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Evaluation of the integration of palliative care in a fragile setting amongst host and refugee communities: Using consecutive rapid participatory appraisals

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Abstract

Background: Palliative care is seldom integrated in healthcare in fragile, conflict affected and vulnerable settings with significant refugee populations.

Aim: This study aimed to evaluate the integration of palliative care into a fragile, conflict affected and vulnerable community in Northern Uganda.

Design: Consecutive Rapid Participatory Appraisals were conducted to evaluate the integration of palliative care in Adjumani District. The first established a baseline and the second, 4 years later, evaluated progress. Data collection included documentary review, key informant interviews and direct observation.

Setting/participants: A rural district in Uganda with equal numbers of refugees and host populations living side-by-side. 104 key informants were interviewed, and practice observed in 11 health facilities.

Results: At baseline, palliative care was not routinely integrated in the health system. Barriers included health system challenges, cultural beliefs, understanding and trust, mental health issues, gaps in palliative care provision, the role of the community and beliefs about illness impacted care with the village health teams being a trusted part of the health system. Following integration activities including training, mentorship and community sensitisation, the repeat rapid appraisal after 4 years showed a significant increase in palliative care delivery. New themes identified included increased provision of palliative care, the impact of training and community engagement and ownership of palliative care.

Conclusion: Community engagement and participation, training interventions and referral pathways enabled the integration of palliative care. Rapid Participatory Appraisal provides a useful framework to evaluate activities aimed at integration of palliative care in a community.

Keywords

Palliative care, low-income population, primary health care, displaced persons, needs assessment, volunteer workers, evaluation study, community based participatory research, fragile conflict affected and vulnerable populations

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What is known already?

- Palliative care integration in primary care health and community systems is needed in fragile, conflict affected and vulnerable settings.

What this paper adds?

- Refugee and host populations suffer from many dimensions of distress that could be addressed by culturally appropriate palliative care and support.
- Community and health centre workers in primary care working in fragile, conflict affected and vulnerable settings can be trained to integrate a culturally appropriate compassionate person-centred palliative care approach.
- Community engagement, participation and ownership is crucial in ensuring effective and culturally competent palliative care.

Implications for practice, theory or policy

- The palliative care approach should be integrated in national policy documents and training manuals for healthcare workers in the community and health centres, including within fragile, conflict affected and vulnerable communities.
- Rapid Participatory Appraisal can identify many broad health needs in a community, and inform the development of culturally acceptable interventions. It may also give a structure to evaluate outcomes of palliative care initiative in the community.

Introduction

Integrating palliative care in community and primary care settings is essential for the attainment of health and well-being as part of universal health access.[1] Despite much progress in the development of primary palliative care and models of integrated palliative care there are still significant challenges and resultant unrelieved 'serious health related suffering'.[2,3] Rising rates of displaced populations globally influenced by climate change, political instability and weak health systems present particular challenges.[4] The term *'fragile, conflict affected and vulnerable'* states encompasses such environments and are home to a quarter of the world's population and almost three quarters of those living in extreme poverty.[5] Such states include humanitarian crises and protracted humanitarian settings[6] where palliative care has long been missing from response planning and implementation.[7] Whilst revised guidelines give useful frameworks for integration of palliative care[8–10] and non-communicable disease, effective implementation is lacking despite being recognised by the World Health Organization as a priority area.[11]

The Astana Declaration envisions primary care being offered within environments *'in which individuals and communities are empowered and engaged in maintaining and enhancing their health and well-being'* emphasising the need to ensure ground up community-led models of care to ensure access to palliative care for those in need.[1] Although this is particularly challenging in fragile, conflict affected and vulnerable settings, there is a need for quality and culturally appropriate care with community ownership.[12]

Uganda is recognised as a leader in palliative care and as a model for low-and-middle-income settings.[13,14] However integration is still not achieved in most Ugandan districts.[15,16] With over 1.5 million South Sudanese displaced due to conflict into Northern Uganda,[17] Uganda's Ministry of Health has sought to address their significant health needs together with the host population through partnership with the humanitarian sector.[18,19] Palliative care integration is minimal and must include an understanding of the context, how health care is provided, how palliative care can be provided within the specific context, the challenges faced and ways to overcome these. Local initiatives in Northern Uganda need to be understood in the wider community and refugee context and a model of integrated palliative care designed, implemented and evaluated. Thus, research into palliative care need and implementation in refugee and host settings in Uganda is urgently required. We thus set out to evaluate the integration of palliative care into a fragile, conflict affected and vulnerable communities in Northern Uganda.

Methods

Study setting

The study was conducted in a Northern Uganda district (Adjumani), on the border with South Sudan, which represents a fragile, conflict affected and vulnerable population as defined by the Organization for Economic Cooperation and Development.[5] Almost equal numbers of refugees and host population live side by side and share health care facilities in the district (Total population of 439,400 with 232,400 host and 207,500 refugee).[20] Health care is delivered through a tiered approach of Health Post I, Health Centres II-IV and District hospitals.[21] Health Posts are usually serviced by non-stipended, community health workers known locally as the village health team. They have been nominated by their community and carry out health promotion and disease control activities for a designated list of households, and are trusted representatives. Health centres II, III and IV, are largely staffed by nurses and clinical officers, and are based close to the communities and can refer individuals to the District Hospital. The local system of governance includes the Refugee Welfare Committee, security from the Office of the Prime Minister (OPM) and support from government and humanitarian agencies.

Developments in palliative care over 10 years within Adjumani District have been led by a nurse specialist in Adjumani Hospital (VO) who had undertaken a leadership programme,[22] alongside other healthcare workers, and one non-governmental organisation – Peace Hospice Adjumani. The latter offers home-based care support which had extended to provide a minimal service within the refugee communities.

Design

Rapid Participatory Appraisal offers a framework to gain community perspectives of local health and social needs and to translate these findings into action. Such methods are designed to draw inferences, conclusions, hypotheses, or assessments in a limited period of time and are thus relevant to health service research, with particular relevance to an unstudied community population.[23–25] This technique has been effectively used in primary palliative care in the UK and in Africa, and consecutive appraisals have also been used to evaluate outcomes of community interventions.[26,27]

Rapid Participatory Appraisal usually utilises three main data sources[26]:

- Existing written records about the neighbourhood (document review).
- Interviews with a range of local key informants.
- Observations made in the neighbourhood or in the homes of the interviewees.

Informants are selected ‘purposefully’[26] to include a range of people who are in the best position to understand the issues. Professional insights are incorporated by including relevant interviewees and summary health data.

Data collection

The study utilised consecutive Rapid Participatory Appraisals, initially at baseline and again after activities aimed at integration, to evaluate the integration of palliative care (Figure 1) and using the three main data sources.

Rapid Participatory Appraisal 1

(a) ***Document review*** – documents with information relevant to advanced chronic illness, patient experiences and reports of care provision in the refugee and host settings were collected with the help of the local health care providers and analysed for relevant information.

(b) ***Key informant interviews*** – semi-structured interviews were conducted by ML, GP, CV and VO. All interviewers were females, three were specialist palliative care clinicians (ML, CV and GP), CV is also a psychiatrist, and VO a specialist palliative care nurse. All four had prior experience in carrying out qualitative research. With the support of the District Health Officer and local palliative care leadership, and building on the documentary review information, purposive sampling was used to identify participants. Participants were invited to face-to-face interviews over a three-week period and in the most convenient place for the participants – for example, at home for patients and at work for other informants. Where family members were present with the patients, they were encouraged to stay and participate. Inclusion criteria for the patients were: over 8 years of age; able to give consent and complete the interview in English or in a local language (Madi or Luganda) with contemporaneous translation; had advanced chronic illness (supported by a checklist) and were receiving care from either the village health teams or from the health centres. As participants were interviewed additional informants previously unknown were identified and added. For key informants, inclusion criteria were: over 18 years of age; able to give consent and complete the interview in English or in a local language (Madi or Luganda) with contemporaneous translation; were either community leaders, worked for the ministry of health, local government or a humanitarian agency working in the district, were palliative care providers, or referred to or interacted with palliative care providers.

Interview guides were adapted for each category of informant to explore the experience of living with advanced chronic illness and the perspective of those offering clinical care and those in leadership roles (see Supplementary Materials 1). Informants were asked about the broad health and social needs of refugees and host communities living with advanced chronic illness, their understanding of palliative care and also how palliative care might address the diverse needs of those with advanced chronic illness. Interviews lasted 20–60 min, were conducted by two researchers, with contemporaneous notes and back up

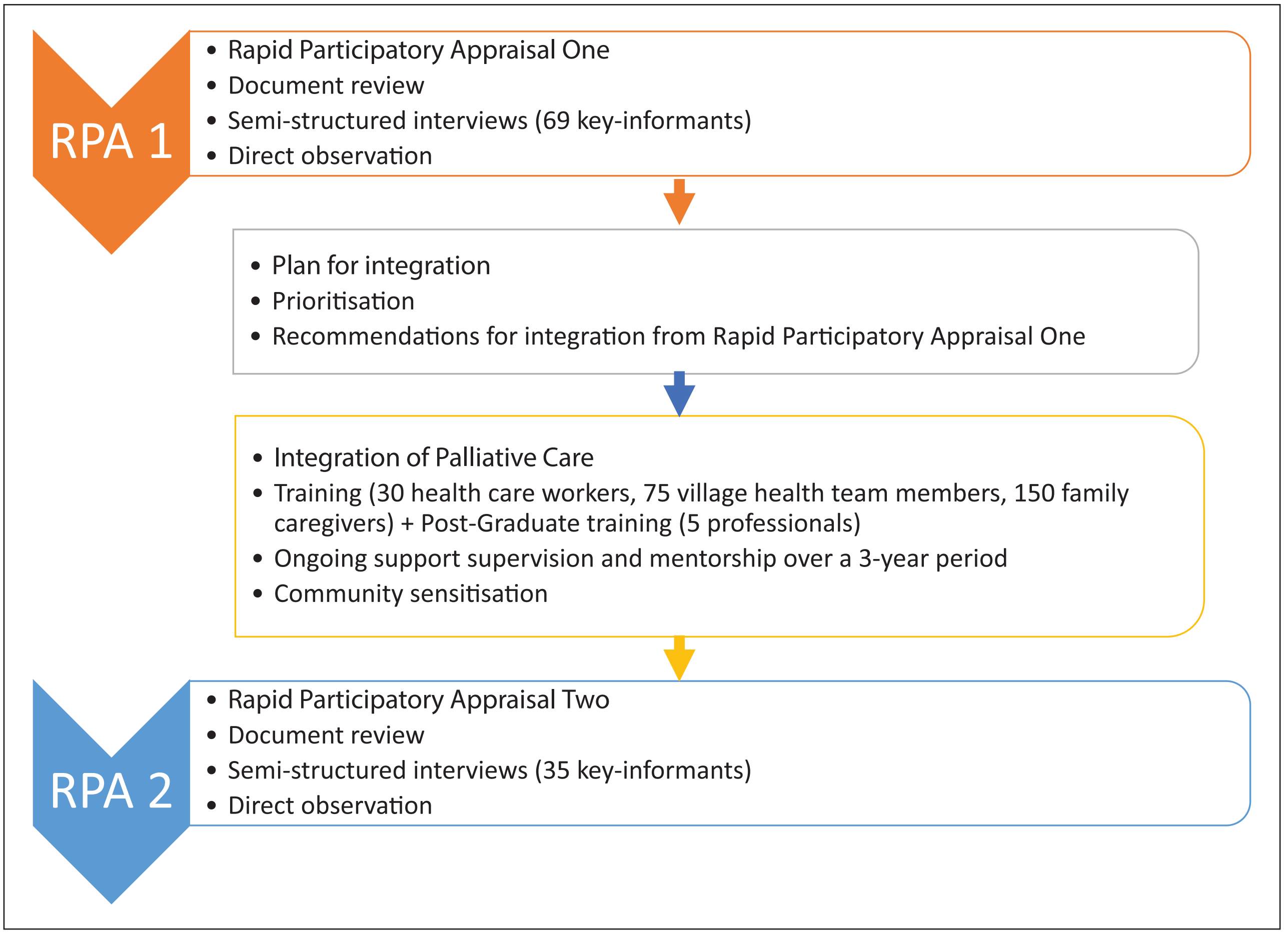

Figure 1. Study design.

digital recordings which were then transcribed. Research and field notes were reviewed the same day, assessed for data saturation and then stored securely and anonymised for coding.

(c) ***Direct observation*** – The provision of care by health professionals and village health teams was observed and detailed field notes taken. Observation was carried out in five Health Centres II–IV and Adjumani District Hospital. This included three within the refugee settlement and two within the host communities.

A range of documents were reviewed during the consecutive Rapid Participatory Appraisals. These included information at the different levels of the "pyramid' in order to describe the communities problems and priorities (Figure 2). This provides a framework for holding together and integrating data from each of the three sources. Documents reviewed included: national, regional and local health and humanitarian sector strategic plans, guidelines, policy documents, health centre reviews and reports. In Rapid Participatory Appraisal 2 documents related to the activities implemented to integrate palliative care (Figure 2) were also reviewed, including training records, patient registers and relevant anonymised patient documentation, availability of medicines, pharmacy documentation and referral pathways.

On the basis of the first Rapid Participatory Appraisal, recommendations were developed and discussed at a wide stakeholder meeting. Interventions were then carried out based on these recommendations and with local co-design (Supplementary Materials 2). These interventions are described (Table 1) and documentary evidence from reports included in Rapid Participatory Appraisal 2.

Rapid Participatory Appraisal 2. The second Rapid Participatory Appraisal was undertaken in 2022 in Adjumani district in both the refugee and host communities. Key-informant interviews were initially conducted over a three-week period, however due to challenges caused by the COVID-19 lockdown, patient interviews were completed face-to-face within a six-month period.

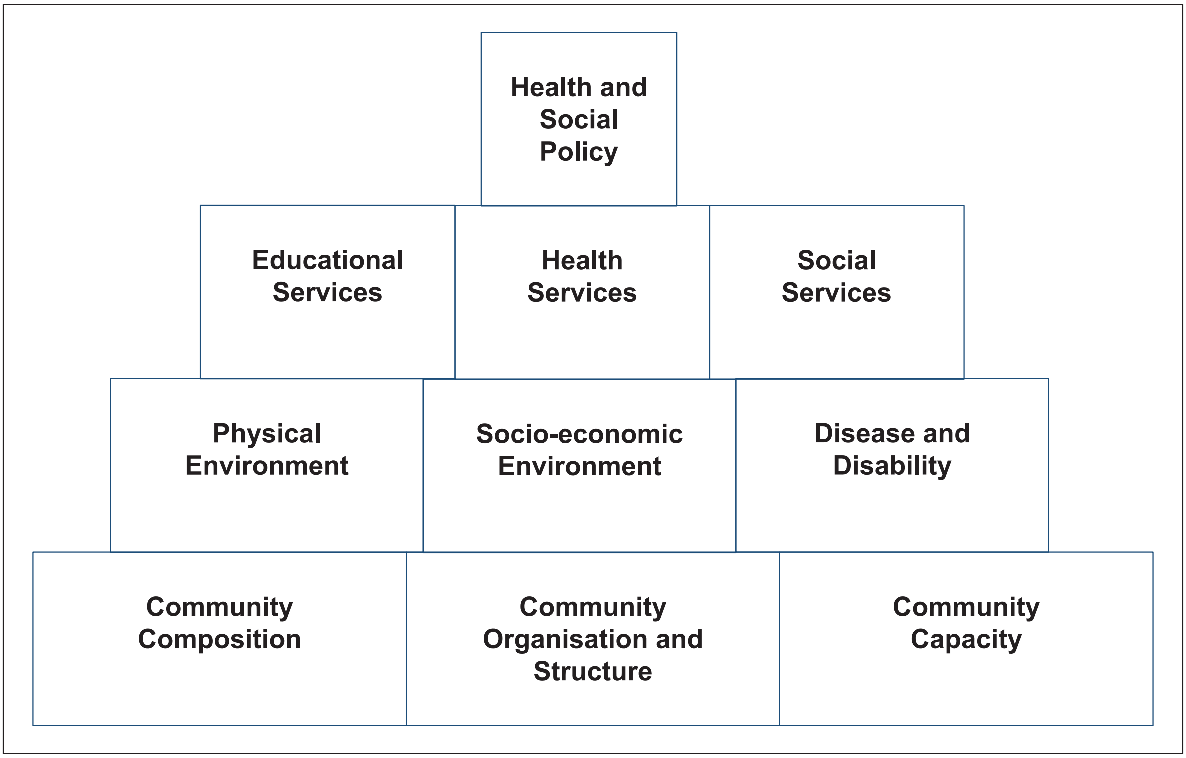

Figure 2. Information pyramid for Rapid Participatory Appraisal.[26]

(a) ***Document review*** – documents with information relevant to advanced chronic illness and patient experiences were again reviewed and included reports and evaluations of the activities undertaken as a result of the first Rapid Participatory Appraisal e.g. training reports, patients' registers, pharmacy records and needs assessment reports were also reviewed and included a neighbouring district baseline. The neighbouring district had no previous interventions so acted as a comparator.

(b) ***Key informant interviews*** – semi-structured interviews were conducted by ML, LN and VO. Informants were once again identified with the support of the District Health Officer and local palliative care providers, utilising the same inclusion criteria as in Rapid Participatory Appraisal 1 with an expanded interview guide to include the impact of activities and progress towards palliative care integration.

(c) ***Direct observation*** – The provision of care by health professionals and village health teams was observed and detailed field notes taken. Observation was carried out in five Health Centres II-IV plus Adjumani Hospital, across three refuge settlements and the host community.

Data storage and analysis

All data was stored on a secure device only accessible to ML, LN and EN and may be made available to any other parties on requisition. Qualitative data was obtained from the documentary review, key informant interviews and directly observed visits. Data was reviewed manually and coded by three researchers for Rapid Participatory Appraisal 1 (ML, LN, JD) and by two researchers for Rapid Participatory Appraisal 2 (ML and LN) using thematic content analysis.[28] For Rapid Participatory Appraisal 1 all themes were derived from the data, whilst Rapid Participatory Appraisal 2 built on prior themes adding any new themes that emerged. Themes generated were coded manually and reviewed. Where quantitative descriptive data was available through the document review this was reviewed but no further analysis undertaken. Triangulation of data was carried out through the three different data sources. The reporting of the appraisal study follows the COREQ checklist.[29]

Ethics

Ethical approval was gained from the Mulago Hospital Research Ethics Committee, the Hospice Africa Uganda Research Ethics Committee and the Uganda National Council of Science and Technology for both Rapid Participatory Appraisals. All participants were informed about the study and participation was voluntary. Written consent was gained by all participants in the study who had the right to withdraw at any time. Whether patients chose to participate or not did not negatively impact on the care that they were given.

Table 1. Activities carried out for the integration of palliative care following the review of findings and recommendations from the first Rapid Participatory Appraisal.

A. Training

- Local and international educational experts used a competency, transformational learning approach appropriate to the local setting and resources.
- Materials were designed influenced by the Rapid Participatory Appraisal to allow scale up and sharing of good practice.
- Numbers trained:
    - *30 Health Care Workers*, two from each participating health centre, attended a 5-day training in generalist palliative care.
    - *75 Village Health Team members*, five from each of the 15 participating communities attended a 3-day training in the palliative care approach which included identification of those in their supervision who had advanced chronic illness, referral pathways and providing holistic care in the home setting.
    - *150 family caregivers of those living with advanced chronic illness* attended a 1-day training to support them in caring for relatives and community members.
    - Selected health care workers were supported to attend advanced postgraduate training in palliative care within Uganda including: 1 BSc, 1 Diploma, 1 Post Graduate diploma, and 2 Leadership Fellowships.
    - Evaluation of competencies was undertaken pre and immediate post plus eight months following completion of the course for both health care workers and village health team members. Details of clinical interactions were also reviewed.

B. Ongoing support supervision and mentorship

- This was provided over a three-year period to the selected health cluster through local, national and international mentorship.
- Health centre visits reviewed essential medicines availability, referral pathways and identification of patients by the village health teams.
- A house-to-house needs assessment was undertaken as part of ongoing supervision of the village health teams and included combined home visits.

C. Wide community sensitisation

- Community outreach visits, district level events and local radio led by local palliative care clinicians focussed on community engagement. In addition, ongoing stakeholder engagement for local community, health and humanitarian leaders.

Results

104 key informants were interviewed, 69 in Rapid Participatory Appraisal 1 and 35 in Rapid Participatory Appraisal 2. The majority of participants were key opinion leaders (*n* = 50, 48%), followed by health care providers (*n* = 37, 36%), service users (*n* = 17, 16%). Out of the 37 health care providers, 30% (*n* = 11) were palliative care providers (Table 2). None of the participants approached declined to participate.

Themes generated from the data

The data was thematically categorised, summarised (Table 3) and highlighted in bold in the text with accompanying narrative and direct quotations.

Rapid Participatory Appraisal 1

Health system challenges were significant. A lack of resources, both financial and human, and challenges with coordination, planning and implementation which affected host and refugee populations. The focus on acute interventions as well as the rural setting left gaps for chronic illness including documentation, follow up and referral pathways. No home visits were provided in any part of the health system though clinics were usually close to the villages. District health leaders were supportive of the integration of palliative care but also emphasised the many challenges in the delivery health care.

> *'We must be able to document cases so we can make a case and justify the need and I can become an advocate of what you're doing'. (RPA1 Local Government Official 1)*

> *'With palliative care we have clients who need the help so much. Palliative care is very very very important.' 'People are empowered more for curative and less at these palliative care issues. . . . . but the palliative care and the dignity was left out'. (RPA1 Health Care Worker 3)*

Cultural beliefs and understanding of illness added great richness but could lead to stigma particularly for those with mental health needs and living with HIV. Although many of the refugee population shared ethnicity with the host population, there were others from different tribal backgrounds, leading to misunderstandings though few tensions. Indeed, the welcome and sense of common brotherhood was clearly stated. The limited access to healthcare in South Sudan combined with repeated traumatic experiences before and during migration made refugee communities wary of **trust**, further complicating access to healthcare in Adjumani.

> *'The way these community are structured there are cultural issues that are part of the problem and really engaging and continuing to build trust is very important. Creating awareness*

Table 2. Participants interviewed during the Rapid Participatory Appraisal process.

Users of service	RPA 1	RPA 2	Palliative care providers	RPA 1	RPA 2
Gender			Gender		
Female	6	4	Female	3	3
Male	7	0	Male	3	2
Nationality			Cadre		
Refugee	12	3	Counsellor	0	1
Ugandan	1	1	Nurse	5	4
			Volunteer	1	0
Total	**13**	**4**	**Total**	**6**	**5**
Health-care providers	RPA 1	RPA 2	Key opinion leaders	RPA 1	RPA 2
Gender			Gender		
Female	1	0	Female	6	4
Male	13	12	Male	30	10
Cadre			Role		
Clinical Officer	4	5	Community Leaders	15	1
Doctor	0	0	Humanitarian	9	2
Nurse	7	4	Local Government	9	7
Social Worker	0	1	Ministry of Health	3	4
VHT	3	2			
Total	**14**	**12**	**Total**	**36**	**14**

Table 3. Themes generated from the data.

Rapid Participatory Appraisal 1
(a) Health systems challenges
(b) Cultural beliefs, stigma and trust
(c) Mental health
(d) Role of the community
(e) Gap in palliative care provision
Rapid Participatory Appraisal 2
(a) Health system challenges
(b) Increased provision and impact of palliative care
(c) Gap in palliative care provision
(d) Impact of training
(e) Impact on patients and families
(f) Community engagement and ownership
(g) Role of the village health teams
(h) Cultural beliefs, stigma and trust
(i) Stakeholder engagement

> *of people and that whatever is being done is being done for their benefit'. (RPA1 Humanitarian Worker 1)*

> *'Trust is part of the issue of trauma. For the south Sundanese people trauma is not a single event it has been again and again and again.' 'When trauma happens you question your belief system. For someone who is bereft they will say where is God? All the trust you have before this is broken down . . .. . .The fact that people who love us could betray us so much has big impact'. (RPA1 Community Leader 1)*

> *'These refugees, we are the same people. We have the same future we have the same destiny. When your house is on fire where do you run, you run to your neighbours. Whenever they are here they are like us and if they run for help they must get it'. (RPA1 Local Government Official 2)*

Given the significant needs for **mental health** support including those living with complex learning needs we sought out additional key stakeholders and observation visits. Services were fragmented and people either presented late or were managed through non-governmental trauma counselling services. Suicides were rising and this was a focus area for health development and coordination.

> *'With mental challenges you see people moving in the streets and children kept at home. You find them at the bore hole and people say this one is an epileptic. There is a belief that those people are bewitched and little belief that such people can be helped by treatments. They would rather take for traditional treatments. It needs a change in mind set; they don't think they should come to the health centre unlike malaria. We are Africans. It would be nice to support, identify, intervene and this overlaps with gender base violence'. (RPA1 Village Health Team Worker 1)*

Community cohesion and ownership was highly valued with importance given to recognised community leaders, especially when those communities had themselves been fractured through migration. With the Health Post 1 being embedded in the community through the village health teams this is an important way to understand the cultural richness and be a bridge to the health system.

> *'I am very glad you are using village health teams they connect health care system to refugees so they really need to come on board . . . . . . .so we are strengthening the system'. (RPA1 Humanitarian Worker 4)*

All these thematic areas had an impact on the provision of **palliative care**. Healthcare and humanitarian workers saw the critical **gap** of the need for palliative care. Where available palliative care support was greatly appreciated but with little prioritisation for planning and service delivery.

> *'Much as we want to have more of a holistic approach they are not allowing us to have that intervention. We work with a number of partners but there is no partner who has come with the idea of palliative care. They are preventative and curative. . . . . They die alone in pain, there is a critical gap. Then those who are well are taking the food, they are abandoned so they also die of malnutrition'. (RPA1 Humanitarian Worker 2)*

Rapid Participatory Appraisal 2

We were able to access significant documentation from the activities undertaken towards palliative care integration including: surveys of palliative care activity; a house-to-house needs assessment; reports from the training and community engagement interventions. These all added to the richness and detail of the themes reported which show significant impact in terms of palliative care integration.

Despite the ongoing **health system challenges** more palliative care patients were being identified and seen in the primary care clinics and there were reports of improved planning and coordination, but this was not yet firmly embedded in routine planning. A new Health Management Information System (HIMS) system was in preparation and it was anticipated this would include palliative care interventions. Clinical care pathways had improved but the need for resources to visit patients at their homes was emphasised and referral pathways for specialist care were not robust. These health system challenges were further emphasised by the **impact of COVID-19 though this also revealed some positive impact.**

> *'I feel grateful with the support, I did not know that people can visit me like you are doing, I was feeling lonely but when she visited I feel better, the morphine is helping with the pain, I feel God has answered my prayers . . .may God bless you abundantly'. (RPA 2 Patient 2)*

> *'We have incorporated Covid, in the general services, we also think the same should be for palliative care, it should also be incorporated with other services. It may be incorporated in terms of services, but only that, this is specialised care which may not be done by everybody unless one has interest'. (RPA 2 Ministry of Health official 2)*

> *'On our medical ward are so many palliative care patients with chronic illness who need to be attended to the home-based care because even here the management may not change much according to their prognosis. So, handling them at the community level would be the most appropriate plan'. (RPA2 Ministry of Health Official 3)*

> *'I am encouraged by palliative care because ever since I trained I can go and give holistic care to these patients and make them comfortable. . .you know if a patient dies in pain, it is not ok. . .even when I am not there I tell my friend to do that for patients. . .I am very interested and I love being a palliative care nurse'. (RPA2 Health Care Worker 4, HC4)*

Evidence of integration was supported by the **increased provision of palliative care.** Documentation showed that 3850 people with advanced chronic illness in the refugee and host settings had received holistic palliative care interventions by trained health care workers and the village health team. This contrasted with the neighbouring district where no training had taken place and which had no documented palliative care interventions (Supplemental Materials Figure 4).

More was also understood about the **scope and gaps for palliative care** through a house-to-house needs assessment survey undertaken during the mentorship and supervision process. 331 individuals were screened in Adjumani District for advanced chronic disease, and 182 identified as having palliative care needs who were then surveyed. Individuals reported a range of chronic conditions with unmet need identified using the Palliative Outcome Scale (Supplemental Material Figures 1 and 2).[30] High levels of psychological, social and spiritual issues were reported, with key physical symptoms including weakness, pain, poor appetite and drowsiness (Supplemental Material Figures 2 and 3).

Training had made an **impact** with a desire to develop their skills further. Knowledge and confidence improved among health care workers and village health teams across both the host and refugee communities in both identifying and caring for those with palliative care needs (Supplemental Material Figures 5 and 6). **Mentorship and supervision** visits from local, national and international experts had supported knowledge into practice and led to a request for mentorship training to be included for village health teams. Reports, observation and interviews confirmed that village health team and health care workers were working within the health cluster. This included confidence in the identification of those with palliative care needs, skill in assessing and managing symptoms as well as communicating with patients and their families. These new found competencies were much appreciated and embedded in values based attitudes with a profound sense of compassion for those neglected or marginalised and a desire to see change; a powerful demonstration of the holistic values and compassion underpinning palliative care. This was further reflected by **patients and families** who were beneficiaries of palliative care.

> *'Palliative care training helps me to handle patients with chronic illness and help them to live well, to manage their stress and to help them end in their eternity peacefully' (RPA2 Humanitarian Worker 2)*

> *'Before we didn't know about palliative care. . . but the after the training, we realised that there were patients in the homes and community who needed palliative care. So after this training, we used to go and identify those who need palliative care and we would report to the health facility'. (RPA2 Village Health Team Worker 3)*

> *'After training there should be mentorship and then it will be in the system'.*

> *(RPA2 Health Care Worker 2)*

Community engagement and ownership was profoundly impacted. Wide community sensitisation reaching over 12,000 members through community outreach events, regular slots on the very popular community radio station and local media coverage were significant in changing palliative care from something known and appreciated by a few to something appreciated and championed by many. Trained family caregivers spoke of wishing they had known about palliative care earlier as they would have cared for their loved ones differently.

> *'I think with the training I have been able to create awareness and the community is also aware that there are groups of people who move to give help to the helpless. You find there are conditions where really people have abandoned them, but when a palliative caregiver goes this person gets hope and the community gets to know'. (RPA2 Health Care Worker 1)*

The **role of the village health team** was very important in changing community attitudes; acting as a bridge into the health system. Village health team members were enthusiastic and evangelistic with one standing for and being elected to a senior political role in his community, which he attributed to his palliative care work. Interviews showed a change in attitude of the community towards those with advanced chronic illness and a desire to help the community support their own people. Consequently the understanding of **cultural** issues of importance and building trust helped address the **issues of stigma** and removed a barrier to seeking health care.

> *'The training gave me a stepping stone to sell palliative care, you know even when we go to the community we talk about palliative care, we create awareness and even when I was campaigning I would talk about palliative care, because of the knowledge I got'. (RPA2 Village Health Team Worker 3)*

Health, district and humanitarian leaders and stakeholders were engaged and enthusiastic about the progress for the integration of palliative care who expressed commitment to ongoing values-based support. The District Health Officer from Adjumani, who was a key part of the integration progress, now wanted to extend the interventions to the neighbouring district where he was elected as the new member of parliament.

> *'We have incorporated Covid, in the general services, we also think the same should be for palliative care, it should also be incorporated with other services. It may be incorporated in terms of services, but only that, this is specialised care which may not be done by everybody unless one has interest'. (RPA 2 Ministry of Health Official 2)*

Discussion

At baseline there was little integration of palliative care. Health system challenges predominated but there were also challenges in ensuring that cultural issues were incorporated, stigma addressed and trust built with communities. The gaps for palliative care overlapped with mental health, a crucial need for refugees with a history of multilayered trauma. But there was awareness of the need for palliative care integration and appreciation for the existing small service. Crucially the village health teams were trusted to act as community bridges to build ownership.

After 4 years there was considerable integration. While there were still challenges in the health system in this fragile, conflict affected setting, the palliative care interventions in training, mentorship and community sensitisation had made an impact and this resulted in more patients being identified and referred. Health care workers and villages health teams showed greater confidence to support patients and families who also narrated the impact of palliative care. Community engagement and ownership was now evident, and this was ensuring culturally appropriate care and addressing areas of stigma. This community impact alongside broad stakeholder commitment to palliative care integration as well as to extending to the neighbouring district was encouraging.

Previously reported studies in fragile settings had emphasised the need for cultural preparedness and context orientation as well as acknowledging the multidimensional needs and the challenges of developing models in humanitarian settings.[31,32]

Strengths of the study

Using consecutive Rapid Participatory Appraisals to evaluate the integration of palliative care into a fragile, conflict affected and vulnerable community in Northern Uganda enabled a wide baseline that then informed inventions that included training and community sensitisation. Little is known about integrating palliative care in the community in such settings and this wide stakeholder engagement and the deep learning afforded by interviews and direct observation is a crucial step in ensuring community and key stakeholder ownership and therefore investment in the outcomes of any intervention. This has particular relevance to the cultural issues and the unique environment where refugees from shattered communities and the more settled host population share health facilities but also live together with a marked level of mutual support. The second Rapid Participatory Appraisal was effective in evaluating progress towards palliative care integration while still showing areas for future development such as the need to extend mentorship and the ongoing gap for home-based care. Rapid Participatory Appraisal is also responsive and flexible allowing new themes to emerge and then be explored such as mental health and the impact of COVID-19. Community settings and primary care initiatives are crucial in ensuring rural populations have access to palliative care that is culturally relevant and effective. Consecutive Rapid Participatory Appraisals allowed for ongoing wide community participation and stakeholder engagement and participation as previously described[26] and in this case allowed evaluation of the integration of palliative care in a refugee situation, the first time this method has been used in this situation.

This study may have wide relevance in such settings. The interventions were co-designed for this context but also may act as a model providing there is contextualisation. In a humanitarian setting where the population is exposed to significant and repeated trauma there is a need to further understand the overlapping needs for palliative care and mental health. Care pathways remain a challenge in a fragile, conflict affected and vulnerable setting and need further study.

Rapid Participatory Appraisal allows for real time learning and in-depth exploration that is community focussed. Issues, such as the massive impact of mental health, allowed additional interviews to be collected which is a huge strength of the methodology. The time for all permissions and interviews in fragile settings with the addition of the COVID-19 pandemic meant that some interviews were conducted after the interventions had started. Using a wide stakeholder identification methodology which allows responsiveness minimises bias whilst allowing for in depth exploration. The interviewers were not involved in the delivery of palliative care but did visit on many occasions during the interventions and evaluation. This experience plus the local lead's extensive network of trusted relationships will impact the data collected but we feel mostly enhances the depth and scope of the Rapid Participatory Appraisal

Conclusion

Palliative care can be successfully integrated into the primary care setting for both host and refuge populations in fragile, conflict affected and vulnerable communities. Community engagement and participation along with training, mentorship and health cluster strengthening enabled the integration of palliative care. Serial Rapid Participatory Appraisal offers a feasible and novel approach to understanding a rural community and health system that includes refugee and host populations. The baseline appraisal has a role in shaping interventions to ensure their relevance and ownership to the community. The evaluation appraisal ensures the assessment of impact has wide community and stakeholder engagement and identifies unmet needs.

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Author contributions

ML, GP, CV, JD, PB, LG and OV contributed to the conception, design, data collection and data analysis. KH, KM and CS participated in data collection. ML, CV, LN, EN, PB and JD prepared the manuscript. All authors critically appraised and approved the final version of the manuscript, and have participated sufficiently in this work to take public responsibility for this paper.

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Research ethics

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Supplemental material

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