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Multicultural family members' experiences with nurses and the intensive care context: A hermeneutic study

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Introduction

When a family member becomes critically ill resulting in admission to an intensive care unit (ICU), the whole family is adversely affected. According to Quinn et al. (1996), the patient usually arrives at the ICU in a biological crisis, while his/her family members seem to enter hospital in a psychological crisis. Stress affects the family's ability to cope with the situation, while the crisis impairs their ability to process relevant information (Tracy and Ceronisky, 2001). Van Horn and Tesh (2000) reported that the most important care for families is that provided by other family members and friends. Families that experience acute and critical illness and injury may be exposed to double-stress due to double trauma (Corrigan et al., 2007). For multicultural patients and families, double-stress in hospital as well as dependency and raw emotions could be triggered by their previous traumatic experiences as immigrants or refugees. Family members of critically ill patients are confronted by an alien environment when they enter an intensive care unit. The background of this study is based on the premise that all human beings are born free and equal in terms of dignity and rights. They are entitled to be treated with respect, irrespective of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status (United Nations, 1948). Likewise, the family has been declared to be the fundamental unit of society and has the right to security in sickness and disability. In addition, one of the overall goals of European health systems is to be effective and responsive to people's expectations, including safeguarding confidentiality and autonomy and being sensitive to the specific needs and vulnerabilities of all groups within the population (WHO, 2008). These statements underline the need to reflect on both an individual and group level when critically ill patients are admitted to ICUs, irrespective of their cultural background.

Although some studies on families and intensive care refer to the concept of multiculturalism, few deal with it directly. Åstedt-Kurki et al. (1997) described family members' experiences of their role in hospital, where about half of the informants reported the need to meet nurses in order to obtain support. Åstedt-Kurki et al. (1999) investigated how families experienced the hospitalisation of a loved one and revealed a variety of negative emotions such as worry, fear, shock, anxiety and depression. In contrast, Eggenberger and Nelms (2007) found that being a family bonded the family members and made them exceedingly strong. Although the above-mentioned studies focused on family members, neither of them directly took account of the situation of multicultural families. In relation to such families, Kutash and Northrop (2007) recommended that future research should focus on identifying family members' needs across cultures and the impact of the ICU waiting room design on them. The provision of culturally congruent care was investigated by Marrone (2008), who reported behavioural, normative and control beliefs among critical care nurses, which highlights the need for culture-specific debriefing and interdisciplinary learning models. Furthermore, in a study of Muslim women's experiences of health care providers in the United States (U.S.), Simpson and Carter (2008) identified the following themes: the perceived power of the provider, religiously defined gender relations and being a stranger in the health care system. These authors recommended that further research should focus on developing strategies to promote the provision of culturally sensitive care.

The main focus of this study is immigrant families with a non-Western cultural background, whose next of kin were admitted to a Norwegian hospital due to an acute and critical illness. It is estimated that there are around 509,000 immigrants in Norway, who constitute 10.6 per cent of the total population. Of these, 6.6 per cent are from non-Western countries (Statistics Norway, 2009). In view of the fact that the term 'non-Western' may be deemed imprecise, in this paper 'western' countries are defined as those in Europe and North America. The term 'family' is generally used to refer to groups of people who are linked together by blood, marriage or an emotional bond (Wright and Leahey, 2000).

There is a dearth of nursing research on multicultural families' experiences of intensive care. It is important to gain such knowledge, as cultural differences can result in difficulties explaining symptoms and understanding

treatment, as well as having a potentially negative influence on relationships with health care professionals. In this study we focused on family members' interactions with ICU nurses, as distinct from the ICU team as a whole.

The aim of this study was to illuminate the experiences of multicultural family members in intensive care units in Norwegian hospitals when a loved one was acutely and critically ill. The research question was: What are the experiences of multicultural family members of critically ill patients when they encounter nurses in the ICU?

Methods

The study utilised a Gadamerian hermeneutic design (*cf.* Schneider et al., 2007) in order to interpret the experiences of multicultural family members when encountering ICU nurses. Hermeneutics is used in studies where the purpose is to understand experiences and gain knowledge of a topic (Føllesdal and Walløe, 2000). Gadamer (2004) presupposed that all understanding needs a preceding comprehension, which he termed 'prejudice'; a judgement delivered before the final inspection. He asserted that, when meeting people from another culture, one gradually becomes aware of a 'horizon of understanding', which may change over time. In that way, prejudice can be compared with pre-understanding. Furthermore, he claimed that understanding by its very nature is based on dialogue. The interpreter stakes him/herself and his/her pre-understanding, which in this context means risking something in the interpreting encounter with the object or other subject. Gadamer (2004) described experience as a negation, because it may appear as a break in expectations. Furthermore, although it has its limitations, language is a medium in the hermeneutic experience. Human beings strive to build a bridge between 'the inner word' and the 'pronounced word', although we never totally succeed (Gadamer, 2004). Verbal statements contain far more than what it appears initially, because they are delivered in a certain tone. In accordance with the Gadamerian approach, the researchers in this study were aware of the importance of dialogue, openness and a listening attitude in their communication, which ensured that they understood the family members. The researchers managed the participants' mode of expression, especially those who were first generation migrants with limited knowledge of Norwegian, by devoting extra time to the meeting and paraphrasing what they said.

Participants

Participants ($n = 5$) were recruited from three university hospitals and one regional hospital in Norway. Inclusion criteria were: (1) being a family member of a patient who had been critically ill (life-threatening) and admitted to the ICU for a minimum of three days within the previous six months; (2) aged between 18 and 70 years; (3) with a non-Western ethnic and/or cultural background; and (4) able to speak and understand the Norwegian language.

Sample

The sample consisted of five family members, for the most part first generation immigrants, with different cultural backgrounds. The mean age of the participants was 29.4 years and they represented four main religions (Table 1).

Table 1.

Demographics of participants.

Participants	Gender/age	Family relation to patient	Cultural background	Status as immigrant	Religion	Education/Employment	Patients' health status when interviews took place
A	♂/28	Acquaintance	Somalian	First generation	Islam	Medical courses/unemployed	Not discharged from ICU
B	♀/24	Daughter	Chinese	Second generation	Buddhism	University/maternity leave	Deceased
C	♂/37	Husband	Sri Lankan	First generation	Hinduism	University college/travel business	Not discharged from ICU
D	♀/29	Daughter	Vietnamese	First generation	Buddhism	University college/pre-school teacher	Deceased
E	♀/29	Sister	Eritrean	First generation	Christian	Student/nutritional science	Not discharged from ICU

Abbreviation: ICU = intensive care unit.

There may be as many differences between the participants' cultures as there are between the participants and those with a western cultural background. However, the participants were homogeneous in the sense of being first or second generation migrants and having integrated their families' values, lifestyle and religion in Western society.

Data collection

Potential participants who gave their written consent to participate were interviewed. Data were collected through in-depth interviews conducted by the first author (S.H.). The interviews lasted for approximately 1.5 hours and the transcribed words amounted to 29 110. Three of the participants were interviewed at the hospital during the two weeks following the most critical period of the patient's illness, when he/she was still in the ICU. The interviews with participants whose loved one had died took place in their homes six and seven weeks after the death. In the interviews, the participants were asked about practical nursing situations concerning

their loved ones, their communication with nurses and their satisfaction and disappointment with the way in which they were treated as a family member of an acute and critically ill person in an ICU. All interviews were audio-taped and transcribed verbatim. Spontaneous reflections after each interview were noted immediately by the first author (S.H.) as a preliminary interpretation of the meaning content. Examples of the questions asked in the interviews are: ‘How did you feel about the nurses who were looking after your father/wife/sister?’ ‘What kind of help did you receive from the nurses?’

Data analysis

All data were subjected to an interpretation inspired by Lindseth and Norberg's (2004) phenomenological hermeneutical method for researching lived experience. The text of each interview was scrutinised by means of naïve reading on several occasions in order to gain an understanding of the meaning of the content as a whole, bearing in mind the aim of the study. The text was then divided into meaning units, which were condensed and sorted, abstracted and compared with each other, on the assumption that some of the content would not be relevant to the research question. The condensed meaning units were then incorporated into sub-themes, themes and an overall outcome. An example of the phenomenological hermeneutical interpretation is presented in Table 2.

Table 2.

Example of phenomenological hermeneutical interpretation: meaning units, condensed meaning units, sub-themes, theme and main subject.

Meaning units	Condensed meaning units	Sub-themes	Theme	Main subject
There was different clan belonging for the patient and the visitor, however the brother of the visitor made a link to the patient's parents.	Strong bond between the patient's parents and acquaintance	Cultural cooperation		
Family member learned a lot of the Vietnam tradition and Buddhism, especially transmigration of souls, according to the death of my father.	Understanding of one's own culture		Protecting cultural traditions	Struggling to preserve the families' cultural tradition supported by the health care system
After his death the nurses met cultural ceremonies like playing Buddhist music.	Alertness to rituals	Religious rituals		
The nurses placed a replica Indian god near by my wife (the patient), which she loved dearly, and they wrote notes near by it.	Respect for religious symbols			

In order to meet the requirement of confirmability (Denzin and Lincoln, 2003), both authors translated the meaning units into themes separately and then jointly by means of peer-debriefing. In addition, the steps in the translation into sub-themes and themes were discussed in The Health and Illness Research Group at the University of Stavanger (2007), thus establishing dependability (Denzin and Lincoln, 2003). This process deepened the researchers' understanding of the participants' experiences in the ICU context. The participants did

not review the findings of the study due to difficulties related to geographical distance between them and the researcher. In addition, the differences in language would also have made it difficult to convey the complexity of the hermeneutics analysis. These facts may weaken the credibility of the study.

Ethical considerations

The research protocol was approved and accepted by The Regional Committee for Medical Research Ethics in Norway (No. 18-04198). The participating family members were recruited by the ward nurses based on the inclusion criteria. They received oral and written information, gave their written consent and were informed that they had the right to withdraw at any time. In addition, they were assured of full confidentiality and anonymity, which represents respect for their personal integrity. The study was conducted in accordance with The World Medical Association (2004) declaration. The Norwegian Social Science Data Services reviewed the privacy and license requirements of the study and gave their permission to carry out the project (No. 11753) in accordance with the Norwegian Personal Data Registers Act. Interview data were stored as voice files and saved as proof files in a personal computer with user ID and password. The participants were given pseudonyms in the transcripts.

Findings

The analysis yielded one overall outcome and four themes, which provided an understanding of family members' experiences of their stay in the ICU, and their encounters with health care professionals. The main outcome: 'Struggling to preserve the families' cultural belonging within the health care system', encompasses the four themes: (a) filtering information to reduce concern; (b) understanding and being understood; (c) protecting cultural traditions; and (d) interacting between roles, rules and expectations (Table 3).

Table 3.

Overall outcome, themes and sub-themes in multicultural family members' experiences of intensive care.

Overall outcome	Struggling to preserve the families' cultural belonging within the health care system			
Themes	Filtering information to reduce concern	Understanding and being understood	Protecting cultural traditions	Interacting between roles, rules and expectations
Sub-themes	Separate information	Professional interpreters	Cultural cooperation	Cooperation within the
	Adapt messages	Family interpretation	Religious rituals	family
	Indirect information	Technical support		Hospital routines
				Participation in care
				Facilities

Filtering information to reduce concern

This theme was mainly based on the family members' tendency to determine and convey aspects of information that they considered appropriate for their loved one. One participant said:

In a way it is consoling for her [the patient] because she meets other people who she doesn't understand, thus they can't talk about her illness. We just conversed in general terms and did not tell her everything that the health care workers told us (A),

and,

If the nurses tell the family about a serious illness, they give them the information in an understandable way. I have to use my own psychological judgement when telling the patient the seriousness of her illness (A).

One participant reported the use of culturally bound, indirect information to spare the patient anxiety.

In our culture one doesn't tell the truth directly. Anyhow, concerning death one doesn't say; 'You're going to die'. Rather: 'You are going to get well' and in that way one gives hope (E).

The theme focused on the family members' perceived responsibility to take the best possible care of their loved one by filtering and adapting messages in order to reduce sorrow, stress and anxiety.

Understanding and being understood

The theme understanding and being understood concerns the communication challenges faced by the participants when they first encountered the ICU nurses and tried to speak on behalf of their loved one. Some of the difficulties were due to the patients being unable to talk and explain that they were in pain because of the endotracheal tube or sedation, as expressed by one participant:

Looking back, it was difficult to communicate with him. He couldn't write due to the medication. He could only blink to indicate 'yes' or 'no'. It was difficult for him to explain what kind of pain he had (B).

A professional interpreter was generally preferred, especially one with expertise in the area and terminology of health care.

If an interpreter is to be engaged, it should be a professional, authorised one as well as one with knowledge of medical terminology in order to ensure the most accurate interpretation (E).

When no interpreter was available, a family member acted as translator. They felt confident with the task and the interpretation seemed to be based on cultural preferences. A family member commented:

I do think I understand more than a professional interpreter and in our culture we don't tell everything when the patient wakes up (E).

To overcome the linguistic difficulties, several devices were used by the family members, such as:

Before I left my father I wrote a list of words in Norwegian and in our language that were often used in the daily nursing care (D).

All in all, the participants took the initiative to support their loved one by making practical arrangements to increase mutual understanding. In addition, they seemed to rely more on family interpretation than professional interpreters, due to the patients' own wish to have health matters explained by family members. No participants reported children visiting critically ill family members.

Protecting cultural traditions

Within this theme, participants reported multiple examples of cultural cooperation and use of religious symbols and rituals, which led to various reflections among family members. The family bond was looked upon as stronger in crises triggered by illness and hospital admission.

In the first week after admission everyone was here (in the hospital) and we felt more secure being near to each other than being far away (E).

There were examples of the rapid dissemination of information within the extended family when a change in the patient's health status occurred.

The jungle telegraph is so quick among my people that half an hour after the death of my father, a lot of them came to the hospital because they wanted to say good-bye (D).

Regarding religious behaviour, the participants reported a preference for both symbols and some rituals, as expressed by the following two family members:

I brought an Indian God which my wife [the patient] is very fond of. I told the nurses that it would help to make her well (C),

and,

They placed a note on the bedside table and it remained there, and after my father's death we recited Buddhist verses; a sort of mantra (D).

Although the religious rituals and ceremonies seemed important for some, there was also one comment that indicated that they were of less significance:

Patients aren't all that preoccupied with religion when they're admitted to hospital (A).

The participants mainly considered family cooperation and the family bond as very important factors in managing stress and crises. For those who have strong religious beliefs, symbols and rituals were often deemed to have a positive impact. For others, religion and symbolic gestures were not very important.

Interacting between roles, rules and expectations

This theme relates to the family members' participation in decision-making, their expectations of the nurses as well as issues related to hospital rules. While most of the issues in this theme are also relevant to Western families, they may represent a greater challenge for those with different cultural backgrounds. A few family members found decisions related to the withdrawal of treatment emotionally difficult. Some may have had values and beliefs that facilitated such decisions, while for others they represented a struggle. It was especially difficult when the family members had been involved in the care process, as expressed by one of the participants:

We participated and decided whether we wanted him to remain in the same condition or if they should withdraw the tube (B).

Hospital routines and facilities were described as challenging for some family members, including the important function of the nurses to inform them of standard visiting procedures:

We should have talked to the nurses at the beginning because we should have been told about practical matters, such as hand washing. It was a long time before we realised (D).

In addition, the participants highlighted some of the difficulties related to visiting routines, although one participant indicated compliance and sought alternatives:

If there were many visitors, we sat in the waiting room. If the waiting room was occupied, we withdrew to the corridor (A).

This theme highlighted the importance of being aware of the contextual challenges facing family members in ICUs. It is possible that these challenges were more difficult for those with a non-Norwegian cultural background and family tradition. The role and function of ICNs should be made clear in order to avoid misunderstanding, maintain standards and meet expectations. Rules, routines and facilities served as reminders of the structure required to ensure the provision of health care.

Discussion

The overall theme of 'Struggling to preserve the families' cultural belonging within the health care system' focuses on family members' efforts to deal with the different and sometimes difficult aspects of their encounters

with ICNs, including information issues and the often alien rules and routines of the hospital system. They struggle to take care of and protect their own cultural traditions in the context of a western medical model and interaction with the nurses in the ICU. Reflecting on their experiences with culturally diverse family members, intensive care nurses themselves described events as challenging and somewhat ambiguous (Høye and Severinsson, 2008).

An interpretation of the theme 'Filtering information to reduce concern' is that some multicultural families act in a paternalistic way and are influenced by protectionism, where the intention is to minimise the patient's worries. This behaviour may be due to a cultural preference for patients to be passive and not fully informed, innate knowledge of how to reduce stressors that may make the crisis worse, or male domination (Bourdieu, 2001).

Irrespective of cultural characteristics, nurses are legally obliged to provide accurate and understandable information to both patients and families. However, in some cases family members in the present study adapted the information for their loved ones. Similarly, as a consequence of some family members' cultural tradition, the full truth may be withheld from their loved one, or a blatant untruth told in order to protect him/her. Such inaccuracies, for example a family member telling a patient that he/she is getting better when in fact the prognosis is poor, can have an adverse effect and lead to a communication/ethical dilemma for the nurses.

Truth telling is a central value in the western medical model of health care and while it may be a cultural tradition to misrepresent the truth in an attempt to prevent additional stress and anxiety for a loved one, it contradicts western standards and principles. On the other hand, such discrepancies are only to be expected given Fan and Li's (2004) investigation of the difference between western and Chinese medical ethics, where the latter offers the possibility of concealing the truth or even lying if deemed to be in the best interest of the patient and his/her family members. This would appear to be the case with the family members in the present study, who withheld the truth and/or adapted information. It should be emphasised, however, that withholding the truth is not standard practice across all non-Western cultures. However, Konishi and Davis' (2001) investigation of nurses' perceptions of the right to die in western and Japanese settings revealed cultural differences. The withholding of information could indicate a view of the patient as dependent and lacking the competence to make decisions about further treatment or the right to die. This view is supported by Hanssen's (2004) study of ethics in intercultural nursing, where the author discusses conflicts when patients and nurses have different views on the value of autonomy.

When it comes to 'Understanding and being understood', the participants experienced challenges related to interacting with both their loved one and the staff. They sometimes had difficulty understanding what the patient was feeling or trying to communicate, although this is not unusual in cases of sedation, intubation or altered consciousness. With regard to using the nurses as a link between themselves and the patient, family members preferred and generally relied upon family interpretation as opposed to official services. International conventions related to linguistic equality state that patients and families have a right to the service of a professional interpreter ([Ministry of Justice and the Police, 1967] and [Ministry of Health and Care Services, 2003]). Such professionals interpret accurately, prevent the withholding of information and can often avoid emotional dilemmas for family members who feel that they are obliged to interpret in a stressful situation. However, while interpreters with knowledge of healthcare terminology were preferred when it came to conveying information of a technical/medical nature, family interpretation was favoured if the intention was to withhold or adapt information. Nevertheless, the perceptions of the family members indicated that family interpretation should be complemented by professional interpretation in daily nursing care. The finding by van der Smagt-Duijnsteet et al. (2001) that in The Netherlands female relatives request more information than their male counterparts is of cultural interest and may also be valid in other western countries.

Some participants addressed the language difficulties by providing self-made glossaries and alphabets for the patients. This may indicate a limitation in the nursing service, as it could be expected that supportive communication equipment such as lists, glossaries in different languages and electronic recorders would be available to facilitate communication within the families as well as between the family members, patient and staff. Furthermore, improvements related to interpretation cannot be limited to communication equipment. It must also be acknowledged that behaviour and expression of feelings are influenced by cultural traditions (Giger and Davidhizar, 2002) and should be taken into account.

In the theme 'Protecting cultural traditions', family members found security in being together during the crisis caused by the critical illness and while this is not uncommon across cultures, the extended nature of some families can be problematic in the confined space of an intensive care unit. ICU nurses have expressed concerns

about the potential disruption caused by large family groups fulfilling a cultural obligation to gather during a health crisis (Høye and Severinsson, 2008). With regard to other traditions, the participants reported that the nurses were sensitive to multicultural families' religious symbols, headwear and rituals and thus seemed to meet their expectations and wishes. However, it was also acknowledged that not all families were preoccupied with religion. The participants who believed in religious symbols and remedies expressed the view that these could promote healing, thus acknowledging spiritual needs. Murray et al. (2004) found that while spiritual issues were important for many patients and their carers in the last year of the patient's life, some health care professionals were reluctant to raise such matters due to lack of time and skills. On the other hand, excessive focus on religion and traditional remedies in multicultural families could indicate distrust of western nursing and medicine. In addition, focusing on religious actions and beliefs when a family member is critically ill may limit the patient's participation in his/her own recovery and strengthen the view of the influence of a collective culture on the recovery process.

The theme of 'Interaction between roles, rules and expectations' demonstrated that some multicultural family members, in the same way as western families, participated in decision-making about treatment and care. Nurses seem to be aware of the families' rights of co-determination and participation in such discussions (Hov et al., 2007). However, cultural expectations and roles can differ considerably, particularly when it comes to withholding or withdrawing treatment. Traditions and rituals can play an important part in the decision-making process, for example in some non-Western cultures characterised by paternalism, decisions are made by the male family members on behalf of, for instance, a wife or daughter (Hanssen, 2002). Some religions also have ritualistic approaches to death and dying. The expectation of family members that nurses should be aware of cultural needs corresponds with the findings of Marrone's (2008) and Foronda's (2008) analyses of cultural sensitivity. The findings of the present study also underline the fact that some participants were very satisfied with the nurses' professional attitude, while others reported lack of respect for their feelings and a failure to provide them with information about rules and routines when visiting ICUs. Waiting rooms are primarily places of rest and should be easily accessible to all families when their loved one is admitted to an ICU. However, the issue of overcrowding was frequently mentioned, especially when large and extended families gathered, which can lead to a certain amount of frustration about who should have access (Kutash and Northrop, 2007).

When encountering nurses in ICUs, the multicultural family members experienced challenges related to communication, cultural norms and behaviour as well as role conflicts. We do not know whether the situations in ICUs might occur in other contexts in Norwegian hospitals. Nevertheless, interaction, challenges and cultural preferences in encounters between families and professionals are probably not solely dependent on the environment, but are universal human phenomena.

Methodological considerations

The Gadamerian approach highlights the dialogue with participants, which is the basic premise for hermeneutic interpretation. Furthermore, the structural analysis following the naïve reading encompassed the decontextualizing of the meaning units, thus rendering the text more transparent. A limitation of the analysis is that the whole truth cannot be revealed, especially as the family members' understanding of the situation was affected by stress due to critical illness or the sudden change in the family's circumstances when the patient was admitted to hospital. Five or six other family members had considered participating in the study, but declined shortly before data collection began because of sickness among close relatives, the death of their loved one, uncertainty about their contribution to the topic or concern that their own anonymity would not be respected. This drop-out led to a small study population, which may be due to lack of confidence, cultural issues or general concerns. Additionally, some potential informants did not meet the inclusion criteria, especially in relation to age. Gerrish (2000) also reported practical and methodological concerns when recruiting participants for research on ethnic diversity.

Conclusion

Multicultural family members have specific methods of dealing with the hospitalisation of a critically ill loved one. Within some cultures the family members decide what and how much information to convey to the patient in an effort to reduce his/her anxiety. It is essential that these family members understand the health related information and have different ways of dealing with it. The maintenance of cultural traditions includes symbolic religious representations and rituals involving long held customs. Family members with an ethnic background that differs from that of the majority of the population experienced different challenges within the complex ICU environment when confronted by rules and unmet expectations. Encounters within ICUs are multifaceted by

nature, being characterised by difficult health related decisions, inadequate facilities and patients' as well as relatives' understanding of the role and function of staff.

Different cultures have their own beliefs, values, customs and traditions and it seems difficult for nurses to grasp the range and diversity of the family members with whom they interact. However, every human being, irrespective of cultural background, has a right to be informed and treated with respect and dignity. The context of critical illness can be a challenging experience for those whose language and belief pattern differs that of the nurses who provide the health care.

Implications for practice and future research

The findings revealed that nurses must be sensitive to families' cultural expressions in order to address their needs and expectations in a respectful way. Strategies for maintaining and possibly improving nurses' competence could be to focus on their attitudes, thus making them more aware of the needs of multicultural families, and to increase their understanding of the impact of culture and religion on illness and recovery. Nurses' competence in this area could be included in all nursing curricula by means of nursing supervision and in-service training.

There is a need for further research on cultural diversity and family perspectives within the health care system in order to enable a more utilitarian approach to clinical care across a range of settings and among different health care professionals.

Author contributions

S.H. was responsible for the idea and design of the study and also performed the data collection. S.H. and E.S. carried out the data analysis. S.H. was responsible for writing the manuscript and E.S. for the critical review and supervision of the study. S.H. obtained the funding.

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