

REPORT ON UCS MEMBER VISITS TO PROVIDE COVID-19 RELIEF SUPPORT



EXECUTIVE SUMMARY

The COVID -19 pandemic brought to light several existing gaps in access to health services. These were highlighted particularly at the time when the Government put in place measures to curb the spread of the virus among the population. Some of these measures though necessary directly affected the access to health services and as per this report emphasis is on cancer services. This was primarily because of the centralization of cancer services at the moment which hindered access through measures like suspension of public transport.

Uganda Cancer Society (UCS) through her members has over the years worked to mitigate these gaps and support access to cancer services. Initiatives such as patient hostels which provide accommodation to patients and their caregivers in a bid to reduce crowding of patients at the Uganda Cancer Institute who sleep around the campus are evidence to these efforts. UCS through its regular member organisation meetings came to understand that this period in particular had raised several challenges as shared by patients, caregivers and health workers and volunteers. The reduction in funding support in this period further heightened these challenges making it difficult to sustain these supportive services.

UCS in a bid to ensure continued provision of patient support initiatives made an appeal to some of her supporters who contributed funds that were used to procure personal protective equipment (sanitizers, gloves and masks), cleaning materials(liquid soap), and food stuffs (maize flour, rice and beans). As of this report the mentioned items have been distributed to 4 patient hostel organisations and 1 service provider organisation to ensure patients are supported to access cancer services during this period. This is however a drop in the ocean of the needs submitted with more resources needed to provide more support to patients.

In implementation of these visits, UCS was able to come up with key components that need to be addressed to further ensure increased access during this period. In light of these, UCS calls upon its partners and champions to come on board and support its upcoming fundraising initiatives aimed to reduce the current gaps faced by patients during this period and beyond.

INTRODUCTION

The COVID -19 pandemic came with numerous challenges globally not only on the health sector but also affecting social, economic and political aspects of any country. In the context of health, the different measures related to transportation and travel, social distancing, curfew among others have caused interruptions in access to health services including cancer services.

According to 2018 GLOBOCAN, the cancer burden is rising in Uganda with over 32,617 new cases and 21,829 deaths related to cancer. Some of the initiatives designed to reduce this burden and increase access to cancer services among the community are early diagnosis through screening, adherence to treatment, health camps and campaigns such as national day of physical activity. These have however been affected by the measures in place with healthcare institutions suspending cancer screening and outreach programs as well as revising patient appointment schedules to maintain physical distance by limiting the number of patients within the hospital campus.

Currently Uganda's cancer services access are highly centralized with majority of the diagnosis, treatment and related services being found in Kampala. Whereas there are ongoing efforts to decentralize some services including screening, this is still a work in progress with majority suspected cases still having to come to the Uganda Cancer Institute. This in turn leads to large numbers of a patients and suspected cases being seen at the facility causing overcrowding with patients and their caregivers to sleeping outside the designated wards. Cancer patients require special attention whilst undergoing treatment to improve their outcomes and prevent other challenges such as infections that maybe picked from various sources.

Civil society organisations have come in to bridge the gap and ensure increased access to cancer services and among the initiatives include the cancer patient hostels which were established to support patients. In doing this, patients are accommodated, fed, transported to and from hospitals and given other services such as counseling among others based on availability of funds. Other organisations provide services such as community screenings, home visits to patients, and awareness campaigns among other services which were interrupted.

INTERMEDIATE ACTIONS

UCS started by holding virtual meetings with members to discuss the changes resulting from the COVID-19 pandemic so as to forge a way together to support patients during this pandemic. The aspect of improved patient treatment outcomes is a combination of various aspects from consistent treatment, good nutrition, psychosocial services and other services that improve survivorship chances. It was very important therefore for patients to continue receiving and accessing services despite the current times.

In light of this, UCS reached out to some partners who were able provide immediate support towards the cause namely Union for International Cancer Control and Uganda Cancer Trust UK in addition to funds from Cancer Sukuma Dance. UCS has been able to purchase and avail Hand sanitizer, liquid soap, facemasks, medical gloves and assorted food items to 5 organisations as is indicated in this report.

CANCER CHARITY FOUNDATION

The Cancer Charity Foundation is a non-profit making organization located in Bukoto Kampala serving as a center for hope to all cancer patients in Uganda. The aim for which this foundation was established was to contribute towards patient support through availing comprehensive care, cancer awareness, coordinating patient relief, and palliative care services.

Established in 2008, the Organisation was the first patient hostel offering accommodation to male cancer patients in Uganda. This organisation provides accommodation services free of charge through their Haven Patient Hostel.

Among the challenges established on site was the issue of reduction in funding which impacted on the support they are able to provide towards the patients residing here. This also reduced the funds that supported running costs and as a result we found that their van was down and that patients had to walk to the hospital unlike before when this was moving them to and fro. Furthermore there was a reduction in goodwill which previously supported aspects like food and other consumables used within the hostel.

The Patients within shared their experience of COVID-19 with one prostrate cancer patient sharing the challenges he faced trying to get back to the city for treatment. This gentleman has been abandoned by family save for a nephew who is his caretaker. He thus has limited finances and appreciates how much help the hostel provides in making it easy for him to sleep in a safe clean place, have regular meals and access his treatment at the hospital which is closer than if he were to come from his home. He called upon us to share the voices of the patients some of whom barely had funds to even buy medicines that were unavailable at the hospital.



Figure 1 L-R: Some of the Patients and Caregivers receive donated items, UCS ED interacting with one of the Patients at CCF



Figure2 L-R Patients wearing some of the donated masks, Gloves donated to support patient handling at CCF

PATIENT RELIEF MISSION

Patient Relief Mission provides social, holistic and physical support to communities in need through improving cancer care and management for female patients and their caregivers by providing hostel accommodation to those who come from rural areas in order to receive their treatment from the Uganda Cancer Institute at Mulago Hospital. PRM provides three meals a day, transportation to and from the hospital, psycho-social support, and skills training for both patients and care-givers.

Among the challenges established on this visit was the issue of transportation for some of their patients who found the new costs too high for them. Currently public transport costs are double and in other cases higher due to the limitation in number of persons allowed passenger carrying vehicle. Some of their patients are from very poor backgrounds and this increase has limited their ability to return. Furthermore there was the issue of restrictions on admitting new patients due to COVID-19 pandemic which

has resulted in some of the patients who would otherwise benefit from this staying on verandahs of the hospital.



Figure 3 L-R: UCS ED hands over assorted items to PRM, A cancer patient displays one of the donated items

■ RAYS OF HOPE HOSPICE JINJA

Rays of Hope Hospice Jinja (RHHJ) was founded in August 2005 to provide palliative care to patients with life-threatening/life-limiting illnesses, mainly cancer and HIV/AIDS. RHHJ treats and care for more than 430 patients in nine districts of Busoga Region across an area of 10,000 km² and a population of 3.5 million people. RHHJ exists to provide holistic care to patients and their families.

Among the challenges shared, the team informed us of the challenges their patients were facing returning to Kampala where the cancer services are mainly availed at the Uganda Cancer Society. A story of one cervical cancer patient in extreme pain sitting on a motorcycle to travel to Kampala for over 90km and reaching in worse condition given the means of transport was evidence of this challenge. Further still patients they worked with are very poor and some had their family members lose jobs during this period which made it hard to come by simple things like a daily meal. RHHJ is therefore faced with a need to support these patients with some materials like soap and food over and beyond the services rendered. The need for service decentralization was made evident to ensure patients can easily access services and further still subsidization of costs associated

with tests and medicines for palliative care. Finally, the absence of an enabling policy environment has hampered palliative care services in their areas of operation which include, Busoga and parts of Bukedi and Buganda sub regions.



Figure 4 RHHJ team share with UCS team on challenges during the period, UCS hands over items to RHHJ staff members

KAWEMPE HOME CARE

Kawempe Home Care opened the New Hope Children's hostel in 2016, to provide children who are diagnosed with cancer access to specialist care and a secure and safe home environment whilst they undergo their treatment at Uganda Cancer Institute. The New Hope Children's hostel has capacity to accommodate 30 children and their caregivers at any given time. They are provided with accommodation, meals, counseling, nursing care, legal aid, educational play sessions and daily transport to and from UCI so that the children can access their treatment.

KHC shared the challenges they were facing during this period and among these was the reduction in unsolicited donations which

used to support day to day running aspects such as feeding and fueling. Currently the organisation has to find budget lines to manage these costs which have raised the operating costs. They also mentioned the challenges some of their patients faced in regard to paying for some of their treatment. Previously they were able to get waivers for some of these patients but current times required some level of contribution which some could not afford completely. They requested for support to ensure patients are enabled to travel back from their homes so that they do not miss their appointments. It is important to note that UCS processed car stickers from the Ministry of Health to help all the organisations including KHC in moving patients during the lockdown period.



Figure 5 L-R: Handover of assorted items at KHC, Children at the hostel look on from a distance at the donations



Figure 6 L-R: UCS and KHC teams discuss the status of services and challenges faced, Head of Medical Services at KHC tries on a mask

BLESS A CHILD FOUNDATION

Bless a Child Foundation is a non-profit organization that provides care support services to children from the ages of 0–12 years suffering from cancer and related infections. Established in March 2007, Bless a Child Foundation was founded as a result of a realized need that pediatric cancer patients in Uganda had inadequate access to medical care and support. In addition Bless a Child Foundation provides extra services to ensure pediatric patients under their care continue to the extent possible to live normal lives including making certain that they receive educational services, games and entertainment while undergoing treatment.

At our visit they mentioned the reduction in number of people receiving their services with some children failing to return to Kampala to continue their treatment. There was a slight change in partners of funding with some supporters dropping off but appreciated those that came through during this period. They emphasized the need to continuously ensure access to cancer services mentioning a scenario of two children who had passed away during the COVID-19 lockdown due to failed access to cancer services enhanced by the restrictions that were in place at that time.



Figure 7 T-B: UCS teams interact with Patients currently residing at the hostel, Children at the hostel engage in games as part of their psychosocial program.



Figure 8 L-R: BCF child beneficiaries receive the assorted items from UCS ED, BCF staff member leads in tour of the premises



CRITICAL STEPS

Going forward, UCS needs to continue to address the following aspects given the uncertainties that lie ahead regarding the COVID-19 PANDEMIC.

- There is need to support transportation of patients so as to access cancer treatment services currently mainly found in Kampala. UCS needs to find means to work with public transportation service providers to subsidize these costs or work out a cost sharing plan so that no patient fails to travel to and from the treatment centre.
- There is need to raise resources to support provision of Personal Protective Equipment and food stuffs across this period. This is because currently a number of organisations have reduced funding and support yet these are essential to them supporting cancer patients.
- There is need to find new and innovative ways to avail psychosocial services amidst the current pandemic to patients such as counseling, patient support groups, provision of breast prosthesis among others.
- There is need to provide training on use of PPEs and general protection against COVID-19 for members working in communities or directly with patients. This is important given that the pandemic is still ongoing and yet patients still need support
- There is need to showcase the plight of cancer patients during the pandemic and beyond. As it is the issue of decentralizing cancer services is very important in increasing access to cancer services. UCS therefore needs to take on advocacy efforts towards aspects like adopting the National Cancer Control Plan and cancer services decentralization to at least regional level.

CONCLUSION

UCS appreciates the support given by its partners who have contributed to the funds to ensure the continued operations of organisations in cancer control. As seen above the challenges remain numerous but with collaborative efforts, a lot can be done to ensure no patient fails to access cancer services and hence improve chances of survivorship. UCS will run a fundraising campaign to enable it raise more resources to implement the critical steps needed during this period and beyond. We therefore look forward to continued partnerships and call upon cancer control champions to support the initiatives ahead and help reduce the current gaps for greater results.

