

# Psychological distress and social support among community paediatric palliative care programme caregivers: longitudinal analysis

## INTRODUCTION

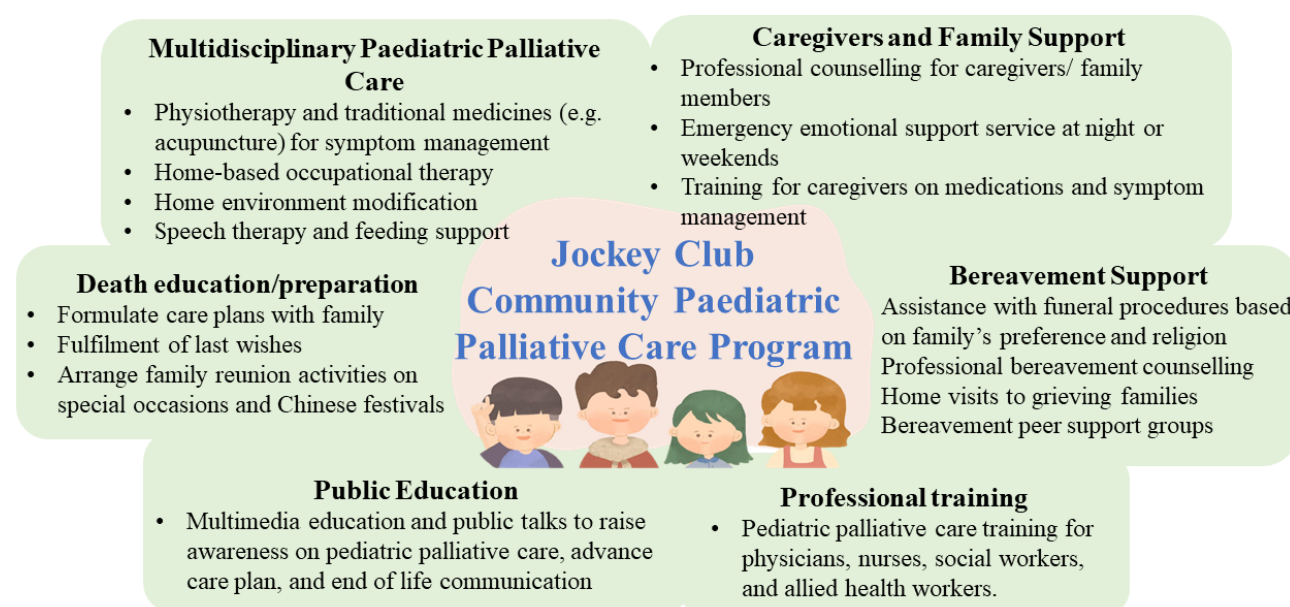
Caregivers of medically complex paediatric patients often experience significant psychological burden, especially in Chinese society where 'end-of-life' is often a taboo subject. Providing adequate psychosocial support for caregivers is crucial, with previous studies showing that they are at risk of becoming financially disadvantaged and socially isolated and typically have very limited access to death-related and bereavement-related information.<sup>1</sup>

In Hong Kong, the public healthcare system collaborates closely with the non-governmental organisations (NGOs) to provide holistic palliative care for paediatric patients and their families. In 2019, the Hong Kong Sheng Kung Hui Welfare Limited, a local NGO, launched the Jockey

Club Community Paediatric Palliative Care Programme (JCPPC).<sup>2</sup> The JCPPC is one of the largest community-based, territory-wide palliative care programmes for children in Hong Kong. Since June 2021, this programme has been providing evidence-based, multi-disciplinary palliative services for medically complex children in line with the literature and international guidelines (figure 1).<sup>3</sup> Eligible medically complex children were referred by either the paediatric palliative care teams of five local public hospitals in Hong Kong, special or hospital schools, other NGOs/local religious institutes, or by self-referral. During the project period (2019–2022), 368 family members participated in >200 family activities and wish fulfilment, such as outings and virtual music therapy classes (during the pandemic). It also organised 28 mutual support groups for 128 family members to build up mutual support for caregivers of children with similar life-limiting conditions, as well as bereaved caregivers. More than 100 advanced care

planning sessions were organised to support 120 family members. A total of 11 bimonthly multidisciplinary meetings were co-organised with the Hong Kong Society of Children's Palliative Care to provide training for 672 families and healthcare professionals. The JCPPC has also implemented culturally relevant adaptations of some services, including the use of complementary medicines for symptom management, psycho-education on death and dying and end-of-life support tailored to the families' religious faith.

There is currently no published data on the effectiveness of paediatric palliative programmes in Hong Kong from the caregivers' perspectives. With the overarching aim of advising the development of future initiatives, we performed a longitudinal analysis on the short-term effect of the JCPPC on 76 informal Chinese caregivers (ie, family members or relatives) who participated in the programme and provided informed consent to participate in the evaluation. Their children (mean age=10.2 years (SD=5.5



賽馬會「友晴同路」社區兒童舒緩照顧計劃  
Jockey Club Community Paediatric  
Palliative Care Programme



聖公會聖匠堂長者地區中心  
S.K.H. HOLY CARPENTER CHURCH DISTRICT ELDERLY COMMUNITY CENTRE  
(由香港聖公會福利協會有限公司營運)  
(Operated by Hong Kong Sheng Kung Hui Welfare Council Limited)

Image source: <https://www.hccjccppc.org/home>

**Figure 1** Components and features of the Jockey Club Community Paediatric Palliative Care Program.

years)) were diagnosed with cancer (37%), neurological conditions (38%), inborn errors of metabolism (18%) or other life-limiting conditions (7%). The assessments of caregivers were conducted on enrolment to the JCPC (T<sub>0</sub>), 3–4 months post-enrolment (T<sub>1</sub>) and 6–8 months post-enrolment (T<sub>2</sub>). At each assessment, the caregivers completed the validated Depression, Anxiety and Stress Scale-21 items and the Multidimensional Scale of Perceived Social Support (MSPSS) to assess changes in their psychological distress and perceived social support, respectively.

At baseline, approximately half of the caregivers reported moderate-to-severe depression (44.2%), anxiety (59.8%) or stress (42.9%). At follow-up assessments (from T<sub>1</sub> to T<sub>2</sub>), up to half of the caregivers reported a significant reduction in the severity of their depression (53%,  $p=0.033$ ), anxiety (50%,  $p=0.049$ ) and stress (33%,  $p=0.045$ ) symptoms (McNemar's test). Based on caregiver feedback, the reduced psychological distress might be the result of several unique evidence-based features of the JCPC that have demonstrated effectiveness in addressing the specific needs of caregivers.<sup>3</sup> For example, the provision of home-based nursing services and access to an emergency helpline at night and on weekends directly reduces the caregiving burden. Additionally, our previous study showed that traditional, complementary and integrative medicine (TCIM) is gaining popularity in the paediatric palliative care setting.<sup>4</sup> Taken together, we propose that the evidence-based features of the JCPC could be further expanded to guide the integration of TCIM services into paediatric palliative care in Hong Kong.

In terms of social support, the multivariable analysis showed a modest improvement in caregivers' perceived social support from NGOs (adjusted MSPSS score: T<sub>0</sub>=41.6,

T<sub>1</sub>=39.6, T<sub>2</sub>=44.6;  $p=0.037$ ), adjusting for the children's diagnoses and caregivers' age and sex (generalised estimating equations). Addressing caregivers' emotional needs might have contributed to their improved perception of social support from the NGO. Consistent with evidence-based recommendations,<sup>3</sup> a collective decision-making process was fostered through early advanced care planning, grief psychoeducation and culturally based family activities, such as reunion dinners during Lunar New Year and Mooncake Festivals. As Hong Kong is a multicultural and multireligious society, the JCPC considered the families' perceptions of death and preferred religious services during the bereavement process. Such a culturally sensitive and individualised approach might have significantly increased the caregivers' perception of support from the NGO.

Overall, the vast majority of caregivers indicated that they had become more motivated to seek palliative care services and advanced care planning (94%), had developed a more positive attitude toward death (86%) and had learnt new coping mechanisms for anticipatory grief, death anxiety and feelings of loss and guilt (93%). Furthermore, 85% expressed that they became more confident in seeking help from the community. However, our results also suggest a potential area for improvement—no significant change was observed in caregivers' perceived support from peers/friends ( $p=0.71$ ) and family ( $p=0.38$ ). One potential reason could be that this programme was conducted during the COVID-19 pandemic, when intra-family gatherings and social activities may have been affected by city-wide infection control measures. Studies have shown that peer support among caregivers of patients with cancer can positively influence family relationships and self-efficacy.<sup>5</sup> Therefore, strategies focusing on strengthening family

relationships and peer support should be a long-term focus of the JCPC.

To conclude, this is the first study in Hong Kong to evaluate the outcomes of a community paediatric palliative programme that provides culturally sensitive, multimodal medical and social support for medically complex children. Our analysis revealed the promising short-term effectiveness of the JCPC in alleviating caregivers' psychological distress and improving their perceived support from the NGO. Future work should include systematic psychosocial screening and triaging of family caregivers to facilitate targeted psycho-interventions within the JCPC, and to assess this programme's clinical significance and long-term impact.

Esther Chui Yan Wong,<sup>1</sup>  
Phillip Lung Wai Au-Doung,<sup>2</sup>  
Yvonne Yuen Ling Chu,<sup>3</sup>  
Sandy Sin Yuet Wong,<sup>1</sup> Chi Kong Li,<sup>3,4</sup>  
Yin Ting Cheung<sup>2</sup>

<sup>1</sup>Sheng Kung Hui Holy Carpenter Church Community Centre, Hong Kong Sheng Kung Hui Welfare Council Limited, Hong Kong SAR, People's Republic of China

<sup>2</sup>School of Pharmacy, The Chinese University of Hong Kong Faculty of Medicine, Hong Kong SAR, People's Republic of China

<sup>3</sup>Department of Paediatrics, The Chinese University of Hong Kong Faculty of Medicine, Hong Kong SAR, People's Republic of China

<sup>4</sup>Department of Paediatrics and Adolescent Medicine, The Hong Kong Children's Hospital, Hong Kong SAR, People's Republic of China

**Correspondence to** Dr Yin Ting Cheung, School of Pharmacy, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong SAR, People's Republic of China; yinting.cheung@cuhk.edu.hk

**Acknowledgements** We would like to acknowledge Mr Wai Fung Lam and the staff of Hong Kong Sheng Kung Hui Welfare Council Limited for the provision of palliative care services. We would also like to thank all the children, caregivers and families for participating in the programme.

**Contributors** All authors contributed to the study conception and design. Material preparation and data collection were performed by ECY, YYL, SSY and CKL. Data analysis was performed by PLWA-D and YTC. The first draft of the manuscript was written by PLWA-D and YTC. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

**Funding** The Jockey Club Community Paediatric Palliative Care Programme is funded by the Hong Kong Jockey Club Charities Trust (Ref number 2022-0134). The funder is not involved in the evaluation, analysis and writing of the final report.

**Competing interests** None declared.

**Patient consent for publication** Consent obtained from parent(s)/guardian(s).

**Ethics approval** This study involves human participants and was approved by the Joint North Territories East Cluster-Chinese University of Hong Kong Clinical Research Ethics Board (Ref 2020.035). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; internally peer reviewed.

© Author(s) (or their employer(s)) 2023. No commercial re-use. See rights and permissions. Published by BMJ.

ECYW and PLWA-D are joint first authors.



**To cite** Wong ECY, Au-Doung PLW, Chu YYL, *et al.* *BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/spcare-2023-004301

Received 24 March 2023

Accepted 24 March 2023

#### ORCID iD

Yin Ting Cheung <http://orcid.org/0000-0001-9874-8938>

#### REFERENCES

- 1 Gill FJ, Hashem Z, Stegmann R, *et al.* The support needs of parent caregivers of children with a life-limiting illness and approaches used to meet their needs: a scoping review. *Palliat Med* 2021;35:76–96.
- 2 The Hong Kong Sheng Kung Hui Welfare Limited. The jockey club community paediatric palliative care program (JCPPC). The Hong Kong Special Administrative Region. 2022. Available: <https://www.hccjccppc.org/> [Accessed 7 Feb 2023].
- 3 Linebarger JS, Johnson V, Boss RD, *et al.* Guidance for pediatric end-of-life care. *Pediatrics* 2022;149:e2022057011.
- 4 Lam CS, Koon HK, Chan CW, *et al.* Use of traditional, complementary and integrative medicine in Chinese paediatric patients receiving palliative care: a multicentre study. *Bmjpo* 2022;6:e001701.
- 5 Melguizo-Garín A, Martos-Méndez MJ, Hombrados-Mendieta I, *et al.* Relation between social support received and provided by parents of children, adolescents and young adults with cancer and stress levels and life and family satisfaction. *Front Psychol* 2022;13:728733.