Barriers to Organ Donation

A qualitative study of intensive care nurses' experiences

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Abstract

Background: An increasing number of patients affected by organ failure can be treated with organ transplantation. The need for organs available for transplantation is critical and patients die while on the transplant list. ICU nurses are essential in facilitating organ donation through their ceaseless bedside care for potential organ donors and their families.

Aims and objectives: To describe the challenges faced by ICU nurses in the organ donation process.

Design: A descriptive qualitative study design.

Method: Semi-structured individual interviews of nine ICU nurses from one university hospital were performed. Data were analyzed using Malterud's Systematic text condensation.

Results: Three themes describe the core of the results: 1) practical tasks, 2) challenging care for the next of kin, 3) ethical and emotional challenges.

Conclusions: Practical tasks represent challenges in the organ donation process that are not previously revealed. Actions to address these challenges should be prioritized to promote organ donation. Simulation-based training may optimize practical aspects of the organ donation process and implementation of simulation-based training should be assessed by future research.

Key words: Critical Care Nursing, Brain Death, Qualitative Research

What does this paper contribute to the wider global clinical community?

- This study describes the ICU nurses´ challenges in the organ donation process.
- The study reveals practical issues not yet described and this knowledge can improve future organ donation processes.
- Simulation based training could be necessary to improve donation rates.

Introduction

Organ transplantation is a cost-efficient[1] and lifesaving treatment for patients with end-stage organ failure. New techniques for organ harvesting and more effective immune suppression medications have greatly improved clinical outcomes, such that organ transplantation is considered as a miracle of modern medicine. [2-4] To be considered for postmortem organ donation patients must have severe brain injuries and suspected brain death. Potential donors are treated in intensive care units (ICUs) where intensive care nurses (ICU nurses) play a vital role in the multidisciplinary team of healthcare professionals by coordinating the organ donation (OD) process and caring for the next of kin.[2,5] The nursing care of the potential donor includes monitoring vital parameters, administration of intravenous therapy to maintain organ perfusion, and reacting to critical medical problems. By facilitating bedside presence and conversations for the families, ICU nurses ultimately promote consent to OD.[2,5] Furthermore, the OD procedure is demanding in terms of resources and requires considerable knowledge and commitment of multidisciplinary teams of healthcare professionals.[6]

In Norway donation rates have decreased over the last decade and implementation of methods such as donation after circulatory death (CDC) has not contributed to an increase in number of organ donations. Donation after brainstem death (DBD) is used in most cases.[7] Confirmation of brain death is based on a mandatory cerebral angiography and a declaration of death by two physicians, where one of them must be a relevant specialist.[8] Looking to Spain, where donation rates have been constantly high over the recent years, sufficient intensive care capacity, medical competence and interest are believed to be crucial in maintaining high donation rates.[9]

A recent systematic review identified several factors that hamper OD including healthcare workers' education, attitudes, and experiences with OD.[10] Another study found that not identifying or referring donors to the donor coordinator is caused by a lack of knowledge

about OD, emotional unreadiness in the next of kin, and suboptimal communications skills of the physicians.[11] Health care professionals attitudes also plays a major part.[12] A recent qualitative study investigating ICU nurses experience with OD report that caring for the donor is experienced as highly demanding and that the process is challenging regardless of years of clinical experience.[13]

The shortage of donor organs is a major problem with the increasing number of patients who require transplantation, and every year patients die while on the organ waiting list.[7,14] Resolving the disparity between organ supply and demand is a global public health challenge. In Norway, legislation was revised in 2015 in order to increase OD rates with emphasis on the wish of the deceased,[8] yet consent of the next of kin is always obtained before proceeding to OD. Despite the Scandinavian population in general being positive towards organ donation,[15] inefficient OD processes in ICUs leads to many potential donors in Scandinavia miss the opportunity to donate their organs. In addition, donation from deceased donors have decreased over the last decade.[7]

A number of studies have reported experiences, perceptions and attitudes of OD from the perspective of ICU nurses,[16-20] while there have been few recent studies specifically addressing challenges experienced by ICU nurses during the OD process. Hence, the purpose of this study is to describe the challenges faced by ICU nurses in the OD process. Considering the essential role of the ICU nurse in their bedside care for the potential donor, describing these challenges may contribute to improving the OD process and achieving higher donation rates.

Methods

Study design

This was a qualitative, descriptive study involving individual semi-structured interviews to

gather data. This design was selected as it allowed the participants to speak more openly. The study adheres to the COREQ guidelines for qualitative studies.[21] (See supporting information in Appendices)

Participants

The study was approved by the Norwegian Centre for Research Data (project no. 54232). A purposive sampling strategy was used. After obtaining permission from the involved ICUs, information letters were posted in the break rooms of the two ICU´s at the hospital that admits patients with severe brain injuries.

Inclusion criteria were post graduate education as an ICU nurse, a minimum of 2 years work experience at an ICU where ODs are performed several times a year, and experience as main caregiver nurse in two or more OD processes where the OD was carried out. Through strategic sampling, including participants with the most experience on the field, seven ICU nurses consented to participate in the study. Through snowball sampling, two more ICU nurses were asked to participate and consented. All the participants met the inclusion criteria.

Time of recruitment and data collection was June–september 2017. and written informed consent was obtained from all participants. To ensure further confidentiality, all audio recordings were deleted after verbatim transcription. The characteristics of the participants are presented in Table 1.

Table 1. Participant's characteristics

Characteristic	Value
Participants	9
Age, years	47 (33–59)
Sex	
Female	7
Male	2
Working department	
General intensive care unit	5
Neuro intensive care unit	4
Experience as intensive care unit nurse, years	13.4 (5–19)
Experience as head nurse in organ donation in the last 5 years	6 (2–10)

Data are presented as n or median (range).

Context

The title ICU nurse in Norway is based on 18 months post graduate education in ICU nursing, with a prerequisite of at least two years of clinical practice after graduation from the bachelor`s degree. The postgraduate education is the preferred competence for working at an ICU. At the hospital where the study was conducted, there is no dedicated coordinator to manage potential organ donations. Instead, the ICU nurse dedicated to the patient care facilitate organ donation by observing vital parameters, facilitating the next of kins time bedside with the donor and coordinate important conversations with the physicians and the next of kin.

The hospital has several ICUs, but two in which patients with severe brain injuries are treated. One ICU is a high-level unit that treats failure in all organ systems in adults with 120 employees among the nursing staff. The second is a neuro-ICU, a considerably smaller unit with 45 nurses in the nursing staff. Both ICUs treat potential organ donors until OD is carried out. The hospital where the study was conducted is located several hours drive from the transplant center.

Data were collected in 2017, but there have been no changes in procedures and regulations since. The hospital has not had any cases in which CDC method was used.

Data collection

The interviews were conducted using a semi-structured interview guide developed by both authors (table 2). The purpose of the interview guide was to facilitate so that the participants could talk freely about the potential challenges they face in the organ donation process. To assess its purpose, two pilot interviews were conducted with interviewees that had retired from being an ICU nurse but had some experience in caring for organ donor patients. No changes were made to the interview guide after the pilot interviews. To promote a rich data material and to elicit a description of the challenges in the OD process, questions were designed to be short, open, and general, with emphasis on asking necessary follow-up questions.

All interviews were performed in a private meeting room near the participant's working department and were audio-recorded and transcribed verbatim before the next one was conducted. The interviews lasted between 35 and 75 min. The participants received written information about the study and its purpose, information about storage of audio tapes, and the consent form in advance. At the beginning of each interview the information described above was repeated orally. Assurance of confidentiality was repeated verbally before the participants signed the consent form.

Table 2. Interview guide

1. Can you share experiences of caring for an organ donor?
2. Can you tell me about the last time you took care of an organ donor?
3. Can you remember any challenges you have dealt with while taking care of an organ donor?
4. Can you tell me about situations with organ donors where donation never was carried out?

After audio recording commenced, the interview included questions about sharing experiences (eg, “Can you share experiences from the last time you were the nurse responsible for an organ donor?”). If necessary, follow-up questions were asked to avoid misunderstandings and ensure that the conversation was directed toward the research questions. After nine interviews, data saturation was achieved as no new information was added. The interviews were transcribed verbatim by the first author.

Data analysis

Data analysis was conducted following Malterud’s Systematic text condensation (STC), a method developed for analyzing qualitative text data based on Giorgi’s phenomenological analysis [22,23]. The method is especially suited for the novice researcher as it facilitates intersubjectivity, reflexivity and feasibility while maintaining methodological rigor. The objective of STC is to describe phenomena as experienced by the participants themselves.[23]

The analysis was conducted stepwise (Table 3). Firstly, to identify preliminary themes, the interview transcript was read several times to get a general sense of the data material. Secondly, text fragments (meaning units) containing information pertaining to the research question were identified and sorted using the preliminary themes from step 1 as a guide. The meaning units were then decontextualized and organized by codes for cross-case synthesis. The raw material and preliminary themes were used as guides to ensure that the coding was correct. In the third step, the content of each of the code groups was condensed and abstracted into an artificial quote. Lastly, a description and content for each subgroup were developed that represented the results of the study. The authors discussed the preliminary themes and codes, and the analyzed text was regularly compared with the meaning units. To ensure and safeguard the meaning content and the participant’s voices, both authors analyzed the data material carefully.

Table 3. Examples of steps in the text analysis

Meaning unit	Condensed quote	Subgroup	Category
"*It is troublesome; I have found myself searching the hospital lobby for the courier service asking people if they are here to pick up the blood work. This system is not satisfying and it's time-consuming when you think about all the other stuff you've got to do.*"	"*I find it time-consuming to coordinate the shipment of the material for human leukocyte antigen typing; the interaction with the courier service makes it difficult.*"	Challenging shipment of blood samples	Practical challenges
"*To complete all the tests and examinations the nursing care is really important. For example, if you are aiming to preserve the lungs, you will be repositioning, performing tracheal suctioning, and repositioning again. But you also need to measure temperature and do a lot of practical tasks and get things right.*"	"*The organ donation process is exhausting to me, with a lot of practical tasks.*"	Heavy workload	Practical challenges

Trustworthiness

We followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (See Supporting Information). The first author, who performed the interviews, was an ICU nurse with several years of experience from the neuro-ICU at the university hospital. The co-author was a university employee/operating room nurse with no experience working in the ICU, but with experience in OD from the surgery department.

Four of the participants knew the first author beforehand, having worked together as ICU nurses at maximum two years before this study was conducted. The interviewer's preconceptions about the interview themes were thoroughly described, written down, and discussed with the co-author before the interviews were conducted. Based on scientific literature and experience from the OD process, the author's preunderstanding of the

phenomena was centered towards OD being an emotional burden for the health care professionals involved. The interpretation of the results was later extensively discussed with regular reflection on previous experiences, values, and preunderstanding. In addition to a thorough description of the analytical method, examples of data analysis and quotations from the raw data contribute to the transferability and authenticity of the findings.[24] After the conclusion of each interview concluded the participants were offered to either listen to the recording from the interview or read the transcript. Only one of the ICU nurses expressed interest in doing so and received the transcript from the interview.

Findings

The data were structured into 3 themes based on the various challenges experienced by the nurses including practical challenges, challenging care for the next of kin, and ethical and emotional challenges.

Practical challenges

Most of the participants described difficulties regarding the shipment of blood samples for human leukocyte antigen (HLA) typing; these were practical issues related to coordination with the external shipment service. The study was conducted at a university hospital in Norway that is several hours drive from the transplant center and blood samples for HLA typing need to be transported to the transplantation center by road and air. This process was described by the participants as problematic. Firstly, participants found it difficult to get the timing right in these situations as the process of sending material for HLA typing includes drawing a sample of blood and coordinating with a courier service, the next of kin, and a flight in order to safely deliver the sample to the transplant center. The entire process was described by several participants as more complicated than necessary. One participant

experienced a situation in which calls were made to the external shipment service offices in Sweden where communication in Swedish and English language was required in order to ship the samples to the transplant center.

> *It is difficult to get hold of the right people, to find the correct telephone number. During weekends or nights, I do not know who to contact. When they arrive at the hospital, they tend to get lost and cannot find the ward […]. There is a lot of coordination related to this procedure that is time-consuming.*

Another participant had to leave the ICU floor to guide the courier service to the ICU ward. In one case, where the courier failed to arrive at the hospital, the participant delivered the package to the airport in person.

> *Once, when I finished a weekend morning shift, I was so fed up with trying to organize transport for the blood samples that I drove to the airport myself to deliver the package.*

One participant described several aspects of the workload related to the potential organ donor; preserving the dignity of the donor; nursing workload with organ preservation in mind; and obtaining consent from the next of kin. The multifaceted challenges made nursing care for potential organ donors more demanding than the care of other ICU patients. The participants described the work as stressful because it requires communicating and planning with the team of healthcare professionals, next of kin, and external services. The participants felt that protecting the patient's dignity was of special importance in the OD process. Caring for the donor and the next of kin was however made difficult by the extensive clinical examinations, intrahospital transportation, and the presence of a large number of health professionals surrounding the donor's bed.

> *Who will speak to the family? When are we going to do it? You are supposed to coordinate the daily care of the ICU-patient, practical tasks, doctors, and family, and you also have to take care of the patient. Finally, you must ship the blood samples in order to get them on the next flight.*

Challenging care for the next of kin

The participants reported that caring for the next of kin was a challenging aspect of the OD process because of the question of OD itself, a lack of relationship to the next of kin, and the next of kin's lack of knowledge of brain death.

The conversations with the family regarding OD was seen as challenging. The participants worried about the outcome from raising the OD question to the next of kin, the doctors' communication skills and approach to the topic, the lack of coordinated planning between the ICU nurses and doctors, and finally the use of medical language. In situations where the doctor used complicated language, the ICU nurses felt that they could contribute after conversations with the next of kin by clarifying difficult terms and phrases at the bedside. However, this was challenging or even impossible if the doctor failed to include the nursing staff in these conversations.

> *During a night shift we were short staffed, so the doctor went ahead and talked to the family without me. When they came back from the conversation, I felt unprepared once they asked follow-up questions.*

The ICU nurses were also of the opinion that the ICU doctors were best suited to making the OD request as the request made by other doctors was seen as a potential barrier to the desired outcome of obtaining consent for OD. The participants also recounted how a lack of planning had resulted in several conversations taking place with multiple relatives instead of just the closest ones.

> *We did not have a good talk in advance, and I was caught off guard. The conversation took a wrong turn, including a lot of medical terms, and the relatives understood nothing of what we were trying to say other than the term 'organ donation', which caused an outcry.*

Caring for the next of kin in OD situations was exhausting for many of the participants. Some

reported a lack of relationship with the closest family members and approaching and connecting with relatives was seen as challenging. When the ICU nurses were unable to get this connection and achieve the desired level of emotional intimacy, they felt unable to make a meaningful contribution. The participants wanted a relationship with the closest family members that was characterized by confidence. They wanted their communication to be felt as supportive and clear by the next of kin, but because of the burden of the OD process and demand for progress, there was insufficient time to establish such a relationship.

> *The seriousness of the situation soon becomes clear and the whole process could be over in a couple of days. You are endeavoring to reach out to the family, but it is challenging to do so in such a short span of time [...]. When this relationship fails, you feel like you have not contributed.*

The ICU nurses perceived that the OD process was complex and confusing for many family members. After several conversations on the topic of OD and even after the question of OD had been raised, the next of kin still doubted whether their loved one was alive and doubted the concept of brain death. The participants recounted that they had to repeat information several times and use means such as talking about the potential donor rather than talking directly to the patient as they normally do, which was perceived as unnatural because of their fundamental notions of life and death. The next of kin’s perceptions also posed challenges for the nurses; as one of the participants was accused on focusing only on the organs for donation, and not on saving the patient. Another participant described a situation where a family did not wish to have their loved one’s organs donated based on their opinion of the donor’s health.

> *Everything looks the same, but he is dead. Am I sending unambiguous signals? How do I act in front of the next of kin? Do they get it? I cannot talk to the patient. For them to comprehend, I must show that I understand that he is dead as well.*

Ethical and emotional challenges

Sometimes the OD process was prolonged by the wait for a matching recipient or uncertainty

of the diagnosis. These situations often prolonged the suffering of the next of kin and left some ICU nurses doubting OD as an option. Some of the participants felt that prolonging the process was unethical with respect to the donor. Doubts over the concept of brain death made care of the potential donor challenging. One ICU nurse stated that despite her education and extensive training, she was skeptical about the definition of brain death. Another described how she had to change her fundamental beliefs about brain death in order to accept that a potential donor was in fact dead.

> *I'm not 100% convinced. However, if an angiography shows no circulation, then it is over. But I still doubt.*

Impressions of the donor corpse also caused emotional challenges. Two participants were affected by the appearance of the donor as hollow or in poor condition due to insufficient wound closure after the organ procurement surgery.

> *How is this possible? What a horrible way to treat somebody who just gave his organs. Seeing the donor in this way immediately had a strong impact on me and after this, I am not even sure I am in favor of OD.*

The participants viewed OD as stressful and described various instances where they felt torn between caring for a potential donor until the end and ensuring the preservation of their organs. These situations reflected a conflict of interest or dilemma that most often arose in the phase where the next of kin had not yet been asked about OD, although the team of healthcare workers was aware of this possibility.

> *Maybe we should ask the family if it is OK to draw blood from the patient with OD as the objective?*

The interviews revealed that participants needed debriefing and follow-ups after their experience of caring for OD patients, which elicited traumatic emotions that were difficult to process afterwards. For some, this led to a feeling of not doing their job properly; others felt

that their efforts were not acknowledged.

> *There are very few support groups among colleagues. There is no defusing or debriefing and you are not acknowledged by the management. By the end of your shift, you are heading home with an overload of thoughts in your head.*

Discussion

The present study aimed to describe the challenges faced by ICU nurses during the OD process. The following challenges were identified: 1) practical challenges; 2) challenging care of the next of kin; and 3) Ethical and emotional challenges.

The participants reported challenges relating to practical tasks, such as blood sample delivery. Collecting donor blood samples for HLA typing is one of the first steps in the OD process. The participants reported that the transport of the blood samples to the transplant center for analysis was a complicated process. The coordination and interaction with the delivery firm was described as inefficient and bewildering and in one extraordinary case, an ICU nurse had to deliver the package containing blood samples to the airport herself. We are not aware of other studies that have reported similar findings regarding practical tasks. One reason for this situation is the long distance between the current hospital and the transplant center. However, limited experience and training in caring for an organ donor may be an aggravating factor. Applying experiences from resuscitation and trauma care to simulation training can enhance communication skills and teamwork [25]. Simulation of the OD process allows adjustment of educational goals to meet the level and needs of ICU staff. Improvements in simulation training performance are reported to be associated with significant changes in real-life patient management in medical emergencies.[26,27] The effects of simulation training on the OD process have previously focused on communication with family or procedures for organ protection and a recent review reported improved communication skills from simulation training and that feedback and facilitated debriefing

increased reflection about OD related issues.[26] Simulation training for the management of practical aspects of organ donor care could be useful and warrants investigation in future studies.

The participants described the workload for the ICU nurse in the OD process as multifocal and demanding, which is in agreement with previous findings.[28] Asking relatives to consent to OD puts healthcare workers in an onerous position.[29] Additionally, the sense of responsibility toward the organ donor and the need to ensure organ quality can add to the workload.[28] This was underscored by the experiences of some of our participants who reported a sense of failure toward the organ recipient if OD was not carried out.

The ICU nurses in the present study were focused on preserving the dignity of the potential organ donor and caring for the next of kin. The lack of a relationship with the next of kin was a concern for some of the participants, given the amount of time spent on the care of the potential donor. Caring for the next of kin presented multiple challenges. The participants described the initial conversation with next of kin to obtain consent for OD as highly demanding. This is supported by the earlier findings, reporting that this conversation was difficult for ICU nurses regardless of their experience level [30,31]. The doctors' communication skills were an important aspect of this initial conversation with the next of kin. The participants found the conversation to be uncomfortable when a doctor was inexperienced or used advanced medical terms. The manner of approaching the next of kin is important, not only from the standpoint of nursing care, but also for the ultimate outcome of the conversation. A study found that 35% of these conversations resulted in families refusing consent for OD. Although there were several reasons for a negative result, the communication skills and personal characteristics of healthcare workers were contributing factors.[32] Good communication skills are essential for healthcare workers to adequately support the next of kin and encourage consent for OD.[33] Communication should be objective, clear, and

simple.[29,34]

The timing of the conversation was another critical issue that was mentioned by the participants in our study. Raising the question of OD too early or at the same time as informing the next of kin that their loved one was brain dead, is shown to negatively influence their willingness to consent to OD.[30] In this regard, the ICU nurses in the present study emphasized the importance of a conversation that was well-planned together with the doctor.[30] Indeed, it was previously reported that ICU nurses found conversations with the next of kin to be more predictable if they participated instead of just the doctors.[30] Additional training to improve healthcare workers' communication skills can facilitate this aspect of the OD process.[26]

The ICU nurses in our study expressed concerns about the next of kin's understanding of the OD process and the concept of brain death. The next of kin in another study found it difficult to understand that circulation to the brain had stopped when the face still felt warm [35]. In our study the participants reported that they were constantly aware of how they approached the potential donor to assure the next of kin that their loved one was brain dead—this included, for instance, talking about and not to the donor, and not informing the donor about procedures as they would have done with any other ICU patient. The latter required reflection and considerable effort for the participants as it contradicts nursing standards.

The OD process and the concept of brain death can be problematic for ICU nurses,[16,18,36,37] which was supported by our findings. One of the participants doubted the brain death diagnosis, while others found it difficult to accept that the potential donor was dead. A previous study found that ICU nurses lacked knowledge about OD and the diagnosis of death.[17] A need to understand brain death both intellectually and emotionally has also been observed among nurses.[18] ICU nurses' attitudes and beliefs regarding OD may influence the care of potential donors, the relationship with the next of kin, cross-sectional cooperation and

ultimately may affect the outcome of the OD process [18].

One of the participants in our study reported that she would not have consented to OD on behalf of her next of kin and had withdrawn her own consent to OD based on her experience of a donor with an unpleasant appearance after organ harvesting. The appearance of the donor after organ harvesting surgery caused some of our participants to reflect on this process and has led to ICU nurses doubting or even withdrawing their own organ donor consent.[10,28,36] ICU nurses have an important role in the OD process and are usually the members of the multidisciplinary team who are closest to the next of kin. Therefore, it is not surprising that they will be concerned with aspects of the donor's appearance after organ harvesting surgery such as proper wound closure. As healthcare workers' attitudes toward OD can impact the number of actual ODs, [10,19,31] these negative experiences should be communicated to the whole surgery team.

Our participants expressed a desire for debriefing after OD, which was not routinely offered. An investigation of ICU nurses' experiences with withdrawal of life-sustaining treatments found that the nurses wanted more time for debriefing than was offered and that there was a lack of processes that ensured that the medical staff's needs were addressed.[38] This is a significant concern, as it is well known that ICU nurses frequently experience burnout.[39,40]

Limitations

Four of the participants had worked together with the first author before this study was conducted. This personal relation could have impacted the data collection by limiting the participants ability to speak freely on the matter. However, this relation was perceived as a contributing factor to rich descriptions of the phenomena.

Due to a limited number of brain dead organ donors admitted to Norwegian hospitals in general,[7] Norwegian ICU nurses, including the participants in this study, only have some degree of experience in caring for braindead patients. In addition, interviewing other groups of health care professionals could have contributed to a more widespread data material. Ultimately, conducting all interviews in a single university hospital reduces the possible generalization of results to other populations.

Implications for practice

The results of this study indicate that ICU nurses would benefit from routine debriefing after each OD experience. Furthermore, practical tasks related to the OD process should be streamlined to ensure that the nurses can remain focused on the care of the potential donor and next of kin. Finally, simulation training could improve the workflow and alleviate the burden of a heavy workload on the nurses. Such simulation training should involve all parts contributing to the OD process, including external shipment service.

Although data in the current study were collected in 2017, guidelines and professional practice remain unchanged in ICU-nursing in Norway. Hence, simulation training, streamlining of practical tasks and routinely debrief could improve the ICU nurses ability to facilitate higher donation rates in the future.

Conclusions

Waiting lists for organs is increasing in Norway but donation rates are not rising accordingly. ICU nurses are critical in facilitating OD by caring for the potential donor and the next of kin. Therefore, the purpose of the current study was to describe the challenges faced by ICU nurses during the OD process. The findings show that ICU nurses faces practical challenges; challenging care for the next of kin; and ethical and emotional challenges. To alleviate the

workload, these challenges should be addressed in order to achieve higher donation numbers. Furthermore, practical challenges could be more burdensome than previously known and implementation of simulation-based training may alleviate this burden. The latter should be addressed for future research.

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COREQ (Consolidated criteria for Reporting Qualitative research) checklist.

Topic	Item No.	Guide Questions/Description	Reported Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	7
Occupation	3	What was their occupation at the time of the study?	7
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	6
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	7
Sample size	12	How many participants were in the study?	4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5, 6
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5, appendix
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A

Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	4
Field notes	20	Were field notes made during and/or after the interview or focus group?	5
Duration	21	What was the duration of the interviews or focus group?	6
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	8
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding tree	25	Did authors provide a description of the coding tree?	Table 3
Derivation of themes	26	Were themes identified in advance or derived from the data?	6, 7, table 3
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?	8-12
Data and findings consistent	30	Was there consistency between the data presented and the findings?	8-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	8-12
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	8-16

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357