

Identifying Barriers for Oncology Patients in Accessing Rehabilitation: A Qualitative Study

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Abstract

Purpose/Rationale: Thanks to improved detection and treatment, more patients are surviving cancer but having to cope with its chronic sequelae. Even with evidence indicating that cancer rehabilitation improves quality of life, it remains a gap in the healthcare system to which few resources are being allocated. This study looks at barriers to accessing such resources.

Subjects: Thirteen multidisciplinary healthcare workers directly involved with discharge planning of cancer patients from three Toronto hospitals with a large oncology patient population.

Methods and Materials: Qualitative interviews were done using standardized questions. Participants were asked about barriers to their patients in accessing cancer rehabilitation and recommendations to their improvement. All interviews were taped and transcribed.

Analysis: Framework analysis was used to group themes from the interviews into two categories: I) Personal Barriers; and II) Organization of Health Care Structure Barriers.

Results: Main problems identified were system barriers including the lack of designated beds for oncology patients in rehabilitation hospitals, distance between rehab and acute care hospitals, and inefficiencies in the discharge process. Personal barriers identified were disease severity, psychology, and transportation.

Conclusion: Barriers to accessing cancer rehabilitation exist at both the system and the patient level. The given recommendations reflect a need for increasing resource allocation to cancer rehabilitation, in order to ensure comprehensiveness and continuity of cancer care.

Introduction

With earlier detection and better clinical treatment, cancer patients now enjoy an increased life expectancy.¹ Although this accomplishment is laudable, for a sizeable subset of oncology patients, cancer becomes a chronic illness and rehabilitation is required to mitigate the side effects from cancer treatment or the cancer itself. For example, breast cancer patients who undergo axillary lymph node dissection may experience arm numbness, pain, and lymphedema, while chemotherapy may cause ataxia and

peripheral neuropathy.¹ Other cancer-related impairments include aphasia, dysphagia, myelopathy, encephalopathy, paresthesia, pain, and changes in cognition.² Also, oncology patients often have to deal with cancer fatigue, which has rapid onset and is energy draining.

Rehabilitation is defined as “the process by which a person is restored to an optimal physiological, psychological, social and vocational status.”³ Rehabilitation can take place within hospitals, in the home setting (with arrangements through a Community Care Access Centre (CCAC)), or in an outpatient facility such as a rehab clinic. Cancer rehabilitation is a relatively new concept. In the 1970s, research was primarily focused on finding a cure for cancer. Late in that decade, when it was realized that with the complexity and multitude of cancer types a quick cure for cancer would not be found, focus turned to prevention and early detection.¹ Although the idea of cancer rehabilitation is relatively new, its advocacy is backed by recent studies reporting that acute rehabilitation produces functional outcome gains regardless of the type of cancer.^{4,5} For example, the types of functional gains of brain tumor patients receiving inpatient rehabilitation were shown to differ significantly to acute traumatic brain injury or acute stroke patients.⁶⁻⁸

With evidence indicating that cancer rehabilitation improves quality of life, impetus lies on providing this service to those who need it. Both the Association of Rehabilitation Nurses (ARN) and the Oncology Nurses Society (ONS) maintain the position that “oncology rehabilitation includes timely access to and reimbursement for a coordinated, comprehensive interdisciplinary approach.”⁹ In 1999, this importance of timely access was recognized by the Ontario government’s Health Services Restructuring Committee of Ontario, through the establishment of the Greater Toronto Area (GTA) Rehab Network, which has the vision of creating an integrated rehabilitation system in the GTA. However, although the GTA Network has specific task groups and committees that advocate for equitable and available resources for the stroke and musculoskeletal rehabilitation patient populations, no committee looks after the needs of oncology patients.¹⁰ Moreover, despite growing evidence of the importance of cancer rehabilitation, especially in the face of the growing numbers of people who survive cancer and have to cope with its chronic comorbidities, Cancer Care Ontario prioritizes its funding for cancer prevention and treatment, and not rehabilitation.¹¹ Oncology

patient access to rehabilitation appears to be a justifiable health concern that is being overlooked.

With this in mind, we set off to examine if there are barriers to accessing rehabilitation for the cancer population. A qualitative interview method was used to seek the opinions of healthcare providers are involved with discharging cancer patients to rehabilitation.

Materials and Methods

Sample Selection

Healthcare workers who were interviewed were involved in the discharge planning of oncology patients from the hospital ward to inpatient rehabilitation care. In order to collect reliable and valid data, we attempted to seek the perspectives from a heterogeneous population of subjects. Healthcare workers interviewed were from three Toronto hospitals with a large oncology patient population: Mount Sinai Hospital (MSH), Princess Margaret Hospital (PMH), and Sunnybrook and Women's College Health Sciences Centre (SWHSC). PMH is the largest comprehensive cancer centre in Canada, while SWHSC is home of the Toronto Sunnybrook Regional Cancer Centre. To recruit healthcare workers to interview, we approached individuals on the surgical oncology team at MSH. A list of known health care workers on similar multidisciplinary oncology teams from PMH and SWHSC was generated from these initial contacts, and these healthcare workers were subsequently contacted by phone or email. A wide range of healthcare workers – physicians, nurses, social workers, physiotherapists, and care coordinators – was interviewed in order to get a variety of perspectives.

Definitions

Inpatient rehabilitation is for patients admitted to a hospital bed, within a rehab hospital. Sometimes, patients receive limited rehab services during their acute care hospital admission, but this is excluded from the above definition of inpatient rehabilitation. *Outpatient rehabilitation* is designated for patients who can travel to a rehabilitation facility for each rehab session. *Home-based care* refers to when a rehab professional comes to the patient's home to provide care, usually because the patient cannot travel to receive this care. This is usually provided through Community Care Access Centres (CCAC).

Data Collection and Analysis

All interviews were taped and subsequently transcribed. Analysis of qualitative interviews was done using framework analysis.^{12,13} The questions asked were standardized for each subject in order to minimize bias. As well, a wide spectrum of oncology healthcare workers were recruited to minimize response bias. To decrease researcher bias, a medical student with no prior knowledge and thus no prior subjective views of the cancer rehabilitation system in the GTA interviewed the subjects.

Qualitative analysis was chosen over quantitative analysis in an effort to get a complete perception of the topic from our subjects so we could identify barriers without making assumptions of which ones existed.

The framework approach was developed specifically for applied qualitative research where objectives are set beforehand and are

shaped by the information requirements of health care authorities. Thus, this type of analysis is conducive to our goal of identifying barriers to cancer rehabilitation and providing specific recommendations to improve this access to cancer care policy makers. Furthermore, as framework analysis uses a stage-specific approach to indexing data, policy makers can be clear about which stage of the rehabilitation framework that recommendations emerge from.

Data was processed using the five key stages of framework analysis: familiarization, identifying a thematic framework, indexing, charting, mapping and interpretation.¹³ The thematic framework was identified as the rehabilitation model of care. As framework analysis allows for *a priori*, preformed concepts,¹³ we established two core categories of barriers to accessing health care based on literature from Wilson and Rosenber:¹⁴ I) Personal Barriers (e.g. travel time, convenience of medical appointments¹⁵ and patient perceptions); and II) Organization of Health Care Structure Barriers (e.g. waiting time¹⁶ and finances). Themes from the interviews were grouped under these two categories. Indexing of themes was done until saturation level, at which point the student had discussed and resolved all categorization issues with the supervisor.

Results

Thirteen healthcare workers were interviewed. Seven healthcare workers were from Mount Sinai Hospital, three were from Princess Margaret Hospital, and three were from Sunnybrook Hospital. In total, two surgical oncologists, two physiotherapists (PTs), two occupational therapists (OTs), two social workers, one Community Care Access Centre (CCAC) coordinator, two patient resource coordinators, and two nurse team leaders were interviewed. Of the two surgical oncologists, one dealt with melanoma, breast cancer and colorectal cancer while the other focused on gastrointestinal cancers. The CCAC coordinator, one physiotherapist, and one social worker also focused on gastrointestinal cancer patients, while the other staff interviewed dealt with multiple cancer types, but primarily blood, bone, and breast cancer.

Barriers to accessing rehabilitation care were identified both at a structural organization level and at a patient level, in concordance with categories previously established in the literature.¹⁴

1. Health Care Structure Barriers

At the health care structural level, barriers to accessing rehabilitation care exist at three stages: during the acute care hospital stay, during the discharge process, and during the admissions process to inpatient and outpatient rehab facilities.

a) Accessing rehabilitation at the acute care hospital

In terms of accessing rehabilitation services in acute care, four of the thirteen healthcare workers expressed a need for more physiotherapists at this level. It was reasoned that more rehab care to patients in the acute setting would prevent patients from needing to access future and more intense rehab programs.

Two health providers expressed concern that when patients are denied admission to an inpatient rehab hospital, an acute care hospital cannot provide the extent of rehab needed to get the patient functional enough to return home. At times, because of the lack of bed space at the acute care hospital, patients end up being sent home, without receiving the daily rehab they need. To help patients

who are sent home despite possible benefits from further rehab, it was suggested that patients should receive rehab consultation at the hospital when returning for their regular clinic appointments with their oncologist. This would also save time for the patient.

b) Discharge process

Many barriers were described within the discharge process which prevented patients from accessing rehabilitation care post-discharge. One major cause mentioned by four healthcare workers was the delay in paperwork for inpatient rehab admission. Reasons for these delays included miscommunication, misfiling of papers, waiting for physicians to fill out forms, and papers being completed on a Friday, which meant that the earliest they would be assessed would be the following Monday. For patients requiring outpatient or home-based rehabilitation, the two physicians interviewed felt unsure about how rehabilitation care was coordinated. One physician recommended that brochures be made stating how to get in touch with outpatient rehab and CCAC, with contact information. However, social workers did not see this as an issue, as they reasoned that knowledge of the rehab system was a part of the social worker's job as opposed to the physician's.

Another problem stated was that different forms are issued by different inpatient facilities. One subject suggested that the discharge process could be simplified if paperwork was standardized for all inpatient rehab centers.

c) Admission into inpatient rehabilitation facilities

Seven healthcare workers voiced concern that rehab hospitals were hesitant to accept cancer patients. Several reasoned that the inpatient hospitals are reluctant to take patients who may eventually need nursing home placement, and who could potentially take up bed space for longer than other patients. As one healthcare worker explained:

“Just in general, rehab facilities get a red flag when they see it's an oncology patient. When they see oncology they tend to be cautious, shy away, and want to know a lot more about it, whereas in a stroke patient, they wouldn't look at it as much.”

Seven subjects said that there must be better understanding from inpatient facilities that cancer patients can be good rehab candidates, and that programs may have to be tailored differently for this population. Arguments were made that the goals of rehab - to improve quality of life, self-care and independence - are feasible for oncology patients. One healthcare worker argued that although a cancer patient can potentially go to a nursing home, he/she would be able to do so at a much higher level of independence given rehabilitation. It was suggested that better communication, such as in the form of videoconferencing, should occur between discharging and admitting staff, to prevent good rehabilitation candidates from being denied access based only on their cancer prognosis.

Exclusion criteria also hindered oncology patients from admission into inpatient rehab facilities. The Hillcrest Centre of the Toronto Rehabilitation Institute (TRI) is the only inpatient rehab facility in Toronto that has designated beds for oncology rehabili-

ation. Several inpatient rehab hospitals would not allow oncology patients to leave the hospital for extended periods for chemotherapy or radiation treatments, as this would disrupt their rehabilitation programs. Impaired cognitive status, which some cancer patients experience, can also be an admissions barrier, since memory and the ability to follow instructions are criteria for admittance into inpatient rehab programs. One healthcare worker countered that rehab could improve cognition and help patients learn strategies to cope with self-care.

Eight healthcare workers mentioned the lack of existing inpatient facilities for oncology patients. Three healthcare workers recommended that all major oncology hospitals should have dedicated rehab beds. As explained by a staff member at the PMH, currently 50% of their oncology patients live outside the GTA and must be sent back to their hometown general hospital for rehab. In this situation, the patient may receive only 30-40 minutes of rehab per day, whereas in a rehab hospital the full day would be focused on rehab. Lack of beds and resultant long waitlists at inpatient facilities were cited several times as barriers to accessing rehab care. It was suggested that more oncology-specific rehab beds, such as the designated ones at Hillcrest site of the TRI, would be beneficial.

d) Admission into outpatient and home care rehabilitation

Three subjects saw no barriers to accessing outpatient and home care. As one healthcare worker reasoned, “If they can walk to a clinic, they're ok. They're well enough to go home”. Four saw finances as a constraint to receiving outpatient care - with one subject saying that there should be more OHIP-covered outpatient clinics. Two other healthcare workers stated that outpatient facilities were rarely recommended to their patients. One mentioned that it seemed illogical that PMH, the largest cancer centre in Canada, has no outpatient rehab services. It was suggested that there is a definite lack of continuity of care at PMH, as it offers acute care, radiation, surgery, inpatient care, outpatient medical care, and palliative care, but no outpatient rehab care.

In terms of barriers to CCAC care, one subject mentioned that it would take a few weeks for patients to see a homecare PT arranged through CCAC. No other subjects brought up any concerns with home care.

2. Personal Barriers

Barriers that prevented patients from individually seeking rehabilitation care were sorted into five core categories: 1) Disease-related; 2) Psychological; 3) Transportation; 4) Financial; and 5) Social Support. Disease-related, psychological and transportation barriers were the most commonly listed by healthcare workers to be problems. Two healthcare workers said that personal barriers were not a problem.

For cancer patients, increased severity of disease, poor prognosis, and cognitive issues were all factors healthcare workers listed as reasons preventing their patients from seeking rehab care. Reduced endurance prevents patients from participating actively in a rehab program, and this was thought to be more prevalent in oncology patients than in any other rehab patient population. Patients with a low predicted life span understandably preferred to spend their time at home as opposed to rehab. The patient's per-

Table 1**Recommendations made by oncology health care workers to improve specific barriers to accessing cancer rehabilitation**

1. Structural Barriers**i) Patients are denied admission to an inpatient rehab hospital**

- Have patients receive rehab consultation at the hospital when returning for their regular clinic appointments with their oncologist
- Better understanding from inpatient facilities that cancer patients can be good rehab candidates
- Tailor rehabilitation programs differently for the cancer population
- Better communication between discharging and admitting staff

ii) Delay in paperwork for inpatient rehab admission

- Standardize paperwork for all inpatient rehab centers

iii) Lack of existing inpatient facilities for oncology patients

- Have dedicated rehab beds at all major oncology hospitals
 - Make more oncology-specific rehab beds available
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2. Personal Barriers**i) "Separation anxiety" when moving from their home hospital healthcare staff to new staff at a different location**

- Have an onsite rehab unit at the acute care hospital, in order to provide continuity of care from the inpatient department

ii) Transportation from the inpatient rehab facility to the acute care hospital for appointments costs time and money

- Establish oncology rehab beds at the rehab hospital (TRI²) physically linked to the cancer centre (PMH²), enabling patients to be transported by wheelchair back and forth for chemotherapy and/or radiation appointments
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ception of inpatient rehab may also dissuade a patient from going. Patients may think that they can manage without it, or fear going to rehab because they think that they will have to stay there longer than is actually needed. One social worker stated that elderly patients have refused to go to inpatient rehab because they feared losing their independence.

Six healthcare workers cited psychological barriers such as depression and anxiety as contributing to patients refusing rehabilitation care. For example, two healthcare workers described patients who had "separation anxiety" when moving from their home hospital healthcare staff to new staff at a different location. One suggestion made to alleviate this problem was to have an onsite rehab unit at the acute care hospital, in order to provide continuity of care from the inpatient department. Several healthcare workers also suggested that inpatient rehab beds specifically reserved for oncology patients would be psychologically beneficial, as patients would be able to interact and identify with others with similar problems related to cancer.

Transportation is concerning for many rehab patients and was mentioned by four healthcare workers. As one healthcare provider stated:

"They have to leave the facility they're in, get a wheelchair transport or something to get [to the acute care hospital], have to wait, see their doctor to get their treatment, and get back. This can take half a day or a whole day and they'll lose their rehab care."

A suggestion made by this interviewee from PMH was to establish oncology inpatient rehab beds at the neighboring University Centre of the TRI. She rationalized that since PMH and TRI are linked underground by tunnels, it would make sense to send patients to TRI for rehab care, so they could be transported over to PMH by wheelchair for chemotherapy and/or radiation

treatment. This solution would also save taxpayer money spent on transportation needed to send a patient over from a rehab hospital further away.

Due to recent changes in government funding, OHIP coverage for outpatient physiotherapy is only limited to a minority of the patient population.¹⁷ Patients who do not qualify for OHIP coverage need to seek private outpatient care. Thus, one healthcare worker said that financial barriers exist for patients who do not have workplace benefits or private insurance and require private outpatient care. The same healthcare worker also mentioned that social support may be a problem, depending on whether or not family encourage or discourage the patient to get rehabilitation care. She also mentioned that culture could be a problem in terms of language barriers.

3. Recommendations made by healthcare workers

Recommendations made by subjects interviewed to address these specific problems in cancer care rehabilitation are displayed in Table 1.

Discussion

This study examined where barriers exist for oncology patients accessing rehabilitation. Structural organization problems addressed include the lack of rehab services in acute care, lack of inpatient rehab facilities, discharge delays, and admission denial. Patient personal barriers were less emphasized by subjects in this study. This may be because healthcare providers may not personally realize the extent of personal barriers that make patients hesitate about accepting care. Nonetheless, personal barriers that were brought up that may be investigated include psychological anxiety about rehabilitation, finance, and location and transportation issues.

Although a larger evidence-based body of knowledge in cancer rehabilitation still remains to be developed, clinical application suggests that the application of the fundamental principles of rehabil-

itation is likely to improve the care of these patients.¹⁸ Thus, for oncology patients who require rehabilitation, lack of timely access to rehabilitation impedes restoration of function, impinges on quality of life, and places a burden of care on their caregivers.¹⁹ Gaps in the healthcare system exist as cancer patients who require rehabilitation may not be able to access it in due time. Many patients are forced to stay in their acute care hospital, as they are not healthy enough to return home. Within the acute care setting, they will not receive the focused amount of rehabilitation they require. Others may be discharged home and have to cope with pain and mobility problems with little help. In both situations, subsequent disability may occur because of extended bed rest and de-conditioning. For most hospitals, the delay in discharging a patient also means that acute care bed space, which is often in short supply, will be held up.

Certain limitations existed in this study. Sample size was small because time constraints limited recruitment levels. In future studies, a larger sample size of different types of healthcare workers could be used to establish associations between specific professional groups' attitudes and the types of patients they service, in order to better target where changes can be made. For example, access to rehabilitation care may be more of an issue for patients with a certain type of cancer, with a certain severity of disease, from a certain age group. As well, in order to better realize where problems specifically exist in getting oncology patients into rehab care, interviewing a large sample size of patients considering inpatient rehabilitation would be beneficial.

Qualitative data tends to be less generalizable than quantitative data. To improve internal validity, we would have had to seek the opinions of cancer patients. Unfortunately, based on time constraints, a suitable sample size of patients was not possible for this study. Possible biases also exist in interviewing different healthcare personnel from only three hospitals, as their experiences are only generalizable to their patient population. The rehab access issues presented are also not generalizable externally, within other cancer populations, or within other cities.

Our primary goal was not to establish these types of internal and external generalizability, as these qualities are inherently difficult to measure in a qualitative study. Rather, we wanted this project to be an introductory study of issues arising in cancer rehabilitation access. As a qualitative study however, the study does possess catalytic validity, which is "the degree to which research moves those it studies to understand the world and the way it is shaped in order for them to transform it."²⁰ As the study highlighted the issues underlying cancer rehabilitation admission, it paves the way for improvement of barriers to its access. Studies such as this one will lead to development of well-constructed quantitative studies where internal and external validity will be of primary concern.

This qualitative study revealed that oncology patient access to rehabilitation is a justifiable health concern. The voiced concerns and recommendations made by oncology health care workers in this study reflect a need for focus improvements on access to cancer rehabilitation, in order to ensure comprehensiveness and continuity of cancer care.

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