

Maintenance of palliative care services during the COVID-19 pandemic in the Busoga Region, Uganda

Country / Institution

Uganda
Rays of Hope Hospice Jinja
African Palliative Care Association

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Key learning points

- The COVID-19 pandemic and resulting control measures such as lockdown created a lot of worry for patients in need of palliative care. It became clear that failure to secure continuity of care exacerbates the psychological distress of patients, resulting in a negative impact on health outcomes and quality of life. For the very vulnerable patients, food represented a critical necessity needing to be provided, alongside their medical care.
- To strengthen integration and continuity of care, palliative care services should strengthen collaboration with other service providers. In our case aligning care and support plans to those developed by the Uganda Cancer Institute made it feasible to support cancer patients in care to continue with their treatment.
- Health workers were also affected by the negative consequences of the COVID-19 pandemic. It is clear from our experience that caring for health workers and showing appreciation is vitally important, boosting morale and reducing absenteeism. Support to health care staff has proved to be an important aspect of responding to a pandemic, if continued access to care is to be ensured.

Background

The African Palliative Care Association (APCA) is a membership-based non-profit pan-African organization with its Secretariat located in Kampala, Uganda. At the core of APCA's work are patients, their families, their carers and the multidisciplinary teams of health workers that deliver palliative care services. APCA works through partners to ensure that palliative care is available to all those that need it across Africa. APCA also engages directly with ministries of health, hospices and other service providers, academic institutions, national associations, civil society, cancer survivors and advocates.

Rays of Hope Hospice Jinja (RHHJ) is one of APCA's partners in Uganda and engages directly in palliative care service delivery. It is a nongovernmental organization offering holistic palliative care to patients with cancer, severe HIV/AIDS and other severe life-limiting diseases, in the Busoga Region of Uganda, with an area of 10 000 km² and a population of 3.5 million (2014 census).

This action brief describes the interventions carried out by RHHJ to mitigate some of the common challenges imposed by the COVID-19 pandemic and resulting lockdown, which affected palliative care service delivery in Busoga Region and Buikwe District. These were informed by a survey conducted during the period of the total lockdown (31 March–26 May 2020) and findings from post-lockdown surveys that examined the impact of the interventions.

Impact of COVID-19 on delivery of essential health services

The COVID-19 pandemic impacted access to essential health services in Uganda and palliative care and rehabilitation were not spared. The COVID-19 control measures in Uganda included physical distancing, restrictions of public movement and curfews, which affected access to palliative care services. Many health institutions suspended screening services, rehabilitation and community outreach programmes, and reduced patient appointments to be able to maintain adherence to physical distancing guidelines. This led to delays in patients seeking care, as well as in the provision of timely care, but also interruptions in treatment adherence, which negatively impacted outcomes of care.

In particular, travel restrictions caused reductions in home-based care visits and access to treatment at the Uganda Cancer Institute (UCI). During lockdown, out of 12 (20%) patients who had an appointment at UCI, seven (58%) managed to go, while five (42%) were unable to get there.

Additionally, loss of work and school closures due to lockdown caused a number of socio-economic challenges, such as shortages in food supplies for some.

What was the intervention or activity?

The interventions addressed five specific priorities.

1. To maintain supplies of consumables and medicines.

In anticipation of lockdown and the resulting travel restrictions, RHHJ provided all patients with two months' supply of medicines.

2. To maintain access to palliative care services.

Home visits were reduced and replaced by phone calls to the patients on their usual appointment days. The RHHJ contact line was kept open 24/7.

Travel permissions were secured for two cars which allowed RHHJ staff to conduct home visits for very ill patients who needed home care.

3. To mitigate treatment interruption for cancer patients.

UCI developed a robust plan for providing cancer care during the pandemic, although this came with some interruptions to patient appointment schedules and the suspension of some services such as screening. By providing transport to the cancer care centre, RHHJ supported cancer patients enrolled in care to continue treatment at UCI. Discharged patients were transferred home with special travel permits. However, no new patients were enrolled for treatment.

4. To address social support and basic food supply.

In the first quarter of 2020, RHHJ supported patients with monthly 3 kg rice, 2 kg beans and 1 kg sugar, as well as nutritious porridge. The number of patients/families covered were expanded over time as the Government extended lockdown until June 2020.

5. To support staff.

Personal protective equipment (PPE) was provided to a core team of staff who continued working at the clinic while the remaining staff worked from home conducting phone consultations. Staff also received some direct relief from the facility, in the form of extra food support.

How did this intervention/activity contribute to the maintenance of EHS?

1. Maintaining supplies of consumables and medicines

A total of 234 patients were reached during the week prior to lockdown. Forty-seven (77%) of the patients surveyed received extra stocks of medicine from RHHJ before lockdown began.

Of the 47 who got medication before lockdown, 22% ran out of medicines. Of these, 63% were re-supplied by RHHJ, 17% got the refills from pharmacies and 4% from health centres. This helped to mitigate treatment interruptions. However, 17% did not get the medication needed until the next scheduled visit from RHHJ.

2. Maintaining access to health services

HIV/AIDS patients got drug refills.

3. Mitigating treatment interruption for cancer patients in care

In March 2020, RHHJ supported 64 patients to get treatment from UCI. Transportation was provided for 5 out of 12 patients surveyed who had an appointment with UCI, to ensure continuity of treatment.

4. Social support and supply of basic foodstuffs

In the first quarter of 2020, RHHJ supported 119 patients with rice, beans and sugar, while 73 patients received additional nutritious porridge.

Because of the effects of the pandemic on livelihoods, RHHJ increased the number of families benefiting from social support during this time. Between April and June 2020, the numbers receiving support needed to be expanded to 145, 250 and 220 patients' families respectively, over those three months. The provision of basic food helped prevent critical cases of malnutrition among patients and their families. Additionally, patients' fear of being neglected or forgotten was mitigated, hence improving their psycho-social well-being.

5. Support to staff

Social support provided to hospice staff helped with the relief of distress associated with social support demands and allowed for continued service delivery without duress.

What were the key challenges involved? How were these challenges overcome?

Lack of access to palliative care services due to lockdown and travel restrictions was a major challenge, particularly for those patients living in remote areas. The use of mobile technology came as a solution, with consultations via mobile phone replacing in-person visits. However, not all households possessed a mobile phone.

The economic shock caused by the pandemic had serious impacts on households, with many needing additional relief beyond their medical care.

Response to the pandemic resulted in more costs for RHHJ. These included the extra costs of phone calls to support continuity of care, transport for cancer patients in care to continue with their treatment at the UCI, direct relief to some critically vulnerable households, social support for staff, and expenditure towards PPE and the need to purchase a buffer stock of medicines and supplies. These increased costs for the RHHJ programme naturally constrained available budgets.

What are the areas of support you require in the maintenance of essential health services.

As an NGO, RHHJ is working in Busoga Region to fulfil the basic human right of access to affordable health. The pandemic increased the financial needs resulting from the additional challenges presented.

COVID-19 funding needs to extend well beyond the provision of PPE and should address the enormous challenge of maintaining access to quality care for the millions of patients and their family, who would otherwise be left behind, stuck in their suffering.