

PallCHASE Webinar #7 War and Conflict - Pediatric palliative care research in conflict settings: Emerging evidence from the Middle East region

By Dr Sabah Boufkhed (Lecturer in Global Health, University of Manchester)
Ghadeer Alarjeh (Senior Palliative Researcher, King Hussein Cancer Center)
Facilitated – Dr Mhoira Leng

In October 2022, PallCHASE hosted a webinar looking at Pediatric Palliative Care Research in Conflict Settings with a focus on emerging evidence from the Middle East region.

One question that the speakers expanded upon was ...

What matters to children and young people with advanced care cancer in conflict-affected settings like Turkey and Jordan?

Dr. Boufkhed, Mrs. Alarjeh and their team conducted a cross-national qualitative study Jordan and Turkey to identify what matters to children and young people (CYP) with advanced cancer and their families, and ultimately inform culturally appropriate palliative care and policy.

A total of 104 participants, including 50 CYP, 30 caregivers and 24 healthcare professionals were interviewed in both countries.

What matters to CYP & their families?

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- **Priority PC Outcome**
 1. Physical pain and symptoms
 2. Psychological concerns and needs
 3. "Tawakkul" (faith and reliance on God), spirituality and uncertainty over the future*
 4. Social dimension
 5. Burden on caregivers and their families
- **Other key themes / papers**
 - Communication & Information sharing (Ghadeer)
 - Quality of care (next paper)

* Ref. Hammoudeh W, Hogan D and Giacaman R. From a Death Sentence to a Disrupted Life: Palestinian Women's Experiences and Coping With Breast Cancer. Qual Health Res 2017; 27: 487-496

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The concerns for pediatric palliative care encompassed five domains, four of which were mostly comparable to the WHO's domains: Physical pain and symptoms, Psychological (e.g. anger and mood changes) concerns, Spirituality domain including the use of religion as a way to cope with the illness, and a Social dimension covering the negative impacts caused by the illness such as disrupted social support systems. A fifth dimension was specifically identified and described the

Burden on caregiver and families, which included financial issues related to supporting the child's care and torment when thinking about the other children. Throughout the study, we found that there were similar issues for immigrant or refugee patients, but the issues around Social and Burden were particularly emphasized for this group.

What about the conflict-setting aspects?

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- Overall similar concerns for caregivers and children
- Burden of families and caregivers was emphasised for those displaced/refugees
 - Emotional and Financial burden of being away from family, other children, social support
 - Expectations in terms of care may vary depending on the country of origin
- Structural barriers for refugees and those coming from neighbouring countries like Palestine especially in Jordan
 - Difficult control at borders for Palestinians seeking for care
 - Difficulties for patients in refugee camps to go to treatment centre (getting authorisation, public transport options)
 - Difficulties for health professionals to visit refugee camps to provide care
 - Health professionals may visit patients in refugee camps but limited community-based care in Jordan
 - Indirect costs and logistical aspects related to seeking care far from home

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Sabah Boufkhed

Ghadeer Alarjeh

Shereen Al-Awadi

Shereen Al-Awadi

Anwar Al-Nassan

Anwar Al-Nassan

Physical pain and symptoms (eg mobility, symptoms)

"I never expected the operation to be like this. I had a lot of pain, and I could never move my foot. I said, it's over now, that's it." - Jordanian boy CYP [11-16]

Psychological concerns and needs

"psychology is 50% of the treatment, the way you feel and social things that happen in a person's life" Jordanian boy CYP [11-16]

Social life, activities and support

"We just come out and walk around. We're not seeing anyone. In fact, this is the most important, we are going through an unsocial process." Turkish mother aged [36-40]

"In Gaza I am with my family, but here I am not." Palestinian girl CYP receiving care in Jordan aged [08-10]

"Tawakkul", spirituality and uncertainty over the future


"Hope Allah cures everybody and us too. If only God heals our child, as long as the child is with me, I can accept to be beggar from door to door [which means she accepts to be poor]." Turkish grandmother aged [51-55]

"It affected my studies. I am going to waste my future, the semester is almost over. This is hard, I don't know how I am going to deal with that" Turkish girl CYP [17-18]

Burden on caregivers and families (emotional, financial, caring for siblings)

"I'd go to work with my heart on fire. I wait and count the hours and wonder when I'm going home [...] If they don't deduct from our salaries, I would leave work and sit at home with them. I have no relationships, I don't even see my neighbor." Jordanian mother aged [41-45]

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Sabah Boufkhed

Ghadeer Alarjeh

Rana Yamout

To provide good quality palliative care that is centered on the patients and their families' needs and priorities, the concerns we identified needs to be addressed not only in the care centers but also by the wider health and social systems.



PallCHASE's next webinar will be on Jan 18 2023. More details to come.

Read the full research article at

<https://journals.sagepub.com/doi/pdf/10.1177/02692163211000236>

Compounded trauma: A qualitative study of the challenges for refugees living with advanced cancer