Supportive care for oral cancer survivors in COVID-19 lockdown

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Abstract
Objective: Availability and accessibility to routine health care services for cancer patients were a cause of concern during the COVID-19 pandemic, which induced stringent enforcement of lockdown and social distancing in Sri Lanka. Oral cancer patients who have undergone surgery recently encountered problems such as pain, difficulty in swallowing. However, accessing routine treatment and obtaining medication emerged as the most pressing concerns among them. Therefore, we aimed to provide supportive care for affected oral cancer patients.

Methods: A rapid situational analysis was conducted among 25-randomly selected oral cancer patients of an ongoing interventional study aimed at improving life situation of oral cancer patients.

Results: Over-the-phone supportive care tailored to the needs of oral cancer patients, provided by a health professional, deemed a simple but helpful intervention.

Conclusions: Facilitating patients to navigate the health care system to ensure that they can continue in receiving timely treatment was the most critical aspect of the intervention. Interventions tailored to patients’ needs could offer better supportive care for cancer patients in COVID-19 pandemic scenario.

KEYWORDS
COVID-19 lockdown, mindfulness therapy, nutrition, oral cancer survivors, over-the-phone, psycho-oncology, Sri Lanka intervention, supportive care

1 | BACKGROUND

Sri Lanka, is a lower-middle-income developing country, possessing one of the best efficiently pro-poor public health care delivery models across the globe underpinned by simultaneous achievement of strong health outcomes, good financial protection and low cost. Nevertheless, this island nation in the Indian Ocean is grappling with demographic, epidemiological and economic transitions, demonstrating significant increase in non-communicable diseases compounded by a near doubling of cancer incidence within two and a half decades. Oral cancer, comprised of lip, tongue and mouth cancers, is the leading cancer among males in Sri Lanka while ranked as the eighth among females. Moreover, 52.0% and 24.5% of oral cancers were diagnosed as late as at stage IV and III, respectively. Thus, oral cancer survivors in Sri Lanka constitute a priority group with multi-faceted health needs.

Oral cancer patients carry unique health needs that surpass the needs of other types of cancer patients. This could be predominantly attributed to the location of the disease and the side effects of the treatments disturbing the fundamental, vital activities of daily living like eating, speech and breathing. Furthermore, the impact is profound on the appearance. Therefore, oral cancer is more emotionally traumatic with psychosocial dysfunction, thus adversely impacting on the quality of life. A recent explorative qualitative study, conducted in India, revealed that, among oral cancer patients’ concerns, quality of
COVID-19 pandemic denotes an unprecedented public health crisis, which emerged as an epidemic in Sri Lanka with detection of the first case of community transmission on 11 March 2020, resulting in stringent enforcement of lockdown of the country from 20 March 2020 for nearly 2 months, which impacted the availability of, and accessibility to, routine cancer care services. Obtaining regular medication became problematic despite some alternative arrangements made by public sector hospitals. Despite the rapidly evolving burden of 1749 COVID-19 cumulative cases and 11 deaths up to 2 June 2020 predominantly confined to quarantined groups including overseas returnees, stringent enforcement of COVID-19 lockdown and social distancing strategy by the political leadership, security forces and public health officials significantly contributed to curtailing the community transmission of the devastating infection.

2 | INTERVENTION

In January 2020, we introduced an innovative, self-sustainable intervention as a component of an ongoing research study aimed at improving the psychological well-being of the oral cancer patients treated with surgery. They were approached at three time points: (a) soon after diagnosis when they visit the hospital; (b) at home, 1 week after discharge; (c) at home, 2 weeks after the first visit. This intervention was developed by a comprehensive triangulation method of an extensive literature search followed by gaining inputs from patients, caregivers and experts through a qualitative exploration. Furthermore, the health literacy status of oral cancer patients was meticulously considered as the majority had less optimal levels of education. Core Components of the intervention comprised: (a) addressing information needs of the current condition, (b) details about surgery and life after surgery including acute issues such as nutrition, pain, difficulties in swallowing, wound care and oral care and (c) information on empowering the patient to face the society and become an ambassador of goodwill/role model. Psychosocial well-being was addressed by guiding them to practice mindfulness therapy by highlighting its immense benefits to overcome psychological distress. Financial support was offered by coordinating with grass-root level administrative officers to receive a monthly allowance of Rs. 2000.00 for 4 months after the surgery. However, the effectiveness of the intervention has not yet completed evaluation and is currently ongoing, which should be considered as a potential limitation.

Ethics approval for the research study was obtained from Ethics Review Committee, Faculty of Medicine, University of Colombo Sri Lanka (ERC protocol number -EC-18-097). Written informed consent was obtained from participants.

Since Sri Lanka owns a strong primary health care delivery model, the Public Health Nursing Officers (PHNO), who provide community-based palliative care, were selected to deliver the intervention. A self-directed educational booklet and 2-day training workshop comprised of didactic lectures on communication and counselling, oral cancer, palliative care, mindfulness therapy and detailed execution of the intervention were employed to train the PHNOs to deliver the intervention. For a total of 100 PHNOs, 45 participated in the training programme. In the feedback, 91.1% of participants stated that they were confident to deliver the intervention as early as possible. Similar capacity enhancement of oncology nurses to deliver supportive care to parents with advanced cancer had been reported from developed countries.

The ongoing intervention garnered preliminary encouraging responses from oral cancer patients and their care-giving family members. Patients started feeling the benefits "we are no more worried as we know what to do." However, the COVID-19 pandemic and strictly imposed quarantine curfew and lockdown of the country, especially the high risk districts, resulted in temporary restrictions in access to the intervention. People were strictly instructed to stay home except for accessing emergency medical care providers of essential services; defaulters were arrested by the police. Accordingly, an extension/ modification to the intervention was needed. Moreover, oral cancer patients had emerging information needs which were different from the pre-COVID-19 era.

3 | MODIFIED INTERVENTION

The present modified intervention was deemed a blessing in disguise during the enforcement of lockdown in Sri Lanka. Many patients who participated in the intervention have contacted the first author who is the Principal Investigator (NR) for the ongoing research and the PHNOs to seek assistance, especially pertaining to acute problems, for example, pain, clinic dates, availability of drugs, etc. The contact details were available for the participants and vice-versa, thereby ensuring accessibility of the target population to the investigators. An attempt was made to deliver the same or slightly modified intervention over the phone since visiting the patients was not possible during the lockdown period. Furthermore, the PHNOs were temporarily recruited for the field work on COVID-19 prevention and control and were no longer available. Thus, the study PI had to deliver the over-the-phone intervention, which yielded even more encouraging responses from the patients. Patients admitted that just talking to a health professional relieved their tension.

3.1 | COVID 19-Oral cancer-psychological distress—A situational analysis

A rapid standardized situational analysis was conducted by the first author among 25 randomly selected oral cancer patients from the intervention group. It was clearly evident that the patients were in a miserable status mainly due to the lack of information on how to access the routine drugs they were using, obtained from respective public health care facilities free of charge, and due to the unawareness of the clinic dates. It was revealed that 60% of them were facing acute...
issues like swallowing difficulties, pain, etc. Early discharge of patients after surgeries was inevitable during the COVID-19 lockdown. Moreover, there was a dire need in providing tailor-made nutrition advice since a majority faced different nutritional problems. With regard to the financial status and the supply of essentials, majority reported few or no issues. This was due to the fact that the rural set-up in Sri Lanka still possesses a very strong social support network, comprising of care, sharing and empathy mediated by indigenous community support within hamlets/villages and complimented by grass-root level primary health care workers, administrative officers and civil organizations. This helped to lighten the burden of the COVID-19 epidemic as commented by patients and some care givers—this was not the case among the patients who lived in urban and sub-urban communities. Mental well-being was affected in few patients as accessibility for regular drugs was low, which made them think that the disease would progress.

3.2 | Support offered

The singular fact that medical personnel was inquiring about their well-being over the phone uplifted their spirits during this difficult period. This was the comment made by almost all patients who were contacted. Furthermore, the main issue of drug availability and clinic dates was rectified after coordinating with the relevant clinics and specific guidance was provided to the patients. It was evident that a lack of awareness on how to access hospital clinics to get the medicine was the predominant cause for an array of problems cancer survivors encountered. Therefore, adequate time was spent to provide satisfactory information to the patients.

4 | CONCLUSION

4.1 | LESSONS LEARNT

The COVID-19 pandemic had an unprecedented impact on societies and health care systems as stringent lockdown enforcement and social distancing were needed to curtail the community spread of infection. Sri Lanka, as a developing country, faced the challenge well but availability and accessibility to routine treatment were the most pressing concern for cancer patients. Accordingly, many oral cancer patients who underwent recent surgeries were facing problems with pain and swallowing while the majority did not know how to access routine services under constraints posed by the COVID-19 pandemic. Thus, the most critical aspect in the intervention was to facilitate patients to navigate the health care system to ensure that they can continue in receiving timely treatment. This was complemented by advice on practicing “mindfulness therapy” to maintain psychological well-being during difficult times.

“Study Limitations”: The life situation improving intervention for oral cancer patients is ingoing and not evaluated for the effectiveness as yet. Present investigation included only 25 oral cancer patients which is a small sample. Hence, the findings could have got influenced by the small sample size. "Clinical Implications": Assisting cancer patients to navigate the health care system to ensure that they can continue to access timely treatment during COVID-19 lockdown that has impacted routine health care services will be beneficial and useful.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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