hospitalisation and daily life with physical, cognitive, communicative, behavioural or psychosocial limitations (Ates et al., 2018; Hesselvig et al., 2020). For this reason, some of the patient's preconditions for entering a collaboration, will be weakened to such an extent that they cannot participate in decisions about their treatment, rehabilitation and future. These impairments often cause the relative to care for and become a voice to advocate for the patient (Guldager et al., 2019). Further, relatives are seen as active partners readily involved in the hospitalisation process influencing clinical outcomes while providing crucial emotional support and insight (ViBIS). The family constitutes a vital resource during and after rehabilitation since they are the one who knows the patient best (Norup, 2018) and can affect healing and adaptation to treatment (Ates et al., 2018).

It is internationally recognised that severe neurological illness negatively affects the entire family's function (Soendergaard et al., 2019). The demanding physical and emotional responsibilities of caring for a loved one puts the caregiver themselves at risk for compromised health. Furthermore, insufficient support and coping skills can lead the caregiver to depression, exhaustion and worsening underlying medical conditions (Harris et al., 2011). In recent years, these unfavourable effects of being a caregiver have been identified as a considerable public health concern (Ates et al., 2018). A Danish study from 2020 concludes that relatives are emotionally vulnerable due to their loving relationship with a patient in acute neurology. It further describes how it is still essential for the relatives to go 'all the way' to be a strong and resourceful support for the patient (Hesselvig et al., 2020). However, the poor health of caregivers will most likely affect the quality of the care they provide, thus affecting the health care outcomes of the patient (Norup, 2018).

In Denmark, the COVID-19 restrictions included a temporary visitor ban in hospitals effective on 18 March 2020 (STPS, 2020). This brought forth critical consequences for both patients and their

relatives. It is not difficult to imagine how this has further constrained relatives. Therefore, this study aimed to investigate how relatives of neurological patients experienced the visitor ban and identify potential areas for improving our support for them.

Methodology

Design

The present study was designed as a qualitative explorative study.

Participants

The included participants were recruited using purposive sampling. To ensure maximum variation in age, gender, severity and divergence in the participants' neurological disease, the admitted loved one's participants were hand-picked to represent real-life variations. The participant's ages ranged from 43 to 71 years and included 8 women and 4 men. The relatives presented a selection of spouses, siblings, children, men, and women, both young and old, who contributed to thick descriptions of being a relative. Relatives under the age of 18 were excluded as well as relatives not able to speak or understand Danish.

Setting

The study was conducted in three different wards at a university hospital in Denmark in June 2020. These included (1) a neurological department, (2) a neurosurgical department and (3) a highly specialised rehabilitation department for patients with severe traumatic brain injury.

Data Collection

The interviews were conducted using a semi-structured interview guide and were performed by the three authors. Due to the COVID-19 visitor ban, most interviews were performed via telephone. All 12 interviews were recorded digitally and transcribed verbatim by the author team. The participants were contacted after permission was given by the patients. The patient, if possible, asked the participant if we could contact them; otherwise, the responsible nurse at the ward asked the participant.

Data analysis

Different perceptions of thematic analysis exist, and which thematic analysis is most suitable depends on the study's theoretical basis and the research question. Thematic analysis is not tied to a specific theoretical framework and can be used within various theoretical and epistemological traditions. In the version of the thematic analysis that we have chosen, the method does not pretend to be neutral. It is based on the understanding that all analysis is influenced by the researcher, which is in line with the human science tradition. This embodied subjectivity requires a reflexive researcher who strives to critically reflect on her assumptions and how these can shape and delimit the analysis to improve trustworthiness. This is why the researchers continuously considered this during the research process. Further, data collection did not cease until the participant's experiences seemed

to reoccur, ensuring data saturation and thick descriptions of the investigated phenomenon (Braun and Clarke, 2006, 2021a; Clarke and Braun, 2018).

Using a qualitative data analysis software (QSR International NVivo version 10), we chose a reflective thematic approach as presented by Braun & Clark when analysing our data material (the transcribed interviews). A Reflexive Thematic Analysis consists of the following six steps: (1) data familiarisation and writing familiarisation notes; (2) systematic data coding; (3) generating initial themes from coded and collected data; (4) developing and reviewing themes; (5) refining, defining and naming themes; and (6) writing the report (Braun and Clarke, 2021b).

We followed the six steps initiated by all team members, carefully reading all transcripts and labelling meaningful basic segments using descriptive codes. The codes describing similar content were grouped, reviewed and re-coded if necessary. Next, reduced data from all groups were collected to visualise the emergence of themes. These themes were reassessed for internal consistency and validity, which resulted in some being subdivided if their contents were overly broad or renamed to reflect their contents more accurately.

The reflective thematic analysis results consist of several themes that describe people's experiences, perceptions, views or representations of a given topic, hence particularly relevant in our study, where patterns and themes in relatives' experiences of being a relative during the pandemic were investigated.

Results

Visitor ban as a necessary evil

A majority of the interviewed relatives expressed an understanding of the need for COVID-19 restrictions, including the visitor ban. Both concerning the protection their hospitalised loved ones and as an overall societal preventive strategy:

I'm thinking how annoying it is that they can't just take him out so we can be with him, just for 10 min. But then I realise that it's not a good idea. Because if I'm infected, I'm infecting him, and the chance of him dying will probably be considerable because of his general condition.

However, as society gradually opens, it could be increasingly difficult for some relatives to acknowledge and accept the political and societal priorities related to lifting the COVID-19 restrictions, which remained longer in the hospital setting.

In general, the fact that the ban applied to everyone seemed to make it easier for the relatives to handle and accept. Aside from reducing the risk of infection, the relatives could not see any benefits from the visitor ban. However, a few participants described that if they were to see an unintended advantage of the ban, it would be that the pressure of having to visit their loved ones on a regular basis was off. It could be challenging to fit hospital visits into a busy daily schedule for some. Thus, this pressure and expectation were somewhat eased, especially since the relatives themselves were not responsible for not being able to visit:

So, there is no pressure where you HAVE to stop by... here (in the hospital)... this unspoken expectation. You are expected to come, you know?

Losing control and feeling checkmate

Despite the underlying acceptance of the restrictions, most relatives found it extremely challenging not to be allowed to set foot in the hospital, especially during critical situations, not knowing whether they would be deprived of saying the last goodbye to their loved one. Some relatives were aware of the ban from the media and were not surprised. Others described how they were rejected at the door unprepared for this, leaving them in a state of anxiety and distress:

P: I don't know if she is dead or alive, you know, and I call my older big brother...and then the two of us drove into the hospital, and we weren't allowed to get in, and it was so awful...so... so...awful.

F: So, you were rejected at the entrance?

P: Yes. Everywhere...everywhere...at all the entrances. So, we just sat there...I didn't know when she'd come out of surgery. If I'd ever see her again...

The ban on visits placed a significant burden on patients' closest relatives. The participants described how not being able to be present evoked feelings of unrest, anxiety, frustration and loss of control. The tremendous strain was described as a deprivation when not being able to provide a physical presence, care and affection:

It hits you like a hundred times harder when you can't see your relatives, you know? I have sat down and cried over this, thinking you can't hold her hand, look her in the eyes. I have no idea what she looks like. I have no idea how she feels deep down, and I can only listen to what they (the healthcare staff) say. And what she says and what they say are not always the same...

Mending the information gap

Feeling sufficiently informed appeared to be very important for the relatives' hospitalisation experience. Throughout the interviews, it was clear how the relatives had a substantial need for information when not allowed to visit their loved ones. This seemed to be the case in both acute and more prolonged hospitalisations. Common among all participants was the need for information to be factual. *What is going on? What can we expect? What is the status?* Most relatives had mixed experiences during the hospitalisation, and it differed whether they felt well-informed on an overall level. Not being present as a relative meant that they could not see how the loved one was doing. It also meant they could not pull the staff aside in the hallway and ask about the patient's condition. Many relatives did not receive information regularly, and their need to follow their loved one's progression was unmet, leaving them on the side with no experience of continuity of care:

Uh, my wife is extremely affected compared to when I handed her over (to the healthcare professionals).

Uh, back then, she could actually walk... And then when you see her the next time, she can neither walk, stand nor use her arms or anything else. It was so shocking...

Also, the fact that the neurological patient might not be able to pass on reliable information because of a recent operation, serious illness, brain injury or cognitive disorder complicated the exchange of information:

She was talking nonsense all Saturday and was also on morphine, so it was not that easy (laughs). There was not much quality (in the information she provided), so the level of information was miserable because it was her giving it. It would have been easier to just go out into the hallway and get hold of a doctor or nurse.

Waiting by the phone

There was no structured practice for informing relatives or inviting relatives to participate in ward rounds or meetings despite the substantial need for information. During their loved one's hospitalisation, only a few participants had received information about opportunities for visiting or communicating with their loved one or how to contact the healthcare staff. Several of the participants suggested that information on when and how to call about their relatives would have been helpful:

It would have been nice if we had been given a phone number or made an appointment about being called - or just gotten an email or text message if there was any news... we think it's a long time to wait two or three days without hearing anything. ...

When not feeling sufficiently informed or involved, the relatives felt excluded from the recovery process. For some, this meant that they got extraordinarily scared when they finally received a call from the hospital as they feared that something serious had happened to their loved one. A contributing factor complicating the sharing of information might be the common impression of the staff being kind and caring but busy, which could lead to nurses appearing inaccessible. Consequently, the relatives were left in doubt as to whether they were disturbing when trying to contact the healthcare staff:

Some have been nice and have said they would try (to get someone to call back). And then they called back at 8 p.m. saying that for some reason it's not possible. I think that is just fine. It's worse when I sit and wait until 8 or 8.30 pm and think that now they will not call me back for sure...

It is worth mentioning that many relatives felt they had the possibility of calling the ward to request information, but that several chose not to. Many relatives also described how the nursing staff had been accommodating and caring when they did contact the ward by phone.

Empathy and compassion as the core of a good relationship

The collaboration between the relative and the nurse seemed to depend on how the relative assessed the unique human qualities of the nurse. Several relatives had encountered nurses they found cold or unengaged and who they felt neglected the significance of the visitor ban:

They scolded me... and I said, 'I haven't talked to my mother for four days. Do you even know what it's like to be a relative, and you don't know if you'll ever see her (the mother) again?'

A few relatives had experienced receiving information from the nursing staff without requesting it. Some, however, described nursing staff assuring that the information given was, in fact, received or being called after or during meetings. The relatives found this reassuring and enriching for the

collaboration. When a positive collaboration was not experienced, it generated additional worries about whether their loved one was well taken care of:

I can hear she's starting to get a cold, and I think to myself, 'YOU CANNOT GET PNEUMONIA. If you get it, you are 81 years old, and you have just had a stroke', you know? I say: 'Now put on your bathrobe!' 'Bathrobe?' she says. 'I have no bathrobe... nooo/ohhh' (sighs)

Some relatives found the healthcare staff rigid and uncaring. It was requested that the nursing staff be more innovative and flexible in finding solutions to 'circumvent' the visitor ban in a safe way. The nurse could, for instance, help the patient into the hallway or to the window so the relative could wave when they handed over gifts or personal belongings; they could even meet outdoors, an opportunity that had proven possible in the primary sector:

You could have stood on either side of this glass door... You come to XXX (the hospital), and then you hand over the magazine to a nurse and... uhh... some flowers. Goodbye again. Nothing like, should I go get your mother so that you can wave goodbye and shout 'hello'? That's what I think was disappointing...

When the relatives experienced available, empathetic nurses, this was perceived as a positive starting point for the collaboration. In these relations, the relatives had the courage to call in about their loved ones and felt confident that the staff would take over and provide some of the care they were excluded from giving. Some neurological patients required a short-term hospitalisation when undergoing surgery. Others were hospitalised for a longer period. Some were critically ill. The relatives were relatives under different circumstances, which meant they had different needs and expectations when collaborating with the staff.

Caring for a loved one from a distance

Relatives with a loved one capable of using electronic devices had several possibilities that could make them feel supportive despite not being present. These options included text messages, phone calls and video calls. For relatives whose loved ones did not have the opportunity to use electronic means of communication, it was challenging to support the patient from afar. These relatives depended on the staff's readiness to help facilitate this.

For some relatives, the lack of physical presence meant many daily calls, making it possible to follow up on new initiatives while reassuring them they still cared:

First, I asked the nurses if it would be possible for me to hand over my husband's phone so that we could call him directly... Because back then, we were still not allowed to visit. Then we Facetimed on his phone.

In some cases, video calls were a way to help relatives reach their loved ones and get a better impression of their condition. The possibility of looking each other in the eyes was valuable for some. However, for others, this was experienced as too hard and left them in distress rather than reassurance. Likewise, some relatives described how being invited to a video meeting was not

always the appropriate solution. Instead of including the relative, it could have the opposite effect, making the relative feel like a spectator rather than an equal contributor:

The first time I thought it was especially strange, because... you cannot see people... It's a lot like: 'We are these people present' and 'this is how it goes along here' and 'this is what we are trying to do'... There was not all that stuff like just being asked if we wanted a cup of coffee or something.

Discussion

Having a loved one admitted to a neurological ward during the COVID-19 visitor ban greatly restrained relatives and affected the relationship with their loved one and the healthcare staff. Although most of the interviewed relatives expressed an understanding of the need for the COVID-19 visitor ban, the circumstances seemed to leave the relatives in a vulnerable position.

All relatives found it extremely challenging not to be allowed to set foot in the hospital, leaving them in an emotional vacuum, or as one described it, 'feeling checkmate'. In a recent study, Hesselvig et al. illuminate how relatives of neurological patients struggle with unmet emotional needs even before the COVID-19 restrictions (Hesselvig et al., 2020).

A few participants described that if they were to see an unintended advantage of the ban, it would be that the pressure of having to visit their loved ones on a regular basis was off. Being a relative entail a significant increase in daily tasks. According to Soendergaard et al., 43% of relatives of patients with traumatic brain injury spend more than 5 hours per week helping their family members, and 22% spend more than 16 hours per week (Soendergaard et al., 2019). This could explain how the visitor ban temporarily eased the pressure on some relatives.

Most relatives did not receive information regularly even though feeling sufficiently informed appeared important. The fact that the neurological patient may not be able to pass on reliable information further complicated the exchange of information. Several relatives suggested that information on when and how to call about their relatives would be important. However, this request is not uniquely associated with the visitor ban; as Khabarov et al. describe how relatives were unsure as to when and how they should contact the healthcare staff to get information before COVID-19 appeared (Khabarov et al., 2015).

The insufficient information levels that some relatives encountered, seemed to create insecurity and a bad overall experience of cooperation and care. The relatives who did not experience a positive collaboration, generated additional worries about whether their loved one was well cared for. On the other hand, a sufficient level of information seemed to create a feeling of security and an experience of handling the situation. When the relatives experienced available, empathetic nurses, this was perceived as a positive starting point for the collaboration. It was generally requested that the staff be more innovative and flexible in finding solutions to overcome the visitor ban in a safe way, opportunities that have been proven as possible in the primary sector.

Only a few relatives had experienced receiving information from the nursing staff without requesting it. This is unfortunate, since the relatives found this particularly reassuring and enriching. Previous studies have shown how assessing the need for involvement of patients and relatives is a

complex matter and that preferences for involvement are influenced by individual and situational factors and whether the patient is in critical care or not (Busetto et al., 2020; Zizzo et al., 2017).

Several participants mentioned technical devices such as phone or video calls to maintain communication with their loved ones and healthcare staff when not allowed in the hospital. However, an important finding is that relatives with a loved one capable of using electronic devices have several possibilities for supporting their loved ones. In contrast, relatives whose loved ones were not capable of using electronic means of communication were dependent on the staff's readiness to help. Thus, this study has provided an exceptional insight into the concept of relative involvement in an altered context – that is, when relatives are not physically present. This is a unique contribution to the current body of knowledge. Future research would benefit from further investigating how to utilise this opportunity and facilitate appropriate involvement of relatives, whether on-site or from a distance. This is especially pertinent for vulnerable groups, as is the case for people with cognitive and communicative difficulties. Guldager et al. (2019) also found patients and relatives unequal in terms of socioeconomic resources and suggested that the nurse to a greater extent base the involvement on the identification of the relative's needs; thereby, support can be delivered in a more tailored way (Guldager et al., 2019).

The COVID-19 pandemic has pushed forward the use of technology, enabling new ways of delivering healthcare. Price et al. argued that this might be an advantage in the long run; increased use of technology can potentially make healthcare more accessible, provide timely interaction, and alleviate the increasing pressure on healthcare systems (Price et al., 2020). At the same time, however, it may widen the gap in healthcare inequality as this favours families with adequate knowledge and wealth.

Limitations

Performing the interviews via telephones constitutes a limitation that may have impacted our study as behaviour and body language cannot be observed, potentially affecting the interaction between participant and researcher. As our focus was on the perspective of relatives, the view of patients and healthcare staff would have strengthened our findings. This would have broadened the picture and thus, further enabled the development of adequate neurological care for patients and relatives. However, the study was strengthened because it was carried out in three different neurological wards, giving a broader perspective of being a relative of a neurological patient in Denmark.

Conclusion

Most relatives expressed an overall understanding of the COVID-19 visitor ban and found the healthcare staff kind and accommodating. However, this study exposes several unmet needs in the relatives of neurological patients.

To compensate for the vulnerable position the relatives find themselves in, healthcare staff need to take on the responsibility of reaching out and exploring new ways of communicating. It must be considered that relatives have different needs and preferences.

The visitor ban does appear to significantly affect how relatives are involved and informed about the care of their loved ones. Many challenges, however, have also been described before the COVID-19 restrictions existed and are thus pre-existing but further complicated by the pandemic.

Key points for policy, practice and/or research

- Having a loved one admitted to a neurological ward during the COVID-19 visitor ban greatly restrains relatives. To compensate for the vulnerable position, healthcare staff need to take responsibility for reaching out and exploring new ways of communicating.
- Most relatives did not receive information regularly. Several participants suggested that information on when and how to call about their relatives would be valuable.
- The COVID-19 pandemic has pushed forward the use of technology, and participants mentioned the importance of technical devices to maintain communication with their loved ones and healthcare staff. However, this may widen the gap in healthcare inequality as this favours families with adequate knowledge and wealth.
- It was generally requested that the staff be more innovative and flexible in finding solutions to overcome the visitor ban in a safe way.

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Ethical approval

Approval from the Danish data protection agency was obtained (ID P-2020-536).

Informed consent

Approval from the Danish data protection agency was obtained (ID P-2020-536), and the study was conducted according to the principles of the Declaration of Helsinki. Written and verbal information was given before obtaining informed consent. Participants were informed of the voluntary nature of the study and that withdrawal from the study was possible at any time without implications for future treatment or care.

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