A DIGITAL HEALTH APPROACH TO FACILITATE ACCESS TO AND CONTINUITY OF CARE FOR PEOPLE WITH ADVANCED CANCER IN THE BIDI BIDI REFUGEE SETTLEMENT IN UGANDA

Palliative care is largely missing in fragile humanitarian settings. Our multi-disciplinary group of palliative care researchers, clinicians, advocates and health informatics practitioners have been establishing and developing digital health approaches to increase access to palliative care in fragile host and refugee communities.

AUTHORS Dr Eve Namisango 1, Mr Raphael Raphael 2, Mr Mutaasa Nickson 2, Associate Professor Matthew Allsop 3

AFFILIATIONS
1 African Palliative Care Association, Kampala, Uganda
2 International Rescue Committee, Uganda Office, Kampala, Uganda
3 Academic Unit of Palliative Care, University of Leeds, United Kingdom

CONTACT Email: m.j.allsop@leeds.ac.uk
Twitter: @matthewallsop

INTRODUCTION

There is an urgent need for feasible approaches to facilitate access to palliative care in humanitarian settings. [1]

Digital health approaches are promising innovations that can improve the well-being of people in the context of fragile humanitarian settings. [2]

OBJECTIVE

We sought to co-design and pilot-test a digital health approach to facilitate access to and relational continuity of care for patients with advanced cancer in the Bidi Bidi Refugee Settlement in Uganda.

METHODOLOGY

A mixed-methods study design was used.

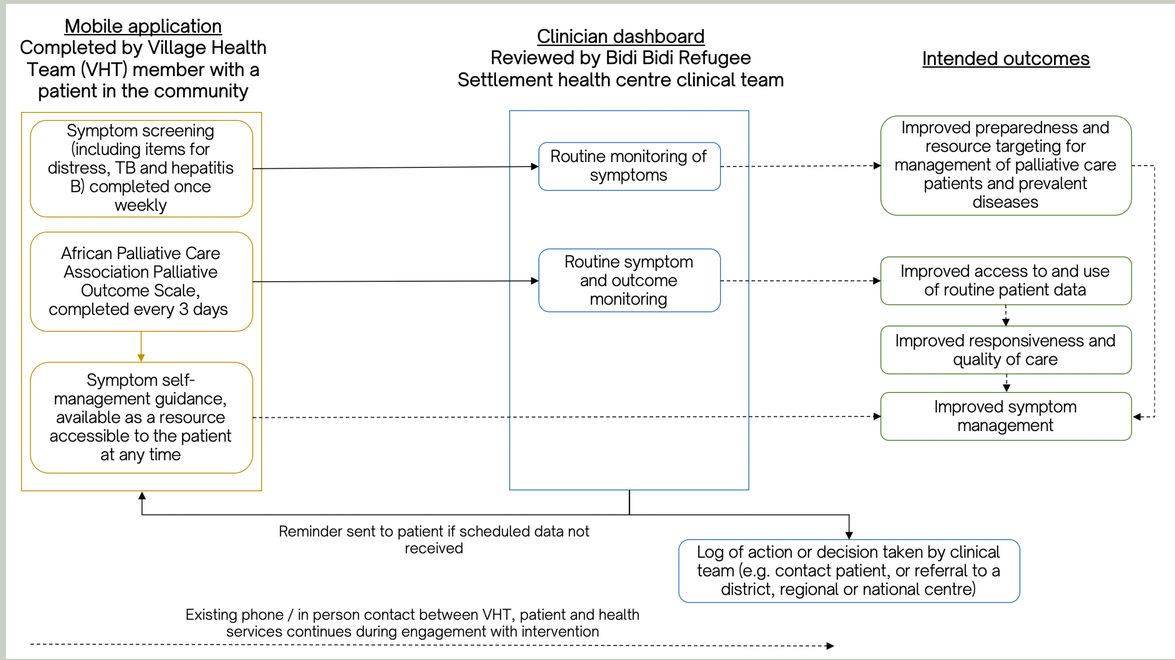
Phase 1: Patient and caregiver co-design workshops to gather requirements for a digital health intervention (DHI)

Phase 2: DHI prototype refinement led by patient, interdisciplinary provider team and policymaker feedback

Phase 3: DHI pilot study of routine reporting of palliative outcomes and COVID-19 symptoms data via a mobile phone application and clinician dashboard (see figure) at the Bidi Bidi Refugee Settlement

Phase 4: Embedded qualitative interviews with patient and health provider participants.

Descriptive analysis of outcome and symptom data was undertaken alongside framework analysis to explore patient and staff experiences of the DHI.



RESULTS/ FINDINGS

Co-design sessions guided intervention content development, including the addition of items to capture symptoms relating to tuberculosis and hepatitis B virus due to their high prevalence in the settlement.

Participants with advanced cancer (n=35) completed 82.3% of scheduled outcome and symptom reports over 6 weeks. Pain, weakness or lack of energy, poor appetite, and worry were most commonly reported.

Patient (n=12) and health provider (n=12) participant experiences highlighted that the intervention: i) prompted meaningful and valued conversations about symptom experiences, ii) facilitated retention of patients often lost to follow-up, and iii) prompted alternative and efficient ways of communicating across interdisciplinary provider teams.

CONCLUSION

A contextually-appropriate DHI can enhance access to and interaction with palliative and supportive care provision in a refugee settlement in Uganda.

Further content refinement and adaptation of clinical pathways to support scale-up and sustainability of the DHI is underway, informed through engagement with key partners and policy actors.

REFERENCES

[1] World Health Organization, Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: A WHO guide 2018, World Health Organization: Geneva, Switzerland. 2018.

[2] Liem A, Natari RB, Hall B. Digital Health Applications in Mental Health Care for Immigrants and Refugees: A Rapid Review. Telemedicine and e-Health 2021. doi: 10.1089/tmj.2020.0012