

Research Article

Family functioning of families experiencing intensive care and the specific impact of the COVID-19 pandemic: A grounded theory study

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ABSTRACT

Objectives: In order to provide a deeper understanding of family functioning, the aim of this study was to identify, describe and conceptualise the family functioning of families where a formerly critically ill family member had stayed at the intensive care unit, with the impact of a pandemic.

Research methodology/design: The study has a grounded theory design including interviews with eight families.

Setting: Former adult intensive care patients cared for Covid-19 infection and their family. Eight patients and twelve family members from three different intensive care units.

Main outcome measures: The results presented are grounded in data and identified in the core category “Existential issues” and the categories “Value considerateness; Anxiety and insecurity in life; Insight into the unpredictability of life.”

Findings: The core category could be found in all data and its relationship and impact on the categories and each other. The core is a theoretical construction, whereas the family functioning of families where a formerly critically ill family member had stayed at the intensive care unit was identified, described, and conceptualised. Being able to talk repeatedly about existential issues and the anxiety and insecurity in life, with people that have similar experiences helps the patient and their family to consider and gain insight into the unpredictability of life, and thereby better cope with changes in life.

Conclusion: There is awareness about the love that exists within the family. A willing to supporting each other in the family even if the critical illness made the family anxious and afraid.

Implications for clinical practice: Even if the pandemic Covid-19 led to restrictions inhibiting family focused nursing, it is important to confirm the family as a part of the caring of the ICU patient. The patients are not alone, their family are fighting together for the future.

Introduction

The Covid-19 pandemic has affected the entire world, including how we care for patients in the intensive care unit (ICU). The ICU is a stressful and scary environment. Prior to the pandemic, most ICUs that cared for patients with critical illness in a technological environment, invited family members to visit the patient 24 h, round-the-clock. During the pandemic, this changed and there were restrictions, and family members had limited opportunities to visit the hospital. Family members were given information about the patient's condition by a physician over the telephone (Kennedy et al., 2021).

Studies before the pandemic show that ICU patients and their family affected by critical illness and ICU care have impaired quality of life, anxiety, and depression (Alfheim et al., 2019; Ågren et al., 2019; Kosilek et al., 2019). This affects the functioning of the families experiencing the ICU. The unknown experiences, and the high mortality at the beginning of the pandemic led to anxiety and insecurity in life (Armstrong et al., 2020).

Family functioning is defined as the family's ability to process the adaptation to new situations (Whall, 1986). In the context of illness, family functioning is about how families communicate, fulfil family roles, accept new family routines and procedures, cope with and adjust

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to family stress, and relate to each other (Zhang, 2018). Due to restrictions and obstructions to being involved in the care of ICU patients there could be impacts on the family and the family functioning. Knowledge about family function can facilitate inclusion of the family in decision and intervention in daily care around the patient and be invited to follow-up together with the former ICU cared family member (Ahlberg et al., 2020; Ahlberg et al., 2021). Our objective of this study was to identify, describe and conceptualise the family functioning of families where a formerly critically ill family member had stayed at the ICU, during the Covid-19 pandemic.

Methods

The study has a classic grounded theory (GT) design, which facilitates the understanding of the adaptation of how people manage social processes, such as family functioning (Glaser and Strauss, 1967). Eight families (20 participants) were interviewed.

Setting

Participants from three general ICUs were involved in the study: one regional hospital and two university hospitals in Sweden. The timeframe of the interviews was June – December 2021.

Ethical approval

The Ethics Review Board approved the study (record no. 2020-04124, 2021-05103, 2021-06585-02). Written informed consent was obtained from all family members, and the research was carried out in line with the Declaration of Helsinki. All family members could withdraw their participation at any time without further explanation or without effects on any future care (The World Medical Association, 2013). All data were coded with a number, saved, and stored (Regulation (EU) 2016/679). In case of inconvenience or the participants needed further information or contact with a health professional, contact information, were given.

Participants

Formerly critically ill patients and their family members were consecutively recruited to the study, followed by theoretical sampling in the selection procedure. The participants are described in Table 1.

The ICU patients received a mail request to participate one to thirteen months after their ICU care and indicated which family members could participate. All family members participating were selected by the ICU patient, who gave their personal data, such as name, address, phone

number, to the first author. Family members were defined as anyone the patient considered as belonging to the family (Whall, 1986) significant to their experience of health and illness to participate. The inclusion criteria for participating in this study were patients cared for in the ICU for ≥ 24 h and ≥ 18 -years-old being diagnosed with Covid-19, or being a family member, ≥ 18 -year-old. The participating patients and their families were different in age, gender, and family structure. The patients' ICU stay, and rehabilitation needs were also different; some were back at work, and some still needed home care, oxygen, and physiotherapy (Table 1). All participants had been socially active and in no need of homecare, oxygen, or physiotherapy before the ICU care. Some had risk factors and a medical history. A typical ICU cared Covid-19 Swedish patient out of 9 408 registered: 69 % men, 80, 8 % had risk factors, mean age 60. ICU cared for median 8 days and 60 % needed respiratory ventilation (SIR, 2023).

Data collection

The first author received patients from an ICU care administrator at the included hospitals. The former ICU patient's medical record gave information about gender, date since ICU discharge and the number of days of ICU care. Social status and the family member's age and relationship to the patient, were asked about during the interview. The first author, booked and conducted all interviews, experienced in ICU care and follow-up but had not been involved in the care of these families. Recorded interview were transcribed and analysed, and categories emerged that determined who to interview next. Theoretical sampling was conducted and a new former ICU patient with another family construction, age, gender, and ICU stay was contacted to participate to broaden the experiences of family functioning. Theoretic sampling for what we believe has the greatest significance for the core variable and its characteristics, such as different genders, ages, and days on a ventilator and without a respirator. Days since discharge from the ICU, rehabilitation need for the patient and an attempt to capture different constellations of family (Table 1). The interview was conducted familywise, i. e., with the former ICU patient and the selected family members. The interview started with an open introductory request to the informants to talk about the family and their experiences in connection with and after the ICU period and follow-up questions/ clarifications were asked. Depending on what emerged in the analysis, the interview guide could be expanded with new questions. The interviews were audio-recorded, and the interviewer made memos on a notepad to process the different question areas.

The interviews were conducted where the participants wanted and followed the restrictions concerning Covid-19 and social distancing. Out of the eight interviews performed, four were conducted in person, in real

Table 1
Characteristics of the participating intensive cared patients and families.

Patient's Age	Patient's Gender	Work/Sick Leave/Pension	Oxygen/Wheelchair/Homecare/Physiotherapy*	Days In Icu	Days Requiring Respirator Care	Days Since Icu Discharge	Family Member Age/Relation	Family Member Age/Relation	Family Member Age/Relation
34	man	work	0/0/0/0	2	0	54	34/wife**		
68	woman	Pension	0/0/0/0	6	4	123	75/husband**		
75	woman	Pension	X/X/X/X	52	43	48	76/husband**	49/daughter***	54/daughter***
51	man	Sick leave	0/0/0/X	6	3	154	51/wife**		
50	man	Work	0/0/0/X	11	7	28	49/girlfriend***	43/niece****	
54	woman	Work	0/0/0/0	13	11	237	51/husband**		
64	woman	Work	0/0/0/0	32	10	392	66/husband**	34/daughter***	
76	man	Sick leave	X/0/0/0	29	24	178	46/daughter****		

Note. * 0 meaning no oxygen, wheelchair, homecare, physiotherapy; X meaning the patient in need of oxygen, wheelchair, homecare and/or physiotherapy.
Living in the same household * Not living in the same household but in the same town **** Not living in the same household and living in another town.

life, in the former patient’s home (3) or in a private room in the hospital (1). One interview was performed in person with the former ICU patient and one family member together, and one family member online throughout the whole interview. Three interviews were conducted on-line with the family in front of one computer and the interviewer in another town in front of another computer.

Information about the study and ethical issues was provided, there was small talk conversation before and after the interview by the interviewer. Notes of the interview were made directly after the interview, noting the atmosphere of the interview, the environment, the place for the interview, who had participated and whether something happened that disturbed or interrupted the interview.

The interviews varied between 44 and 88 min and the mean length was 60 min, median 56.

Data analysis

There was parallel data collection and analysis. Data from the verbatim interviews were read several times. Memos were written continuously, to develop ideas about the concepts that would be included in the theoretical construction. Analysis was performed line by line, with an open mind, and substantive codes were generated. The codes were labelled with origin words from the data. Substantive codes were compared with previous data and similarities and differences occurred, conceptualising took place, and categories were created. Data were examined several times with constant comparison, and the categories were modified and constantly refitted to represent and conceptualise family functioning. The gathering of data and analysis continued until a saturation ‘point’ was reached and then three more interviews were conducted. One of these interviews was made with a former ICU patient that had good knowledge about ICU care. This patient was an experienced ICU nurse. The time since this patient had been cared for was longer than the other participants. This so-called extreme case was used to strengthen or reject the theoretical construction. The interview strengthened the findings, and no new data was revealed. A core category was identified, imbued with data from all categories and raw data (see Fig. 1).

Categories are related to each other and to the core category and are scrutinised to verify their relevance (see Table 2). The members in the team were very familiar with GT (Glaser & Strauss, 1967; Glaser, 1978,

Table 2
Overview of the Findings Presented as Core category and categories.

Core Category	Category
<i>Existential issues</i> - The existential issues concern human living conditions. All of us will die, but it is also about the meaning each of us finds in our lives. The issues can also be about loneliness and togetherness, safety and trust, sadness, guilt, and forgiveness.	<i>Value considerateness</i> - Value considerateness is about appreciating relationships, being grateful for the family’s unselfish willingness to care, and being grateful for support. Considerateness meant putting the former patient at the centre and adapting to the new life even if it meant that the family members had to put themselves aside and make sacrifices. The life-altering experience made them value each other more and show consideration and love, even in small things.
	<i>Anxiety and insecurity in life</i> - Anxiety is an emotion including subjectively unpleasant feelings of fear over expected or experienced events. Anxiety is a feeling of uneasiness and worry. Insecurity in life is strongly related to anxiety, and different events or situations during life can make a person experience insecurity. These emotions could lead to not being able to manage the situation.
	<i>Insight into the unpredictability of life</i> - Getting insight into the unpredictability of life means realising that life can change suddenly and sometimes without reason. Life is unpredictable. The fact that the virus so quickly could make an active and social life change so completely. Changing a person from an active and independent person to a dependent person needing.

2002, 2005).

Findings

The findings section has been organised to first present the core category “*Existential issues*”, then to describe the categories “*Value considerateness*, *Anxiety and insecurity in life*, *Insight into the*

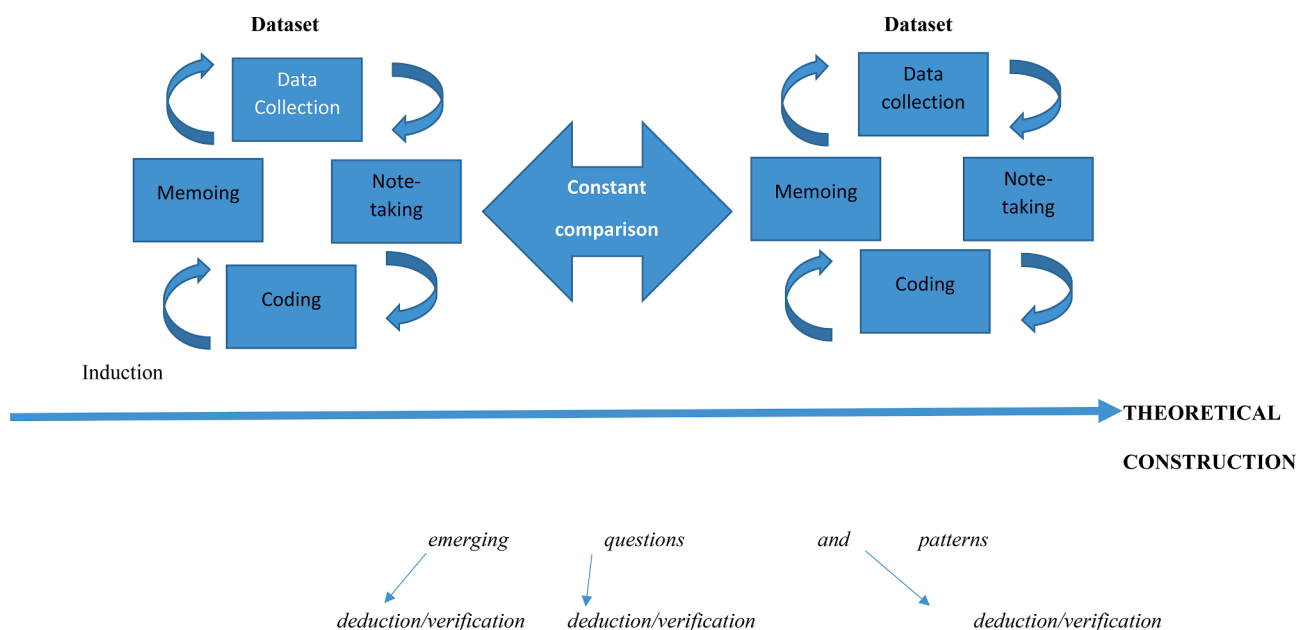


Fig. 1. Constant comparison between the data sets I–VIII (interviews, codes, categories) in a circulation and a final level reached, identifying a theoretical construction, a core category.

unpredictability of life.” Even if quotations are not a choice in GT (Glaser, 1978), there are some to illustrate the core category and categories. These are located at an abstract level, whereas the few quotations presented are located at a descriptive level.

Existential issues

The existential issues concern human living conditions. All of us will die, but it is also about the meaning each of us finds in our lives. The issues can also be about loneliness and togetherness, safety and trust, sadness, guilt, and forgiveness.

Existential issues were discussed by all the families; how their active and social everyday life so suddenly could be taken away, by severe illness and almost lead to death. They had been so well informed, taking all precautions not to be infected, and still, bang, the Covid-19 came so suddenly. After the first panic feelings, when the family were not able to do anything, the family members started taking separate roles. There were thoughts that this could be the end of this family constellation, feelings of being all alone, followed by varieties of reactions; family members being restless, or becoming apathetic.

The family members tried to take command over the feeling by seeking help, from other family members or/and friends, to discuss life issues but also to get help with practical everyday life. The nearest family member got information from the physician's, daily update about the ICU patient's physical status, and progress. This was supportive to the family members when processing the information and their feelings, when given the information further to the rest of the family. Writing a diary or making memos in the phone, was also a way to manage feelings. The family members felt that it helped them get a grip of the situation and organise their own thoughts and feelings to be able to get on with life. This written information gave insights to all family members, both individually and familywise.

The former patient did not recall anything from the care except hallucinations and nightmares. Now they were grateful to be alive. Gratitude for all the love and sympathy made them overwhelmed, gave them strength to survive and struggle for recovery.

Both patients and families were affected by this pandemic, as these issues were discussed daily on the news. 'Being one of those', infected with Covid-19, highlighted that they had someone to relate to.

The outlook on life and the future was changed. They had all been anxious, but now the only thing important was to be together with the family. Togetherness was priority-one. The families talked more to each other, in a changed way; there was willingness to change their everyday life, and to show every-one they were loved and were an important part of the family life. One quote exemplifying this.

"...but now afterwards, I have asked these questions, a lot these existential questions...but then you ask yourself... DO WE REALLY DO WHAT WE WANT IN OUR LIVES.....and have we set the right priorities...is there something that we want to change" (p 6).

Value considerateness

Value considerateness is about appreciating relationships, being grateful for the family's unselfish willingness to care, and being grateful for support. Considerateness meant putting the former patient at the centre and adapting to the new life even if it meant that the family members had to put themselves aside and make sacrifices. The life-altering experience made them value each other more and show consideration and love, even in small things.

Having good relationships within the family before the acute critical illness was important. These grounded relationships made them know they always could count on the family's support.

"...a good contact (in the family) is required to maintain good family contact even during and after an illness and a difficult, life-changing event" (f8 daughter).

The former patients were very happy having the family caring for them, before, during and after the critical Covid-19 infection and the life-threatening illness.

There was a gratefulness for the unselfish willingness to share information, which the closest family member showed by informing the rest of the family, although they had all the responsibility for making life go on, with work, taking care of the children and so on. The former patient thought that they would not have made it at all, or at least this well, if they had not had this support.

All people around showing consideration gave the family members possibilities to discuss and reflect on the illness, and strength to manage the day. The emotional support, having a shoulder to cry on during their despair at the awful situation. The considerateness also brought the opportunity to also have a normal life and allow themselves to laugh and try to believe in a future, getting confirmation that they were doing a good job.

The nearest family showed considerateness as they immediately, after the patient was readmitted to the hospital, and they got the first call from the physician, made calls, and sent text messages to the nearest and the extended family as well as friends, co-workers, and managers. It was rewarding to have lots of feedback and the ability to discuss and process their feelings.

This awareness of the risk of being affected made the patient as well as the family members talk, to every-one that wanted to listen, about the fear concerning how easily been infected. By talking and informing, might help others to be more careful and follow the restrictions better, and even improve the vaccine take-up in their area.

Anxiety and insecurity in life

Anxiety is an emotion including subjectively unpleasant feelings of fear over expected or experienced events. Anxiety is a feeling of uneasiness and worry. Insecurity in life is strongly related to anxiety, and different events or situations during life can make a person experience insecurity. These emotions could lead to not being able to manage the situation.

There was insecurity in life since there were so many things unknown. When the critically ill patient was cared for in the ICU, and the family was informed about how critical and life-threatening the situation was by the physician, the family members felt anxiety and fear about what could happen. There was insecurity in life about what would come out of this and how to manage.

The former ICU patients experienced anxiety due to being afraid to die, remembering nightmares and fighting for life. There was anxiety about being a burden for the family, determined to get well fast and put a lot of effort into rehabilitation.

Grown-up children not living in the same household were anxious and afraid, worried about how the parents would cope. Having to adjust to having homecare personnel assisting, managing the household on their own, not having any self-time. They felt insecurity at not being able to help and about leaving both the former patient and co-habitant alone with all the responsibility.

"Panicked when she was coming home; how would they manage, because I saw what shape she was in, rolled in on a stretcher" (f3daughter1).

Family members had a hard time during this period, and it was almost impossible to manage everyday life. Without close family members, friends or health care professionals that gave them support, mostly emotional support, they believed they would have been sick or sicker. Family members experienced physical illness like chest pains and shortness of breath that they afterwards thought could be symptoms of anxiety due to the situation with the critical ill patient, and the

insecurity about their outlook.

Insight into the unpredictability of life

Getting insight into the unpredictability of life means realising that life can change suddenly and sometimes without reason. Life is unpredictable.

The fact that the virus so quickly could make an active and social life change so completely. Changing a person from an active and independent person to a dependent person needing.

The terrifying experience had made the families come even closer together and this was due to this insight into the unpredictability of life, which made them more willing to adjust and adopt a positive attitude to the new situation. Their priority now was to be with their family, doing things they enjoyed. Showing gratitude to each other and showing consideration, letting guilt pass away and being forgiving. Living life in an effortless way, family and health were the only things that mattered.

The insight into the unpredictability of life adjusting to the situation, grateful for the way they could see problems as something to conquer. Life was changed but the family adjusted even though there was a major difference in everyday life compared to before the critical illness.

"...feel a little more... I think about how it is in the family, heartfelt or... (laughter)... What shall I say? ... If I can put it this way or... Yes, you were important before, but now in some way ...now you are the most important" (p7)

Discussion

The findings presented are grounded in data. The core category "Existential issues" could be found in all data, and there were relationships and impacts on all "Value consideration, Anxiety and insecurity in life and Insight into the unpredictability of life." The core is a theoretical construction, whereas the family functioning of families having a formerly critically ill member staying at the ICU during the Covid-19 pandemic was identified, described, and conceptualised.

The existential issues experienced by the participants about human living conditions are things all human beings experience. But in everyday life we do not usually reflect upon them or talk about them. Often there needs to be a situation that shakes our foundations, making us more thoughtful, which highlights that as health care professionals we should be better at addressing these aspects. A meta-ethnography study show that critically ill patients experiencing delirium appear to face intense existential issues and addressing these memories and issues would be therapeutic (Ortega et al., 2020).

There was consideration among the families. A willingness to understand and care seems to be the key to making it possible to change your routines and make everyday life work. Being a family unit is what gives most families, the ability to endure the emotions and suffering that come with the ICU experience, and nurses can help families bear this experience (Alexandersen et al., 2021). A study with nurse-family relationship pointing out the importance of acting on a commitment to be with and for the family (Eggenberger and Nelms, 2007a).

Communication and someone to talk to outside the family also seem to be important prerequisites for managing the situation. The family members were anxious and worried about the future, and the former patients were worried about their recovery and forthcoming life. The way the family helped by confirming their love, a wish to go on in life, and by communicating with each other, was shown in another study also (Zhang, 2018).

During this pandemic, the possibility to be close to the ICU patient was minimal, as the restrictions in many hospitals meant that no one was allowed to visit. So, consideration had to be shown in other ways. Visits and physical meetings are things that have been crucial for family members in other studies. A GT study of family members working to get through critical illness showed that family members were engaged in

gaining access, to be present with and for the patient cared for in the ICU (Vandall-Walker and Clark, 2011). In our study this was not something that could be investigated, as it was not possible due to the restrictions. Some clinics made it possible for the family members to visit digitally with 'Face-time' to see for themselves how the ICU patient was cared for. Communication via telephone and video in the ICU during Covid-19 appear to be a somewhat effective alternative when in-person communication is not possible. Use of communication strategies specific to phone and video can improve the experience (Kennedy et al., 2021).

There are several emotions and existential issues related to ICU care and these feelings were reinforced by the pandemic. This constant high mortality for ICU-treated, Covid-19-infected patients (Armstrong et al., 2020) was something that affected the anxiety of families having a member staying at the ICU. A qualitative evaluation study recommends a specialised family support role with a nurse-led family support intervention in ICU to improve the quality and efficiency of care provided to families of ICU-treated patients. To increase the healthcare teams' capacity and ability to meet families' needs (Naef et al., 2020). Both the patient and their family had a need to talk about the experiences and to feel well informed in order to be able to continue with their lives. This was shown in a study encouraging health care professionals internationally to involve family members and provide focused information and support throughout hospital admission and recovery (Ågård et al., 2015). The way they talked to persons about their experiences and how to try to stay healthy was an important way to give back to society. It was a response to duty, love, commitment, and obligation, based on their relationship with the patient (Vandall-Walker and Clark, 2011).

The family members were satisfied with having information from the physician at the ICU although they assumed the healthcare professionals had a lot of work to do at the hospital attending the critically ill patients. A study of family satisfaction in the ICU in Norway showed a potential for improvement in relation to how well the family members were informed about what was happening to the patient and the degree of consistency in the information (Haave et al., 2021).

The way the families managed these existential issues with a willing to value consideration, though they feel anxiety and insecurity in life by communication made an insight into the unpredictability of life.

Strengths and limitations of the study

The characteristics of the ICU-treated patients and their family varied considerably. Across this broad range of characteristics, concurrent patterns of family functioning were revealed, increasing the scope of the theoretical construction. Regarding the selection procedure, we wanted a multiplicity of families' experiences regarding intensive care. A limitation could be that due to the pandemic the ICU patients differed regarding age, other underlying diseases or risk factors, and country of birth. Perhaps those included here were not typical pre-pandemic ICU patients. A limitation is that families of foreign origin are not included. The big range in terms of time post ICU discharge for the patient can be a bias but was made to follow the theoretical sampling to find out a range of different families' experiences of family functioning.

Saturation was reached after five interviews, with nothing new emerging from the data, then three more interviews were conducted, just to fill the categories, and make them stable. The interview conducted with the extreme case, strengthened the results and thereby strengthened the theoretical construction (Glaser, 1978, 1998, 2002, 2007). Family interviews were performed in this study because a family's ability to function is hard to determine by asking only one family member, even if families sometimes express their views more openly on this subject in individual settings (Åstedt-Kurki et al., 2001; Eggenberger and Nelms, 2007b). It could be speculated that there might be problems conducting interviews online, but digital interviews are similar to face-to-face interviews (Lackey et al., 2021; Holmberg, 2019).

Workability was ensured by the core category according with the objective of the study, making the concept family functioning useful.

Relevance means that the results given in the core category and the categories are recognised by other family members in similar situations. Relevance and objectivity were ensured by agreement among three independent researchers, who analysed the data and verified the findings (Glaser, 1978, 1998, 2007).

Conclusion

Being able to talk, repeatedly, about existential issues, anxiety and insecurity in life, with people that understand the feelings and have similar experiences helps the patient and their family to consider and gain insight into the unpredictability of life and thereby better cope with changes in life. 'Being one of those' infected with Covid-19, highlighted that they had someone to relate to, and might have made it easier for them to communicate about issues and having a say in the everyday conversation of the pandemic.

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Ethical approval

The Ethics Review Board approved the study (Record no. 2020-04124, 2021-05103, 2021-06585-02).

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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