

Challenges of paediatric palliative care in the intensive care unit during the COVID-19 pandemic

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Abstract

Background: The integration of paediatric palliative care into the Iranian health system is essential. **Aims:** The aim of this study was to identify the challenges of palliative care in the paediatric intensive care unit during COVID-19 through the experiences of healthcare providers. **Methods:** A qualitative study with content analysis approach was conducted. Fifteen physicians and nurses were selected by purposeful sampling. The semi-structured, in-depth interviews were applied in the data collection. **Findings:** Ten main categories were extracted from data analysis, including 'caring in COVID-19', 'communication and family centre care', 'breaking bad news', 'palliative care training', 'pain and symptom management', 'support of the child, family and clinical team', 'physical environment', 'guidelines', 'specialised staff' and 'home based palliative care'. **Conclusion:** Palliative care in the PICU faces several challenges, especially during COVID-19, but the clinical team are making every attempt to improve the comprehensive care of children and their families. Telehealth is important in COVID-19, and education is also a key component to improve palliative care in the PICU in Iran.

Key words: ● Paediatric palliative care ● Challenges ● Paediatric intensive care unit

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Paediatric palliative care (PPC) is holistic care that focuses on achieving the best possible quality of life for children with life-threatening illnesses and their families (Liben et al, 2008; World Health Organization, 2018). It also requires for special and unique attention to be paid to physical, developmental, psychosocial, moral, spiritual and communicative factors related to children (Rhee and Morrison, 2018). Since early 2020, the spread of COVID-19 has had a significant impact on the lives of people around the world. However, children are less likely to be infected with the virus than adults and are usually asymptomatic or mildly affected (Mehta et al, 2020; Ludvigsson et al, 2020). Yet, the implications and consequences of this pandemic on children with life-threatening conditions have been less clear, and caring for children with complex and serious conditions is so important that PPC during the COVID-19 pandemic has continued (Ekberg et al, 2020).

In Iran, palliative care (PC) is new, and although PC provision has progressed slowly across the country, recent efforts to improve the situation are promising. At present, there are only five to six active centres in Tehran, Isfahan

and Zanjan offer systematic PC services (Mojen et al, 2018). Imam Khomeini Hospital Cancer Institute is one of the first providers of PC with a formal programme in Tehran, Iran, that has been providing services to cancer patients and their families, since 2007, to relieve their symptoms (Tahmasebi, 2018). However, PPC in Iran has not been developed, and is facing challenges, and also there is an increasing need to integrate it into the Iranian health system (Mojen et al, 2018; Tahmasebi, 2018). Rassouli et al (2019) examined the challenges of PC in children with cancer in Iran in a literature review, and based on the results, they divided the challenges into two categories; structure-based challenges and process-based challenges. Structure-based challenges included the lack of a clear structure in the health system and classification of services, lack of specialised staff, lack of home care centres and lack of PC insurance coverage.

The process-based challenges included the lack of clinical guidelines, lack of family education programmes, family attitudes and beliefs (such as a belief that their child would get better), communication barriers and lack of access to opioids (Rassouli et al, 2019). The results of a

Table 1. Demographic characteristics of the participants (n=15)

Characteristics	n
Gender	
Male	4
Female	11
Age (years)	
25–35	3
>35–45	9
>45	3
Education	
Fellowship	5
Bachelor of Science degree	10
Position	
Doctor	5
Nurse	10
Work experience (years)	
5–15	4
>15–20	8
>20	3

study by Davies et al (2008) also showed that one of the barriers to PPC is the lack of effective communication between the clinical team and the child's family (Davies et al, 2008).

Communication is critical to achieving holistic PPC (Bradford et al, 2014; Hartley et al, 2016) and during the COVID-19 pandemic, due to the reduced risk of coronavirus transmission among patients, families and medical staff, telemedicine has found a place in supporting palliative care (Calton et al, 2020). Based on a study by Doorenbos et al (2012), the integration of PC principles and practice into the PICU provides an opportunity to promote family-centered care (FCC), and strengthen the link between family members and the interdisciplinary team (Doorenbos et al, 2012). On the other hand, FCC is challenging to accommodate in PC (Kissane, 2016). FCC has been threatened during COVID-19, as it has been restricted in order to prevent the spread of the virus. Restrictions on family presence due to physical or social distance should not impair adherence to FCC principles. In COVID-19, FCC is more important, and requires the use of standard methods and innovative approaches (Hart et al, 2020).

PICUs for the cure and care of children with critical conditions are expanding in number and size (Randolph et al, 2004). They have also experienced increasing activity and complexity in recent decades. One of the biggest developments in PICU is the change of culture towards humanisation (providing

a comfortable environment for the child and family, decreasing environmental stress, paying attention to the family needs and establishing a positive relationship between family/child and professionals) (Esteban et al, 2019) and PC, as a comprehensive care of the child and family, paves the way for humanisation. Evidence shows that almost all patients admitted to PICU need some level of PC (Nelson et al, 2010; Boss et al, 2014; Short and Thienprayoon, 2018). In recent years, the rate of hospitalisation in PICU has increased (Davis et al, 2018), and more than half of paediatric deaths occur in PICU (Truog et al, 2006; Mitchell and Dale, 2015).

In Iran, there are about 450 PICU beds available for the hospitalisation of children with critical conditions. Due to the lack of hospices in Iran, most children at the end of life (EOL) are cared for in hospitals and PICUs. Parents of children admitted to PICU experience a high level of stress due to separation from their child, watching the progression of the illness and distress of their child and the lack of knowledge they have about the future (Hagstrom, 2017), and the PICU staff also deal with a high level of stress their workload (Kumar et al, 2016; dos Santos Moura et al, 2019). During the COVID-19 pandemic, some studies have also reported increased burnout, anxiety, stress, and depression in medical staff, especially nurses (HU et al, 2020; Khasne et al, 2020; Tan et al, 2020; Yoruk et al, 2020).

The challenges of PPC in the intensive care unit in Iran have not been studied, and now COVID-19 has increased these challenges. Issues such as: a disruption of the child-family-clinical care team relationship and FCC, the need to teach coronavirus management instructions to staff members, additional worries of patients and family, anxiety, the excess fatigue and burden of healthcare providers, family and child worries and anxieties, family bereavement, a major need for personal protective equipment, costs of hospitalisation and treatment and medical staff becoming infected are the issues that need to be studied in the PPC in COVID-19 in Iran. Therefore, this study was conducted to explore the challenges of palliative care during COVID-19 into the PICU in Iran based on the experience of healthcare providers.

Methods

This is a qualitative study with a content analysis approach. In qualitative research, the researcher obtains in-depth insights through participants' experiences, perceptions, beliefs, feelings, knowledge and perspectives by interviewing them

(Austin and Sutton, 2014).

Participants and setting

This study was performed in a children's hospital affiliated to the Tehran University of Medical Sciences in Iran. The hospital has five PICUs, with 46 beds, 120 nurses and seven paediatric intensivists. It admits children with critical conditions who need intensive care from all over the country. A total of 15 participants, including five paediatric intensivists and ten nurses (one matron, two head nurses, and seven PICU nurses) took part in this study. The inclusion criteria were 2 years of PICU experience for nurses and physicians, and willingness to participate in the study. The demographic information of the participants is given in *Table 1*.

Data collection

Purposeful sampling was performed to obtain information (Patton, 2002) from people who have sufficient knowledge and experience about the phenomenon of interest (Cresswell and Plano Clark, 2011) from April to October 2020. The interviews were conducted at the participants' workplace with their consent. Individual, face to face, in-depth and semi-structured interviews were conducted by a PhD Nursing Candidate for 30 to 60 minutes, and continued until data saturation was reached. Data saturation was determined by when no new category emerged from the data. Interviews began with the main questions, such as: 'Please describe your experiences in EOL care, or caring for life-threatening illnesses in children in the PICU and during COVID-19?', and 'What are the challenges and barriers of PPC?' Also probing questions, such as: 'Can you explain more?' and 'What do you mean?' were asked to further clarify the responses. The interview questions were formulated based on an unstructured pilot interview and a review of the literature. The pilot interview was not included in the study. At the end of each interview, participants were given the opportunity to comment and add anything else they wished. The interviews were recorded by a digital voice recorder. Immediately after the end of each interview, the recorded data were transcribed verbatim. To ensure confidentiality, the names of the participants were given the codes of P1 to P15.

Data analysis

Qualitative content analysis was used to analyse the data to provide a descriptive understanding of the phenomenon under study (Assarroudi et al, 2018). In conventional content analysis,

coding categories are derived directly from the text data (Hsieh and Shannon, 2005). The researchers used the Graneheim and Lundman (2004) method for data analysis. Content analysis processes consists of three main stages: preparation, organisation and the reporting of results. In the preparation phase, the researchers collected the appropriate data: first they transcribed the interviews verbatim, then they read each text several times and immersed themselves in the data and selected the unit of analysis. In the organising phase, codes and categories were extracted. In the reporting phase, the analysis and findings were reported (Graneheim and Lundman, 2004; Elo and Kyngäs, 2008). MAXQDA 10 software was used to manage the data.

Ethical considerations

This paper is a part of a nursing PhD dissertation. This study was approved by the Research Ethics Board of Schools of Nursing and Midwifery and Rehabilitation, Tehran University of Medical Sciences on 14 July 2019 (approval code: IR.TUMS.FNM.REC.1398.084). All participants signed the informed consent form prior to the interview, and were assured of the anonymity of data.

Trustworthiness

Lincoln and Guba's (1985) criteria, including credibility, dependability, conformability, and transferability were used to ensure data rigour and trustworthiness. The trustworthiness of the data was ensured by:

- The sufficient experience of the researchers (the researchers had experience working in the PICU and undertaking qualitative studies)
- The researcher's engagement and immersion in data gathering and data analysis
- Use of peer review by providing interview transcripts and extracted codes to other researchers
- Use of member check by providing interview transcripts and extracted codes and categories to participants (two nurses and two physicians)
- Application of the maximum variation of participants in terms of gender, age, work experience and expertise and profession
- Periodic monitoring of results and archive of project documents contributed to the trustworthiness of the data (Polit and Beck, 2009).

Findings

Fifteen nurses and physicians participated in this study. They had sufficient experience in caring for

patients with life-threatening diseases at PICU. After analysing the data, ten main categories were extracted:

- Caring in COVID-19
- Communication and family centred care
- Breaking bad news
- Palliative care training
- Pain and symptom management
- Support of the child, family and clinical team
- Physical environment
- Guidelines
- Specialised staff
- Home based palliative care

The main categories and subcategories are

listed in *Table 2*.

Caring in COVID-19

The participants' experiences revealed four sub-categories of 'fear, stress and anxiety of the child, family and clinical team', 'fatigue, burnout and workload of the clinical team', 'lack of personal protective equipment, unavailability and high cost of medicine' and 'silence and prolonged bereavement', which formed the main category of caring in COVID-19.

'In the coronavirus pandemic, this ward was the first ward to admit children with COVID-19.'

Table 2. Main categories and subcategories	
Main category	Subcategory
Caring in COVID-19	<ol style="list-style-type: none"> 1. The fear, stress and anxiety of the child, family and clinical team 2. The fatigue, burnout and workload of the clinical team 3. Lack of personal protective equipment 4. The unavailability and high cost of medicine 5. Silence and prolonged bereavement
Communication and family centred care	<ol style="list-style-type: none"> 1. Policies regarding the open presence of parents in PICU 2. Restrictions on family-centered care due to COVID-19 3. Inadequate competency of medical staff in communication skills in the paediatric intensive care unit 4. Communication with fear and apprehension in COVID-19
Breaking bad news	<ol style="list-style-type: none"> 1. Parents' anger and aggression when staff members tell them bad news 2. Breaking bad news during the COVID-19 pandemic
Palliative care training	<ol style="list-style-type: none"> 1. Inadequate communication skills training 2. Inadequate training of how to break bad news 3. Lack of basic and specialised palliative care training 4. Training needed on coronavirus management
Pain and symptom management	<ol style="list-style-type: none"> 1. Insufficient knowledge related to pain assessment 2. Insufficient knowledge of pain management 3. Insufficient knowledge related to pain and symptom management in COVID-19
Support of the child, family and clinical team	<ol style="list-style-type: none"> 1. Need for the psychological support of the child and family 2. Need for the spiritual support of the child and family 3. Need for the psychological support of the clinical team
Physical environment	<ol style="list-style-type: none"> 1. Non-standard structure and spaces 2. Lack of separate rooms for each patient 3. Lack of welfare facilities for parents 4. Additional light and sound
Guidelines	<ol style="list-style-type: none"> 1. Lack of native language palliative care guidelines 2. Lack of pain management guidelines
Specialised staff	<ol style="list-style-type: none"> 1. Need for a specialised interdisciplinary team 2. Need for a supportive team during the COVID-19 pandemic 3. Shortage of nurses
Home-based palliative care	<ol style="list-style-type: none"> 1. Lack of home-based palliative care centres 2. Legal issues 3. Financial issues 4. Lack of home care insurance coverage

In that situation, anxiety and stress, everyone in cyberspace posted a video or article about COVID-19 and those clothes ..., we were not ready yet, we were in a bad situation, and parents were very upset. The children were very scared and anxious. We were really tired ...' (P 13)

'... Another problem we had, especially at the beginning of the coronavirus, was the lack of masks and protective equipment and medicine and the high price of medicine for COVID-19 patients. Not all families could afford to buy medicine. Sometimes all our energy was spent trying to get medicine for these patients, by contacting the pharmacy and the social worker or by other patients that we knew were in good financial condition.' (P 10)

'... But the issue of bereavement for these companions was very important. Parents could not have any contact with the corpse. There was a mother who wanted to lay herself on the corpse and hug it, but we did not allow it. I was in contact with some of the parents, because they could not mourn naturally, their backs were broken by the burden of grief, and for several months after the death of their child, they still had a heavy emotional burden and we could not do anything for them.' (P 15)

Communication and family centre care

Participants' experiences revealed, 'policies regarding the open presence of parents in PICU', 'inadequate competency of medical staff in communication skills in paediatric palliative care', 'communication with fear and apprehension in COVID-19', and 'restrictions on family-centered care due to COVID-19' which formed the sub-categories of this main category.

'One of our problems during the COVID-19 pandemic, was family-centered care, which we feared would affect healthy parents ... That is why we explained to them that because the risk of COVID-19 is higher in adults and is associated with more death, they should have less contact with the child.' (P15)

'The children with COVID-19 wanted their parents to be by their side, but there were two problems, one was worrying about the parents getting infected, and the other seeing the parents with those special clothes, in which not only could the parents not communicate with the child properly, but sometimes even the

children were more frightened. We, the nurses, could not communicate properly with the children with those clothes, hats, masks, gloves and glasses ...'(P 8).

'I have seen many times that when families are by the bedside of end-stage children, they become much calmer. In our traditional PICUs, parents are not allowed to be by the bedside of children at all times, and these rules should be changed for patient's best interest.' (P 15)

Breaking bad news

'Parents' anger and aggression following a nurse breaking bad news' and 'breaking bad news during the COVID-19 pandemic' formed the sub-categories of this main category.

'... But the reality is that, we do not always do this, because we have not received enough training in this area. Maybe that is why, when a child expires, and we give bad news to the family, sometimes the families have a physical encounter with us. I want to be educated in this area.' (P 7)

'In COVID-19, it was very difficult when we wanted to give bad news to parents and maintain social distance, and we could not express our feelings with masks and glasses ...' (P 11)

Palliative care training

The participants' experiences revealed four sub-categories of 'inadequate communication skills training' and 'inadequate training of how to break bad news' and 'lack of basic and specialised palliative care training' and 'training about coronavirus management' which formed the main category of palliative care training.

'Early in the COVID-19 pandemic, we were not well educated and had little awareness and we were very confused. A lot of content in cyberspace confused us. Every moment we saw clips and heard news that were real and false in cyberspace. But gradually the doctors and the educational supervisor taught us the WHO protocols through webinars and placing educational materials and videos in the WhatsApp group of nurses. And we searched ourselves, but we still need to be more up-to-date and, more importantly, to take good care of [following COVID-19 precautions]'. (P 16)

'We nurses have not received full and

continuous training on palliative care. We work according to our experience. Young nurses in particular need more training. Of course, we learn more by attending workshops or practical courses, and we can help our patients better.' (P 6)

Pain and symptom management

According to the participants' experiences, three subcategories of 'insufficient knowledge for pain assessment' and 'insufficient knowledge for pain management' and 'insufficient knowledge related to pain and symptom management in COVID-19' formed the main category of pain and symptom management.

'Many intubated and EOL patients have pain. This endotracheal tube is painful. But sometimes we may not pay attention to the patient's pain. We had an immunodeficient and end-stage child who was intubated. I scored her pain based on the FACE scale. But I think this method is not very accurate. I do not know the pain tools related to intubated child.' (P 2)

'Now I have a patient, a boy with COVID-19 and who is ventilated. He has all the drug drips including Morphine and Midazolam. But he still has pain and is agitated. I would like to reduce the pain and restlessness, but I do not know how, and I cannot.' (P13)

Support of the child, family and clinical team

This category consisted of four subcategories, including 'need for psychological support for the child and family', 'need for spiritual support of the child and family' and 'need for psychological support of the clinical team'.

'... Mothers need psychological support. For example, one of our sick children had a nasopharyngeal mass that progressed very quickly within two months. The child [has] had surgery now, and he must be discharged with a tracheostomy, and that requires regular suction at home. The child's mother is so anxious about whatever we tell her about caring for her child at home, she becomes more worried and anxious. So I think this mother definitely needs counselling and psychological support from a psychologist. The psychologist should support such patients and their families from the early diagnosis.' (P3)

'... Often, when I talk to parents and ask them to trust God and pray, they calm down.' (P12)

'There is a need for a psychologist to come at some point and talk to nurses and ask if they are ok, and whether they have any problems. PICU nurses need emotional support more than others. If I'm in a good mental state, I will take better care of my patients.' (P13)

'In COVID-19 pandemic, we nurses in particular need more support. All this stress and work pressure and fatigue.... We had co-workers who fainted while working. Many of our co-workers got infected, and I got COVID-19 twice and even my teenage daughter got COVID-19 from me. In these circumstances, I expected more support from the authorities, but ...' (P14)

Physical environment

Participants' experiences revealed that 'non-standard structure and spaces', 'lack of separate rooms for each patient', 'lack of welfare facilities for parents' and 'additional light and sound' are some of the challenges of PPC.

'We have little space for the family to stay with the child and be comfortable. We do not have a room for bereavement and spiritual care. Almost all the time the lights are on and the light and all the extra noise in the ward are annoying and prevent the child from sleeping and resting.' (P 9)

Guidelines

Participants' experiences revealed that the 'lack of native language palliative care guidelines' and 'lack of pain management guidelines' were among the challenges of PPC.

'... In regard to PC, our actions as physicians and nurses are not according to guidelines

Key points

- Integrating palliative care into a paediatric intensive care unit (PICU) is necessary to provide high quality care for critically ill children
- COVID-19 has brought many challenges to PICUs, such as communicating and delivering bad news while maintaining social distancing and wearing personal protective equipment, enabling family-centred care, pain and symptom management of the patient and meeting the higher support needs of the child, family and clinical team during the pandemic
- Education is an important strategy to improve paediatric palliative care

Continuing professional development: reflective questions

- What challenges has COVID-19 brought to staff working at a paediatric intensive care unit?
- What are the skills that healthcare providers need for the end-of-life care of children?
- What are the practical solutions to improve paediatric palliative care at paediatric intensive care unit?

and protocols.’(P 14)

Specialised staff

The participants’ experiences made it clear that ‘need for specialised interdisciplinary team’, need for supportive team in COVID-19’ and ‘shortage of nurses’ were among the challenges of PPC.

‘We need a team for PC in the PICU that should include paediatric intensivists, pain or palliative care fellowship, PICU nurse, clinical psychologist, psychiatrist, social worker, and religious counsellor. I have seen many times that head nurses work hard for the comfort of children in the EOL stage and their families, but that is not enough. We ourselves are aware that, the place of multidisciplinary care is empty in the ward’. (P 9)

‘At the peak of COVID-19, with that workload ... the shortage of nurses was well felt. In general, the workload in PICU is high. As a nurse, I need to be aware of drips, ventilators, and drains. Too many times we do not really have time to talk to the child. When we have a very sick patient, there really should be one nurse for one patient, but sometimes I had two, three or even four patients in one shift.’ (P13)

Home-based palliative care

The three sub-categories of ‘lack of home-based palliative care centres’, ‘legal issues’, ‘financial issues’, ‘lack of home care insurance coverage’ formed the category of home-based palliative care.

‘Some intubated patients with chronic conditions are in the ward for 2 months. They need home care, but do not have money to pay for home care and purchase equipment. Palliative care services are not covered by insurance. We may only be able to help them over the phone. We don’t have a home care plan, but I would very much like to be involved in home care.’ (P 2)

Discussion

PPC in the intensive care unit in Iran faces many challenges, and the COVID-19 pandemic made

it more complex. The experiences of the health care providers showed that they experienced a lot of anxiety, stress and fatigue, and the families were very worried and thought that a diagnosis of COVID-19 mean that their child would die. The children also experienced a lot of fear and anxiety. Parents who lost their child during the COVID-19 pandemic could not hug them and mourn naturally, so they experienced chronic and complex grief. The results of the study showed that in COVID-19 related bereavement, due to reduced social support and the limited opportunity for death ceremonies, a greater level of grief is experienced than natural bereavement (Wallance et al, 2020). Zhou et al (2020) reported that children with COVID-19 suffer from fear, ambiguity, social and physical isolation, and separation from their family exposes them to psychosocial problems (Zhou et al, 2020). Some studies have also reported burnout, anxiety, stress, and depression in medical staff, especially nurses during COVID-19 (Hu et al, 2020; Khasne et al, 2020; Tan et al, 2020; Yoruk and Guler, 2020). At the beginning of the pandemic, a lack of personal protective equipment, the unavailability and high cost of medicine were additional challenges of palliative care. This was a global problem, as the dramatic increase in demand for surgical masks, glasses, gowns and gauze reduced existing stocks (Park et al, 2020).

Participants revealed that the clinical team in the study, especially the young nurses, do not have good communication skills for communicating with the child and their family. Also, some parents chose not to be by the child’s bed due to COVID-19. Communication in the paediatric nursing is the basis of care (Martinez et al, 2013), and is a core component of FCC (Gough et al, 2009). A paediatric nurse needs to be aware of verbal and non-verbal communication techniques that are appropriate to the age and developmental level of the child (Duzkaya et al, 2014). In PICU, communication skills are essential for high-risk decision-making and keeping the families updated about the care their child is receiving (Azoulay et al, 2001). The integration of PC in PICU is an important opportunity to develop FCC and strengthen the

relationship between family members and the interdisciplinary team (Doorenbos et al, 2012). The study by Davies et al (2008) showed that one of the barriers to PPC is the lack of effective communication between the clinical team and the child's family (Davies et al, 2008). Also, according to the study of Ghaljeh et al (2016), care-based communication is an important component of professional PC, and is essential in EOL care (Ghaljeh et al, 2016).

Also, the experiences of health providers in the study showed that communication and FCC were more challenging during COVID-19. Some parents were reluctant to have close contact with the child as they did not want to transmit COVID-19, and in some cases, due to a lack of personal protective equipment and the high cost of this for the parents, the health team recommended that the family reduce their contact with their child and FCC was disrupted. Furthermore, at times when parents went to the child's bed, they were unable to emotionally communicate with their child under protective clothing. FCC during the COVID-19 pandemic must continue to be based on standard principles and innovative methods (Hart et al, 2020), and families must be encouraged to still communicate with the children, building on key values such as honesty, trust, kindness, and introduce death as a part of life (Weaver and Wiener, 2020).

Participants' experiences revealed that some parents become angry when they hear of their child's death and attack the medical staff, and due to COVID-19, physical and social distance prevented medical staff from breaking bad news to parents in an appropriate way, and they need further training in this area. Breaking bad news to the family is a basic paediatric skill that is difficult to learn. Medical professors should provide opportunities for medical students to practice and learn this vital skill (Tobler et al, 2014). According to the systematic review study by Camargo et al (2019) breaking bad news is challenging for physicians, and medical schools should focus on integrating education on breaking bad news into their curriculum (Camargo et al, 2019). The issue of how to break bad news to a family is also very important for nurses and doctors who work in COVID-19 wards, and COVID-19 has disrupted health providers' education about this, so breaking bad news training is recommended digitally to health care providers (Soosaipillai et al, 2020). Breaking bad news while still observing social distancing and wearing a mask is one of the challenges of COVID-19, and adaptation strategies need to be taught (Andre, 2020).

Another major challenge in PPC is the lack of ongoing PC training for PICU staff that, at the same time as the COVID-19 pandemic, the problem became more complex and the clinical team needed to be trained in coronavirus management. Education is a key component and one of the most important strategies of WHO for the development of PC (Stjernswärd et al, 2007). Education is also the key to providing knowledge, skills and confidence to paediatricians and nurses who provide quality care at the EOL for children and their families (Downing et al, 2013). Peng et al (2017) showed in their study that education can increase the confidence of paediatric clinicians to provide palliative care for children, and therefore regular and continuous education should be provided to paediatric clinicians. The results of a study by Wright et al (2011), showed that 100% of nurses agreed that there is a need for PC training for nurses who work at the NICU, with only 46% reporting they had received adequate training in this area (Wright et al, 2011).

Participants' experiences revealed that most nurses do not have sufficient knowledge in assessing and managing pain and symptoms in the PICU. Contro et al (2004) showed that half of the paediatric nurses reported that they were inexperienced in managing symptoms, and 30% of them were inexperienced in pain management of children (Contro et al, 2004). In PICU, children receive more complex medical interventions and less attention is paid to their pain and symptom management (Short and Thienprayoon, 2018; Mesukko et al, 2020).

Participants' experiences showed that supporting the child, family and clinical team is another challenge of PPC in PICU especially during the COVID-19 pandemic. PICU staff, especially the nurses, revealed that in stressful situations they need more support from the authorities until they can provide more care and support to their patients.

Studies indicate that the COVID-19 pandemic has affected the mental health of medical staff and that there is a need for social support and support from policymakers. Such support would be in the form of improving working conditions, providing adequate training to staff, preventing long shifts and promoting safe working environments (Hu et al, 2020; Khasne et al, 2020; Tan et al, 2020; Yoruk and Guler, 2020). Families who have been bereaved during the COVID-19 pandemic need increased support from the health team because they could not go through the normal stages of mourning and were unable to be supported by relatives (Helton et

al, 2020). The participants of this study believed that, PICU staff need psychological support more than ever, because they often face critical situations, such as resuscitation and child death. Studies show that one of the challenges in caring for children at the EOL is that healthcare providers are at risk for compassion fatigue and burnout (Papadatou et al, 2001; Maytum et al, 2004). In general, caring for a dying child is stressful (Contro et al, 2004).

A study by Adistie et al (2020) showed that children in the EOL stage need to be fully supported in physical, psychological, social and spiritual dimensions (Adistie et al, 2020).

The participants reported that the structure of the PICU, such as a lack of separate rooms for each patient, lack of welfare facilities for parents and excessive light and noise, creates a challenging care environment. Numerous studies also show that the physical environment is a barrier to providing PC in the NICU (Yam et al, 2001; Wright et al, 2011).

The lack of PPC guidelines in Iran was also reported as a barrier to PPC by the participants of this study. Health care providers providing PC in Iran use their own experiences and knowledge to provide care, due to this lack of guidelines (Rassouli et al, 2019). Wright et al's (2011) study also showed that a lack of PC policies/guidelines is one of the barriers to PC in NICU (Wright et al, 2011).

The participants believed that a specialised multidisciplinary team was needed to develop PC, and they felt that a psychologist was essential to psychologically support the child, family and the clinical team. Over the past decade, PPC teams have been formed to support children with life-threatening illnesses and their families, and to ensure the continuity, coordination, and quality of PPC (Verberne et al, 2018). Studies have shown that comprehensive PC requires the participation of a multidisciplinary team including physicians, nurses, child health professionals, social workers, clergy, psychologists and researchers (Neha and Vivek, 2016; Ansari et al, 2018). PPC teams should also have a telehealth aspect during the COVID-19 pandemic (Weaver et al, 2020).

Home based PPC services in Iran are not covered by insurance, so patients stay in the hospital for longer, which, increases the risk of patients acquiring a COVID-19 infection and, since parents suffer from a high level of stress and financial burden, it is essential that the necessary training be given to families and the care of these children be transferred from the hospital to home as soon as possible. Home

care can empower patients and their families (Khoshnazar et al, 2016).

Limitations of the study

Interviews were conducted during the COVID-19 pandemic. The most important limitations of this study were the high workload of the interviewees and concern about the transmission of the virus between the parties. To overcome this problem, interviews were conducted in the free time of the interviewees and masks were worn throughout the interviews and social distancing was maintained.

Conclusions

The participants of this study recognised that PPC needs to be improved in light of COVID-19 and that PC training for PICU staff is essential. Education must be active, continuous and practical to be the most effective. Implementing basic and specialist palliative care training courses, establishing facilities for FCC, improved communication and family education and family support using telehealth/telemedicine/telenursing technology, medical staff support, designing and localising guidelines, forming a specialised interdisciplinary PPC team, increasing home-based palliative care centres, expanding the coverage of PC insurance, the use of NGOs, and the standardisation of the physical environment of PICU are recommended. *IJPN*

Conflicts of interest: none.

Acknowledgements: *The authors would like to extend their gratitude and sincere thanks to Tehran University of Medical Sciences for the approval and financial support of the project (Grant number: 98-3-100-42881). We also would like to thank the doctors and nurses who helped us by sharing their valuable experiences in this research.*

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