

PALLIATIVE CARE DURING THE COVID-19 PANDEMIC AND TOTAL LOCK-DOWN IN THE BUSOGA REGION

31 MARCH – 26 MAY, 2020

Description of interventions carried out by Rays of Hope Hospice Jinja, evaluation of impact with lessons learned and issues to be addressed.



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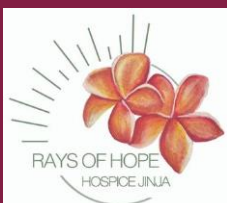
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Introduction

The COVID-19 pandemic has changed the world we are living in, and it will undoubtedly continue to affect us in more ways than we can imagine. The virus itself has taken too many lives, but in the low-income countries the many restrictions have possibly taken even more, and the consequential economic down-fall continues to have serious consequences for all and - in particular - the poor.

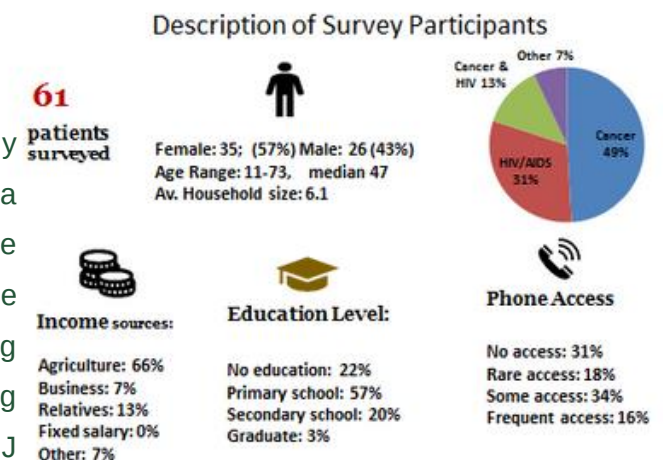
The first COVID-19 case was diagnosed in Uganda on the 21st March 2020, and the country went into strict lock-down from the 31st March. Markets, places of worship and schools were closed, and a curfew was introduced. Of the many restrictions, the prohibitions of both public and private transport had the most serious consequences and were detrimental to Rays of Hope Hospice Jinja's work where we treat our patients where they are – at home or very close to where they live.

In the face of this new situation, Rays of Hope Hospice Jinja adopted new strategies and made adjustments to ensure that patients and their families continued to receive the care they needed. In expectation of COVID-19 spreading to Uganda and restrictions being imposed, RHHJ had already purchased a 3-month stock of medicines as well as a big supply of gloves, masks, and hand sanitizers for the staff and volunteers in the field in mid-March. In addition all activities involving crowds such as: health worker education, community health education and cervical cancer screening were cancelled.

Overall protection of our staff, volunteers and patients was central, and for the continuing care of our patients our priorities were to ensure:

- 1) Sufficient medicines
- 2) Uninterrupted cancer treatment with the Uganda Cancer Institute
- 3) Basic food supply
- 4) Continuing contact with patient and families

This report describes the interventions carried out by the RHHJ team for the 610 patients from the Busoga Region and Buikwe District during the period of the total lock-down (31st March to 26th May 2020). We shall also present the results of a survey involving 10% of our patients, which was carried out following the lock-down, to evaluate impact of the RHHJ Interventions. The survey findings will provide a guide to RHHJ - and possibly other partners – in planning for the continuation of support during the COVID pandemic and for future crises.



Interventions, Implementation and Evaluation during the COVID-19 Lock-Down

1. *Securing medicine supply during lock-down*

Interventions:

The first COVID-19 case was officially diagnosed in Uganda on the 21st March 2020. Worried that travel limitations may soon be implemented, the RHHJ team made a huge effort to reach all our most needy clients with two months' supply of drugs. The patients on morphine were our first priority. We also provided a monthly food support to 100 patients and their families. A total of 234 patients were reached during the week prior to the lock-down. After the total travel ban was implemented on the 31st March, the RHHJ team then continued with phone consultations with clients on their usual designated visit day. When travel permits for two cars were secured, home visits with medicines were done for those in pain or with other severe conditions.

Evaluation results from survey:

A total of 47 (77%) of patients surveyed received extra stocks of medicine from RHHJ before the lock-down. Of the 47 who got medication, 22% ran out of medicines. 63% of those whose medicine ran out were re-supplied by RHHJ, 17% got medicine from drug stores and 4% from health centres. 17% did not get until the next scheduled visit from RHHJ.

Lessons learned and Issues to be addressed:

Providing 2 month's supply of medicines was very helpful. However, our patients are sick and their symptoms and needs keep changing. It was very important that RHHJ got travel permits to visit the most sick and those with extra needs. However, it needs to be noted that those who did not get extra stocks of medicine were from the peripheral, far districts of Busoga Region. A lack of sufficient transport was a major obstacle for reaching everyone.



2. Ensuring uninterrupted treatment with Uganda Cancer Institute

Interventions:

During the first quarter of 2020, RHHJ supported 64 patients to get treatment from Uganda Cancer Institute (UCI). When the travel ban and curfew started on the 31st March 2020, RHHJ managed to collect all of our clients who were stuck at Mulago, after completing their treatment but with no transport to get home, with the help of Transport for Uganda Sick Children (TUSC). In the face of the pandemic spreading and the travel ban, RHHJ decided not to enroll new clients during the lock-down. Throughout the lock-down UCI, thankfully, continued its services and in the second quarter, during the lock-down, RHHJ supported 49 patients to get treatment from UCI. The lockdown travel restrictions placed such limitations on us that we were, unfortunately, not able to support those who had appointments for investigations.



Evaluation results from survey:

During the lock-down 12 (20%) of the patients surveyed had an appointment with UCI. Seven (58%) managed to go, and 5 (42%) did not go. The big obstacle for access of treatment at UCI was transport, RHHJ provided transport for five patients who managed to go to their appointments, one patient went with the help of family and friends and one patient went with the help of RHHJ, family and friends and the district government. All those who did not go for their appointments indicated that they were very worried by missing the appointment.



Lessons learned and issues to be addressed:

All five interviewed patients, who DID NOT go for treatment came from the peripheral far away districts. RHHJ secured transport for 6 out of 7 of those who managed to go. Treatment services for cancer are all located in Kampala and securing transport for poor patients is an essential part of the treatment package.

3. Food Support for Patients and their Families

Interventions:

Food is the first medicine. The patients RHHJ works with are very poor and it was a priority for us to ensure that at least a basic amount of food was given to our most needy clients. In the first quarter of 2020 the usual RHHJ monthly food support programme of 3 kg rice, 2 kg beans and 1 kg sugar, which benefits 119 patients with 73 patients receiving additional, nutritious porridge was given out. Being aware of the lock-down's challenges of possibly less income and more mouths to feed, the RHHJ Food Support Programme was expanded to include: 145, 250 and 220 families respectively per month of the lock-down (April- June).



Evaluation results from survey:

Forty five percent of the clients surveyed had less food available during the lock-down. The main causes being: less money, increase in food costs, more people in the household and bad weather with little garden produce. Food support reached 75% of patients surveyed. Food was provided, by RHHJ, to all but one of these, 9% got support from Church/Mosque; Gov/LC1 and relatives provided for 6.5% each. 93% indicated that the food had helped a lot. Twenty nine (48%) of all surveyed patients had days where they went to bed hungry. 21 (46%) of the 46 people who DID get food indicated that they went to bed hungry and half of those who DID NOT get food also went to bed hungry.

Lessons learned and Issues to be addressed:

Food is the first medicine and an essential part of treatment. It is also a human right. The food support given by RHHJ was very much appreciated; however, it was not enough. Whether or not the patients received food, still half of the patients had days where they went to bed hungry. The 15 (25%) who DID NOT receive food came from the more distant districts of the Busoga Region.

The food from the government COVID task force did not reach our patients. As we are working on the front line with many of the most poor and needy, RHHJ needs to be included in the distribution of government food. Some of the food RHHJ distributed was food donations from local church groups trusting RHHJ with fair distributions. Emergency donations from donors were essential to increase the amount of food distributed.

4. *Keeping In Contact with the Patients and Their Families*

Interventions:

When the travel ban started on the 31st March 2020, home visits were substituted by phone calls to the patients on their usual appointment days. The contact phone number for RHHJ was also kept open for patients or families to call in. As RHHJ managed to get permission for two cars to drive out on home visits, home visits were conducted to the neediest patients. A total of 1,027 patient contacts were made during the lock-down period – 58% being by phone and the remaining were home visits

Evaluation results from survey:

Only 16% have access to a usually working phone (i.e. airtime and charged) on their compound, 34% sometimes have a working phone, 18% rarely have one, and 31% don't have a phone on their compound.

52% of patients received a phone call from RHHJ and 32% called RHHJ. Of the 35 (57%) patients who received and/or called RHHJ 32 (91%) indicated it helped very much; 3 (9%) indicated it helped 'a little'. Asked whether the patient wanted some home visits replaced by phone calls, an overwhelming 89% indicated that they DID NOT want phone calls instead of home visits.

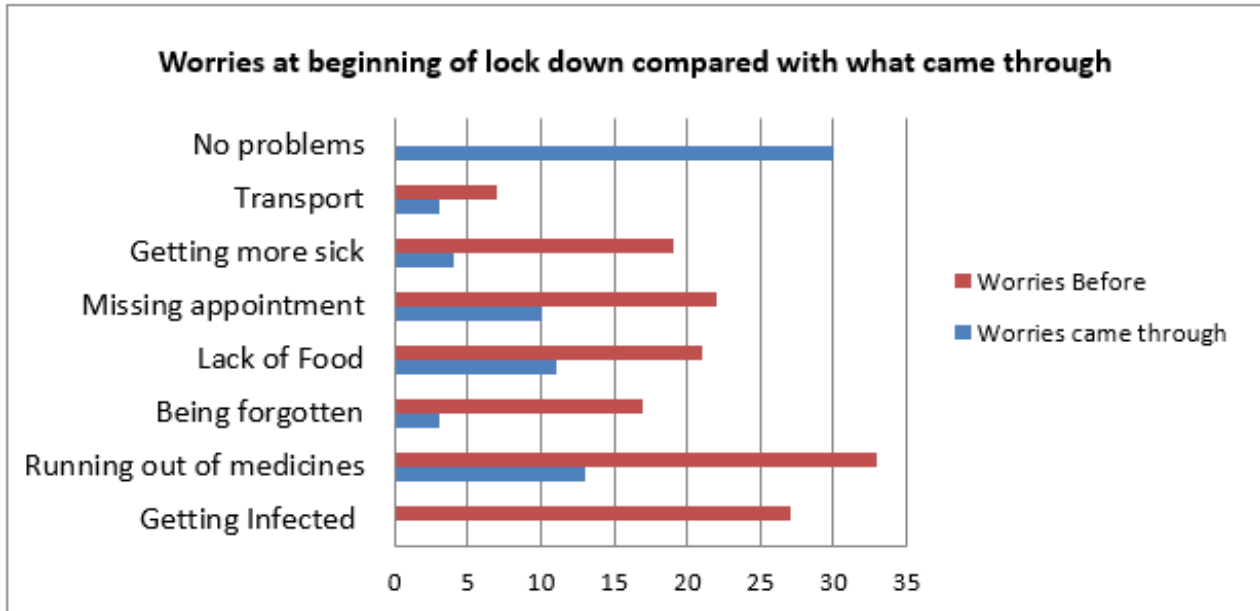
Lessons learned and Issues to be addressed:

The option of home visits by phone worked well for those who were reached. Our patient population has limited access to phones which is a challenge as not all can be reached, and many are only reached after having tried many times, or involving neighbours or volunteers in the area. Phone calls are not an alternative to home visits.



Summary

As RHHJ faced the challenges of the COVID-19 lock-down it was our goal to continue providing essential services for our patients and keep them physically and mentally as comfortable as possible.



Summary evaluation results from survey:

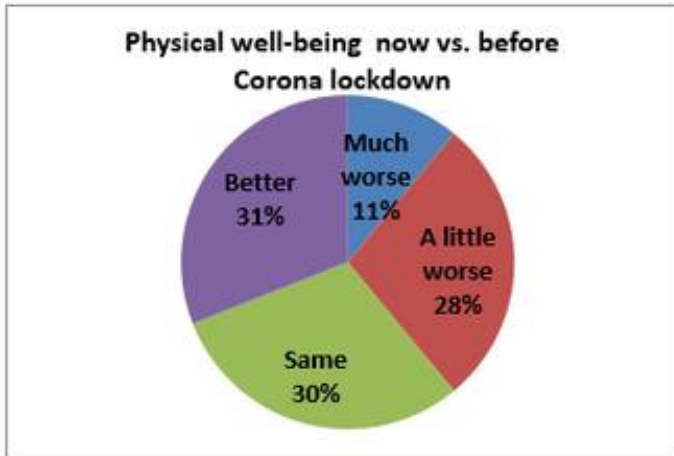
When asked what worries the patients had when the lock-down started, a total 146 worries were listed, compared with 41 worries which actually came true:

NB: for 30 (49%) of all survey participants none of the expected worries came true.

Lessons learned and Issues to be addressed:

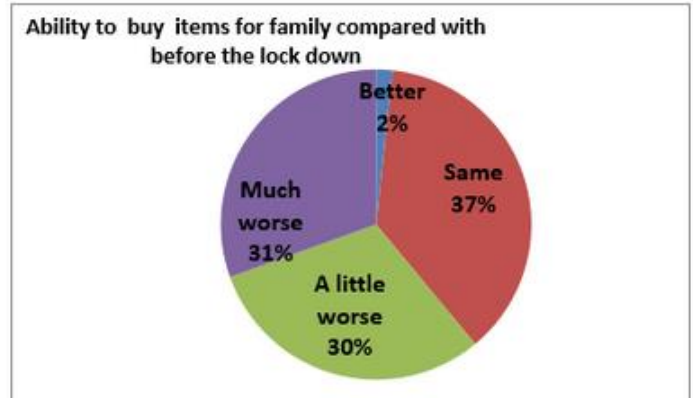
The COVID-19 pandemic reaching Uganda and the many lock-down restrictions put in place were very worrying for the RHHJ patients. They are not only challenged by their disease but also their socio-economic status. It is very positive that half of the patients did not have their worries come true. This may reflect on the interventions which RHHJ put in place, but it certainly also reflects the extreme tolerance to hardship our patients have.

Overall the provision of medicine, food and social support was important, and has undoubtedly helped the patients. Many were afraid of being forgotten, but thankfully only few felt they were. RHHJ sees itself as a friend, and we try very hard not to fail this relationship. Transport and the worries related to transport, such as missing appointments remains a huge problem. Our chief driver expressed it perfectly at our recent staff meeting: "I wish to say that transport in a rural palliative care programme should be available like morphine".



Overall it seems that the patients have gone through the lock-down fairly well physically considering the nature of a palliative care programme: 61% feel stronger or the same, 17 (28%) feel a little worse and 7 (11%) feel much worse.

The ability to buy any item for family compared with before the lock-down has unfortunately gone down with 61% having less or much less money at hand.



Rays of Hope Hospice Jinja is grateful our patients have had less worries coming true than they had feared prior to the COVID-19 lock-down. It is, however, a deep concern that our patients - the majority of whom are already very poor - have sunken down into even deeper poverty. This compares unfortunately with the socio-economic effect of the pandemic from all over the world.

‘Poor people in all parts of the world live and die with little or no palliative care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity.’

This statement in the Lancet Commission Report “Alleviating the access abyss to palliative care” (October, 2017) describes all too well the situation for our patients in the Busoga Region. Lack of access to health services, diagnosis and treatment is the central problem we are facing at Rays of Hope Hospice Jinja. It was there before the lock-down, and during the lock-down it was exacerbated. It is our challenge to use the situation now where this lack of access has become glaringly obvious to join hands across civil society, government and donors. Together we must find ways to decrease the abyss of extreme suffering, poverty and inequity that we see around us.

Rays of Hope Hospice Jinja wants to thank each and everyone for the helping hand they have reached out to us and our patients during the COVID-19 lock-down.

Let us continue and further expand our work together. May God bless you.