Views of Medical and Nursing

Professionals on Palliative Care for Paediatrics and Adolescents in Hong Kong

Authors:

CHAN Chi-Ho, Wallace | LEUNG Mei-Mui, Miranda

LIN Kwok-Yin, Molin | WONG Lok-Yi, Karen | LAM Chak-Lung, Barry

Views of Medical and Nursing Professionals on Palliative Care for Paediatrics and Adolescents in Hong Kong
醫護人員對香港兒童及青少年紓緩服務的意見

Submitted to
Children's Cancer Foundation
By

CHAN Chi-Ho, Wallace 陳智豪
Assistant Professor, Department of Social Work, The Chinese
University of Hong Kong

LEUNG Mei-Mui, Miranda梁美梅
Nursing Officer, Department of Paediatric and Adolescent
Medicine, United Christian Hospital

LIN Kwok-Yin, Molin 林國嬿
Professional Services Manager, Palliative and Home Care Service,
Children's Cancer Foundation

WONG Lok-Yi, Karen 黃樂宜
Research Assistant, Department of Social Work, The Chinese
University of Hong Kong

LAM Chak-Lung, Barry 林澤龍
Research Assistant, Department of Social Work, The Chinese
University of Hong Kong

August 2015

Content

Tables

Figures

RESEARCH TEAM

Principal Investigators

Name	Title	Organization
Dr CHAN Chi Ho, Wallace	Assistant Professor	Department of Social Work, The Chinese University of Hong Kong (CUHK)
Ms LEUNG Mei Mui, Miranda	Nursing Officer	Department of Paediatric & Adolescent Medicine, United Christian Hospital (UCH)
Ms LIN Kwok Yin, Molin	Professional Services Manager (Palliative and Home Care Service)	Children's Cancer Foundation (CCF)
Ms WONG Lok Yi, Karen	Research Assistant	Department of Social Work, The Chinese University of Hong Kong (CUHK)
Mr LAM Chak Lung, Barry	Research Assistant	Department of Social Work, The Chinese University of Hong Kong (CUHK)

Expert Panel

Name	Title	Organization
Dr LI Chi Kong	Director	Lady Pao Children's Cancer Centre, Prince of Wales Hospital
Mrs TIEN LUK Sau Kuen, Gloria	1st President	Hong Kong College of Paediatric Nursing
Dr LAU Kam Shing	COS	Head of Department (Respiratory Medicine & Palliative Care), Ruttonjee Hospital
Ms CHAN Chun Hung, Red	APN (Palliative Care)	Tuen Mun Hospital
Dr Alicia PON	Play Therapist and Social Worker	Private Practice

Co-Investigators

Name	Title	Organization
Dr CHAN Cheong Wai, Stephen	Associate Consultant (PAED)	Caritas Medical Centre / Our Lady of Maryknoll Hospital
Dr CHERK Wan Wah, Sharon	Deputy Consultant (PAED)	Kwong Wah Hospital
Ms CHIU Sau Ying	Nurse Specialist (PAED & AM)	Queen Mary Hospital
Ms HUI Tak Yee, Rebecca	Deputizing DOM (PAED)	Pamela Youde Nethersole Eastern Hospital
Ms Mona LEUNG	Nurse Specialist (P&AM)	Tuen Mun Hospital
Dr NG Sui Fun, Grace	Associate Consultant (PAED&AM)	Princess Margaret Hospital / Yan Chai Hospital

Collaborators

Name	Title	Organization
Hong Kong East Cluster		
Dr SO Lok Yee	COS (PAED)	Pamela Youde Nethersole Eastern Hospital
Hong Kong West Cluster		
Prof CHAN Chi Fung, Godfrey	COS (PAED&AM)	Queen Mary Hospital
Ms Connie WAN	DOM (PAED)	Queen Mary Hospital
Prof WONG C. N., Virginia	Honorary Consultant (P&AM)	The Duchess of Kent Children's Hospital at Sandy Bay
Ms Eliza WONG	Ward Manager 3 & 4	The Duchess of Kent Children's Hospital at Sandy Bay

Kowloon East Cluster		
Dr CHAN Hin Biu	COS (P&AM)	United Christian Hospital
Dr HUEN Kwai Fun	COS (P&AM)	Tseung Kwan O Hospital
Ms Miranda LUI	Ward Manager (PAED-4A)	Tseung Kwan O Hospital
Ms MA Po King	DOM (P&AM)	United Christian Hospital
Kowloon West Cluster		
Ms FUNG Lai Sun	Nursing Officer (PAED)	Yan Chai Hospital
Ms Tany KWONG	DOM (PAED)	Princess Margaret Hospital
Dr LEE C. Y.	COS (PAED&AM)	Caritas Medical Centre / Our Lady of Maryknoll Hospital
Dr Daniel NG	COS (PAED)	Kwong Wah Hospital
Ms TSE Ching Han, Connie	DOM (PED & DDU)	Caritas Medical Centre
Dr Niko TSE	COS (PAED)	Princess Margaret Hospital / Yan Chai Hospital
Ms YU Wan Lan	DOM (PAED)	Kwong Wah Hospital
New Territories East Cluster		
Ms CHAN Suk Han, Becky	DOM (PAED)	Alice Ho Miu Ling Nethersole Hospital
Ms LEUNG Mui Chu	DOM (PAED)	Prince of Wales Hospital
Dr LI Chi Kong	Director	Lady Pao Children's Cancer Centre Prince of Wales Hospital
Dr TONG Chi Tak, Luke	COS (P&AM); COS (PAED)	Alice Ho Miu Ling Nethersole Hospital; North District Hospital
New Territories West Cluster		
Dr KWONG Ngai Shan	COS (P&AM)	Tuen Mun Hospital
Special School		
Mr CHEUNG Chi Ming, Terence	Principal	Caritas Lok Kan School

ACKNOWLEDGEMENTS

We would like to express our sincere appreciation to the Children's Cancer Foundation for granting and funding the opportunity to conduct this study, which facilitates our understanding of medical and nursing professionals' views on paediatric palliative care (PPC).

Moreover, we would like to thank the Ethical Committees of Hospital Authority, some special schools and institutions, Hong Kong Paediatric Nurse Association, and the Hong Kong College of Paediatric Nursing in supporting the study.

We would like to thank the generous time, advice, assistance and support of the expert panel, co-investigators and collaborators of the study. Last but not least, we would like to thank all the participants including those in the pilot study and the formal study for their time and for genuinely sharing their views and experiences, especially given their hectic and full schedule.

Nevertheless, we must give our sincere thanks to our colleagues and friends, Ms Chan Lai Ming, Miss Cecilia SM Chan, Ms Emily SW Chan, Ms Choy Shuk Hing, Ms Janet YC Fung, Ms Emily Ho, Dr Pricilla PC Lo, Miss Alice KL Man, Dr Ng Chun Bor, Ms Meela Tam, Dr William CW Tam and Ms Brenda Yim, for their generous time sharing in the pilot study and valuable comments to the study tool.

PREFACE

Every paediatric medical or nursing professional has the chance to encounter PPC cases no matter working for cancer or non-cancer groups of patients. However, there is a lack of formal PPC services for the sick children in Hong Kong.

Therefore Ms Miranda Leung (an experienced paediatric nursing officer, the convener of this PPC study group) invited Ms Molin Lin (an experienced Home Palliative Care Nurse Specialist for children with cancer diseases) and Dr Wallace Chan (an experienced Social Worker, a scholar, an expert on death work and study) to form a study group for PPC. The first meeting of the study group was held on 18th January in 2012 at the Chinese University of Hong Kong.

In order to enhance the quality of PPC, we have to understand the competence and challenges of medical and nursing professionals in PPC, as well as their views on related services, facilities, and policies. Such understanding will benefit not only the patients but also their family and close relatives. We, therefore, conducted a survey of medical and nursing professionals' views on PPC in Hong Kong from December 2013 to August 2014 after a pilot study.

As this is the first local study on PPC, the questionnaire was developed through a rigorous validation. Firstly, it was suggested by the three experienced professionals (two nurses and a social worker). Secondly, it was examined by an expert panel of five covering palliative medicine and nursing, paediatric medicine and nursing, and psychosocial aspects. Consequently, it was revised and simplified from 13 pages into 4 pages by the leading from the principal investigator Dr. Wallace Chan after a pilot study. This shortening might be one of the successful criteria to achieve quite a large number of reply-680 copies.

Of course, in the 680 respondents, we believe that most of the medical and nursing professionals are really concern the quality of life and quality end-of-life care for the child patients. We hope this study facilitates better quality paediatric palliative care service development in Hong Kong!

CHAN Chi-Ho, Wallace
LEUNG Mei-Mui, Miranda
LIN Kwok-Yin, Molin
WONG Lok-Yi, Karen
LAM Chak-Lung, Barry

August 2015

EXECUTIVE SUMMARY

This is the first local study in Hong Kong, which aims to explore the views of paediatric doctors and nurses in providing paediatric palliative care (PPC). Doctors and nurses who have been working in paediatrics for at least six months were recruited from public hospitals and special schools. Through the survey method 680 paediatric doctors and nurses participated in this study by completing a questionnaire (Table 1). The questionnaire contained two major parts: a) participants' perceived competence and challenges in providing PPC, and b) participants' perceived impact of different macro factors on service quality and their urgency for improvement. One hundred ten participants were doctors and 567 participants were nurses (Table 4). The majority were female (90.3%), and the mean age was 35.3. Participants who had more than 5 years of experience in paediatrics made up to 59.6% of all participants.

Findings showed that participants in general perceived themselves to be competent in the domains of knowledge, skills, and self when providing PPC. They perceived relatively less competence in the work environment. However, participants in general also perceived challenges in the various domains, including knowledge, skills (basic and advanced), professional self, and work environment (sample means were significantly above the midpoint of the rating scale). Nevertheless, participants perceived relatively less challenge in the domain of personal self (the sample mean was significantly below the midpoint of the rating scale). Compared with paediatric doctors, paediatric nurses perceived significantly more challenges in basic skills, advanced skills, professional self, and personal self. Compared with the more experienced group (more than 5 years' experience in paediatrics), participants in the less experienced group perceived significantly more challenges in knowledge, basic skills, advanced skills, professional self, and personal self. Conversely, participants in the more experienced group perceived significantly more challenges in the domain of general work environment.

We categorized the factors for service improvement into two major areas: macro factors and services to clients. For the macro factors, participants perceived adequacy of human resources, and availability of resources as having the most impact on the service quality of PPC and in the most urgent need for service improvement. For services to clients, the interface between hospital service and community service was rated as having the most impact and in the most urgent need for improvement. Other prominent factors include recognition of the importance of PPC, bereavement services for patients' families, and knowledge about palliative care for patients' families.

Findings showed the need of paediatric doctors and nurses for further training to cope with the various challenges in providing PPC, e.g. advanced skills in end-of-life communication with child patients and their parents. Special attention can be given to the possibly masked need for enhancing self-competence in coping with the challenges to the self, such as coping with one's own grief aroused from work. In addition, future training may be developed to meet the different needs of paediatric doctors and nurses in providing PPC. Our study also suggests giving more support to less experienced paediatric doctors and nurses in domains such as knowledge, skills and self, whereas more support could be given to more experienced colleagues in facing the challenges of the general work environment, such as human resources and resources allocation.

A shortage of human resources is an identified issue in this study, but it is also common in all hospital services in Hong Kong. We, therefore, suggest developing appropriate guidelines and workflow to facilitate the provision of PPC. More resources and support should be given to parents, who could be valuable partners to paediatric doctors and nurses in serving child patients. Our study also suggests the importance of strengthening the interface between hospital and community to ensure child patients and their families receive adequate support in the community. Besides, our study suggests giving more emphasis to the psychosocial needs of child patients in PPC and increasing the general public's knowledge of PPC.

| NTRODUCTION

Every paediatric doctor and nurse have the chance to encounter paediatric palliative care (PPC) cases. In order to enhance the quality of PPC in Hong Kong, we used a cross-sectional survey to explore the views of paediatric doctors and nurses on their competence and challenges in PPC, as well as their views on related services, facilities and policies. This report is divided into the following parts: literature review, theoretical framework, objectives, research methodology and data analysis, findings, discussion, implications and recommendations, and conclusion.

1 LITERATURE REVIEW

1.1. Paediatric palliative care

Paediatric palliative care (PPC) has received less attention than has palliative care to adults, possibly because there is less need for the palliative care of children than for adults, particularly older persons. In Hong Kong in 2011, the total number of deaths for all ages was 42,188 (Centre for Health Protection, 2015) but for children (refers to those aged under 18) was only 256 (Child Fatality Review Panel, 2015). However, the needs of child patients are different from those of adult patients receiving palliative care. Another possible reason is that it is socially difficult to accept the death of a child (Morgan, 2009). This indeed prompts an additional aspect of challenges to professionals working with dying children, because the death of children violates the common assumption of the natural order of a lifespan. This will be further discussed.

1.2. Professionals working with dying patients

Whether studies are on palliative care to adults or PPC, most explore palliative care from the perspective of the patient and/or the family. An example of an area of research is the grief of the family over the death or dying of the patient (Papadatou, Martinson, & Chung, 2001). Despite playing a significant role, particularly in providing care and support to the patient and his or her family, professionals are relatively less often the focus of discussion. Even when professionals are part of the discussion, the focus often relates to their knowledge and skills. An example is the Service Self-Assessment Tool invented by ACT (Now, Together for Short Lives) (McNamara, 2011), which assesses whether professionals follow procedures that are in the best interests of the child patient and his or her family. However, other aspects of professionals also influence the provision of quality palliative care.

These other aspects which are equally worth academic attention are, for instance, professionals' stress and burnout from work and thus also issues of turnover (Morgan, 2009; Papadatou, Martinson, & Chung, 2001), grief aroused because of frequent exposure to the suffering, dying and death of patients (Papadatou et al., 2001; Lerea & LiMauro, 1982), and emotions (Morgan, 2009).

Lerea and LiMauro (1982) explored the frequency and nature of grief experienced by healthcare workers over the suffering and death of patients. A questionnaire was used to interview 162 participants who were nurses and aides working in different medical settings: a general hospital (GH) and a skilled nursing facility (SNF) serving geriatric patients. It was found that grief over the suffering and death of patients was a common experience among workers. Workers in the GH experienced grief more often than did their counterparts in the SNF. This was explained by different expectations of the death of patients. In the GH, diseases were seen to be curable and thus death was less expected, whereas in the SNF serving geriatric patients, death was common and even seen as a blessing in ending the prolonged suffering of the patients and was regarded as the natural order. This further explained why GH workers grieved particularly strongly for young patients, because their death went against the common understanding of the natural order. There was no relationship between mourning and professional training. Nurses or aides were not trained to cope with their own emotional suffering. It was found that workers experienced more psychological grief symptoms than they did physical symptoms. Participants reported feeling helpless at their inability to alleviate suffering or save the life of patients. They experienced fatigue, a consequence of keeping busy with their duties as an escape from emotional suffering. It was also a preventive measure against criticism from the family for not trying their best to help save the patient. Recommendations included bereavement counseling and grief therapy programs for healthcare workers.

1.3. Professionals working with dying children

In the literature on professionals providing palliative care, that on palliative care to children, PPC, or working with dying children, is limited (Papadatou, Bellali, Papazoglou, & Petraki, 2002). However, working with children who are dying could be more stressful than working with dying adults, because, as suggested in the work by Lerea and LiMauro (1982), workers often regarded the death of children as against the natural order.

Davies et al. (1996) suggested that, with reference to a study conducted with nurses in paediatric oncology in Canada, working with dying children included two aspects of distress: first, grief over the death or dying of the child patient, and second, moral conflict between the provision of comfort care and curative medicine. The latter included conflicts with the values of doctors, who stressed curative medicine when nurses emphasized comfort care. The ways these nurses coped: admitting and expressing their own grief, attempting to explain the meaning of death of the child patient, and seeking support from peers.

Hinds et al. (1994), noticing the grief over the death or dying of child patients of paediatric oncology nurses, conducted a grief workshop. It was found that the participants had no reduction in grief or stress after the workshop. The conditions of some were even worse. A possible explanation raised by the authors is that the participants were unaware or not very aware of their grief before the workshop, and the workshop has made the participants realize their grief.

Morgan (2009) presented a literature review on the experience of nurses offering PPC across cultures, for example, the United States, Hong Kong, and Greece, summarizing some universal experiences, particularly challenges. It was found that professionals may not be aware of their grief over the death and dying of the child patient, or may deny it, because the death of children seemed to be against the perceived natural order. Citing Papadatou's work, the death of a child patient was a 'triple failure' to nurses, because the death seemed to be a reflection of their inability to save the child patient as professionals, the inability to protect the child patient as adults, and the inability to help parents who relied heavily on them. Morgan highlighted several issues with regard to the experience of nurses offering PPC. First, 'moral and ethical distress' (p. 88) was suggested. Nurses tended to opt for more palliative care, particularly from a nursing professional point of view. This led to conflicts between curative medicine and palliative care, conflicting with the views of doctors, who stressed curative medicine. Also, nurses grieved over the death and dying of the child patient. In order to protect themselves from emotional suffering, they consciously kept an emotional distance from the child patient and his or her family. Moreover, many nurses reported inadequate support from colleagues although this support was an important source for overcoming hurdles in working with dying children. Distress, emotional suffering, and limited peer support contributed to the feeling of burnout and thus high turnover of nurses. Furthermore, it was suggested that there was inadequate training and education in skills and knowledge, physical care of the child patient, adaptation in switching from physical care to comfort care, communication with the child patient and his or her family, as well as comforting the family. Finally, in response to the above challenges, Morgan highlighted the role of the advanced practice nurse on advocating policy and practice changes, supporting colleagues, promoting education and training, and initiating research.

The experience of professionals working with dying children is a research area, which is traditionally a strength of nursing. So far, the literature reviewed above has explored the experience of nurses. Literature also exists which explored the experience of other professionals. The following is an example of literature exploring the experience of not only nurses but also doctors. Papadatou et al. (2002) explored the experience of professionals caring for dying children suffering from cancer in Greece. Thirty paediatric oncology doctors and nurses were involved in the study. The interview was the primary research method. Additionally, participants were invited to rate a list of items regarded as stressful in working with dying children. Qualitative data analysis was used, supplemented by quantitative data analysis. It was found that grief over the death and dying of child patients was a common phenomenon for nurses and doctors. Both professions found caring for dying children stressful and experienced helplessness and grief. However, doctors felt helpless at their inability to alleviate pain and save lives as professionals. They often grieved alone and did not seek support from peers. They also consciously avoided or suppressed grief. Nurses, in contrast, stressed the relationship with the child patient and his or her family as rewarding and the aspect of their work that made the most contribution.

They thus grieved more over the separation from the child patient with whom they had built a relationship, because of death. They also often turned to their peers for help. Different care roles were found to be performed by doctors and nurses, attributed to different training. Whereas doctors tended to provide more physical care, nurses tended to provide more social care. It was observed that there was a swing between grieving and avoiding grief for both nurses and doctors, attributed to their work environment, for example, rules and policies of the hospital. The authors stressed the importance of taking social and cultural factors into account when analyzing the experience of professionals working with dying children. They suggested factors related to the work environment, for example, shortage of staff, difficulties collaborating with colleagues and limited facilities and services. They also suggested the Greek society's expectation of professionals to be emotionally competent, which impeded the expression of their grief. Recommendations were suggested supporting professionals in grieving and accepting grief, offering consultation to professionals, and providing education and training to professionals in palliative care, social care and not only in physical care, as well as personal preparation for death and dying.

1.4. Local literature on professionals working with dying children

So far we have reviewed overseas literature. The following reviews local Hong Kong studies, aiming to explore the extent to which the experience of professionals working with dying children in Hong Kong is consistent with the experience of their overseas counterparts. Local literature on professionals and PPC is limited but inspiring, showing that this topic has plenty of potential for further exploration in the Hong Kong context. Papadatou et al. (2001) conducted a study comparing the experience of nurses working with dying children in oncology and critical care units in Hong Kong and in Greece. This study is worth reviewing because there are limited relevant studies in Hong Kong, but Papadatou is an internationally renowned Greek expert in this area. This study preceded the one by Papadatou et al. (2002) reviewed above. Qualitative interviews were conducted with 63 nurses. The data were primarily analyzed using qualitative data analysis supplemented by quantitative data analysis. The study was particularly interesting in finding similarities and differences in the experience of the participants in cultures and work settings. Key findings suggest that working with dying children is a stressful experience because the suffering, dying, and death of a child seemed to be against the common understanding of the natural order. Participants felt challenged by two aspects. First, they felt helpless at not being able to address the physical, emotional and sometimes also spiritual suffering of the child patient as well as that of his or her family. This was accelerated by conflicts with doctors. Nurses stressed comfort care, whereas doctors tended to prefer curative medicine. Second, they encountered communication difficulties with the child patient and his or her family. Participants grieved over the dying and death of the child patient, swinging between experiencing and expressing grief and avoiding and repressing grief. In another publication by Papadatou et al. (2002), the authors commented that this swinging is a healthy adaption to grief for professionals.

Compared with their Greek counterparts, Chinese nurses suppressed their grief more often by keeping themselves busy although this was a universal experience in different cultures. Participants gave or searched for meaning of the death and dying of the child patient, a majority referring to religious forces. Compared with Greek nurses, Chinese nurses accepted more the death and dying of the child patient, attributed to differences in ideologies between cultures. Nurses regarded caring for dying children as rewarding, feeling that they were making a contribution. However, there were differences in contributions between nurses working in oncology and those in intensive care units. Nurses in oncology stressed their contribution as being with the child patient and enhancing the quality of life (QOL), whereas those in intensive care emphasized alleviating the physical suffering of the child patients. The authors found that, surprisingly, the potential reasons for leaving the units were unrelated to the child patients but rather to the difficulties collaborating with doctors and the shortage of staff. As suggested, the origin of the conflicts with doctors was the discrepancies between the emphasis on comfort care and curative medicine; the nurses' perspective on comfort care was often ignored. Recommendations were made for education, support groups, professional consultation and further research.

Yam, Rossiter and Cheung (2001) explored the experience of nurses working in neonatal intensive care units in Hong Kong, by conducting qualitative interviews with 10 nurses. Several themes were observed. Participants reported grieving and feeling a sense of helplessness over the dying and death of the infant patient. Because of fear of being hurt emotionally, they kept an emotional distance between themselves and the infant patient and his or her family. They tended to give comfort care rather than curative medicine. They understood the importance of emotional support to the family, such as comforting the parents, but rarely did so, worried about making things worse. The authors explained this according to the Chinese culture of subtle emotional expression, lack of communication skills and lack of self-preparation. Participants also placed priority on physical care or curative medicine over comfort care in daily practice despite recognizing the importance of comfort care. This was attributed to the traditional focus of nursing training, shortage of staff and the policy of the unit. Recommendations were made for death education and communication skills workshops, peer support groups, bereavement teams, policy reforms and creating a supportive work environment.

1.5. Research gaps and relevance of proposed study to Hong Kong

Despite the importance and urgency of reforming PPC in Hong Kong and the crucial role of the views of paediatric doctors and nurses on enhancing PPC, as suggested above, there are limited local studies exploring the experience or views of professionals on PPC. Relevant studies are mostly conducted outside Hong Kong or about palliative care or death work generally and not specifically about PPC, for instance, the study about the competence of death work professionals conducted by Chan and Tin (2012). Even when the studies are specifically about the experiences and views of professionals on PPC in Hong Kong, they are mainly qualitative and have restricted sample sizes, such as those exploring nursing professionals' experience and views on PPC by Papadatou and Martinson (2001) and Yam et al. (2001).

Relevant quantitative studies were conducted in places other than Hong Kong, for example, the US (Rushton et al., 2006). Notwithstanding the significance and strength of exploring concepts in detail, the shortcoming of qualitative studies means it is difficult to generalize findings from data, due to the restricted sample size. A quantitative study with a significantly larger sample size should be a good supplement to validate the findings of the qualitative studies. Therefore, there is a research gap and thus a need to explore the views and experiences of professionals providing PPC in Hong Kong, using a quantitative study. Our study aimed to fill this gap.

2 THEORETICAL FRAMEWORK

Our study was exploratory research, so there was no hypothesis or experimental or control group. For the theoretical framework, this study suggested grouping the related elements recommended in literature under the death work competence model by Chan and Tin (2012). This model was used to conceptualize different domains of challenges and competence in providing PPC. Most importantly, the model was relatively simple and straightforward to understand and had the advantage of flexibility in being applied to different situations. For example, death work was broadly defined by Chan and Tin (2012, p. 900) as 'any supportive, therapeutic, or remedial work in response to death or matters related to death'. This broad definition of death work is thus applicable to different settings, including PPC. In the original study of Chan and Tin (2012), helping professionals who do death work, such as nurses, doctors, social workers, and chaplains, were asked to respond to an open-ended question: "what do you think are the necessary competencies performing death work?" The data were analyzed by content analysis. Four competences were identified: practice competence, knowledge competence, self-competence, and work-environment competence (e.g., competence in collaborating with colleagues or working as a team). Self-competence was highlighted as the most frequently mentioned in the study but rarely discussed in previous literature. Self-competence was further divided into existential coping, emotional coping, and personal resources. Existential coping refers to coping with existential challenges (e.g., meaning of suffering). Emotional coping refers to coping with emotional challenges (e.g., grief over the death of patients). Personal resources are personal abilities and were described as fuel to facilitate the other two elements of self-competence. Recommendations were made for cultivating self-competence, such as promoting the self-awareness and self-reflection of professionals. Our study elicited the four competences of the model: knowledge competence, practice competence (renamed skill competence in our study, for better understanding of the term in Chinese), self-competence, and work-environment competence as the theoretical framework, as shown in Figure 1. Relevant elements elicited from professionals' experience working with dying patients and their families previously suggested in the literature review were grouped under each competence. Competence can be understood from two perspectives, challenges and coping. Therefore, in the questionnaire of our study, for each competence, questions were asked about the extent to which the participants felt competent and challenged with respect to working with dying children and their family.

Figure 1

Theoretical framework: Death work competence
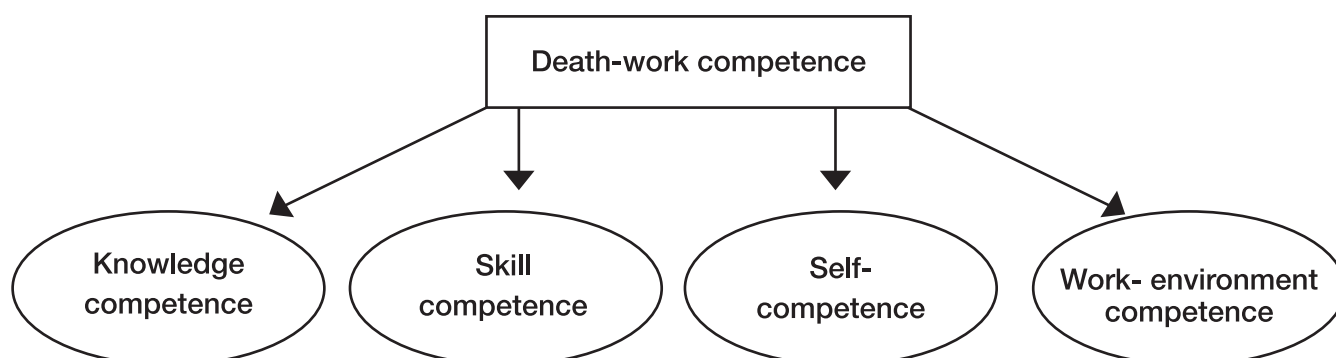
3 OBJECTIVES

Derived from the theoretical framework of the four competences in knowledge, practice/skill, self and work environment of the death work competence model by Chan and Tin (2012), the study aims to better understand the views of paediatric doctors and nurses in Hong Kong on:

    a. the perceived challenges in different aspects of paediatric palliative care

    b. the perceived competence in different aspects of paediatric palliative care

    c. the impact of different structural factors on the service quality of paediatric palliative care

    d. the urgency for improvement in different structural factors in the service quality of paediatric palliative care

4 RESEARCH METHODOLOGY AND DATA ANALYSIS

4.1. Study design

The research method was a cross-sectional (one time point) survey by a self-completed questionnaire (see Appendix 1). Data collection lasted from December 2013 to August 2014.

4.2. Ethics

The study first gained the ethical approval of the Research Ethics Committee of the Chinese University of Hong Kong. In consideration that the data collection process of our study mainly took place in public hospitals, we also applied for the ethical approval of clusters of hospitals involved in our study to establish formal collaboration with the hospitals under the regulation of the Hospital Authority (HA).

Several measures were implemented to ensure the confidentiality of the participants. For example, participants had only to fill in the questionnaire and not a consent form. These measures ensure that our study did not identify any individual or party.

All study data were locked in cabinets where the university keeps confidential information. Electronic data were saved in a secured computer of the university, with restricted access. Data will be kept for 5 years after the study. Hard copies will be destroyed by the shredder. Soft copies will be deleted from the hard disk of the computer.

4.3. Selection criteria of samples

Inclusion criteria were as follows:

1. Nurses or doctors of all paediatric and adolescent wards, clinics, centers or community services, e.g., Neonatal Intensive Care Unit, Neonatal Unit, Special Care Baby Unit, Paediatric Intensive Care Unit, Paediatric High Dependency Unit, Developmental Disabilities Unit, Paediatric Rehabilitation Unit, General Paediatric wards, Paediatric Oncology Units and GPs (private practice paediatrician/oncologist);
2. Caring for paediatric patients between 0 and 18 years old;
3. Currently working;
4. Having worked in paediatrics for 6 months or more.

Because every paediatric doctor and nurse had the chance to encounter a PPC case, we used broad inclusion criteria. Criteria were not limited only to those with PPC experience or those who worked in paediatric specialties that frequently encountered palliative care cases, such as paediatric oncology, but all paediatric doctors and nurses.

We aimed for a sample diverse of hospitals and work settings. Therefore, in addition to public hospitals, data from NGOs, special schools and professional bodies were collected.

4.4. Sampling and sample size

Data were collected by convenience sampling. In Hong Kong, paediatric services are provided in various public hospitals in each of the seven clusters (Hong Kong East, Hong Kong West, Kowloon East, Kowloon West, Kowloon Central, New Territories East and New Territories West) under the HA. We recruited paediatric doctors and/or nurses from hospitals from each cluster. Also, participants were recruited from various hospitals in six out of the seven clusters. NGOs, special schools and professional bodies were also contacted for recruiting participants for this study. We identified co-investigators in each cluster or organization, and these co-investigators then helped identify potentially suitable and interested participants and promoted our study. Most the data were collected from the public hospitals of the HA. Participants could choose to complete the questionnaire either on paper or online (Table 1).

4.5. Questionnaire development

Three rigorous steps were taken to ensure the validity of the questionnaire.

First, the questionnaire was developed with respect to the professional experience of the principal investigators, who were highly qualified and experienced nurses and a medical social worker. A literature review and discussions among the investigators were also taken into consideration.

The questionnaire consisted of questions about participants' background, profession and experience in paediatrics; their views on their competence in knowledge, skills, self and work environment working with dying children; and their views on services, facilities and policies in PPC.

Second, the questionnaire was examined by an expert panel of 5 between May and July 2013 with highly qualified and experienced professionals from diverse backgrounds, consisting of 1 psychosocial professional, 2 doctors (1 from paediatrics and 1 from palliative care) and 2 nurses (1 from paediatrics and 1 from palliative care). They were invited to comment on specific questions and on the overall questionnaire (e.g., relevancy, applicability, clarity and exhaustiveness of the questionnaire). Corresponding amendments to the questionnaire were made.

Third, a pilot test of 36 nursing and medical professionals was conducted between August and October 2013. The size of about 30 was with reference to the suggestion by Johanson and Brooks (2009) on the size of a pilot test. We invited the pilot test participants to fill in the questionnaire and comment on their understanding of the questions. On the information statement of the pilot test, we reminded the pilot test participants not to participate in the actual survey. We also conducted a preliminary data analysis using the data collected from the pilot test to see if we would be able to observe any initial findings. After the pilot test, major feedback from participants was that the contents of the questionnaire are valid, but it was too long for frontline workers. This may significantly affect the return rate. Therefore, investigators re-examined the questionnaire and trimmed it down to the existing version used in the study. Other minor revisions were made with reference to the comments of participants in the pilot study.

Table 1

Number of questionnaires collected from different sources

Sources	N	%
Public hospitals (Hard copies)	634	
Hong Kong Island		23%
Kowloon		48%
New Territories		29%
NGOs, special schools and professional bodies (Hard copies)	9	
Online copies*	37	
Total:	680	

*The sources of online copies are from public hospitals, NGOs, special schools and professional bodies.

4.6. Measures

Death Work Competence

Death Work Competence measures the self-perceived competence of the respondents in doing death work. It includes four single items assessing four aspects: knowledge, skill, self, and work environment. Respondents answered according to how competent they felt about themselves in these four aspects on a Likert scale (1 = very incompetent, 5 = very competent).

Death Work Challenges

Death Work Challenges measures the perceived challenges of the respondents in doing death work. Items were measured by a Likert scale assessing the perceived level of difficulty (1= lowest/not difficult, 5 = highest). The items were originally designed as having four aspects but were further categorized by exploratory factor analysis (EFA). Statistical results of EFA are shown in Appendix 2. The items of the scale can be divided into challenges in seven aspects: knowledge, basic skills, advanced skills, professional self, personal self, general work environment, and support to staff. The conceptual definitions are listed in Table 2. Averages of the subscales were calculated. The reliabilities ranged from .73 to .84 (Table 3).

Factors for Service Improvement

Factors for service improvement include 13 possible factors affecting the service quality of PPC. Five items are related to macro factors (e.g., policy, human resources) and the other eight to services to clients. The respondents were asked to rate the effect on service quality and urgency for improvement respectively. A Likert scale was used to measure the rated effect and urgency for improvement (1 = very low, 5 = very high).

4.7. Data processing and analysis

The collected questionnaire data were input and managed by a research assistant. The statistical tests were run with the aid of the statistics program SPSS.

Table 2

Definitions of perceived challenges

Types of Challenge	Subtypes	Definition
Knowledge		Lacking systematic information that assists work in paediatrics
Skill	Basic skills	Difficulties in the skills required in routine or daily paediatric service such as communication with clients and their family, symptom management, care service, and management of emotions
Skill	Advanced skills	Difficulties in the skills required in handling acute events, often directly related to life and death issues

Self	Professional self	Challenges related to working self or professional identity. This includes sadness perceived in the work context or from patients and their family, and helplessness regarding one's own identity of the helping profession.
	Personal self	Challenges carried over to personal context of paediatric professionals, which affect more directly one's life and death philosophy and arouse one's imagination or memory of personal encounters.
Work environment	General work environment	Challenges related to the immediate context of daily work (e.g. human resources, communication among colleagues)
	Support to staff	Lack of guidance, supervisory, or emotional support given to the staff

Table 3

Measures of the questionnaire

Category/Scale	Potential Range	Reliability (Cronbach's Alpha)
Competence		
Knowledge	1–5	n/a
Skill	1-5	n/a
Self	1-5	n/a
Work environment	1-5	n/a
Challenges		
Knowledge	1-5	.82
Basic skills	1-5	.85
Advanced skills	1-5	.87
Professional self	1-5	.91
Personal self	1-5	.92
General work environment	1-5	.73
Support to staff	1-5	.84
Structural factors		
Impact	1-5	n/a
Urgency	1-5	n/a

Note: Cronbach's Alpha 0.6 or higher is interpreted as reliable in this report.

5 FINDINGS

5.1. Demographics of participants

The background information of the participants is shown in Table 4. Of the 680 participants, the mean age was 35.3 (SD = 10.0). The majority was female (90.29%), and 59.41% had no religion; 47.65% were married, and 58.38% had no children. The majority were nurses (83.8%). More than half the respondents had 5 years of working experience in the medical profession (65.3%) or paediatrics (59.6%). The mean years of experience in the profession was 13.0 (SD = 10.0), and the mean years of experience in paediatrics was 10.3 (SD = 8.5). Only a minority of the respondents had received death-work-related training (27.1%). The types of training they received are shown in Table 5.

5.2. Do paediatric professionals feel competent?

The midpoint of the scales was assigned "3". As shown in Table 6, the ratings of competence in knowledge, skills and self-preparation were significantly above midpoint. Paediatric professionals generally feel competent in these aspects.

However, the rating in work environment is not significantly higher or lower than midpoint, as shown in Table 6. In comparison to the rating of competence in other aspects, fewer people feel competent (30% answered "4" or "5") and more people feel incompetent (20% answered "1" or "2") about their work environment. *Although the rating of the work environment is not significantly lower than midpoint, the results show that paediatric professionals are comparatively less competent in this aspect.*

Table 4

Demographics of participants

	N	Percentage	Range	M	SD
Age	542		20–63	35.3	10.0
Gender					
Male		9.7			
Female		90.3			
Religion					
No religion	404	59.4			
Protestant	204	30.0			
Catholic	42	6.2			
Buddhist	20	2.9			
Chinese traditional religion (e.g. ancestor worship)	4	.6			
Other	1	.2			
Missing	5	.7			
Profession					
Doctor	110	16.2			
Nurse	567	83.4			
Missing	3	.4			

Years of experience in medical profession	676			.5–42	13.0	10.0
≤ 5 years	232	34.1			
> 5 years	444	65.3			
Missing	4	.6			
Years of experience in paediatrics	680			.5–45	10.3	8.5
≤ 5 years	275	40.4			
> 5 years	405	59.6			
Marital status					
Single	340	50.0			
Married	324	47.7			
Divorced	10	1.5			
Widowed	1	.2			
Other	2	.3			
Missing	3	.4			
Number of children					
no children	397	58.4			
1 child	90	13.2			
2 children	163	24.0			
3 children	19	2.8			
Missing	11	1.6			
Received death-work-related training or education					
Yes	184	27.1			
No	459	67.5			
Missing	37	5.4			

Table 5

Distribution of types of death-work-related training received by participants

	N	Percentage
Experience in palliative and end-of-life care training		
Yes	120	17.7
No	539	79.3
Missing	21	3.1
Experience in life and death education		
Yes	97	14.3
No	554	81.5
Missing	29	4.3
Experience in bereavement care/counseling training		
Yes	176	25.9
No	493	72.5
Missing	11	1.6

Table 6

One-sample *t*-test of perceived competences with the midpoint of 3

Category	Potential range	M	Cohen'd
Competence			
Knowledge	1–5	**3.30***	.44
Skill	1–5	**3.29***	.43
Self	1–5	**3.22***	.32
Work environment	1–5	3.05	.06

***significantly above midpoint of 3 at .001 level

Table 7

Distribution of perceived competence

	Percentage %				
	Very Incompetent				Very Competent
	1	2	3	4	5
Knowledge	1.2	7.8	51.9	37.9	1.2
Skills	.7	8.4	53.5	36.1	1.2
Self-preparation	1.2	10.6	54.1	33.4	.7
Work environment	2.7	18.1	51.2	27.7	.3

Note: missing values are not included.

5.3. Do paediatric professionals experience challenges?

Similar to the analysis of competences (Section 5.2), "3" was assigned the midpoint of the scales. One-sample *t*-test was used to test if the sample means were significantly above the midpoint (Table 8). Of the types of challenge, only the mean of the challenge to the personal self was significantly lower than the midpoint. All the means of other challenges were significantly higher than the midpoint. As shown in Table 9, except for the challenge to personal self, more than half the respondents had scores higher than the midpoint in the other types of challenge. *The results show that paediatric professionals generally experienced challenges above the moderate level in various aspects, except the challenge to the personal self.*

Table 8

One-sample *t*-test of perceived challenges with the midpoint of 3

Challenges	Potential range	N	M	SD	d
Knowledge	1–5	671	3.35	.70	.49
Basic skills	1–5	655	3.11	.70	.16
Advanced skills	1–5	669	3.78	.80	.97
Professional self	1–5	668	3.26	.72	.36
Personal self	1–5	677	2.54	.91	-.50
General work environment	1–5	671	3.50	.66	.77
Support to staff	1–5	679	3.45	.74	.60

Note: all sample means were significantly different from midpoint of 3 at .001 level.

Table 9

Distribution of perceived challenges with reference to the midpoint of 3

Challenges	Potential range	N	Percentage ≤ 3	Percentage >3
Knowledge	1–5	671	35.8	64.2
Basic skills	1–5	655	46.4	53.6
Advanced skills	1–5	669	23.6	76.4
Professional self	1–5	668	38.5	61.5
Personal self	1–5	677	76.1	23.9
General work environment	1–5	671	29.4	70.6
Support to staff	1–5	679	41.5	58.5

5.4. Difference in perceived challenges between doctors and nurses

The study involved two kinds of paediatric professional: doctors and nurses. T-test was used to test if there was a difference between the perceived challenges in these two groups (Table 10). A significant difference was found in three aspects: nurses perceived more challenges in advanced skills, professional self and personal self than doctors did.

Table 10

Mean difference in perceived challenges between doctors and nurses

Challenges	N	M	SD	t	df	p	d
Knowledge							
Doctors	109	3.30	.72	-.75	666	.45	-.06
Nurses	559	3.36	.70				
Basic skills							
Doctors	107	3.06	.77	-.83	651	.41	-.07
Nurses	546	3.12	.68				
Advanced skills							
Doctors	106	3.58	.89	-2.79	664	.01	-.22
Nurses	560	3.82	.78				
Professional self							
Doctors	109	3.10	.83	-2.17	138	.03	-.19
Nurses	556	3.28	.69				
Personal self							
Doctors	109	2.29	.91	-3.11	672	.002	-.24
Nurses	565	2.59	.90				
General work environment							
Doctors	109	3.40	.76	-1.53	138	.13	-.13
Nurses	559	3.52	.63				
Support to staff							
Doctors	110	3.36	.78	-1.40	674	.16	-.11
Nurses	566	3.47	.73				

Note: the group difference of means is statistically significant when p <.05.

5.5. Correlation between competence and challenges

Correlations between competence and challenges were tested (Table 11). Each type of competence was negatively correlated with corresponding type of challenge. More perceived competence is related to less challenge perceived. For instance, the more competence the paediatric professionals perceived in skill, the fewer challenges they perceived in basic skills and advanced skills. However, it should be noted that the correlations are not strong. Weaker correlations appeared in some aspects (competence in knowledge and challenge in knowledge, competence to self and challenge to personal self).

Table 11

Correlations between competence and challenge in the four categories

Competence	Competence	Correlation (r)
Knowledge	Knowledge	-.29
Skill	Basic skills	-.40
	Advanced skills	-.34
Self	Professional self	-.43
	Personal self	-.27
Work environment	General work environment	-.42
	Support to staff	-.33

Note: correlations are all significant at the .01 level.

5.6. Difference in perceived challenges between more and less experienced professionals

The sample was divided into two groups, using 5 years of experience in paediatrics as the cutoff point (the categorization generally used in the medical profession in Hong Kong). The difference between these two groups in perceived challenges was tested (see Table 12). *In general, the less experienced felt more challenges than the more experienced did. The difference is stronger in challenges in basic skills (d = .49) and advanced skills (d = .52). However, the less experienced felt less challenge in the general work environment (d = -.20).*

Table 12

Mean difference in perceived challenges between more experienced professionals (over 5 years working in paediatrics) and lessexperienced ones (5 years or less)

Challenges	N	M	SD	t	df	p	d
Knowledge							
5 years or under	271	3.45	.61	3.28	646	.001	.25
more than 5 years	400	3.28	.75				
Basic skills							
5 years or under	266	3.31	.61	6.35	625	<.001	.49
more than 5 years	389	2.98	.72				
Advanced skills							
5 years or under	273	4.02	.68	6.90	648	<.001	.52
more than 5 years	396	3.61	.84				

Professional self							
5 years or under	269	3.39	.65	3.84	666	<.001	.30
more than 5 years	399	3.17	.75				
Personal self							
5 years or under	272	2.63	.89	2.03	675	.04	.16
more than 5 years	405	2.48	.92				
General work environment							
5 years or under	273	3.43	.63	-2.50	669	.01	-.20
more than 5 years	398	3.56	.67				
Support to staff							
5 years or under	274	3.41	.72	-1.01	677	.31	-.08
more than 5 years	405	3.47	.76				

Note: the group difference of means is statistically significant when p <.05.

5.7. Factors for service improvement: impact and urgency

Tested by one-sample t-test, all the means were significantly higher than the midpoint of 3. This shows that all proposed factors were considered by participants as having affected service improvement and as being in urgent need of improving service. According to Table 13, for the macro factors, adequacy of human resources and availability of resources were rated in the sample as having the most impact on service quality and regarded as the most urgent aspect to be improved.

For the factors about services to clients, the interface between hospital service and community service was rated as having the most impact and the most urgent for improvement. Other prominent factors include recognition of the importance of PPC, bereavement services, and knowledge about palliative care among patients' families.

Table 13

Means of perceived impact on service quality and urgency for improvement

	Potential Range	Impact		Urgency	
		M	SD	M	SD
Macro Factors					
Adequacy of human resources					
足夠人手	1–5	4.18	.80	4.20	0.81
Availability of resources					
資源足夠及配合，例如：暫住服務	1–5	3.84	.84	3.75	0.90
Support from organizational culture and policy					
機構文化或政策上的配合，例如：探訪規則	1–5	3.52	.87	3.37	0.90

Efficiency of department/unit 部門/單位管理的效率	1–5	3.52	.82	3.43	0.85
Legal arrangements (e.g. procedures for certifying death) 法律上的配合，例如：證實死亡的程序	1–5	3.23	.94	3.12	0.96
Services to clients					
Recognition of the importance of PPC 兒童紓緩服務的重視程度	1–5	3.71	.80	3.70	0.79
Facilities to child patients and families (e.g. rest area for families) 給予病兒或家屬使用的設施，例如：家屬休息室	1–5	3.68	.88	3.55	0.94
Services for improving QOL of child patients (e.g. play therapy, Augmentative & Alternative Communication Training) 給予病兒以提升他們生活質素的服務，例如：遊戲服務、輔助溝通系統訓練	1–5	3.74	.87	3.60	0.90
Bereavement services 給予家屬的喪親關顧服務，例如：喪親輔導	1–5	3.82	.79	3.69	0.80
Services to support other family members (e.g. siblings of child patients) 除病兒的父母外，給予其他與病兒相關的重要人士的服務，例如：病兒的兄弟姊妹	1–5	3.61	.87	3.53	0.86
Recognition of the importance of child patients' rights (e.g., right to live, and the issue of abandoned babies) 家屬對患病孩子的權益之重視，例如：漠視孩子的生存權、或棄嬰	1–5	3.59	.88	3.47	0.92
Knowledge about palliative care for patients' families 家屬對紓緩服務的知識	1–5	3.76	.80	3.68	0.80
Interface between hospital service and community service 醫院服務與社區服務的銜接	1–5	3.80	.83	3.76	0.82

Note: all means were significantly above the midpoint of 3 at .01 level.

6 DISCUSSION

6.1. Representativeness of the sample

In this study, we invited public hospitals from all seven clusters in Hong Kong, which provide paediatric services to join this study. We got hospitals from six clusters to join. Though we could not estimate the percentage of paediatric doctors and nurses participating in this study compared with the total number in the HA, paediatric doctors and nurses from six of these clusters may somehow enhance the representativeness of our samples.

6.2. Preparation of professionals in doing death work

The profile of the samples showed that a substantial proportion of the participants are inexperienced (Table 4). More than 40% had under 5 years of working experience in paediatrics (40.4%). Moreover, less than one-third (27.1%) received death-work-related training or education Findings suggest that there is paramount need for equipping paediatric professionals with training in palliative care and the area of death, dying and bereavement.

6.3. Perceived challenges on personal self

Participants perceived challenges significantly above the midpoint (a rating of 3) in all aspects, except "personal self". Participants perceived the greatest challenge in "advanced skills", which involves handling of life and death issues. Findings suggest that paediatric professionals perceived different challenges in providing PPC, especially in handling death-related issues, such as advance care planning and breaking bad news.

In this study, participants perceived the least challenge to the personal self (e.g. challenge in managing own emotions in providing PPC). This finding is not consistent with that in previous studies in which challenges to self was emphasized in doing the death work (e.g. Chan and Tin, 2012, Chan, Tin, Wong, Tse, Lau, and Chan, in press). One possibility for this inconsistency may be due to the method of data collection. Previous studies collected the data of participants in a relatively safe environment (e.g., in-depth interviews, and completing an open-ended questionnaire when they attended training on death, dying and bereavement), and they may tend to disclose their real perception in challenges to "personal self". Instead, participants in this study completed the questionnaire by rating the level of challenges without having a prior relationship with the researchers. Therefore, they may be more reserved in acknowledging personal weaknesses. Instead, it seems to be more professionally appropriate for participants to acknowledge challenges in advanced skills, such as handling life and death issues. Instead of underscoring the importance of self in providing PPC, we may need to be aware of whether the challenge to "personal self" (e.g., managing own emotions) is masked by paediatric professionals and presented indirectly through their perceived challenges in advanced skills. In fact, handling death-related issues, such as advance care planning and breaking bad news, may not only require skills but may also depend on whether the professionals are personally prepared and feel comfortable in these end-of-life discussions.

Our above interpretation seems to have received support from other findings of this study. For example, participants showed competence significantly above the midpoint (a rating of 3) in knowledge, skill, and self. It seems that participants in general would like to indicate that they are competent in different aspects of PPC. This is consistent with our view that participants may tend not to acknowledge their personal weaknesses.

6.4. Relationship between competence and challenge

Although negative correlations were found between competence and challenges, the strengths were not strong (section 5.5). The weak to moderate correlations indicated that one may still feel substantial challenges in different aspects of PPC though feel competent in these aspects at the same time. One reason for this finding is that participants are able to cope with the challenges and thus feel competent though experiencing challenges. Another possibility is that they may tend to maintain the image of being a competent professional and thus presented themselves as competent although experiencing great challenges. Future studies may help to verify these explanations.

6.5. Environmental factors

Although the professionals felt competent in knowledge, skill and self, they did not feel competent relatively in the work environment (section 5.2). All listed factors for service improvement also had mean scores higher than midpoint in impact on service quality and urgency for improvement (section 5.7). Not only did the professionals recognize the influence of environmental factors, but they also expressed the need for improvement in those areas. To the participants, the areas of most concerns for improvement are human resources, availability of general resources, comprehensibility of palliative care service (bereavement service, interface with community service), and public recognition of PPC (knowledge about palliative care, recognition of the importance).

6.6. Challenges felt differently in different groups

The findings show that participants did not perceive challenges in the same way. Nurses perceived more challenges in advanced skills, professional self and personal self than doctors did (section 5.4). The difference may be explained by the differences in roles and duties: nurses may be more involved in the daily care of patients, so the closer interaction may expose them to emotional vulnerability in doing death work. Another reason is that nurses may be more willing to acknowledge the challenges in providing PPC, whereas doctors may be more likely to underscore the challenges to maintain the image of being competent professionals.

The less experienced group perceived more challenges in most aspects than did the more experienced group (more than 5 years of experience working in paediatrics), especially in basic skills and advanced skills (section 5.6). It is likely that the more experienced professionals had developed better capacities after years of working. However, the more experienced felt more challenges in the general work environment. The more experienced participants may be higher ranking, which involves more coordinating and administrative work and exposes them to more challenges in the work environment.

6.7. Address the training needs of paediatric professionals for providing PPC

With reference to the findings of this study, we would like to highlight the importance of enhancing the training given to paediatric doctors and nurses. Training can be provided to help these professionals to cope with the challenges in providing PPC in different areas:

i. Knowledge (e.g., needs of parents of children with life-threatening illness)
ii. Skills in handling death-related issues (e.g., End-of-life (EOL) discussion, disclosure of prognosis)
iii. Attitudes and self-competence (e.g., helping professionals' coping with emotions and existential queries aroused from death work)

6.8. Provide different types of training

Less experienced paediatric professionals may need more support in enhancing their knowledge, skills and self-competence in providing PPC. More experienced paediatric professionals may need more support in facing the challenges of the work environment. Therefore, we suggest providing different training with different orientations to paediatric doctors and nurses with different work experience.

Paediatric nurses and doctors may experience different challenges in providing PPC. Specific attention should be paid to meet the different needs of these professions (e.g. nurses may need to cope with more challenges of the self, such as handling their own emotions, due to their close interactions with child patients on the wards).

6.9. Basic professional education

Curriculum for basic healthcare professional education should be revised and palliative care added. Palliative care should be started when the disease is diagnosed and continue throughout the treatment protocol or the time the patient lives with the disease. All professionals who work on a paediatric ward or paediatric services in the community or special schools should be well equipped with knowledge and skills in palliative care.

6.10. Special training and programmes for teachers

The majority of school-age patients study and live in special schools. The professionals and teachers working in these schools need to have training to enhance their knowledge and skills in PPC.

7 SUGGESTIONS FOR SUPPORT IN POLICY AND SERVICES PROVISION

7.1. Re-examine resources and support

A shortage of human resources is a common problem in healthcare settings. It affects the service delivery process and has to be addressed. Before the problem is resolved, effective use of existing human resources may help to provide appropriate palliative care or end-of-life care to paediatric patients with life-threatening or life-limiting diseases.

Survey findings indicate that most paediatric professionals generally feel competent in PPC, in knowledge and skills. They have the basic skills in PPC, meaning they can implement PPC in daily operations. However, there is a lack of standard of care and service delivery guidelines and procedures for PPC service. Establishing such guidelines and procedures will help existing healthcare professionals in PPC service.

In addition, parents are key persons for the patient. Empowering them as carers not only fulfills their parental role but also enhances the QOL of the patient. This requires an appropriate system and guidelines with support from healthcare professionals.

7.2. Provide facilities for parents

No one can replace the role of parents. Parents staying with their child during hospitalization are extraordinarily important to both. A 24 hour-visitation policy for parents and flexible visitation for the child's close relatives are essential for better family support and social network. Furthermore, rooms for parents with facilities such as phone battery charging, Wi-Fi, sofa bed, television, bathroom, refrigerator, microwave etc. are extremely helpful for parental support. This can help the family stay connected with the child. A hospice home is the ideal place at the end stage of life or for respite care.

7.3. Strengthen community support

Survey findings show the linkage between hospital service and community service was rated as having the most impact and being in the most urgent need for improvement. If children with life-threatening or life-limiting diseases are discharged, there is a need to provide appropriate support and follow-up to enhance the patient's QOL and fulfill development needs.

There are many organizations and NGOs in the community providing various services. Collaborating with these institutions to offer home care support using a holistic model of care to provide physical, psychosocial, social and spiritual support to the children and their families is important to patients living with the disease. It aims to provide continuity of care at home and in the community for patients with life-threatening or life-limiting illnesses. Therefore, coordination between hospital service and community service is required prior to the child being discharged.

For example, early education training centers, special schools, and residential schools could provide appropriate developmental training for children. Community services from some NGOs could also offer practical and psychosocial support for parents taking care of their children. However, there is a gap between hospitals and schools in caring for children with special needs. Although there is a lot of written information about the children when they are discharged, the special school caregivers and teachers lack support in healthcare matters. Therefore, it is better to identify a healthcare professional to be the coordinator along the patient's journey. Most children with life-threatening or life-limiting diseases have to attend a series of special consultations and follow-up clinics at different times. Arranging a same-day follow-up is necessary to lessen the burden on patients and families in travelling back and forth. An outreach care service like the Community Geriatric Assessment Teams is also helpful.

7.4. Strengthen bereavement support

There should be a system to provide appropriate bereavement support to the family members before the child's death, at death and after death. A better way to say good-bye to their loved one and 'good luck' to the deceased are very important to all family members and close relatives. In addition, organ donation may have meaning to the deceased and the parents. Organ donation information and arrangement, a bereavement package, bereavement risk assessment, funeral arrangements, telephone follow-up, bereavement counselling, memorial ceremony or rituals are essential in providing holistic family-centered care.

7.5. Strengthen public education

PPC is a holistic family-centered care approach with multidisciplinary collaboration for patients under 18 with life-threatening or life-limiting conditions. It can be initiated when the disease is diagnosed. It can also co-exist with curative treatment. The focus is on enhancing QOL until the end stage.

There is a perception by families that introducing palliative care indicates healthcare professionals are giving up. Therefore, families are reluctant to accept palliative care. Educating the patients and their families as well as the public about the concepts of PPC, life and death education and the options available in palliative care will help the implementation of PPC inside and outside the hospital. Also, enhancing parents' understanding of available community resources, referrals to NGOs, communication and collaboration between hospital and NGOs can support the patient in achieving a better QOL.

7.6. PPC service proposal

In order to promote and support PPC service, we suggest forming a PPC Consultative Team to provide expert advice on individual case management and service development. A PPC process flowchart is proposed in Figure 2.

The consultative team is multidisciplinary, including a PPC physician, a PPC specialist, a dietitian, a paediatric clinical pharmacist, a psychologist, a medical social worker, a play therapist, an occupational therapist, a physiotherapist, a chaplain, and the parents/family.

Services provided by the PPC Consultative Team should include:
- In-patient palliative care service (in the hospital)
- Out-patient palliative care service (in the hospital)
- Community palliative care service (outside the hospital)
- Day palliative care service (in/outside the hospital)

Though we may not be able to extend a child's life, we can help to promote the QOL for both patients and their families through the PPC approach. Quality EOL and bereavement care may also be facilitated with the trusting and therapeutic relationship established since stage 1 (see Figure 2)

Figure 2

Proposed Paediatric Palliative Care Process Flowchart
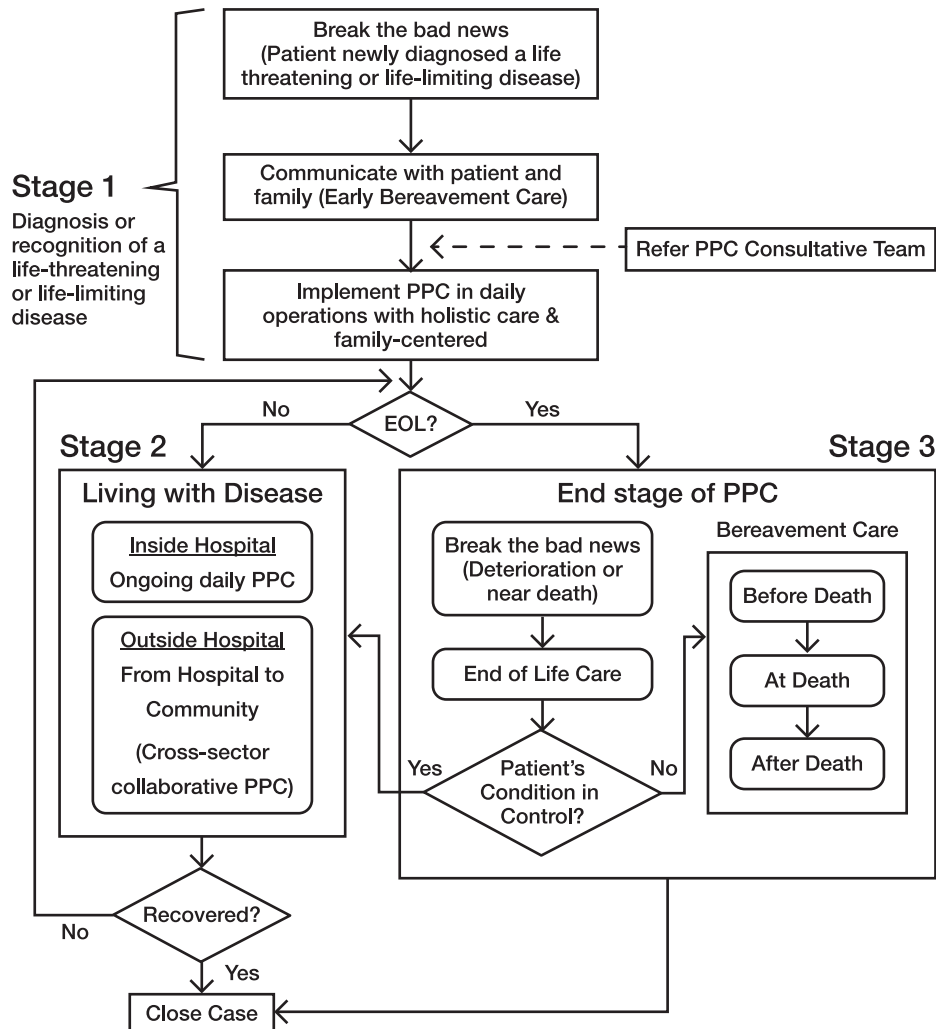
CONCLUSION

This is the first local study in Hong Kong, which aimed to explore the views of paediatric doctors and nurses in providing PPC through a larger-scale quantitative study. Over 600 paediatric doctors and nurses participated in this study and showed their perceived competence and challenges in different domains of paediatric palliative care: knowledge, skills, self, and work environment. They also expressed their views on what macro factors, such as availability of human resources and general resources, services to clients, such as interface between hospital and community, most affect the service quality and are in the most urgent need of service improvement. Based on the findings, we provided several recommendations for training to paediatric doctors and nurses, as well as improvement in various factors to enhance the quality of PPC.

We sincerely hope that this study arouses the concern of both more professionals and the public for the importance of PPC in Hong Kong. We also look forward to seeing the improvement of PPC in Hong Kong.

REFERENCES

Centre for Health Protection. (2015). *Number of Deaths by Leading Causes of Death, 2001 - 2014.* *Retrieved from http://www.chp.gov.hk/en/data/4/10/27/380.html*

Chan, W. C. H., & Tin, A. F. (2012). Beyond knowledge and skills: Self-competence in working with death, dying, and bereavement. *Death Studies, 36*(10), 899–913.

Chan, W. C. H., Tin, A. F., Wong, K. L. Y., Tse, D. M. W., Lau, K. S., & Chan, L. N. (in press). Impact of death work on self: Existential and emotional challenges and coping of palliative care professionals. *Health and Social Work.*

The Child Fatality Review Panel (2015). Second report for child death cases in 2010-2011. Retrieved from http://www.swd.gov.hk/doc/whatsnew/201507/CFRP%20Second%20Report%20Eng.pdf

Costello, A. B., & Osborne, J. W. (2005). Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Practical Assessment, Research & Evaluation, 10*(7), 1–9.

Davies, B., Clarke, D., Connaughty, S., Cook, K., MacKenzie, B., McCormick, J., O'Loane, M., & Stutzer, C. (1996). Caring for dying children: Nurses' experiences. *Pediatric Nursing, 22*(6), 500–507.

Hinds, P., Pauckett, P., Donohoe, M., Fairclough, D., Phipps, S., Martin, G. A., & Payne, K. (1992). Impact of a Grief Workshop for Pediatric Oncology Nurses on Their Grief and Perceived Stress. *Journal of Pediatric Oncology Nursing, 9*(2), 54–55.

International Children's Palliative Care Network (ICPCN) (2012). Priorities for global research into children's palliative care: A Delphi Study.

International Children's Palliative Care Network (ICPCN) (2008). What is Children's Palliative Care? Retrieved from http://www.icpcn.org.uk/page.asp?section=0001000100080004&itemTitle=What+is+Children%92s+Palliative+Care%3F

Johanson, G. A., & Brooks, G. P. (2010). Initial scale development: Sample size for pilot studies. *Educational and Psychological Measurement, 70*(3), 394–400.

Lerea, L. E., & LiMauro, B. F. (1982). Grief among healthcare workers: A comparative study. *Journal of Gerontology, 37*(5), 604–608.

Leung, M. M. & Yeung, W. F. E. (2012). Overseas Corporate Scholarship Program for Clinical Leaders 2011/12 (Palliative Care): Report on Study Training (Canterbury Hospital, Concord Repatriation General Hospital, Sydney Local Health Network, Australia, Training Period: from 7 November to 2 December, 2011). *Only accessible through the intranet of Hospital Authority.* **Click here to access (HA staff only)**

Leung, M. M. & Yeung, W. F .E. (2013). Sharing Forum on Overseas Corporate Scholarship Program for Clinical Leaders 2011/12 – Palliative Care Overseas Experience: Canterbury Hospital, Concord Repatriation General Hospital, Sydney Local Health Network, Australia. *Presented on April 8, 2013 at Hospital Authority Head Office. Only accessible through the intranet of Hospital Authority.* **Click here to access (HA staff only)**

McNamara, K. (2011). Standards framework for children's palliative care. Bristol: Together for Short Lives.

Morgan, D. (2009). Caring for dying children: Assessing the needs of the pediatric palliative care nurse. *Pediatric Nursing, 35*(2), 86–90.

Papadatou, D., Bellali, T., Papazoglou, I., & Petraki, D. (2002). Greek nurse and doctor grief as a result of caring for children dying of cancer. *Pediatric Nursing, 28*(4), 345–353.

Papadatou, D., Martinson, I. M., & Chung, P. M. (2001). Caring for dying children: A comparative study of nurses' experiences in Greece and Hong Kong. *Cancer Nursing, 24*(5), 402–412.

Rushton, C. H., Reder, E., Hall, B., Comello, K., Sellers, D. E., & Hutton, N. (2006). Interdisciplinary interventions to improve pediatric palliative care and reduce health care professional suffering. *Journal of Palliative Medicine, 9*(4), 922–933.

Yam, B. M. C., Rossiter, J. C., & Cheung, K. Y. S. (2001). Caring for dying infants: Experiences of neonatal intensive care nurses in Hong Kong. *Journal of Clinical Nursing, 10*(5), 651–659.

APPENDIX 1
COMMUNITY RESOURCES

Here are some community resources providing paediatric palliative care and/or children bereavement counselling services:

Organization	Website
兒童癌病基金 Children's Cancer Foundation	https://www.ccf.org.hk/
香港癌症基金會之彩虹會 Cancer Fund - Rainbow Club	http://www.cancer-fund.org/RainbowClub/tc/about-us.html
進心會 EQ Ambassador Society	http://www.eq.org.hk/?page_id=864
寧舍 Hospice Home	http://www.hospicehome.hk/
聖公會聖匠堂長者地區中心安寧服務-護慰天使 S.K.H. Holy Carpenter Church District Elderly Community Centre	http://www.decc.holycarpenter.org.hk/chi/p5.asp
善寧會「賽馬會善寧之家」及譚雅士杜佩珍安家舍長哀傷輔導 Society for the Promotion of Hospice Care-SPHC's Jockey Club Home for Hospice & Jessie and Thomas Tam Centre Bereavement Counselling	http://www2.hospicecare.org.hk/our-work/jchh/ http://www2.hospicecare.org.hk/our-work/bereavement-support/jessie-and-thomas-tam-centre/
贐明會「共童導過」兒童哀傷輔導服務 The Comfort Care Concern Group (CCCG) – "Walking with Children" Child Bereavement Counselling	http://www.cccg.org.hk/en/taxonomy/term/39

APPENDIX 2
QUESTIONNAIRE

醫護人員對香港兒童及青少年紓緩服務的意見

Views of Medical and Nursing Professionals on Palliative Care for Paediatrics and Adolescents in Hong Kong

請填寫或「√」出適當的答案。

1. 年齡：＿＿＿＿＿＿＿歲

2. 性別：☐ 男　　☐ 女

3. 宗教信仰：☐ 無宗教　　☐ 基督教　　☐ 天主教　　☐ 佛教　　☐ 傳統拜神　　☐ 其他 請註明 ＿＿＿＿＿＿

4. 專業：☐ 醫生　　☐ 護士　　☐ 其他 請註明 ＿＿＿＿＿＿

5. 從事於問題4答案所述醫生/護士/其他專業工作多久？＿＿＿＿＿＿年

6. 你服務兒童及青少年病房/單位的年資是：＿＿＿＿＿＿年

7. 婚姻狀況：☐ 單身　　☐ 已婚　　☐ 離婚　　☐ 喪偶　　☐ 其他 請註明 ＿＿＿＿＿＿

8. 子女數目：☐ 沒有子女　　☐ 1個　　☐ 2個　　☐ 3個　　☐ 4個或以上

9. 你有沒有曾經接受過以下的紓緩服務訓練？　　　　　　有　　　　沒有

   a Palliative and End-of-Life Care Training　　　　☐　　　　☐

   b Life and Death Education　　　　　　　　　　☐　　　　☐

   c Bereavement Care/Counseling Training　　　　☐　　　　☐

   d 如你曾經接受過以上沒有提及的紓緩服務訓練，請註明：

   ＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

   ＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

在問題10 - 19，請根據你個人的想法，「√」出你在照顧患有危疾 (Life-threatening[1] / Limiting[2] Diseases) 的病兒上最適當的答案。

10. 你對自己照顧患有危疾的病兒的知識 (knowledge)，整體來説有多大信心？

1最沒有信心	2沒有信心	3一半一半	4有信心	5最有信心
☐	☐	☐	☐	☐

11. 以下的項目是一些醫護人員在知識層面上有可能會遇到的困難。在你照顧患有危疾的病兒上，這些困難的難度有多大？

	難 度				
	1最小/ 沒有	2	3	4	5 最大
a 何時從治療模式 (curative medicine) 轉為紓緩治療	☐	☐	☐	☐	☐
b 於急症病房/單位 (acute setting) 提供紓緩服務	☐	☐	☐	☐	☐
c 紓緩服務的知識	☐	☐	☐	☐	☐
d 有關處理死亡或死亡過程的知識，例如居家善終 (planned home death)	☐	☐	☐	☐	☐
e 對社區服務的認識	☐	☐	☐	☐	☐

12. 你對自己照顧患有危疾的病兒的技巧 (skills)，整體來説有多大信心？

1最沒有信心	2沒有信心	3一半一半	4有信心	5最有信心
☐	☐	☐	☐	☐

---

[1] Life-threatening conditions: those for which curative treatment may be feasible but can fail. A child with cancer has a life-threatening condition. Children in long-term remission or following successful curative treatment are not included (ICPCN, 2008).

[2] Life-limiting conditions: for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers (ICPCN, 2008).

13. 以下的項目是一些醫護人員在技巧層面上有可能會遇到的困難。在你照顧患有危疾的病兒上，這些困難的難度有多大？

	難 度				
	1最小/ 沒有	2	3	4	5 最大
a 與家屬溝通	☐	☐	☐	☐	☐
b 與病兒溝通	☐	☐	☐	☐	☐
c 症狀處理 (symptom management)	☐	☐	☐	☐	☐
d 為病兒的死亡作準備，例如：安排宗教 　臨終禮儀，或計劃喪禮	☐	☐	☐	☐	☐
e 面對或處理病兒的情緒	☐	☐	☐	☐	☐
f 面對或處理家屬的情緒	☐	☐	☐	☐	☐
g 與病兒及家屬建立互信關係	☐	☐	☐	☐	☐
h 與家屬在照顧病兒上意見有分歧	☐	☐	☐	☐	☐
i 處理或應付具控制性 (controlling) 或要求 　過高 (demanding) 的家屬或病兒	☐	☐	☐	☐	☐
j 向病兒及家屬交待惡耗 (breaking 　bad news)，例如：病情惡化 　(deterioration)，治療無效 (incurable 　disease)，死亡將近 (impending death)	☐	☐	☐	☐	☐
k 與病兒或家屬討論預設臨終照顧計劃 　(advance care planning)，例如： 　「不作心肺復甦術」(Do-Not-Attempt 　Cardiopulmonary Resuscitation 　DNACPR) 的決定，或臨終照顧的選擇 　(end-of-life care preferences)	☐	☐	☐	☐	☐
l 向家屬交待病兒突然死亡(sudden death)	☐	☐	☐	☐	☐

14. 你對自己照顧患有危疾的病兒，在個人準備 (self-preparation) 上，整體來説有多大信心？

1最沒有信心	2沒有信心	3一半一半	4有信心	5最有信心
☐	☐	☐	☐	☐

15. 以下的項目是一些醫護人員在個人準備上有可能會遇到的衝擊。在你照顧患有危疾的病兒上，這些衝擊程度有多大？

	衝擊程度				
	1最小/沒有	2	3	4	5 最大
a 病兒危殆的情況出於突然	☐	☐	☐	☐	☐
b 為病兒的死亡過程或離世感到悲傷 (grief)，例如：感覺死亡將自己與已建立關係的病兒分開	☐	☐	☐	☐	☐
c 為家屬在情緒上所受的痛苦而難過	☐	☐	☐	☐	☐
d 專業身份 (professional identity) 為個人情感 (personal emotions) 帶來的壓力，例如：作為專業人員擔心在家屬面前表達情緒	☐	☐	☐	☐	☐
e 對病兒的離世或所受的痛苦感到無能為力	☐	☐	☐	☐	☐
f 對家屬的痛苦及情緒感到無能為力	☐	☐	☐	☐	☐
g 病兒的離世或死亡過程引起自己的負面情緒	☐	☐	☐	☐	☐
h 對自己的生命價值或意義產生懷疑	☐	☐	☐	☐	☐
i 認為病兒所受的痛苦或死亡是違反生老病死的自然定律	☐	☐	☐	☐	☐
j 工作令自己想起過往一些未能解決的遺憾 (personal unresolved grief)	☐	☐	☐	☐	☐
k 想到自己的親人也有可能一天如病兒一樣受患病的痛苦或離世	☐	☐	☐	☐	☐
l 想到自己也有可能一天如病兒一樣受患病的痛苦或離世	☐	☐	☐	☐	☐

16. 你認為現時的工作環境 (work environment)，包括監督、團隊合作和溝通等，在提供紓緩服務上，整體來說有多理想？

1最沒有信心	2沒有信心	3一半一半	4有信心	5最有信心
☐	☐	☐	☐	☐

17. 以下的項目是一些醫護人員在工作環境層面上有可能會遇到的挑戰。在你照顧患有危疾的病兒上，這些挑戰程度有多大？

	挑戰程度				
	1最小/ 沒有	2	3	4	5 最大
a 人手問題	☐	☐	☐	☐	☐
b 同事間溝通	☐	☐	☐	☐	☐
c 不同部門/單位間溝通	☐	☐	☐	☐	☐
d 工作環境，例如：空間及設施不足	☐	☐	☐	☐	☐
e 給予同事與死亡或紓緩服務相關的 培訓或資訊	☐	☐	☐	☐	☐
f 對同事情緒上的支援，例如：解說會、 追思會或轉介輔導服務	☐	☐	☐	☐	☐
g 對同事臨床的督導，例如：死亡個案 檢討會 (Mortality Meeting)	☐	☐	☐	☐	☐

18. 總括來說，你對自己照顧患有危疾的病兒有多大信心？

1最沒有信心	2沒有信心	3一半一半	4有信心	5最有信心
☐	☐	☐	☐	☐

19. 以下的項目是一些有可能會影響紓緩服務質素的因素。你認為在現今香港醫療架構和環境下，
    對患有危疾的病兒和其家屬，甲、這些因素的影響性有多大？
    乙、這些因素需要改善的急切性有多大？

	甲、這些因素的影響性					乙、這些因素需要改善的急切性				
	1極小/沒有	2	3	4	5極大	1極小/沒有	2	3	4	5極大
a 兒童紓緩服務的重視程度	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b 足夠人手	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c 資源足夠及配合，例如：暫住服務	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d 機構文化或政策上的配合， 例如：探訪規則	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e 部門/單位管理的效率	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f 法律上的配合，例如：證實死亡的 程序 (certifying death)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
g 給予病兒或家屬使用的設施， 例如：家屬休息室	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
h 給予病兒以提升他們生活質素的服務， 例如：遊戲服務、輔助溝通系統訓練 (Augmentative & Alternative Communication Training)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
i 給予家屬的喪親關顧服務， 例如：喪親輔導	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
j 除病兒的父母外，給予其他與病兒 相關的重要人士的服務， 例如：病兒的兄弟姊妹	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
k 家屬對患病孩子的權益之重視， 例如：漠視孩子的生存權、或棄嬰	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
l 家屬對紓緩服務的知識	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
m醫院服務與社區服務的銜接	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

20. 如對上述問卷有任何補充或意見，請闡述：

_____

_____

_____

【全問卷完，感謝參與！】

APPENDIX 3

CATEGORIZATION: EXPLORATORY FACTOR ANALYSIS

To allow better conceptualization about responses from paediatric professionals, the items in each section of perceived challenges and structural factors in the questionnaire were categorized through exploratory factor analysis (EFA). This process substantiates the categorization with the response pattern of the respondents. Then, indexes were computed according to the results of EFA. Although most items can be successfully categorized, a few were discarded because they cannot be conceptualized with enough statistical rigour: they are not exactly related to any categories found (low factor loading), or related strongly with more than one category (cross-loading).

To test if EFA can be performed on each section, a test of factorability was run. The values of different indicators are shown in Table 14. The results suggest that EFA can be run.

EFA is performed following the recommendation of Costello and Osborne (2005): principal axis factoring (PAF) with direct oblimin rotation. Factor loading less than .4 was suppressed.

Table 14

Factorability of different aspects of perceived challenges

	Kaiser-Meyer-Olkin measure of sampling adequacy	Bartlett's test of sphericity*			Average communalities
		x^2	df	p	
Challenges					
Knowledge	.77	1332.29	10	< .001	.49
Skills	.71	4417.36	66	< .001	.54
Self	.91	6195.19	66	< .001	.66
Work environment	.82	1742.73	21	< .001	.52
Structural factors					
Impact	.91	3702.79	66	<.001	.50
Urgency	.92	3447.65	66	<.001	.50

Challenges in knowledge

One factor solution is generated, so no rotation is performed. All factor loadings are over .50. The factor is called "Knowledge challenge". Tested by Cronbach's alpha, the internal consistency is .82.

Table 15

Factor Loadings of items of perceived challenge in knowledge

Items	Knowledge challenge
knowledge challenge A: Change of mode of care: from curative medicine to palliative care 何時從治療模式轉為紓緩治療	.63
knowledge challenge B: Provision of palliative in acute setting 於急症病房/單位提供紓緩服務	.57
knowledge challenge C: Knowledge of palliative care in general 紓緩服務的知識	.81
knowledge challenge D: Knowledge of handling dying process and death (e.g. planned home death) 有關處理死亡或死亡過程的知識，例如居家善終	.75
knowledge challenge E: Knowledge on relevant community resources 對社區服務的認識	.72

Challenges in skills

One item is excluded due to cross-loading (skills challenge F: Handle emotions of family members；面對或處理家屬的情緒), and one due to low loading (skills challenge D: Preparation for the death of child patient, e.g. arrangement of religious rituals or planning of funeral；為病兒的死亡作準備，例如：安排宗教臨終禮儀，或計劃喪禮"). A 2-factor model was produced. No cross-loadings exist, and most loadings are over .50. The two factors were "Basic skills" and "Advanced skills". Tested by Cronbach's alpha, their internal consistencies are .85 and .87 respectively. They are positively correlated (r = .67).

Basic skills are required in routine or daily paediatric service, such as communication with clients and the families, symptom management, care service, and emotion management. Advanced skills are required in handling acute events which are often directly related to life and death issues.

Table 16

Factor loadings of items of perceived challenge on skills

	Factor	
	Basic skills	Advanced skills
skill challenge A: Communication with family members 與家屬溝通	.69	
skills challenge B: Communication with child patients 與病兒溝通	.81	
skills challenge C: Symptom management 症狀處理	.58	
skills challenge D: Preparation for the death of child patient, e.g. arrangement of religious rituals or planning of funeral 為病兒的死亡作準備，例如：安排宗教臨終禮儀，或計劃喪禮 (low loading)		
skills challenge E: Handle emotions of child patients 面對或處理病兒的情緒	.59	

skills challenge F: Handle emotions of family members
面對或處理家屬的情緒 (cross-loading)

skills challenge G: Build up trustful relationship with child
patients and their family members 與病兒及家屬建立互信關係   .72

skills challenge H: Having disagreement with family members
in care of child patients 與家屬在照顧病兒上意見有分歧   .48

skills challenge I: Handling controlling or demanding child
patients and family members 處理或應付具控制性或要求過
高的家屬或病兒   -.53

skills challenge J: Break bad news with child patients and
family members (e.g. deterioration in prognosis, incurable
disease, and impending death) 向病兒及家屬交待惡耗，
例如：病情惡化 ，治療無效，死亡將近   -.81

skills challenge K: Communicate with child patients and
families about advance care planning, e.g. Do-Not-Attempt
Cardiopulmonary Resuscitation DNACPR); end-of-life care
preference 與病兒或家屬討論預設臨終照顧計劃，
例如：「不作心肺復甦術」的決定，或臨終照顧的選擇   -.80

skills challenge L: Sudden death 向家屬交待病兒突然死亡   -.84

Challenges to self

A 2-factor model was produced. No cross-loadings exist, and all loadings are over .50. The two factors are "Professional self" and "Personal self". Tested by Cronbach's alpha, their internal consistencies are .91 and .92 respectively. They are positively correlated (r = .63).

"Professional self" refers to challenges related to the working self or professional identity. It includes sadness perceived in the work context or from patients and their family and the helplessness regarding one's own identity in the helping profession. In contrast, "Personal self" are the challenges "derived" from the personal context of paediatric professionals, which affects more directly one's life and death philosophy and arouses the imagination or memory of personal encounters.

Table 17

Factor loadings of items of perceived challenge to self

	Factor	
	Professional self	Personal self
self-challenge A: Sudden deterioration of child patient's condition 病兒危殆的情況出於突然	.59	
self-challenge B: Grieving the death and dying of child patients, e.g. feeling that death separated the relationship with child patients 為病兒的死亡過程或離世感到悲傷，例如：感覺死亡將自己與已建立關係的病兒分開	.82	
self-challenge C: Feeling sad for the emotional sufferings of family members of child patients 為家屬在情緒上所受的痛苦而難過	.86	
self-challenge D: Professional identity may bring burden on the emotional reactions (e.g. As a professional, one may worry about expressing own emotions) 專業身份個人情感帶來的壓力，例如：作為專業人員擔心在家屬面前表達情緒	.74	
self-challenge E: Feeling helpless to the sufferings and death of child patients 對病兒的離世或所受的痛苦感到無能為力	.84	
self-challenge F: Feeling helpless to the sufferings and emotions of family members of child patients 對家屬的痛苦及情緒感到無能為力	.80	
self-challenge G: Aroused negative emotions due to the death and dying of child patients 病兒的離世或死亡過程引起自己的負面情緒	.54	
self-challenge H: Query the meaning and value of own life 對自己的生命價值或意義產生懷疑		-.77
self-challenge I: Perceive the sufferings and death of child patients violated the law of nature 認為病兒所受的痛苦或死亡是違反生老病死的自然定律		-.83
self-challenge J: Induced personal unresolved grief due to their work 工作令自己想起過往一些未能解決的遺憾		-.89
self-challenge K: Thinking that one's family members may also experience pain and death like child patients 想到自己的親人也有可能一天如病兒一樣受患病的痛苦或離世		-.80

self-challenge L: Thinking that one may also experience pain and death like the child patients 想到自己也有可能一天如病兒一樣受患病的痛苦或離世	-.86

Challenge in the work environment

A 2-factor model was produced. No cross-loadings exist, and all loadings are over .50. The two factors are "General work environment" and "Support to staff". Tested by Cronbach's alpha, their internal consistencies are .73 and .84 respectively. They are positively correlated (r = .56).

"General work environment" means the challenges related to the immediate context of daily work. "Support to staff" means challenges about guidance, supervisory, or emotional support given to staff members.

Table 18

Factor loadings of items of perceived challenge in work environment

	Factor	
	General work environment	Support to staff
work environment challenge A: Adequacy of human resources 人手問題	.52	
work environment challenge B: Communication between colleagues 同事間溝通	.59	
work environment challenge C: Communication between different units and departments 不同部門/單位間溝通	.76	
work environment challenge D: Environment, e.g. space and facilities 工作環境，例如：空間及設施不足	.62	
work environment challenge E: Information and training (e.g. related to death and palliative care) given to colleagues 給予同事與死亡或紓緩服務相關的培訓或資訊		-.58
work environment challenge F: Emotional support to colleagues, e.g. debriefing, memorial, referral for counseling services) 對同事情緒上的支援，例如：解説會、追思會或轉介輔導服務		-.97
work environment challenge G: Clinical supervision given to colleagues (e.g. conduct mortality meeting to review deaths of child patients) 對同事臨床的督導，例如：死亡個案檢討會		-.74