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## Chemotherapy and radiation treatment decision-making experiences of older adults with cancer: A qualitative study

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### ABSTRACT

**Purpose:** Little is known about the perspectives of older adults (OAs) with newly-diagnosed cancer on their experiences with cancer treatment decision-making. The objective of this study was to explore the factors that were important for accepting or refusing cancer treatment by older adults undergoing chemotherapy and/or radiation therapy.

**Patients and methods:** A qualitative study using semi-structured interviews with 20 OAs aged  $\geq 65$  years with newly diagnosed cancer ( $< 6$  months) receiving either curative or palliative chemotherapy and/or radiation or who had declined therapy. The COREQ reporting guideline was utilized.

**Results:** The majority of patients accepted the recommended cancer treatment. Most OAs followed their oncologist's recommendation, but spoke of making their own decisions and felt confident about their decisions. Second opinions were not commonly sought. Themes emerged can be divided into two categories: 1) pertaining to cancer treatment decision-making, which includes: "Trust in oncologist", "prolong life", "expected outcomes of treatment", "other people's experience", "skeptical about going online" and "assertion of independence", and 2) pertaining to oncologist-patient interactions, which includes "communication".

**Conclusion:** Older patients largely followed their cancer specialists' treatment recommendations. Most patients were satisfied with their treatment decision and were confident in their decisions. Seeking of second opinions was rare. More needs to be done to address the communication gaps and support needs of this population.

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### 1. Introduction

Cancer is predominantly a disease of older adults. With the aging of the population, there will be a considerable increase in the number of older adults diagnosed with cancer [1,2]. Many older adults will be faced with making treatment decisions with regard to cancer treatment. The decision-making process in older patients with cancer regarding cancer treatment is not well understood, and this may be attributable in part to the underrepresentation of older patients in cancer clinical trials [3]. So far, little is known about the perspectives of older men and women with newly diagnosed cancer on cancer treatment. Two recent systematic reviews exploring cancer treatment decision making showed that there have been very few studies exploring treatment decision in older adults aged 70 years and over [4,5]. Furthermore, the older adult population is very heterogeneous in terms of health, functional status, and treatment preferences and these should be taken into account [6]. There have been multiple studies investigating the preferred

and actual role in the decision-making process. However, most studies have been conducted with a relatively young population and years ago [7,8]. As more older adults with cancer are offered treatment and with advances in treatment (e.g. oral systemic agents), current older adults may have different views than those more selected older adults included in older studies. Therefore, the objective of this study was to explore the cancer treatment decision-making experiences of older adults.

### 2. Study Design

This qualitative study involved conducting one-time semi-structured interviews with older adults who were offered chemotherapy and/or radiation therapy, regardless of whether or not they underwent the treatment. Convenience sampling strategy was utilized. We used the COREQ [9] checklist to provide framework for the study.

### 3. Study Participants

We recruited patients aged  $\geq 65$  in the curative/palliative setting (presenting with breast, prostate, colorectal, or lung cancer) and who

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had made a treatment decision in the preceding six months at the Princess Margaret Cancer Centre (PM), University Health Network or the Odette Cancer Centre (OCC), Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada, between September 2012 and February 2014. Patients unable to speak English or give informed consent were excluded.

These two centers were chosen as they are two of the largest comprehensive cancer centers in the country which provide the majority of cancer treatments in the Greater Toronto Area (catchment area 6 million). At the Princess Margaret Cancer Centre, patients were recruited through the treating physicians while at the Odette Cancer Centre, the participants called the research coordinator in the cancer centre after seeing the recruitment flyer (in which older participants were sought to discuss treatment decision experiences) in waiting areas. The study was approved by the research ethics board of UHN, Sunnybrook Health Sciences Centre and the University of Toronto. Written informed consent was obtained from each participant prior to interview.

#### 4. Data Collection

Semi-structured interviews were conducted using a topic guide (see Appendix A). Interviews included questions regarding participants' general health status (no details about specific comorbidities were asked), recommended cancer treatments, factors that influenced their treatment decision-making, and information and support needs. Additionally, there were also questions regarding satisfaction with their decision as well as suggestions to enhance the decision-making experience for older patients with cancer. The questions were developed based on the expert consensus of the research team. Interviews took place at the location of the patient's preference (in hospital/at home/by telephone) between November 2012 and February 2014. All participants were interviewed individually except for two patients who chose to be interviewed together with their family members. Interviews were conducted by a female interviewer, MP (RN, PhD), who is a registered nurse and academic researcher who has clinical and research experience with frail older adults and in treatment decision-making. The researcher had no relationships with the participants prior to the study. The participants were aware that the researcher was interested in exploring the treatment decision-making process of older patients with cancer. The one-time interviews lasted between 10 and 60 min and were audio recorded and transcribed verbatim. Field notes were made during interviews.

#### 5. Data Analysis

The data collected from interviews underwent thematic analysis by MP and SS on paper as outlined by Braun & Clarke [10]. Thematic analysis is a method of identifying, analyzing, and reporting patterns within data. For this analysis, specifically, an inductive approach was utilized. This approach involves coding the data without attempting to fit it into a pre-existing coding frame or theoretical framework; therefore, the data underwent a form of data-driven thematic analysis. Each theme captures elements that are pertinent about the data in relation to the research question. The six-phase approach as outlined by Braun & Clarke [10] was followed: 1) familiarizing with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report. In case of disagreement MP and SS discussed the coding and themes with SA (who read the transcripts and reflected on the themes) to arrive at a consensus.

#### 6. Results

##### 6.1. Description of Participants

Twelve men and 8 women participated. All 10 participants from Sunnybrook were recruited passively via the flyer; while the 10

participants from Princess Margaret Hospital were actively recruited by the PI. There was no data on how many were approached and refused. None of the participants dropped out from the study. Treatment decisions made included 18 decisions regarding radiation treatment and 10 decisions regarding chemotherapy treatment. The age of participants ranged from 66 to 78 years. The diagnoses included: breast ( $n = 4$ ), prostate ( $n = 8$ ), colorectal ( $n = 2$ ) and lung ( $n = 6$ ). Sixteen patients (80%) had accepted the cancer treatment recommended to them. Four patients had declined treatment, of which two later reconsidered. Four patients were accompanied by a family member during the visit with the oncologist for treatment decision-making; four patients were alone; and for 12 patients, there was no indication whether they were alone or accompanied by a family member or close ally.

##### 6.2. Treatment Decision Experience

The majority of the patients voiced that their treatment decision making was easy for them. Most patients were satisfied with their treatment decision and expressed confidence in their decision. The majority made their decisions on the spot without consulting others.

##### 6.3. Themes Emerged

The themes emerged from the interviews can be divided into two categories: themes pertaining to treatment decision-making and themes pertaining to communications.

###### 6.3.1. Pertaining to Decision-making

"Trust in oncologist" refers to patients' confidence that their oncologists had recommended the treatment that was the best for them. The majority of the patients chose to rely on their oncologists' professional expertise when it comes to treatment decision-making.

"Prolonging life" refers to the wish to prolong one's life expectancy. The desire to stay alive was an important reason for accepting recommended treatment.

"Expected outcomes of treatment" refers to the anticipated outcome of the cancer treatment influencing whether one accepted or declined recommended treatment. A number of patients weighted the potential degree of benefit of the recommended treatment before making their decisions.

"Other people's experience" refers to how cancer and treatment experiences of others influenced one's own treatment decision-making. Some patients mentioned that they had factored in the past experiences of others into their decisions on whether to accept or decline recommended treatment.

"Skeptical about going online" refers to patients being cautious regarding going online for information. Some felt that looking up information online could lead to confusion.

"Assertion of independence" refers to upholding a sense of independence and autonomy in one's treatment decision making. Patients alluded to taking control, making their own decisions and not needing any help.

###### 6.3.2. Pertaining to Communications

"Communication" is a theme. While about half the patients were satisfied with their communication with oncologists, the other half experienced poor communication during their treatment decision process and beyond. For instance, oncologists' use of medical jargons, downplaying of treatment side-effects, lack of sensitivity and lack of time spent with patients are some of the issues voiced by patients in this regard. (Please see Table 1 for quotes from interviews).

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