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Case Study

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Barriers and Facilitators to the Referral of Patients with Cancer for Physiotherapy Rehabilitation: A Uganda Cancer Institute (UCI) Case Study

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Abstract

Background: Cancer and its treatment are linked to a variety of physical complications. Physiotherapy is recommended as the treatment of choice for improving cancer patients' physical function and quality of life. Patients with cancer and rehabilitation needs at Uganda Cancer Institute (UCI) receive inadequate physiotherapy services. There is little information available about the factors influencing health workers' decisions to refer patients with cancer for physiotherapy rehabilitation in underdeveloped countries like Uganda. This study aimed to determine barriers and facilitators to the referral of patients with cancer for physiotherapy rehabilitation at UCI.

Methods: A qualitative descriptive phenomenological design was adopted to conduct a case study at UCI. In-depth interviews were conducted on 12 UCI doctors and nurses who were selected using a convenience sampling from a population of 25. Thematic analysis was used to analyze the results. The UCI Research Ethical Committee granted ethical approval.

Results: Participants reported that facilitators to the referral of patients with cancer for physiotherapy rehabilitation included, but were not limited to; good communication between referring health workers and physiotherapists, patient clinical characteristics and previous positive outcomes of physiotherapy in management of patients with cancer. On the other hand, barriers included; inadequate knowledge on who should be referred for physiotherapy rehabilitation, fear of overworking the few physiotherapists, cancer complications that are perceived to be contraindicated for physiotherapy like intense pain

Conclusion: Doctors and nurses at UCI have experienced good outcomes and appreciate the benefits of physiotherapy management of patients with cancer. A limited knowledge on proper assessment of patients with cancer and deciding who to refer for physiotherapy and fear to overwhelm the few physiotherapists with a lot of patients limit referral of patients with cancer for physiotherapy rehabilitation at UCI.

Keywords: Cancer; Oncology; Physiotherapy; Rehabilitation; Referral; Barriers and Facilitators.

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Introduction

Cancer is an increasing public health burden globally, with an estimate of more than 19 million registered new cases and 10 million deaths annually [1]. It is estimated that the major cancer burden will be higher in low and middle-income countries by 2030, especially lifestyle-related cancers, which come along with various comorbidities [2].

Cancer and its treatment are associated with numerous complications, including musculoskeletal problems, sexual dysfunction, depression, and pain, among others, which lead to different forms of disabilities in these patients, thus affecting their quality of life [3,4]. Physiotherapy rehabilitation is one of the recommended treatments of choice to mitigate the complications associated with cancer, aimed at improving physical function and quality of life among cancer patients and survivors [5,6]. In virtue of this, there has been an increasing need to integrate physiotherapy services into oncology care [7].

An effective and established rehabilitation referral system for cancer patients is one of the major components that can enable the effective integration of physiotherapy into cancer care settings, as it facilitates informed referrals by health workers in oncology care [8]. Oncology doctors and nurses are also key to the rehabilitation referral of cancer patients, as they are responsible for assessing the needs of cancer patients and making referral decisions for these patients to needs-based rehabilitation and survivorship care [9]. Numerous studies indicate loopholes in the referral of cancer patients for physiotherapy globally due to several reasons, including; lack of a standardized referral screening tool, health workers' unawareness about the role of physiotherapy in cancer care, and guideline-based referral considerations [10-12]. On the other hand, the facilitators to the referral of cancer patients have been indicated to include an active inpatient rehabilitation unit, a rehabilitation screening tool, and good inter-professional communication [13]. In Africa, there is limited utilization of physiotherapy services by cancer patients, mainly due to limited referrals of these patients by healthcare workers [14]. This has been linked, among others, to the inadequate specialization of physiotherapy in oncology care and increased costs for rehabilitation services [14,15]. Similarly, at the Uganda Cancer Institute (UCI), it has been reported that rehabilitation service utilization by patients with cancer is affected by limited referrals [16]. However, to the best of our knowledge, limited data exist regarding the rehabilitation referral system at UCI and how it affects the utilization of physiotherapy services/care and thus the quality of life of the patients at UCI.

This study aimed to investigate the facilitators and barriers to the referral of cancer patients for physiotherapy by healthcare workers at UCI. Understanding these factors in a resource-constrained setting like Uganda is crucial in informing policies and strategies that limit barriers to the referral of cancer patients and promote cancer patient referral for physiotherapy rehabilitation that will result in addressing the rehabilitation needs of patients.

Methodology

A qualitative, descriptive phenomenological design was adopted to

conduct a case study and study barriers and facilitators to the referral of cancer patients for physiotherapy rehabilitation. Uganda Cancer Institute is a public, specialized tertiary care cancer center that works in collaboration with Uganda's Ministry of Health. It is an 80-bed hospital and a national cancer centre located in the Ugandan capital city, Kampala. At UCI, doctors and nurses who are on duty in wards are responsible for making decisions and referrals for rehabilitation through referral forms, calling the physiotherapists and verbal referrals. The convenience sampling technique was used to select a total study sample of 12 participants out of the 25 doctors and nurses at the Uganda Cancer Institute (UCI) based on their average number in each department. Six doctors and six nurses from solid tumors, liquid cancers, and private, outpatient, and pediatric departments consented to participate in the study. In-depth interviews were performed while using audio digital recorders and taking field notes. Thematic analysis was used to analyze the results. The UCI Research Ethical Committee granted ethical approval.

Results AND Discussion

Demographics

The study included twelve health workers, seven of whom were male and five of whom were female. Six doctors and six nurses were among the participants. Five participants were from the solid tumor department (S001-S005), three from the outpatient department (O001-O003), two from the private ward (P001-P002), one from the paediatric department (C001), and one from the liquid tumours department (L001). Half of the participants held a diploma, and the other half held a degree or master's degree. Seven of the participants had two to five years of experience dealing with cancer patients, three had six to ten years, and two had eleven to fifteen years.

Factors influencing the referral of patients with cancer for physiotherapy rehabilitation at UCI

Weak patients: It was found that patients who were bedridden and unable to walk were more likely to be referred for physiotherapy by some participants to prevent complications associated with immobility. On the other hand, other health workers do not refer weak patients for physiotherapy rehabilitation because they are too weak to manage exercises.

For example, S003 said, "……. then the other patients are those that have been in bed for so long because sometimes we get patients who stay in the bed 24/7 and so we refer them to physiotherapy to make their body active again." while L001 said, "There are some who are very sick and you can't refer…… first, we manage them first and would prefer referring the more stable patients because they will be worked on."

This could be due to the discrepancy in the health workers' understanding on who and what conditions to refer for physiotherapy rehabilitation. Generally, weakness and decreased strength have been associated with patients with cancer, providing a basis for health workers to refer these patients for physiotherapy [17]. There is a need for health workers to be educated on how safe, applicable, and beneficial exercise is in reducing fatigue and weakness in cancer survivors [18].

Facilitators for the referral of patients with cancer for physiotherapy rehabilitation

Availability of physiotherapists: Health workers refer patients with cancer for physiotherapy rehabilitation because the facility employs physiotherapists who attend to these patients. L001 mentioned, "…. here, like we have physiotherapy and they come on ward. If not, we call them to come and attend to the referred patients"

Similarly, oncology professionals in high-resource settings admitted the role of physiotherapists and tend to refer patients with cancer for recruited physiotherapists [18]. On the other hand, there is a lack of implementation plans, funding and organizational prioritization to employ physiotherapists in oncology facilities, which has limited the referral of patients for rehabilitation in Africa [19].

Inter-professional communication: When there are clear inter-professional linkage routes, health professionals find it convenient to refer cancer patients for physiotherapy rehabilitation. Physical interaction, availability of patient files, and technological communication means such as the ability to call physiotherapists for patient referrals were identified.

S002 mentioned, "Mhhhhhh i think for us it is easy to refer because we just have to write in patient files for review by physiotherapy or when discharging……..." and P001 stated, "It is easy to refer patients for physiotherapy because we easily call them because we have their contacts. We also give the contacts of these physiotherapists to the patients as we are discharging."

This could be because communication tools like files and calls enable doctors and nurses to directly transfer patient information to the physiotherapists. Inter-professional communication is an attribute that increases patient referral in cancer care [20], but communication and interactions between disciplines are limited in oncology settings [16]. Implementing appropriate and feasible interdisciplinary communication channels and systems would increase the number of cancer patients referred for rehabilitation.

Appreciated benefits of physiotherapy rehabilitation on cancer patients: Health professionals participating in cancer care report positive outcomes from physiotherapy treatments in cancer patient management.

C001 responded, "…. actually, for the patients where physiotherapy has been incorporated into their management, there has always been a positive result as compared to those who are not and that is why I refer these children for physiotherapy."

This could be because through the participants' experience, have witnessed physiotherapy improve the functional activity and quality of life of patients with cancer. Physiotherapy has been shown to enhance cancer patients' physical function and quality of life [6,21], and the same findings have been reported by cancer patients and caregivers [22,23]. Clinicians in cancer settings have reported impressive experiences working with physiotherapists due to the positive impact they bring to patients with cancer [18]. Physiotherapy has been scientifically proven and recommended to mitigate physical impairments and improve the quality of life of patients with cancer [24,25].

Request for referral for physiotherapy: Cancer patients and caregivers who express a desire for physiotherapy rehabilitation are more likely to be referred. Seeking rehabilitation services in cancer care is motivated by the individual's understanding of the function of physiotherapy rehabilitation in cancer care [26].

P001 stated, "There are also patients for example those from India, USA, Turkey and have been on treatment and physiotherapy was part

of it so they request for it here and we refer them."

This could be because doctors and nurses feel obligated to fulfill patients' needs by referring those that have shown interest for physiotherapy rehabilitation. It has been found that when a patient initially develops a physical disability, he has fewer possibilities for expressing the need for referral to physiotherapy rehabilitation than when he has previously received the service [27]. This necessitates educating the cancer community and the general public about the significance of rehabilitation in cancer care.

Young patients: Because young patients have a better prognosis, healthcare providers are more likely to prioritize them over the elderly and refer them for physiotherapy.

S001 responded, "… if it is a young man, I would really want them to be on their legs and more active as opposed to someone that is very old."

Doctors and nurses may consider referring young patients for rehabilitation than the elderly because they perceive young patients to have more functional needs than the elderly. This pattern is consistent in high-resource settings [9], where young cancer patients are more likely to be recommended for rehabilitation. This contradicts cancer recommendations, which urge referring cancer patients regardless of age [8, 28].

Clinical characteristics

Patients with cancer who have had surgery are more likely to be recommended for physiotherapy. This could be because doctors and nurses have seen physiotherapy helpful in managing post-surgery patients.

S004 responded, "The patients I refer majorly are patients done with surgery. When they operate them, we send them to physiotherapy" and S005 said, "…….and amputees. I refer them to physiotherapy because we expect and have improvements in these patients with physiotherapy services."

Post-surgery patients with cancer have been associated with physical complications like pain, scarring, lymphedema, and postural deformities, among others, which require physiotherapy rehabilitation [29,30].

Cancer patients who present with musculoskeletal and neurological complications are likely to be referred for physiotherapy because health workers believe that these complications are the ones that require rehabilitation. This is because health workers consider physiotherapists to be specialists in managing such conditions compared to them [31].

Breast, bone, prostate, lung, and brain cancers, as well as multiple myelomas and lymphomas, are the most commonly recommended cancer types for physiotherapy rehabilitation at UCI.

S002 mentioned, "…. but mostly prostate cancer, breast cancer, those are the most patients who get spinal cord compressions. Then mostly lung cancer for chest physiotherapy."

This is due to health professionals seeing clinical symptoms that necessitate rehabilitation in patients with these cancer types (32,33). In ideal circumstances, cancer type should not be used to determine who should be referred for rehabilitation because all cancer types can benefit from physiotherapy rehabilitation and exercises [8].

Barriers to the referral of patients with cancer for physiotherapy rehabilitation

Lack of trust in external physiotherapists: Healthcare workers at UCI cited a lack of trust in physiotherapists outside the facility as a reason for not referring cancer patients with rehabilitation needs.

P002 reported, "……. I am not sure of what the outside "physiotherapist" can do. For patients on the ward, I refer because I know they do it gently and professionally."

Participants might have been biased about other physiotherapy facilities outside the UCI and this cannot be generalizable to other settings. Similar results were previously reported in Ireland [34], where oncology health workers believed and had confidence in physiotherapists based in the facility compared to those in the community, and they were likely to refer patients with cancer internally.

There is generally limited regulation of physiotherapy practice in Africa and a lack of respect for professional boundaries [35]. As a result, cancer facilities are concerned about the external infrastructure, personnel, and patient safety [36]. There is need to explore factors to external referral of patients with cancer for physiotherapy rehabilitation.

Health workers' knowledge gap: Health workers admitted to having limited knowledge about assessing rehabilitation needs and what conditions to refer for physiotherapy rehabilitation and they may not refer cancer patients for rehabilitation.

S003 responded, "Maybe we also don't have much knowledge about physiotherapy as nurses and doctors and maybe that is why we are reluctant" and O003 said, "Maybe lack of the best knowledge physiotherapy because am not a specialist in that field…… physiotherapy is not my concern and I just give the patient chemotherapy and the patient goes back home"

Inadequate knowledge about the role of physiotherapy in cancer care and a gap in the physical assessment of patients with cancer has notably been noticed in junior clinicians [37]. Since most of our participants, about 58% were below the age of 35 and had not more than five years of experience, it could be an explanation for admitting inadequate knowledge on assessing and deciding who to refer for physiotherapy rehabilitation. Although there have been increased guidelines on what to assess and refer for physiotherapy in patients with cancer, there hasn't been a significant change in the trend of inappropriate referrals [21].

Under-staffed physiotherapy: According to health workers, the limited number of physiotherapists employed by UCI limits the referral of patients with cancer for physiotherapy rehabilitation. As a result of too much workload being placed on the few physiotherapists, health workers reported that they provide services like exercise prescriptions, which would have been done by the physiotherapists.

S001 said, "Because the physiotherapists are few … what we do, we just teach the attendant those motion exercises compared to a private setting where I was, all those would be candidates of physiotherapy" and S002 mentioned, "Also we tend to tell the nurses to do some of the simple exercises and turning and since they can do them, sometimes we don't see the need to refer."

Similar findings, namely that a scarcity of oncology-experienced health professionals, such as physiotherapists, has prevented health workers from referring cancer patients for rehabilitation in Africa

[11, 14]. It could be one of the reasons non-physiotherapists like nurses prescribe and do physiotherapy work [14]. More recruitment of physiotherapists is needed in cancer care facilities. Doctors and nurses giving their perceived workload of physiotherapists might have been biased and there is need for capturing firsthand information from physiotherapists themselves.

High costs of physiotherapy services: One of the reported barriers to patient referral was the fact that patients lack sufficient financial resources to cover physiotherapy rehabilitation.

O3 said, "You see physiotherapy goes on for so long like it is not a one-day treatment and it is expensive for some people like patients with cancer who have already spent a lot on treatment. So, when you are to refer them out, the money of someone matters."

Health workers indicated bias towards the economic capability of patients. There is need to understand the patients' perceived barriers to physiotherapy rehabilitation. In Africa, health professionals may decide not to recommend physiotherapy to patients with cancer due to financial constraints [38]. Unlike in Africa and other low-resource settings, the uptake of physiotherapy services by patients with cancer is high because the patients can pay for these services and health workers find it easy to refer to them [39].

Advanced cancer complications: Health workers reported that they did not refer patients with advanced cancer complications, that is; Deep Vein Thrombosis (DVT) and intense pain because they regard these complications as contraindications to physical rehabilitation. This could be because of the health workers' understanding of what physiotherapists which they perceive harmful in these conditions.

L001, "There are those who have intense pain……. first, we manage them first and would prefer referring the more stable patients."

Severe pain was reported to limit referral of patients with cancer for physiotherapy rehabilitation hence clinicians prioritize patients' comfort and the use of strong analgesics over referring them for physiotherapy [40]. Physiotherapists play a vital role in pain management and it is advised to incorporate physical exercise and physiotherapy modalities at every stage of pain management to accompany other pain treatment options [41]. This calls for a need for informing health workers on the benefits of physiotherapy in the management of severe pain.

On the other hand, there isn't a guideline yet that draws a line on exercise prescription in patients with cancer diagnosed with DVT but clinical reasoning should be used to gauge the risks and benefits of physiotherapy [42]. Physiotherapy and early mobilization of patients with cancer who are diagnosed with DVT are strongly recommended once therapeutic levels of anticoagulants have been established and hemodynamics are under control [43].

Conclusion

Doctors and nurses at UCI appreciate the role of physiotherapy in cancer management and have realized positive outcomes of physiotherapy. Health workers' limited knowledge on assessment of patients with cancer and determining who to refer for physiotherapy rehabilitation and fear to overload the few physiotherapists with patients constrain the referral of patients with cancer for physiotherapy rehabilitation at UCI. This study highlights the need for consideration of physiotherapy in cancer care through the recruitment of more physiotherapists, informing the doctors and nurses on who to refer for physiotherapy. Future studies can consider exploring factors that influence referral of patients with cancer for rehabilitation in settings that have broader referral systems like external referral systems.

Declarations

Competing interests: The authors declare that they have no competing interests.

Ethics approval and consent to participate: The study was conducted in accordance to the Uganda National Council for Science and Technology (UNCST) for conducting research involving human participants and all relevant regulations. Ethical approval was obtained from the UCI Research Ethics Committee (REC) and the study was allocated study number [SR. 08/22]. Informed consent was obtained from all participants through a standard written consent form and detailed explanation of the study

Consent for publication: Not applicable

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