Response to a 2022 EMHJ paper on palliative care models in the Eastern Mediterranean Region

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Dear Editor,

In our search for journal articles that discuss paediatric palliative care models in the Eastern Mediterranean Region (EMR), we came across this 2022 EMHJ report (1). The last sentence of the introduction claims that no country in the EMR had "achieved integration of palliative care services" in their healthcare system and that only 4 had "better than isolated care provision" (1,2). This assertion is inaccurate especially for Kuwait. Looking into the references, the data appears to have been sourced from 2 major reports: the WHO/WHPCA's 2020 Global Atlas of Palliative Care and the IAHPC's 2017 Atlas of Palliative Care in the EMR. Upon further reading, we discovered that the information in these sources was not entirely representative of the scope of palliative care services in Kuwait, as the services our centre offers were not explicitly mentioned.

The Kuwait Association for Care of Children in Hospital (KACCH) was founded in 1989 to provide psychosocial support for children and families at Amiri Hospital (3-5). Today, KACCH manages child life programmes across 7 government hospitals (6). The paediatric palliative homecare programme was initiated in 1992, driven by a single mother's wish to have her son die at home (3). The homecare service continued until a physical facility was built. In 2012, the freestanding Bayt Abdullah Children's Hospice (BACCH) was opened to offer specialized paediatric palliative care (4-6). BACCH is currently the only children's hospice in the Middle East (5), and its services include multidisciplinary clinical and medical support, terminal and emergency care, schooling, and even community outreach and

respite programmes (4-6). Patients have the flexibility of receiving psychosocial and medical care at home, in the hospital, or at BACCH (4,5).

In 2020, these 2 entities merged into one organization, KACCH & BACCH, which has helped streamline our integrated in/outreach model and dual-keyworker system (5,6). Each child and their family members are assigned a clinical and psychosocial keyworker, who coordinate internally to ensure consistent and appropriate care provision (5). This duo acts as a link between the hospice and the hospital-based medical teams, which is meant to promote early referrals (5). As a non-profit private entity, BACCH is primarily funded by donations and support from the Kuwait Ministry of Health based on a Memorandum of Understanding.

Before writing this letter, we contacted Dr Eric Krakauer to inform him about this issue and he graciously connected us to the University of Navarra team and the Global Atlas editor to correct the misinformation. During our conversations, we found that the cause of this misrepresentation was that both reports used for the paper had relied on data that were provided by 1 or 2 key local informants (2,8). Although informants are typically screened and selectively chosen, the selection process is not totally error-free. With these newfound connections and the subsequent correction, we hope that a more comprehensive and more accurate documentation of adult and paediatric palliative care services in Kuwait will be presented.

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