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Strict isolation requires a different approach to the family of hospitalised patients with COVID-19: A rapid qualitative study

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ABSTRACT

Background: The outbreak of the COVID-19 pandemic influenced family-centred care dramatically due to restricting visiting policies. In this new situation, nurses were challenged to develop new approaches to involve family members in patient care. A better understanding of these changes and the experiences of nurses is essential to make an adaptation of procedures, and to secure a family-centred approach in care as much as possible.

Objectives: The aim of this study was to investigate how family involvement had taken place, and to explore the experiences of nurses with family involvement during the COVID-19 outbreak. In addition, we aimed to formulate recommendations for the involvement of family.

Methods: We conducted a qualitative study using patient record review and focus-group interviews between April and July 2020. We reviewed records of patients with confirmed COVID-19, who were admitted to the COVID-19 wards at two affiliated university hospitals in the Netherlands. All records were searched for notations referring to family involvement. In two focus-groups, nurses who worked at the COVID-19 wards were invited to share their experiences. The Rigorous and Accelerated Data Reduction (RADaR) method was used to collect, reduce and analyse the data.

Results: In total, 189 patient records were reviewed and nine nurses participated in the focus-group meetings. Patient records revealed infrequent and often unstructured communication with focus on physical condition. Nurses confirmed that communication with family was far less than before and that the physical condition of the patient was predominant. The involvement of family in care was limited to practicalities, although more involvement was described in end-of-life situations. Nurses experienced moral distress due to the visiting restrictions, though some acknowledged that they had experienced the direct patient care so intense and burdensome, that family contact simply felt too much.

Conclusion: The communication with and involvement of family in hospital care changed enormously during the COVID-19 outbreak. Based on the identified themes, we formulated recommendations that may be helpful for family-centered care in hospitals during periods of restricted visiting policy.

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What is already known about the topic?

- Family-centred care is beneficial for both patients, family members and healthcare professionals.
- Regular and structured communication with family members are core elements of family-centred care.
- It is highly valued that both patients and their families are engaged in communication and decision-making.

What this papers adds

- During the COVID-19 outbreak the communication with family was mainly made through video or telephone calls, was often unstructured and the physical condition of the patient was predominant.
- The involvement of family in the care was limited to practicalities.

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- A list of recommendations, e.g. provide regular and structural communication that includes physical, psychological, social and spiritual aspects, facilitate video calling, and explore and facilitate the involvement of families especially in situations of delirium and in end-of-life care.

1. Introduction

The COVID-19 pandemic forced hospitals worldwide to restrict their visiting policies. The presence of family members was limited or even eliminated in order to protect patients, families and healthcare professionals, and to save the limited personal protective equipment. These new policies put the family-centred care approach in hospital care under enormous pressure. In family-centred care, presence of family facilitates "a mutual beneficial partnership in the planning, delivery and evaluation of care among healthcare providers, patients and families" (Institute for Patient- and Family-Centered Care 2020). However, COVID-19 restrictions made this partnership difficult to realize.

Family-centred care is important as it improves the quality of care (Berger et al., 2014). There has been a growing number of studies showing that family-centred care benefits both patients, family members and healthcare professionals (Park et al., 2018). Nurses have the opportunity to promote the involvement of families in patient care, and their attitudes and perceptions may help or hinder this practice (Mackie et al., 2018, Luttik et al., 2017, Benzein et al., 2008). In several studies, nurses reported that family involvement in care is important as they often gain a lot of worthwhile knowledge about a patient (e.g. about a pre-admission condition) and it gives family a feeling of being useful (Mackie et al., 2018, Luttik et al., 2017, Benzein et al., 2008, Maaskant et al., 2020).

The COVID-19 pandemic challenged nurses to develop new ways to involve family members in care. A better understanding of these changes and the nurses' experiences is needed to inform changes relating to family-centred procedures and to advise healthcare professionals and policy makers how to secure the benefits of family-centred care as much as possible. The aim of this study was to investigate how family involvement had taken place, and to explore the experiences of nurses with family involvement during the COVID-19 outbreak. Based on the findings, we aimed to formulate recommendations for the involvement of family members in situations when this cannot be taken for granted.

2. Method

2.1. Design

We conducted a qualitative study, using retrospective patient record review and semi structured focus-group interviews, between April and July 2020. The reporting of this study complies with the consolidated criteria for reporting qualitative research (COREQ) recommendations (Tong et al., 2007).

The Institutional Review Board of the Amsterdam UMC, location AMC decided that ethical approval of this study was not required as per the Medical Research Involving Human Subjects Act (W20_184#20.218). The Medical Ethics Review Committee of the Amsterdam UMC, location VUmc endorsed this decision (2020.265). All data were collected, analysed and reported anonymously. Participants of the focus-groups gave written informed consent and confirmed their consent for audio recording at start of the focus-group interviews.

2.2. Context

In the Netherlands, the first COVID-19 case was confirmed on 27 February 2020. The rapid spread of the disease resulted in a so-called "intelligent lock down". Social distancing rules were strongly advised. All citizens were requested to stay at home as much as possible, not to shake hands, and to keep at least 1.5 m distance from other people. Restaurants, schools, gyms and contact professions such as hairdressers were closed for approximately three months (De Haas et al., 2020). The number of beds on Intensive Care Units (ICU) was gradually scaled up from 1150 beds (6.4 beds per 100,000 citizens) to 1700 during March and April. At the peak of the outbreak in late March, 915 patients with a confirmed COVID-19 infection were admitted to an ICU (National Institute for Public health and the Environment (RIVM) 2020). A national coordinating centre for patient distribution was installed to ensure optimal use of the scarce ICU beds on a national level. Also, all non-urgent hospital care was cancelled to ensure capacity for COVID-19 patients. Hospitals did not permit visitors on COVID-19 wards and ICUs. On other wards, visiting options depended on patient category or ward policy, and exceptions were made in individual patient situations. During the first COVID-19 wave, hospitals and other health care institutions faced impending shortages in personal protective equipment, especially face masks.

2.3. Setting and participants

The study was conducted on five COVID-19 wards of Amsterdam University Medical Centres (Amsterdam UMC), consisting of two affiliated university hospitals. Originally, these wards provided care to patients admitted for surgery, internal medicine or lung diseases, and as from March 2020 changed to COVID-19 wards. The permanent nursing staff was temporarily complemented with nurses from other wards to fulfil the increased patient-nurse ratio. Adult patients ($\geq$18 years) with a confirmed COVID-19 infection, who were admitted to one of the COVID-19 wards, were eligible to be included in our study. For the focus-groups, we invited purposively nurses who had worked for at least four days on one of the COVID-19 wards during the study period. The nurses were approached by email, explaining the aim and practical details of the focus-group interviews.

2.4. Data collection and analysis

We used the Rigorous and Accelerated Data Reduction (RADaR) technique to collect, reduce and analyse the qualitative data (Watkins, 2017). The RADaR technique consists of the following consecutive steps: (1) data collection, (2) coding the information, (3) reduction, and (4) identification of main themes (Watkins, 2017). This technique has proven to deliver valid and timely findings, with an acceptable agreement with results from thematic analyses (Taylor et al., 2017, Vindrola-Padros and Johnson, 2020).

2.4.1. Phase 1: data collection

We used two sources of data; first, we reviewed patient records, followed by focus-group interviews with nurses. We made a random selection of 200 patients admitted to one the COVID-19 wards between 23 March and 26 April 2020. These patient records were searched for notations referring to family involvement. Only the COVID-19 admission period was reviewed; when a patient was admitted to the ICU, this period was excluded. To support data collection, we constructed easy-to-use tables that structured the data per patient per day. The data collection tables were pilot-tested by two researchers (JM, AE) through collecting data from five patient records independently. Discrepancies in interpretation were resolved through discussion.

A team of 11 senior and junior researchers collected the data. All researchers were nurses familiar with the electronic patient records. Each researcher received a short manual. During an online

meeting, additional instruction was given to familiarize the team with the research question, methods and data collection forms. A second meeting was organized after one week to discuss uncertainties and to establish consistency in reviewing the patient records. The leading researchers (JM, IJ, AE) were available for advice and supervision during the data collection period. To increase the reliability of our findings, two researchers (JM, IJ) double-checked the collected data of a random sample of 20% of the reviewed patient records. Discrepancies were discussed and resolved.

In addition to the patient records review, we organized two focus-group interviews. A topic list was used (Appendix A), based on the Families Importance in Nursing Care - Nurses' Attitudes (Benzein et al., 2008). The focus-groups were moderated by a female senior researcher (IJ, PhD and research associate public and occupational health) with a longstanding experience in qualitative research. Two researchers (MJ or ID) took notes, such as striking topics or emotions. The researchers had no formal hierarchical relationship with the participants. The focus-group interviews were conducted online with only the research team and participants present during the interviews. Nurses were asked to share their experiences with family involvement on the COVID-19 wards, as well as their lessons learned from contact with family during the pandemic. The focus-groups were audio-recorded and lasted approximately 60 minutes. The interviews were directly transcribed and relevant quotes were added to a focus-group data table.

2.4.2. Phase 2: coding the information from the patient records

For the coding of the extracted patient records data, the original data collection forms were adapted by adding a column. To facilitate the coding, a preliminary list of codes was constructed, mainly based on the core aspects of family-centered care (Kokorelias et al., 2019). This preliminary list consisted of 34 codes clustered in six categories: 'communication and collaboration with the family' (10 codes), 'education and support of family' (5 codes), 'context of the family' (7 codes), 'experiences of the family' (5 codes), 'experiences of the patient' (5 codes), and 'barriers and facilitators for contact' (2 codes). See Appendix B. Additionally, new codes could be added when considered relevant.

The information retrieved from patient records was randomly assigned among four researchers (JW, JB, SM, MJ) for coding. During an online meeting, the researchers undertaking the coding received instruction and practiced with quotes from a selected patient record. It was emphasized that the codes were suggestions and that the researchers were free to suggest new codes or give comments. Again, the leading researchers (JM, IJ, AE) were available for advice and supervision. The information from the focus-group interviews were coded using the same predefined coding list by two senior researchers (AE and IJ). Differences in coding were resolved through discussion.

After the coding was finished, the experiences of the researchers were discussed in an online meeting.

2.4.3. Phase 3: reduction

After coding, the four coding researchers were instructed to reduce the large amount of data from the patient records by deleting notes that they considered meaningless or repetitious by using the 'track changes' function in the texts. Two senior researchers (JM and IJ) double-checked all the suggested reductions. Subsequently, the senior researchers reread all the quotes and codes in the reduced data collection form, and further removed quotes that did not contribute to answering the research question. The remaining information was organized per code in a separate Excel document (AE). The data from the focus-group interviews were reduced by two researchers (IJ and AE) by removing quotes (by means of 'track changes') that did not contribute to the research question or was merely repetition of previous information.

2.4.4. Phase 4: identification of main themes

Three researchers (JM, AE and IJ) read the organized text from both patient records and focus-group interviews independently in an iterative way, keeping the research question in mind. Trends in the data and striking issues were discussed and summarized in categories. In consensus meetings, the identified categories of information were critically examined and overlapping issues were further refined and reduced into main themes. Quotes from the patient records and focus-groups that illustrated the themes were earmarked. In addition, preliminary recommendations were formulated.

2.5. Validation

We documented all stages of the study and its procedures to achieve transparency and coherence regarding the study data and the interpretations. The researchers crosschecked the data as described above. The preliminary results of the patient records analyses were checked in the focus-group interviews to increase validity. The researchers gathered and processed feedback and additional information from the research group during every stage of the study.

3. Results

3.1. Participants

We included 189 patients who were admitted to one of the COVID-19 wards during the study period (Table 1). Eleven patients were excluded, as COVID-19 was not confirmed. In total, 120 of the patients (64%) were male and the mean age was 63 years (SD 13). The median duration of the primary admission on a COVID-19 ward was five days (IQR 3.0–11.8). In total 49 patients (26%) were transferred to the ICU, which extended the hospital length of stay to nine days (median, IQR 5–14). Sixteen patients (8%) died on a COVID-19 ward and 13 patients (7%) were readmitted after initial hospital discharge. Subsequently, nine nurses participated in the online focus-group interviews, representing all COVID-19 wards in the two affiliated hospitals. Most nurses were female (89%), with a median age of 32 (range 23–56) and median work experience of nine years (range 2–22). Six nurses worked permanently on one of the four COVID-19 wards, two nurses occasionally when there were nurse shortages. One nurse was not directly involved in patient care, but pro-actively contacted families to give an update about the patient's condition.

Analysis of the qualitative data from both the patient record review and the focus-group interviews identified several themes concerning family involvement in the care. Data from the focus-groups revealed an additional theme: nurses' emotions and dilemmas. We present a narrative description of the themes, along with supporting quotes. Both the patient records and the focus-groups revealed barriers for family-centred care. These were used to formulate recommendations, which we present in Table 2.

3.1.1. Communication changed

Contact between family and healthcare professionals was mainly made through video or telephone calls. The person who made contact and the frequency were organized differently per ward, and changed over time. Most units had unstructured communication with family, often depending on individual actions of the family or the bedside nurse. Additional contact was provided by dedicated nurses or support teams. These teams consisted of nurses and physicians not involved in direct care, who had access to patient records and handovers. The support teams pro-actively contacted the family at least once a day to provide an update on the patients status. In the focus-groups the nurses told us

Table 1
Patients' characteristics.

		Total (n=189)
Baseline characteristics		
Male, number (%)		120 (64)
Age in years, mean (sd)		62.8 (13.1)
Living situation, number (%)		
	Living together with family members	110 (59)
	Living alone	40 (21)
	Other	8 (4)
	Unknown	31 (16)
Marital status, number (%)		
	Not married	24 (13)
	Married, registered partnership	104 (55)
	Widow	6 (3)
	Divorced	9 (5)
	Unknown	46 (24)
Primary admission		
Total length of stay in days, primary admission (i.e. COVID-19 ward and ICU), median (IQR)		5 (3.0-11.8)
Length of stay in days, primary admission on COVID-19 ward, median (IQR)		4 (3-8)
ICU admission, number (%)		49 (26)
Length of stay in days, primary admission on ICU, median (IQR)		9 (5-14)
Discharge location, number (%)[a]		
	Own living environment	102 (53)
	Rehabilitation	27 (14)
	Nursing home	22 (12)
	Family	3 (2)
	Other hospital	5 (3)
	Other healthcare institution	13 (7)
	Other	2 (1)
	Unknown	2 (1)
Mortality, number (%)		13 (7)
Secondary admission		
Readmission COVID-19 ward, number (%)		13 (7)
Length of stay in days, readmission COVID-19 ward, median (IQR)		3 (2.5-7)
Readmission ICU, number (%)		3 (2)
Length of stay in days, readmission ICU, median (IQR)		3 (0-3)
Discharge location re-admission, number (%)[b]		
	Own living environment	6 (46)
	Rehabilitation	2 (15.5)
	Nursing home	2 (15.5)
Mortality, number (%)[b]		3 (23)
Data Primary and Readmission Combined		
Total length of stay in days, COVID-19 ward, median (IQR)		5 (3-8)
Mortality, number (%)		16 (8)

Abbreviations: sd = standard deviation; IQR = inter quartile range; ICU intensive care unit
[a] Patients who deceased are reported in a separate row.
[b] Percentages only based on a subgroup of patients (i.e. patients who were readmitted).

that they had no involvement or input with the information conveyed when other others took over the contact with the family. They knew of these contact moments, but were unaware of the content of the communication. They also explained they sometimes felt uncomfortable not being in contact with the family themselves, and were not sure whether the processed information was complete and reliable.

> "It felt very unnatural to pass on and get back information via an intermediary. You never knew for sure whether the information had been communicated correctly." (Nurse, focus-group 1)

In the focus-groups, nurses explained that contact with families was far less than before the COVID-19 outbreak. The restricted visiting policy resulted in the absence of family, and (informal) communication stopped.

> "I had a lot less contact with the family, really a lot less. Especially since the patient did not receive visitors anymore, in the early days" (Nurse, focus-group 2)

According to nurses, family seemed sometimes reluctant to contact the ward; it seemed as they did not want to disturb the healthcare professionals. However, others contacted the ward frequently to get an update of the situation and to be reassured.

> "In the beginning there were many phone calls from the family to the ward. That took a lot of time, and was not always convenient. The family was very concerned, because there was so little contact with the patients themselves. They were so ill." (Nurse, focus-group 2)

In patients with language barriers, either family members were asked to translate, or colleagues who mastered the language. The usage of professional translation facilities was rarely mentioned.

> "Communication with Mrs. is difficult. Her daughter acted as interpreter this morning, which gave more clarity about how Mrs. felt." (Patient ID 084)

We noticed an increase in notes about the communication with the family when the care became more complex. This was especially prevalent when the patient deteriorated and was moved toward palliative care; documentation of the conversation with patient and family was given more attention, such as options for palliative care and preferences of patient and family towards end-of-life care.

An important precondition for contact between patients, their families and/or healthcare professionals was the availability of (working) telephones and tablets and skills to use them. On all wards, these devices were distributed; however, nurses were not

Table 2
Recommendations to address barriers in communication by telephone and video calling.

Barriers	Recommendations
Communication	
Less communication with the family.	Contact family as soon as possible after hospital admission (or transfer) to define a communication plan. Involve the patient when possible. Make clear who the (legal) family spokesperson is and how this person can be reached.
Families being ambiguous in seeking contact with the healthcare professionals.	Organize video calling (or telephone contact) with the spokesperson of the family as a standard at least daily on a scheduled moment. Assess daily the patient's ability to participate.
No devices available to make telephone or video calls, or nurses not aware of the availability.	Provide patients and healthcare professionals with telephones or tablets to make video calling possible 24/7. Make sure all healthcare professionals know about the availability of the devices. Encourage the family to organize devices (including charging equipment) to make video calling possible.
Limited technological literacy. Both patients and healthcare professional not familiar with video calling.	Provide patient instructions for video calling for different literacy levels and different languages. Organize training for healthcare professionals in the use of devices and how to support the patient and family using them.
Burdensome and high clinical workload on the ward.	If the bedside healthcare professional cannot guarantee the communication with the family, give this task to dedicated healthcare workers (support teams). Try to organize scheduled time to contact the family by nurses who care for the patient.
Focus on physical condition.	Do not limit the conservation to physical condition of the patients, but also talk about the psychological, social and spiritual aspects.
Several different healthcare professionals involved in the communication with the family.	Encourage continuity in who contact the family when possible. Try to involve healthcare professionals with an established relationship with the family. Make sure the healthcare professional responsible for contacting the family has got all information needed: medical, nursing and paramedical aspects of care.
Limited and unstructured documentation on the communication with family.	Make sure that the all information (clinical condition of the patient, situation of the family and the content of the communication) is documented, available to all healthcare professional involved. Describe and document the communication with the family on a daily base in the patient record.
Communication can be unstructured and difficult over the telephone and tablet.	Provide instruction on how video calling best can be performed, e.g. make an agenda, limit the conversation to the main topics, encourage story telling. Consider to use a communication framework, e.g. CALMER (Check in, Ask, Lay out issues, Motivate, Emotions, Record). Use the Teach Back method.
Mask hiding the face of the healthcare professional.	If possible make the video call from a place, where wearing a mask is not necessary. If protection materials are required, use pictures and nameplates, so the family gets an idea whom they are talking to.
Family and/or patient have a different primary language as the healthcare professionals.	Make use of translation services. Be reluctant to use family members as official translators.
Videocalling considered too confrontational.	Start the video call outside the patient's vision and prepare the family on the patient's situation. Check the emotional condition of the family during the conversation.
Family involvement in care	
Patients all look the same.	Use the possibility of proxy-anamneses at admission. Ask family members to describe the patient's life, life events, and important people. Also, learn about the patient's favorite food, music, television preferences. Use video calling or pictures to show the patient's environment to the family. This information facilitates conversation between healthcare professionals and patient.
Family involvement limited to practicalities.	Explore the wishes the involvement of the family in the care, and try to facilitate this as much as possible.
No role of the family in situation of delirium and anxiety.	Encourage family to bring personal belongings of the patient to the hospital: children's drawings, religious items, pictures. Help the patient and encourage the family to send audio, video or written messages to each other. Consider the use of a diary.
Limited attention for religious and cultural aspects.	Support family to share religious moments, like praying together. Request and facilitate pastoral care if desired. Pay attention to cultural rituals.
Limited role of family in end-of-life situations.	Explore the wishes of the family when the patient becomes terminal. Facilitate the wishes as much as possible without violating the safety measures. If the family is allowed to come to the ward, make sure it follows the protection measures strictly.
Discharge organization and preparation.	Contact family as soon as possible when discharge becomes in sight to define a plan: planning, destination, care at home. Involve the patient when possible. Provide information on the COVID-19 measures at home after discharge for different literacy levels and different languages.
Patient worries about the wellbeing of his family.	Make the wellbeing of the family part of the communication and discusses concerns.
Family experiences feeling of stress and anxiety.	Assess the psychological situation of the family. Include discussion relating to stress and anxiety as part of the communication, and organize support if needed, e.g. by a family support team.
Nurses' personal experiences and dilemmas	
Nurses experience conflicts and dilemmas, and feel dissatisfied with their profession	Organize daily moments of reflection, intervision or supervision. Stimulate nurses to discuss their experiences of the day. Ensure nurses feel supported, organize professional help or peer support if needed.

always aware of the availability. In addition, lack of skills to make video calls was hampering the communication.

> "I did not use video calling, I'm not used to this yet […], we never had a telephone that made video calling possible. This was all new to us." (Nurse, focus-group 1)

3.1.2. Communication was mainly focused on the physical condition

In the patient records, nurses frequently documented that the family had been informed about the physical condition of the patient, treatment and care planning. Information relayed to the families, e.g. saturation, laboratory values and changes in medicines was also included in the patients progress notes. Short-term prognosis (i.e. stable, deteriorating or recovering) and different 'what if' scenarios were described as well.

> "The family is told that we will treat her to the maximum with oxygen and antibiotics. The patient has deteriorated compared to yesterday. Explained that if the situation becomes worse, we will not transfer her to the ICU, nor resuscitate her. This because of the extensive medical history of the patient." (Patient ID 083)

The nurses who participated in the focus-groups confirmed that the physical condition of the patient was the predominant focus of the discussions with the families. All conversations seemed to focus on COVID-19 disease management only, and other existing health problems were given less attention. Even family members asked different questions as compared to the pre-corona period.

> "How is his respiratory rate, how is the saturation? Normally they [family] never ask that, never so specific." (Nurse, focus-group 1)

In contrast to the physical situation, healthcare professionals rarely reported information about the psychological condition of the patient. Incidentally, they verified the pre-COVID condition with the family when the patient's behavior was deviant or difficult to understand.

> "Partner still finds him somewhat confused and emotional. Gets angry and annoyed quickly. [….] Very different from how she knows him." (Patient ID 136)

3.1.3. Family involvement in care was limited

In the patient records, notes relating to family involvement were mainly restricted to practicalities, such as providing clean clothes and food. Sometimes, the family was explicitly involved in the care through video calls, i.e. when a patient experienced severe symptoms of delirium or anxiety. However, in the focus-groups nurses mentioned this had happened rarely, and that they had missed the presence family in those situations.

> "Is disoriented in time and location. Is delusional and hallucinates. Calling with partner gives some peace of mind." (Patient ID 136)

> "Perhaps if family had been around, they could have taken away the anxiety. They [the patients] came and left with a lot of fear. Understandable. If the family had been there, the experience might have been less traumatic." (Nurse, focus-group 1)

Both patient records and focus-group interviews revealed that visiting restrictions were loosened in end-of-life situations. Family often utilised the opportunity to visit the patient while sharing the limited time left. Their involvement seemed limited to being present.

> "Daughters were on the ward all evening. Son will be sleeping here tonight." (Patient ID 049)

Few notes mentioned discharge planning or questions from family about discharge. When family expressed concerns about potential transmission of COVID-19, an information sheet with instructions for the home was available for the family. However, not all nurses seemed aware of the availability of this information sheet. Sometimes family expressed feelings of not being competent with care activities that needed to be continued at home, e.g. oxygen and medicines, and were referred to information on the internet.

> "Everything is arranged for discharge. Daughter called that she did not know how the oxygen tank worked. She had not received information from the company. I gave her instruction and suggested that she could watch video instructions on the internet." (Patient ID 027)

3.1.4. Nurses' personal experiences and dilemmas in family contact

Nurses expressed ambiguous feelings about the possibility of family being present on the ward. Although they realized this was very important for patients and their families, they were also aware of the risks. They expressed concerns about the health of the family, especially when they noticed the visiting family did not act strictly according to the infection control policy. Beside the heavy workload demands of caring for a COVID-19 patient, nurses expressed having family present felt too much.

> "The disease was unknown to us, there was so much uncertain. Most of the time you needed to focus really well. You did not have time for family to be around." (Nurse, focus-group 2)

On the other hand, nurses felt it as unacceptable to refuse a family to the ward when the patient had become terminally ill.

> "It is against your feelings. Someone in the last phase of his life, and we had to tell that only one or two family members were allowed to come. We made exceptions though, yes, we did, maybe too often." (Nurse, focus-group 1)

Nurses were aware of the seriousness of the patients' situations and were therefore sometimes reluctant to organize video calls between patients and family. They expected seeing the patient in this situation would be frightening and worrying for the family. Others still organized video calls, and noticed that patients and families were grateful and happy, even if the patient looked exhausted.

> "At first I thought it would be very confronting and worrisome to see him on screen with an oxygen mask. However, when I saw how family and patient reacted; I felt that they were not more concerned, but more reassured. ……. They enjoyed seeing each other." (Nurse focus-group 2)

Nurses expressed feelings of depersonalization. With the focus on the physical condition of the patients COVID-19 symptoms, all patients looked more or less the same to the nursing staff. In addition, nurses themselves found it difficult to recognize each other due to the protective clothing.

> "What I noticed was that we all started to see the patients as the same kind of persons, and that the attention was mainly paid to things like oxygen, saturation, and breathing. Everything else, which is also part of the patient, like pressure sores or the social situation or other underlying problems, had disappeared to the background." (Nurse, focus-group 1)

4. Discussion

We aimed to investigate how family involvement had taken place, and to explore the experiences of nurses with family involvement during the COVID-19 outbreak. Our findings show that

the COVID-19 pandemic had a major impact on family-centred inpatient care. The communication with family seemed less than before and the physical condition of the patient was the focus in the conversations. The involvement of family in the care was limited to practicalities, although more involvement was described in situations of delirium and anxiety, and in end-of-life situations. Nurses experienced new moral dilemmas in the care of patients with a COVID-19 infection.

Regular and structured communication with family members, which is considered as one of the core elements of family-centred care (Kokorelias et al., 2019), was often lacking at the start of the pandemic. This may be explained by the enormous work pressure in COVID-19 care. This workload complicates the already challenging communication between healthcare professionals, patients and the family about prognosis, personal values and goals (Sanders et al., 2020). Nowadays, it is highly valued that hospitalized patients and their families be engaged in communication and decisions about the care in order to ensure that the care meets their needs and preferences (Heyland et al., 2013). This is also encouraged by studies that report favourable outcomes for patients, families and healthcare professionals when family-centred care interventions are implemented (Park et al., 2018).

Our study shows there was a strong focus on the physical condition of the patient. This might be explained by the uncertainty about the new virus. However, the focus on physical care is also observed in regular hospital care; most nurses seem to find it difficult to integrate the physical and psychosocial care in their interaction with patients (van Belle et al., 2020).

Communication methods changed during COVID-19. Healthcare professionals were often limited to use video and telephone calls for the communication with the family of hospitalized patients. Face-to-face contact was impossible and only occurred in exceptional situations (e.g. end-of-life care). Despite the fact that nowadays advanced technological tools are available to communicate (e.g. tablets, smartphones), our study revealed barriers, such as the unfamiliarity with these tools and limited skills on how to communicate via video calls. Indeed, studies revealed that hospital nurses hardly use devices and technology (Jongerden et al., 2019), and they do not feel competent using technology (van Houwelingen et al., 2016). Apart from the virtual conversation that already demands new skills, the pressure of explaining a rapidly changing reality, clarifying decisions in situations of scarce resources and supporting emotional conversations between a patient and his family by video calls, are new as well (Rubinelli et al., 2020). To overcome this barrier, communication training is strongly advised (Rubinelli et al., 2020, Back et al., 2020). Instructions and tools to support the communication between healthcare professionals, patients and their families using telecommunications have been recently published (Flint and Kotwal, 2020, Calton et al., 2020, Negro et al., 2020) and can be used to develop local protocols. Most of these (expert opinion based) instructions are congruent with the recommendations based on our research.

The nurses involved in our study mentioned that family involvement was limited to practicalities and they missed the presence of the family, especially in situations the patient was delirious or anxious. It is suggested that the incidence of delirium among COVID-19 hospitalized patients is rising, probably due to the isolation measures and personal protective equipment of the healthcare professionals (Mcloughlin et al., 2020, Cipriani et al., 2020). Because family can play an important role in the prevention and treatment of delirium (McKenzie and Joy, 2020), research on how to involve family in the care for delirious patients during periods of visiting restrictions is urgently needed.

COVID-19 may not only affect patients' well-being, but also the emotional well-being of families due to social distancing. Studies revealed that families find it stressful if they are regarded as a resource for the patient without being seen as persons with their own needs (Andersen et al., 2019). It is, therefore, important to recognize if family members suffer physically and/or mentally, as illness affects both patient and the family, and family may play an important role in the recovery through providing practical and emotional care (Northouse et al., 2012, Northouse et al., 2012). In this study, we focused on the experiences from the nurses' point of view. We acknowledge that the voice of patients and family members can add value to our results. However, our recommendations are in line with recently published studies revealing that patients admitted to a COVID-19 ward often feel lonely, anxious and stressed due to the viral nature of the disease and the isolation measures (Fan et al., 2020, Sun et al., 2021, Brooks et al., 2020, Azoulay et al., 2020, Hafner, 2020, Bouchoucha and Bloomer, 2020). Furthermore, patients experience concerns regarding family health and living arrangements after hospital discharge (Fan et al., 2020, Sun et al., 2021). The results are congruent with reported experiences from patients who were isolated during previous pandemics, such as SARS, Ebola and H1N1 influenza (Brooks et al., 2020). Publications reporting on the experiences of families of hospitalized COVID-19 patients suggest that the concerns of the hospitalized patients are shared by their families (Azoulay et al., 2020, Hafner, 2020, Bouchoucha and Bloomer, 2020). The experiences of patients and families strengthen our recommendations.

Family support may become even more important when the patient is discharged home where the family often have an important role in the recovery and rehabilitation (Desai et al., 2015). As most patients with COVID-19 need care after discharge, the engagement and support of the family during transitions is crucial. Although strong evidence is lacking due to the novelty of illness, this may be done by earlier described interventions such as individualized discharge plans, transitional needs assessments and family tailored discharge education (Desai et al., 2015, Mallory et al., 2017). As bedside teaching is impossible, new education materials such as instruction videos and e-Learnings must be developed (Frentsos, 2015).

In addition to these results, we also found that the visiting restrictions caused moral distress and ethical dilemmas to some nurses. Moral distress can be described as the negative experience of psychological imbalance related to a moral dilemma (Morley et al., 2019). This may occur when nurses cannot fulfil their moral obligation to a patient, such as delivering the best care possible, or fail to pursue what they believe to be the correct course of action caused by forces that are out of their control (Mehlis et al., 2018). In this study, nurses often felt that the absence of families on the ward resulted in reduced quality of delivered care (e.g. in situations of delirium and anxiety) and found it hard to cope with (e.g. in end-of-life situations). A systematic review about nurses' experiences during pandemics shows that the rapid changes of policies and guidelines, increases the stress levels among nurses, who are already very busy (Ferandez et al., 2020). In addition, the lack of preparedness of the organization in terms of staffing, protocols and personal protection equipment is seen as burdensome for bedside nurses (Ferandez et al., 2020). The nurses in our research also described quickly changing protocols and working with very strict personal protection rules were burdensome.

Communication with and involvement of the family during social distancing rely on the availability of computers, smartphones or tablets, stable internet access and technological literacy. One should be aware of differences between families, e.g. age and socioeconomic status, access and skills to electronic devices and internet (Smith and Magnani, 2019). In order to avoid health disparities, it is essential to find solutions when barriers exist. Privacy considerations must also be taken into account. The security of technology and technology platforms, compliant with the privacy

legislation must be prioritized when video calls become part of our care (Wierda et al., 2020).

4.1. Methodological considerations

This study has several limitations. First, we retrospectively reviewed the patient records and the results are based on the documented information that may be biased. Therefore, we used the experiences of the nurses in the focus-groups to supplement the data from the patient records. This triangulation increases the validity of our results (Carter et al., 2014). Secondly, using focus-groups might create reluctance among the participating nurses to share experiences. However, we emphasized confidentially and anonymity. As the nurses shared emotional and difficult topics, the gathered information appeared open and honest. Thirdly, a well-known phenomenon in qualitative research is the influence of pre-existing opinions of the researchers. To ensure the validity and credibility, we therefore made field notes during all stages of the research and reflected on subjective interpretations. Finally, we used the RADaR technique to analyse the qualitative data instead of the thematic analyses that is considered the golden standard. However, the RADaR method has proven to deliver valid and timely findings (Taylor et al., 2017, Vindrola-Padros and Johnson, 2020).

5. Conclusion

In conclusion, our results highlighted that the involvement of the family in the hospital care changed enormously during the COVID-19 outbreak. Family was mainly contacted by telephone and video calls, the communication was unstructured and the conservations were focused on the physical condition of the patient. Family involvement was very limited, although this increased in end-of-life situations. Nurses shared their dilemmas in the contact with family on the COVID-19 wards. Based on the identified themes, we formulated recommendations for family-centred care in hospitals during periods of restricted visiting policy.

CRediT authorship contribution statement

J.M. Maaskant: Conceptualization, Methodology, Validation, Formal analysis, Data curation, Writing - original draft, Writing - review & editing, Supervision, Project administration. **I.P. Jongerden:** Conceptualization, Methodology, Validation, Formal analysis, Writing - review & editing, Supervision. **J. Bik:** Validation, Investigation, Writing - review & editing. **M. Joosten:** Validation, Investigation, Writing - review & editing. **S. Musters:** Validation, Investigation, Writing - review & editing. **M.N. Storm-Versloot:** Validation, Investigation, Writing - review & editing. **J. Wielenga:** Validation, Investigation, Writing - review & editing. **A.M. Eskes:** Conceptualization, Methodology, Validation, Formal analysis, Resources, Data curation, Writing - review & editing, Supervision, Project administration.

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Declaration of Competing Interest

None.

Appendix A. Topic list used in the focus-group interviews

Communication with the family

1. How was the communication organized? Who were contacting the family.
2. Were there guidelines/protocols for the communication with the family?
3. Do you have any experience with video calls?
4. Can you describe the facilitators and barriers you experienced in collaboration with the family?
5. Can you share a situation that you remember about the communication with the family?

Involvement/participation

6. How were families involved in the care? Did you see opportunities?
7. Can you describe a situation that the family was present in the hospital?
8. When were families allowed to come to the hospital?
9. Did you missed the presence and involvement of the family?
10. Can you describe situations that you wished the family to be around?

Preliminary results from the patient records review

11. Do you recognize the following impression we gathered from the patient records? Please comment

    - Focus on medical condition.
    - Unstructured communication with the family.
    - Video calls not part of the plan of care.
    - More contact in complex situation (palliative and end-of-life situations).
    - Limited involvement of family in the care.
    - Some support of the family during discharge.
    - Limited and unstructured documentation of family communication and involvement.

Lessons learned

12. What would you do different next time?
13. What do you think are priorities for the communication with and involvement of the family with restricted visiting policies.

Appendix B. Code list used in the patient records review

Research question

Explore the experiences of families and nurses regarding communication with and involvement of the family in the care during the COVID-19 outbreak.

Communication and collaboration with the family

1. Physical condition patient.
2. Emotional condition patient.
3. Situation at home.
4. Transfer.
5. Discharge planning.
6. Proposed plan of care (curative).

7. Proposed plan of care (palliative).
8. Terminal care.
9. Wishes and preferences of the patient with regard to the plan of care.
10. Wishes and preferences of the family with regard to the plan of care.

Education and support of family

11. Written information, like leaflets.
12. Care after discharge, e.g. quarantine advices.
13. Emotional support.
14. Information on the physical condition of the family members.
15. Information on the emotional condition of the family members.

Context of the family

16. Presence of family in hospital.
17. Possibility of being present.
18. Involvement of family in the care.
19. Practical support by family (e.g. clean clothing).
20. Cultural background.
21. Religious background.
22. Barriers in communication with the patient, language/translator.

Experiences of the family

23. Satisfaction with the possibilities of contact.
24. Dissatisfaction with the possibilities of contact.
25. Expressions of worries and fear/anxiety.
26. Satisfaction with the plan of care.
27. Dissatisfaction with the plan of care, anger.

Experiences of the patient

28. Satisfaction with the possibilities of contact.
29. Dissatisfaction with the possibilities of contact.
30. Expressions of worries and fear/anxiety.
31. Satisfaction with the plan of care.
32. Dissatisfaction with the plan of care, anger.

Barriers and facilitators for contact

33. Availability of a mobile phone, iPad.
34. No internet access.

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