



# Quarterly Report Apr - Jul 2020

Rays of Hope Hospice Jinja



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# Executive Summary

Rays of Hope Hospice Jinja has a mission and a commitment to provide palliative care to all palliative care patients in the Busoga Region. With an ultimate goal of making the patients as comfortable as possible, we have developed our focus on holistic care for total pain and distress relief.

Our core patients' care work in quarter two was adversely affected by the COVID-19 pandemic and its consequential restrictions. The pandemic restrictions came with lots of challenges in the delivery of palliative care services. We have seen a serious deterioration of both the health and the social status of our patients. The inadequate food, the difficulty of getting essential medicines from health centres (especially AIDS medicines), and the difficulty of accessing essential treatment from the Uganda Cancer Institute and elsewhere have caused tremendous suffering to patients and their families. Facing these challenges, the RHHJ team rose to the occasion – adjustments were made, and new strategies were adopted to ensure that our patients and their families received the much-needed care. Indeed, we made sure to keep close with our patients during this time, with the goal of forgetting none and leaving none behind.

Our team reached patients through phone calls and obtained travel passes for home-based care for the patients that were in critical condition. The Psychosocial Department's teams took to tele-counselling the patients in order to keep the patients' hopes high and to let them know that they were not alone and that we cared for them.

In spite of these very challenging conditions, we were able to reach 691 patients and their families. We owe all these great achievements to our very committed staff and wonderful donors.

I welcome you to enjoy reading our progress during this second quarter of 2020, we are very grateful for your support and we hope to further deepen our collaboration so as to help us reach as many as we can reach in the Busoga Region and beyond.

RAYS OF HOPE HOSPICE JINJA STAFF AND MANAGEMENT

## Background

Rays of Hope Hospice Jinja (RHHJ) cares for patients with life-limiting/life-threatening illnesses through pain relief and symptom management. RHHJ's approach to care is patient-focused, where holistic care is offered to make the patient as comfortable as possible; relieving physical and social distresses of patients and their families. Family is at the front of patient-care and RHHJ plays the role of training the main caregivers and giving guidance to the family as much as possible. Locally-based community volunteers are part of the care network, helping to find patients and follow up with them to ensure that they are pain and distress free. RHHJ has clinical care as the core service offered to patients and their families. Psychosocial support services have also been embraced to ensure that patients' social, economic and spiritual distresses are also relieved as much as possible. The administration and management support services enable patients to be able to receive all the help they need when they need it from the team of Rays of Hope Hospice Jinja.

## Clinical Palliative Care of Patients and their Families

The clinical activities of this second quarter of 2020 were adversely affected by the COVID-19 pandemic and its related movement and socialization restrictions. In order to make sure to reach all patients in spite of the travel restrictions, we reduced the number of visits per client to one per month. The lock-down seriously affected patients' access to treatment especially those living with HIV/AIDS who had difficulty accessing their ART therapy. Those referred to the Cancer Institute also suffered travel challenges thus, receiving treatment late or missing treatment.

The total number of active patients at the beginning of the quarter were 616 and by the end of the quarter we had cared for a total of 691 patients: 54.8 % cancer, 21.3 % HIV/AIDS, 6.6% Ca/HIV and 17.1% others illnesses. Holistic care has continuously been embraced as an important component to achieve total pain and symptom control for patients and their families. Patients care is primarily done by the families, and so families are trained to give physical, psychosocial, spiritual and financial support where possible to patients. Our main goal is to keep our patients as comfortable as possible, despite their illnesses. Efficiency and quality of care is paramount to reaching the patients early enough and to prevent as much distress and suffering of the patients and their families as possible. Rays of Hope Hospice Jinja adopted new strategies to cope with the COVID-19 pandemic and its related restrictions. The care of patients throughout this quarter has been carried out differently as compared to our normal routine of two weekly visits in order to minimize exposure of the virus to communities and staff. Most patients were seen once a month and telephone contacts were used for very stable patients.

<b>Patient Numbers April – June 2020:</b>			
	<b>April</b>	<b>May</b>	<b>June</b>
<b>Active patients:</b>	584	570	565
<b>New patients enrolled in RHHJ Programme:</b>	11	15	49
<b>Contacts made with patients:</b>	737	290	520
<b>Patients consulted and referred to other health providers:</b>	10	41	21
<b>Deaths reported:</b>	30	26	31

## Treatment Support

Clinical care to patients and their families has continuously embraced treatment support for curative and palliative purposes. Treatment support was premised on the fact that many of the patients enrolled had illnesses that needed further management but they were unable to do so due to financial, bureaucratic or inaccessible services. The treatment is palliative or curative with an aim of improving the quality of life of patients, and includes chemotherapy, radiotherapy and surgeries accessed from the Uganda Cancer Institute. 49 patients were supported this quarter, 11 were newly enrolled on the program and 38 were continuing patients from past quarter. Treatment support was extended to 80% cancer, 6% Ca/HIV and 14.6% other illnesses. As the majority of these patients are already economically constrained, RHHJ provides transport, upkeep and meets all bills in relation to investigations and treatment.



### Ronald's Story

Ronald, who is a 33 year old married man and father of four, started seeing itchy skin swellings on his feet in 2013. His efforts to find appropriate treatment in the nearby local health centre did not yield much. Instead the skin on his feet was becoming hard and affecting his ankle joint movement. Limited by a lack of resources, Ronald was not able to get a diagnosis or even the right treatment for his illness.

In November 2018, Ronald was enrolled for pain and symptom management on the Rays of Hope Hospice Jinja Program. Ronald was also referred to the Uganda Cancer Institute for diagnostic tests and investigations. A biopsy confirmed Endemic Kaposi's Sarcoma and with support from RHHJ, Ronald received 6 cycles of chemotherapy in 2019. Now in 2020, Ronald's lesions are completely healed and the mobility of his feet was restored. He is now able to work in his sugarcane plantation to support himself and his family.



## Psychosocial Care of Patients and their Families

The majority of our patients have used most of their resources in search for cure for their conditions by the time we find them. Ours being a rural-based programme, our patients are among the extreme poor. They are then faced with a lack of their basic essentials like food, shelter and income and so, when we find them they are often living in very distressing conditions. To offer all-round care, the RHHJ Programme responds by offering counselling and provision of the basic needs for our patients and their families. Various psychosocial support activities were carried out in the 2nd quarter 2020, which included: counselling, day cares, house construction and renovations, purchase and distribution of patients' food, distribution of bedding, income generating support, bereavement support, distribution of wheelchairs, school fee payment for orphaned or sick children and school visitations/ monitoring.

### Food Support and Comfort Fund



Food is the first medication in managing patients' distress and suffering. Most of our patients are very sick and have very weak immune systems, and no food to help strengthen them and improve their immunity. Our food support and comfort fund facilitation helps to improve the quality of life of patients and their families. Rays of Hope Hospice Jinja provides a monthly basket of food that includes: 1kg of sugar, 3kgs of rice, 2kgs of beans and a

bar of soap to the very needy families for nutritional and sanitation purposes. During this lock-down period, due to the COVID-19 pandemic, many of the patients and their families were unable to afford to feed their households. This quarter saw an increase in food support and 145, 250 & 220 patients and their families received food baskets in April, May and June 2020 respectively. The food support is primarily to boost patients' immunity and enable patients adhere to medication especially those on HIV/AIDS therapy. Patients who need financial support are helped to be able to make purchases of what they need or finance their travels to pick up medication. 58, 85 and 88 patients were supported with UGX 10,000/= (USD 3) each in the months of April, May and June 2020, respectively.



## Food Support During COVID-19 Lock-down

Our dedicated social workers went to the field to deliver much needed food parcels to some of our most needy patients in light of the COVID-19 pandemic and the ensuing lock-down restrictions, which have made many people extremely desperate for even their most basic essentials. Our team was very touched by all of the patients, but one family in particular really highlighted how dire the situation is for some people, and just how important the work we do is – both the clinical palliative care and the social support we provide.

We supported this family when their father was enrolled in our programme for palliative care as he had advanced HIV/AIDS. His three children were enrolled in our School Fee Programme and unfortunately, their father passed away due to his illness leaving his wife and children behind. This family was left in a very bad situation when the lock-down hit – the children's' mother and grandmother had left to go to a different village for the burial of someone close to them, leaving her children behind at their home when the lock-down restrictions were put into place. This means that these three children have been left completely alone while their mother and grandmother are stuck in a village far away from them with no way to get back since March!

The children are too young to get 'real' jobs to take care of themselves, so they have been relying on the support of well-wishers in their village for food (many of whom are struggling to feed themselves at the moment). The children have also been trying to do small jobs in return for a meal. When the team got to their house and asked them what they were eating, they brought out a jackfruit that had been cut in half and said that they would share half that day, and keep the other half for the next day just so that they'd have something to eat! This situation is exactly why we need, and are so grateful for, the tremendous support from all of our donors, near and far.



This family is so poor, even with the mother's help, that they do not even have mattresses or bedding to sleep on. Our team was able to leave 10kg of Posho (maize flour), 5kgs of beans, 1kg of sugar and a bar of soap for each of these poor stranded children so that they have something to eat until their mother can get back to them. The eldest boy was so grateful that he couldn't help but kneel in the mud, left after heavy rains in the area, in thanks for the support. THANK YOU as always to everyone who supports us and allows us to continue this incredibly important work.



## Wheelchairs and Crutches



Many of our patients are bedridden after losing their ability to walk and move around freely due to their illnesses. This leaves them confined to their beds or houses as they have no way of leaving. Rays of Hope Hospice supports our patients with mobility challenges with: walkers, walking crutches and wheelchairs to enable them to move in and out of the house and within the neighborhood. This also has a positive effect on their main caretakers who could then rest or



engage in other activities since they don't have to care for the patients full time. In this second quarter of 2020, one patient received a wheelchair and one received a pair of crutches to aid their movements in and out of the house.

## School Fee Programme



Due to COVID 19 and its effects, the schools were closed and this means that all the students have had to sit at home for months. Therefore, the RHHJ team decided to visit the students on our School Fee Support Programme at their homes. During such visits, children were counselled and provided with government availed self-study materials. Due to the poverty of the children and their families who are on the School Fee Programme, we decided to provide them with



food support which included 10kgs of maize flour, 5kgs of beans, 1kg of sugar for nutritional purposes and a bar of soap to keep the children and their families clean. Furthermore, some of our children were given bedding which included: a mattress, a blanket and a pair of bed sheets especially those sleeping in very poor conditions. The support is aimed at ensuring that those children stay safe and comfortable during the lock-down. The teenage girls were provided with re-usable sanitary towels and they were counselled to encourage them to avoid risky behaviour.

## Counselling

Most of our terminally ill patients and their families are in a lot of distress when we find them, due to a multitude of reasons; the fear of losing their loved ones, the pain they endure, poverty as a result of their resources being depleted due to the illness among many others. We have routine counselling of all the patients on our programme and specially planned counselling for the patients with complex psychological challenges. This quarter, routine and special counselling were adversely affected by the COVID-19 pandemic and the lock-down. Patients who could not be reached physically were counselled through telephone calls. Even with the many challenges of getting to our patients, we managed to reach and counsel 106 patients and their families on different matters and aspects of life; spiritual counselling, emotional counselling, pre-bereavement, and bereavement counselling. We even managed to reach and bereave twenty one families with a financial gift of UGX 10,000/= (USD 3) as condolence to families of deceased patients.



Internal team bereavement of our deceased patients was done in this month of June. This was done to enable the staff of Rays of Hope Hospice Jinja to emotionally release the pain of losing patients that they have bonded with as they reach out to them with the routine care. This was the first one of its kind and we hope to hold one every month.

## Bedding

Some of the patients enrolled are too poor even to afford decent bedding and so many of them sleep either on the floor or on papyrus mats which decreases patients' quality of life. We try to make our patients as comfortable as possible and so the provision of bedding helps the patients sleep better and keep warm. A set of bedding includes one mattress, a blanket, a pair of sheets, a makintosh mattress cover and reusable diapers for incontinent



patients and clothes are given to patients and their families. In this quarter, 8 mattresses, 8 pairs of bed sheets and 8 blankets were given out as way of keeping patients comfortable and warm thus improving their living conditions. A couple of households were given clothes as they had none that were decent. For incontinent patients, 6 received reusable diapers which enabled them to keep warm and dry.





# Operations, Administration and Management

## Human Resources

RHHJ boasts of a 26 member (22 contract and 4 volunteers) team that is so committed to patients care work and delivering on the organizations' annual commitments. The team was also affected by the COVID-19 related restrictions and lock-down but we were able to pick up and drop off staff for duty every day and work within the daily curfew hours. Observing the standard operating procedures to minimize exposure and the spread of COVID-19, staff used masks, moved with personal sanitizers and guarded themselves with hand gloves while on duty.

## Vehicles and Logistics

Rays of Hope Hospice Jinja owns 4 vehicles - three are strong for daily use and one old vehicle is on standby. The vehicles are maintained in good running conditions for the safety of the staff and efficiency of the patient care services. The fuel to run the vehicles is available thanks to the generous donors. We had a rise in the fuel and mechanical repair costs because of the increasing movements to the different outreaches. Shorter working hours of the day due to curfew, daily return journeys from very distant parts of the region and picking up/dropping off staff explain the surge in fuel costs.

## Management

Board sessions, staff meetings, departmental meetings and team building activities are very important component of the efficiency at RHHJ. We ensured that we kept the practice of meeting as a team through conference calls in April and physical meeting in May. Management and board meetings also happened in the quarter. Meetings help us to reflect on what has been done and assess both successes and challenges with regards to efficiency and effectiveness of our patient care services.

## Challenges

We never could have planned for nor expected the trying and challenging times created by the COVID-19 Pandemic. The organization had to adapt to the new standard operating procedures in order to minimize infections. We were especially worried for our already immune compromised patients and also for the staff that we depend on to deliver our services to patients. We have had to put many activities on hold as they would contradict the guidelines for COVID-19 infection control. Activities affected include: all trainings, cervical cancer screening activities, sleep-over for patients care among many others. We are now thinking of new strategies that will enable us to adjust and work within the guidelines and still carry on such activities. The patients and their families have become more distressed due to inadequate health care services, social services and closed markets. The lack of food and difficulty accessing treatment/medicines add to the patients' distress. The costs of our programme have increased which is explained by the fuel increase, more costs for those accessing treatment in Uganda Cancer Institute and more patients added onto food and comfort fund support.

## Finance Report

Expenditure in April, May June:		
Core Mission Support	Ugandan Shilling (UGX)	United States Dollar (USD)
Clinical Care	65,660,814	17,989
Psychosocial Support	29,046,286	7,958
Programme Transport	27,442,142	7,518
Capacity Building	8,690,500	2,381
<b>Total Core Mission Support</b>	<b>130,839,742</b>	<b>35,847</b>
Programme Support	6,589,359	1,805
Capital Support	140,000	80
Administration	23,707,629	6,495
<b>Total Quarter Expenses</b>	<b>161,276,230</b>	<b>44,227</b>

## Appreciation and Commendations

We are so grateful to our very committed staff and volunteers. They worked so hard amidst the fears of the COVID-19 spread and the very harsh restrictions.

We are very thankful to our committed development partners and donors who have stood with us to deliver palliative care services to the needy patients and their families. Without the funding support, all our plans and aspirations would never be achieved.

