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## Clinical education

## Nursing students' reflections on caring for end-of-life patients in a youth volunteer association

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## ABSTRACT

The aim of the study was to describe nursing students' reflections on caring for end-of-life patients in a youth volunteer service. A purposive sample of 11 nursing students in one province in China were interviewed and diaries were collected. The data were analysed using qualitative content analysis. The students described the service as “an empowering care that makes a difference – but not without challenges on different levels”. The service was said to provide devoted caring adjusted to the person's need, condition and wishes. According to the students, the service had an impact on them; the internal and/or external support was stimulating and rewarding, whereas deficient support was frustrating and made them feel helpless. They emphasized the need for improvements at different levels. In conclusions, the youth volunteer service empowers both patients and students and can be seen as person-centred care. The students' professional knowledge, skills and ability improved, while these aspects were still perceived as deficient. Appropriate curriculum and training for nursing students are necessary and should be tailored to improving students' caring ability and confidence. Expanding the service was emphasized and suggestions for improvements were identified.

## 1. Introduction

Caring for end-of-life patients is part of holistic nursing care. Yet the topic of end-of-life care is a cultural taboo among medical professionals, patients and families in some countries (Charalambous and Kaitte, 2013; Hsu et al., 2009; Zheng et al., 2015). Nurses have also reported they are unlikely to communicate with patients near death (Razban et al., 2013) and that they are lacking knowledge of end-of-life care and communication skills (Zheng et al., 2015). However, it is nurses' responsibility to prevent and relieve patients' sufferings, to integrate physical, psychosocial and spiritual care, and to offer patients and their family support (World Health Organization, 2014). Thereby, clinical practice and training for nursing students are of importance to improving such care in the future. The focus here is on a volunteer service for end-of-life patients in China and the participating nursing students' reflections on the service.

## 2. Background

Studies have shown that nurses report poor knowledge about end-of-life care (Zheng et al., 2015) and feeling not adequately prepared

even if education in end-of-life care for undergraduate nursing students has increased (Cavaye and Watts, 2010). Furthermore, that limited education on end-of-life care was available during their school time (Razban et al., 2013). It has also been found that nurses report neutral to moderately negative attitudes to palliative care; registered nurses being more positive than auxiliary nurses, and that education in palliative care was positively related to more positive attitudes (Razban et al., 2013). In a study from China (Zheng et al., 2015), oncology nurses reported lack of communication skills and knowledge when caring for end-of-life patients. Limited education and training may, in turn, cause nurses and students to feel not prepared to provide end-of-life care (Andersson et al., 2016; Peterson et al., 2013; Wallace et al., 2009; Zheng et al., 2015).

During clinical practice education nursing students are participating in caring for end-of-life patients. However, students have reported they need more theoretical and clinical training (Charalambous and Kaitte, 2013; Edo-Gual et al., 2014), which, when lacking, made them feel helpless and emotionally distressed (Charalambous and Kaitte, 2013; Huang et al., 2010; Van Rooyen et al., 2005). Furthermore, nursing students have reported that they felt inadequately prepared when meeting their first death in clinical practice (Parry, 2011) and that this

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first experience had a big impact (Edo-Gual et al., 2014). A Swedish interview study (Ek et al., 2014; Österlind et al., 2016) found that first year nursing students felt it difficult to communicate with dying patients, and that meeting with family members was reported as important but challenging and demanding. They expressed both fear but also positive personal experiences from caring for dying patients. Huang et al. (2010) found that nursing students both experienced and lacked support from clinical instructors and nurses when providing care for end-of-life patients. Patients' death influenced their feelings; whereas some experienced growth and others escape. It is essential to provide the students' with necessary guidance and support (Ek et al., 2014; Van Rooyen et al., 2005), improve their confidence, nursing knowledge and skills, as well as to promote their psychosocial well-being, support their self-development and help them acquire the insights needed to provide end-of-life care (Kent et al., 2012; Sanford et al., 2011). Though, negative feelings have been reported, most nursing students and nurses felt caring for end-of-life patients was also rewarding (Ingebretsen and Sagbakken, 2016; Vejgaard and Addington-Hall, 2005; Zheng et al., 2015), and contributed to positive personal and professional experiences (Edo-Gual et al., 2014; Ek et al., 2014). Grubb and Arthur (2016) showed that nursing students in UK mostly reported positive attitudes towards caring for dying patients. Having experienced death and caring for end-of-life patients during clinical practice, and being at a later stage of their education were all associated with more positive attitudes. Still almost all students reported the need of more education in end-of-life care. While, others found low scores/less positive attitudes towards caring for dying patients among Palestinian nursing students (Abu-El-Noor and Abu-El-Noor, 2016) and Turkish nursing students (Arslan et al., 2014). More education and training in end-of-life care are emphasized and intervention studies have found that increased education in caring for the dying patient also improves nursing students attitudes (Bailey and Hewison, 2014; Lewis et al., 2016). Henoch et al. (2017) found that having had a five-week theoretical palliative care course during their nursing education predicted positive changes in attitudes towards caring for dying patients compared with nursing students that had less theoretical education.

Understanding nursing students' experiences of end-of-life care can help educators design courses that better prepare students to face end-of-life care. Nevertheless, there is a lack of studies describing nursing students' reflections on caring for these patients. Furthermore, the area of volunteer service needs to be explored more in detail. Even though volunteers have been described as key resources (Pesut et al., 2014; Walshe et al., 2016), the research on volunteer services in palliative care has been sparse (Candy et al., 2015). According to a review (Candy et al., 2015), there seem to be some benefits, but thus far studies are primarily from North America and more research is called for. A descriptive qualitative method was thus used and the aim of the study was to describe first- to third-year nursing students' reflections on caring for end-of-life patients in the context of a youth volunteer service in China.

### 3. Methods

#### 3.1. Design

A descriptive design with a qualitative approach was applied. As the context, the youth volunteer service, and nursing students' reflections on caring for end-of-life patients in that context was central to the study, qualitative content analysis was chosen as "... the method, to a great extent, focuses on the subject and context, and emphasises differences and similarities ..." (Graneheim and Lundman, 2004, p. 111). Both the manifest content and/or the latent content of the data can be described using inductive qualitative content analysis (Graneheim and Lundman, 2004; Graneheim et al., 2017).

#### 3.2. Participants

Purposive sampling of 11 nursing students was used. Inclusion criteria were nursing students who were members of the Youth Volunteer Association and who provided care relatively often and thereby would have experiences of the study phenomenon (Graneheim et al., 2017). Most participants were female (n = 10), the mean age was 21 years (range 20–22). They were in their first (n = 3), second (n = 6) and third year (n = 2) of a nursing programme at one university in China. Most of them had previous personal experiences of death. They had experienced death in their families and regretted not having cared for their relatives, either because they were too young or too busy with their studies. The knowledge they had before about end-of-life care was mostly from books, the Internet, other organizations dealing with various communication skills, and courses in the nursing programme. Their length of experience working in the volunteer service was between one semester and two years. Their first thoughts about the service when they heard about it were mostly positive. Participants were curious about it, thought it was a creative idea, a challenge and a meaningful thing to do. Most of the students had not been close to a dying patient, except for one participant.

#### 3.3. Data collection

All interviews were conducted by the first author in a quiet room at the university during July 2016. The interviews lasted from 30 min to 1 h. A semi-structured interview guide was used including topics such as: students' opinions regarding their own knowledge, skills and abilities in caring for end-of-life patients and their experiences from the youth volunteer service. Participants were encouraged to talk freely and share whatever they had experienced. Probing questions were employed during the entire interview (Polit and Beck, 2017). The students also wrote diaries to help them reflect on the service. In addition to the interviews, diaries from six students were collected.

#### 3.4. Data analysis

Data were analysed using inductive qualitative content analysis (Graneheim and Lundman, 2004). The audiotaped interviews were transcribed verbatim and the diaries were transferred to a word document. Based on the study aim, meaning units were identified, condensed and labelled with codes. Codes were compared and similar codes were sorted into categories. Finally, one main theme and four sub-themes were identified describing the latent meaning of the data (Graneheim and Lundman, 2004) (Table 1). The data were analysed by the first author; who is a Chinese nursing teacher with interest and focus on fundamentals of nursing and with experiences as a nurse working in UK elderly care. For the first five interviews, the transcribed text was translated to English so that all the steps in the analysis process could be discussed between the first and last author to reach consensus. For the rest of the interviews and the diaries, the analysis process was discussed between the first and third author, and parts were translated when there was uncertainty as to how to interpret the data; this was then discussed with the last author. All authors discussed categories, sub-themes and the main theme together to reach consensus (Graneheim and Lundman, 2004; Polit and Beck, 2017).

#### 3.5. Rigor

The trustworthiness of the study will be discussed using the concepts: credibility, dependability and transferability as they are described by Graneheim and Lundman (2004). One person performed the interviews, an interview guide was used and the interviews were conducted during a short time period, all of which strengthens consistency during data collection and thereby dependability. Credibility was strengthened by ensuring variation in the students' level of

**Table 1**  
Examples of condensed meaning units, codes, categories and sub-theme from the content analysis.

Condensed meaning units	Codes	Categories	Sub-themes
If nurses would help us, we could have some preparations and save a lot of time. If nurses brought us to the patient, they wouldn't have doubts. We were just like an idiot to ask them whether they need help.	We can have some preparations and save time if nurses can help us.	Deficient support from nurses.	Internal and/or external support is stimulating and rewarding, while deficient support is frustrating and makes you feel helpless
We often turn to senior volunteers for help. We shared experiences and feelings with each other.	Turn to seniors for help or share experience in small group.	Seeking help from seniors, sharing experiences.	
Situation was different in another hospital. An awarding ceremony was held and volunteers got rewards (some gifts), which was important to us. Our work (value) should be acknowledged, which can motivate us.	Volunteers' care service needs to be acknowledged, which can motivate us.	Rewards and acknowledgement motivate.	

advancement in the nursing programme. Furthermore, credibility was strengthened by the fact that all steps in the analysis process were discussed until the co-authors reached consensus. Discussions of the analysis process among co-authors also helped to keep consistent over time and thereby strengthen dependability. Quotes are used to illustrate the results and strengthen credibility. To help the reader to judge transferability, the sample and data collection are described thoroughly (Graneheim and Lundman, 2004). Data were mainly collected from female students because few men in China choose the nursing profession. The sample might be seen as small, but the interviews were rich in data and, in addition, students' diaries were used.

3.6. Ethical considerations

Before the interviews, written and oral information about the study were given to the participants. They were told that the interviews would be tape-recorded and that participation was strictly voluntary, could be ended without explanation and would not affect their further nursing studies. They were assured confidentiality and informed consent was obtained prior to the interview. Appropriate ethical approval was obtained from the region's ethical review board.

4. Results

The analysis revealed one theme – 'The service: an empowering care that makes a difference, but not without challenges on different levels' – and four sub-themes (Table 2). The theme and sub-themes are presented using quotes from the interviews.

4.1. The service: an empowering care that makes a difference, but not without challenges on different levels

The students reflected on the service as something that empowered both them and the patients. Students described improved professional knowledge, skills and ability, and an insight that what they were doing was something good for the patient, something meaningful. They also described changed attitudes and views on life after taking part in the service. However, when support was lacking, they also reported feeling frustrated and helpless. Regarding patients, the students described feeling more open, positive and harmonious when the patients controlled the encounter, as well as when the patients showed signs of

increased security in response to students' company and care. And the act of providing care, in turn, made a difference for both the patients and the students. However, delivering the care service involved challenges at different levels: the individual student (e.g., need for more knowledge, challenges to their own attitudes and views on life) and within the organization (e.g., the need to expand the service, a need to offer more training for volunteers, families and carers) or within the community/society (e.g., the need for changed attitudes, the need for more support from the nursing programme and better collaboration with the hospital).

4.2. Devoted caring adapted to the person's needs, condition and wishes

The students reflected on the care as devoted care; they tried their best and led with their heart when keeping the patients company and caring for them. They cared for patients by applying various communication skills adapted to the patients' condition, hobbies and personalities, e.g. telling stories, singing songs, playing music, and dancing. On certain festivals, they also sent flowers, wrote cards for the patients. Students emphasized the importance of talking, listening or just being – and doing it with your heart during the service; they described how relationships were built and emotional support offered to the patients. Students reported listening to the patients' stories and complaints patiently. What they did depended on the patients' wishes and conditions. A second-year student shared the following:

*For depressed patients, we chatted with them more often to cheer them up ... we magnified the positive aspects to encourage them, or we helped them pull through. (Participant 2, year 2 student)*

Several students claimed that sometimes having nonverbal communication skills was more meaningful and powerful. Physical/bodily contact was experienced as powerful. One student said:

*He's holding my hands tightly and his eyes glistening with tears. (Participant 7, year 2 student)*

Most of the students commented that bodily contact gave the patients a sense of security. According to the students, caring for end-of-life patients is just like art, which should be done with your heart. However, they also talked about taking care of physical needs, such as giving a massage to patients who liked it for relaxation and pressure ulcer prevention:

**Table 2**  
Theme and sub-themes describing nursing students' reflections on caring for end-of-life patients.

Theme	Sub-themes
The service: empowering care that makes a difference, but not without challenges on different levels	Devoted caring adapted to each person's needs, conditions and wishes Impact on the self Internal and/or external support is stimulating and rewarding, while deficient support is frustrating and makes you feel helpless Improvements needed at the individual level, organizational level (i.e., in the service), and community level (i.e., in nursing education and society)

*He was hemiplegic, I massaged for him first whenever I got there, then we started to chat.* (Participant 1, year 3 student)

Some of them wrote diaries to reflect on the service:

*Thanks to joining such a service team, we have a common desire, we have the same love, we are willing to stretch out our hands to hold the end-of-life patients. Thanks to taking part in such an activity, keeping them company with our youth, warming them with our heart at the end of their life.* (Participant 3, year 2 student)

When reflecting on the patient's family, students observed that most of the families visited the patient for a short while, and some just for paying the bills. Patients were mostly cared for by carers. In the students' view, this was not the best situation, but reflected the fact that families are often under great physical, psychological and economical pressure. Family members have to work to make money to pay for the patients' treatment.

#### 4.3. Impact on the self

Students reported that caring for end-of-life patients had changed them greatly. All expressed deepened knowledge and improved communication skills. One student said:

*I've made most progress in communication skills.* (Participant 3, year 2 student)

Another said:

*... such as how to start a conversation, end an embarrassing situation, make patients happy and offer them positive energy. In addition, I have improved my ability to find an appropriate topic to continue the conversation.* (Participant 2, year 2 student)

The caring triggered different feelings. Some students sometimes felt sad when they returned home after seeing patients. One student said:

*We brought happiness to the patients, but I felt depressed myself. Depression can spread. If you cannot adjust your emotions then you will be very bad.* (Participant 2, year 2 student)

The students reported gaining a deeper understanding of life and death, and that caring for end-of-life patients had been an enriching experience. These caring experiences had changed the students' perspective on life, inspired them to treasure life, cherish love of family, value friendship and would not give up whenever they faced troubles. One student said:

*I will no longer hesitate to work on what I want or be afraid of failing.* (Participant 6, year 3 student)

Another student commented:

*While my family is still living, I should take good care of them and love them even more, because I don't want to regret it in the future.* (Participant 8, year 2 student)

All of the participants talked about having become psychologically prepared for death. Taking part in the service was of some help to students in making their career choice after graduation. Most of the students said they would work with end-of-life care in the future; others stated that this was difficult work and that they could hardly keep a positive attitude all day when facing dying patients.

#### 4.4. Internal and/or external support is stimulating and rewarding, while deficient support is frustrating and makes you feel helpless

Students stated that the support differed across managerial levels in the hospital as well as between hospitals. One of the hospitals held an awards ceremony to acknowledge and encourage the students' service:

*This ceremony meant a lot to us, our work was acknowledged that motivated us. What we have been doing is meaningful and worthy.* (Participant 6, year 3 student)

Students in another hospital complained:

*They asked for students' names to be listed on a caring schedule, we have to work on it strictly ... but how can we? Their management should be flexible. We are helpless.* (Participant 5, year 2 student)

Students thought they could save a lot of time if the nurses would help them identify patients in need of the service. They reflected on nurses being a support in alleviating patients' doubts about the end-of-life service. Some students were disappointed in the support from nurses and/or other staff. A junior student stated:

*They don't care about what we are doing here, not to mention teaching us anything.* (Participant 4, year 1 student)

However, students in another hospital claimed that nurses introduced them to patients who were willing to chat or were alone, which saved the students a great deal of time. Though the service was highly praised at the provincial level, students were only told what to do, without any practical guidance from the organization. One student said:

*They just gave us a task and have never cared about us. We needed not only money, but also more support while we were helping others. There is an extreme lack of this.* (Participant 1, year 3 student)

Students sought help from other students and/or volunteers. They shared experiences and reflected on them in a small group whenever they encountered an emotionally demanding or difficult situation. Senior volunteers shared their experiences and feelings with junior volunteers and supported them.

#### 4.5. Improvements needed at the individual level, organizational level (i.e., in the service), and community level (i.e., in nursing education and society)

Though the service was welcomed and appreciated, students noticed that improvements were needed in many respects. All of the students expressed that, though they did their utmost, their knowledge, communication skills, and clinical experience were insufficient. One student said:

*The knowledge and skills I have learned are not enough. I am completely unable to meet their needs.* (Participant 9, year 2 student)

A junior student said:

*We lack psychological knowledge.* (Participant 11, year 1 student)

Some students said that they needed a compulsory course in end-of-life care; others said that several lectures would help and still others felt that learning-by-doing/clinical training was more beneficial. Most students referred to the wealth of knowledge that could be drawn from experienced staff who worked with end-of-life patients. One student said:

*Death education should be thorough. A lecture or something like that can't do any good.* (Participant 1, year 3 student)

Needed improvements in society that the students brought up included changed attitudes and changed behaviour. Several students noticed that doctor-patient and nurse-patient communication was particularly limited. Students believed that if staff were to pay more attention to communication with patients, then patients would experience better memories prior to death. Students indicated that the family's negative or indifferent attitudes affected the patients' emotions. Family members have limited communication skills and were rarely observed to say 'I love you' to their dying relatives. Students reflected on the reason for this, suggesting that it is likely due to the conservative

ideology in Chinese culture. In the students' opinion, families should communicate more, more openly say 'I love you' and be encouraged to do so. Students also noticed that patients were not satisfied with the caregivers' services, which consisted merely of helping with daily life activities, such as feeding and toileting, i.e. physical needs. According to the students' descriptions, caregivers seldom communicated with the patients or provided emotional support:

*The family should choose a care provider who is more professional, attentive, sensitive and delicate.* (Participant 1, year 3 student)

The students reflected on their responsibility to help both family members and caregivers improve their communication skills and approach to mental support, thus improving the quality of care. In order to accomplish this, family and caregivers need to receive training as well. Students emphasized that all students, families, and caregivers need more mentoring and psychological knowledge:

*We have been caring for patients for one year, no one has ever supported and encouraged us psychologically. We can hardly keep on doing that without support ... If we are given support, we could face life in a more positive way and in a better mood, allowing us to provide a better or longer service for patients.* (Participant 1, year 3 student)

Most students described the need to expand the service, end-of-life care, to the whole university and society. One student described:

*Once a student from the art faculty danced for a patient, he did a good job.*

*This service can be done in other hospitals, nursing homes and other cities.* (Participant 8, year 2 student)

Students also found dialects to be a barrier in communication, thus there was a need for more people with different dialects in the service. The students said that charity is not particularly common/popular and that there needs to be a platform to publicize it, to *change attitudes in society* and to inspire people to help/volunteer in services such as end-of-life care. Students were quite sure that people would change their perspective on life through involvement in the service and hoped that nursing teachers could be involved in teaching and guiding volunteers. Students commented that end-of-life patients in China tend to spend their remaining time at home. One student said:

*End-of-life care is needed more in patients' homes, especially in poor villages. We need a platform for identifying who is in need of care. The community is a good one.* (Participant 7, year 2 student)

## 5. Discussion

The findings provide valuable insights into students' reflections on voluntary caring for end-of-life patients in China. The service was described as empowering both the students and the patients, but as not being without challenges. For the students it meant improved competence, a meaningful activity and doing something that made a difference. This could be compared to Spreitzer's (1995) description of psychological empowerment, which includes aspects such as performing meaningful work, improving one's competence, having a sense of control and being able to exert influence over the outcome – in the present case, doing something good and meaningful for end-of-life patients. However, when they did not experience support in the service, the students sometimes felt helpless. Visits from the students provided the patients with emotional support; the patients were in charge and had the control. The caring was based on each patient's wishes, beliefs and values, and could thus be described as person-centred care (McCormack and McCance, 2006). The students described skills such as active communication and listening, use of open-ended questions or silence, and making physical contact with patients by holding their hand (cf. Ek et al., 2014; King-Okoye and Arber, 2014). They found that, in some

cases, non-verbal skills were more meaningful and powerful (cf. Johnston and Smith, 2006). Non-verbal communication was according to a review (Cavaye and Watts, 2010) especially valued by patients. Person-centred care was delivered based on the patients' wishes, conditions, hobbies and personalities, and this approach was practised with engagement and a sympathetic presence (cf. McCormack and McCance, 2006). Students emphasized that, when caring for dying patients, leading from the heart was very important. This allowed them to alleviate patients' and family members' doubts about end-of-life care and to help promote acceptance and appreciation. According to the students' descriptions, hospital staff, caregivers in the home, and families placed much more emphasis on caring for physical needs; moreover, they reported that staff-patient communication was very limited. Similar findings, nurses that treated patients in a less caring way, were reported by nursing students in a study by Charalambous and Kaite (2013) but also the opposite was reported. Razban et al. (2013) found that less than half of the nurses reported communicating with dying patients and Zheng et al. (2015) found that oncology nurses in China experienced lacking communication skills when caring for end-of-life patients.

Many of the students felt sad when they became attached to the patients. Cooper and Barnett (2005) also found that students felt sad, vulnerable, and helpless in their interactions with end-of-life patients. However, according to Cooper and Barnett (2005, p. 428) "*the rewards of emotional investment may increase their confidence and self-worth*". Despite the inevitable negative emotions, the students also found the service to be highly rewarding and meaningful. They described improved professional knowledge, skills and abilities as well as changed life attitudes; they learned beneficial lessons in the service, such as the importance of treasuring life, families and friends (cf. Huang et al., 2010). The service also made them more positive and boosted their mental strength.

The students emphasized the need for more knowledge and training. These findings confirm results from previous research (e.g. Cavaye and Watts, 2010; Charalambous and Kaite, 2013; Edo-Gual et al., 2014; Grubb and Arthur, 2016). Studies have reported that students who received more palliative care education (at least five weeks theoretical and/or practical placement) had more positive changes in attitudes towards caring for dying patients and felt more prepared to take care of dying patients than students with less education in palliative care (Hench et al., 2017); that students with experiences of taking care of dying patients had more positive attitudes than students without these experiences during clinical placement (Arslan et al., 2014; Grubb and Arthur, 2016) and that nurses with education in palliative care reported more positive attitudes towards palliative care (Razban et al., 2013). Thus, the nursing curriculum should include more end-of-life care (Hench et al., 2017; Mallory and Allen, 2006). The importance of supporting and training the students has been emphasized in previous studies (e.g. Cooper and Barnett, 2005; Grubb and Arthur, 2016). The students in the present study reported that sharing their experiences with their peers was particularly helpful in coping with their stress and confusion (cf. Cooper and Barnett, 2005).

## 6. Conclusions

The present study is the first to describe nursing students' reflections on voluntarily caring for end-of-life patients in China. The results can help nursing educators and clinical nursing professionals understand students' attitudes and difficulties in facing end-of-life patients; the findings can also serve as a guide in designing an appropriate curriculum. Furthermore, it is beneficial to government leaders to formulate relevant policy that can facilitate and encourage this kind of volunteer care service. Additional training and support related to psychological knowledge and communication skills might help the students to deal with emotional problems in end-of-life care (Huang et al., 2010). Despite the challenges and needs for improvement, the students found the service to be important, meaningful and empowering for both

themselves and the patients. They felt they had been involved in something that made a difference for everyone involved.

### Contributions

Study design: LZM, BS, ME; Data collection: LZM; Data analysis: LZ, BS, LCF, ME; Manuscript preparation: LZM, ME (drafting the article) BS and LCF (revising it critically). All authors LZM, BS, LCF, ME have approved the version submitted for publication.

### Conflicts of interest

None.

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### Ethical approval details

Ethical approval was obtained from the region's/the hospital's ethical review board.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.nepr.2018.12.006>.

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