Journal of Geriatric Oncology xxx (2017) xxx–xxx

Contents lists available at ScienceDirect

Journal of Geriatric Oncology

Patient engagement in research with older adults with cancer

Martine T.E. Puts [a,*], Schroder Sattar [a], Vida Ghodraty-Jabloo [a], Tina Hsu [b], Margaret Fitch [a], Ewa Szumacher [c], Ana Patricia Ayala [d], Shabbir M.H. Alibhai [e]

[a] Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada
[b] Department of Medical Oncology and Hematology, Ottawa Hospital Cancer Centre, Ottawa, Ontario, Canada
[c] Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada
[d] Gerstein Information Science Centre, University of Toronto Libraries, University of Toronto, Toronto, Ontario, Canada
[e] Department of Medicine, Institute of Health Policy, Management, and Evaluation, University Health Network and University of Toronto, Toronto, Ontario, Canada

ARTICLE INFO

Article history:
Received 13 January 2017
Received in revised form 27 March 2017
Accepted 24 May 2017
Available online xxxx

Keywords:
Patient and family engagement
Frail elderly
Cancer
Patient and public involvement
Patient partnership

ABSTRACT

Objective: Cancer is a disease that mostly affects older adults. Older adults have been under-represented in clinical cancer research. Around the world there is a push for patient engagement on study teams as it is anticipated to improve study design, recruitment and dissemination of findings. In the current overview we examined the evidence with regard to: 1) the history of patient engagement in research and frameworks developed; 2) impact of patient engagement on patient and research outcomes; 3) use of patient engagement in geriatrics and oncology, 4) recommendations for successful engagement; and 5) gaps in the literature that should be studied further.
Methods: A narrative review was conducted. Articles published in English were searched in Medline with the help of a librarian.
Results: Patient engagement has been shown to improve the conduct of studies by making the study design more relevant and feasible, and improving recruitment rates and uptake of research findings by patients. However, the best way to engage patients is not clear yet. Several resources have been developed to support researchers engaging older adults with cancer in research.
Conclusions: While patient engagement in research seems promising to improve study outcomes, little evidence is available thus far in geriatric oncology settings. Several gaps in the literature are identified that should be further studied to determine the value of, and best approaches to, patient engagement with older adults with cancer.

1. Introduction

Older adults with cancer have been under-represented in clinical research [1]. Moreover, despite studies generating new evidence for clinical practice, some of these findings are never implemented in routine clinical care for various reasons, such as studies not being relevant to clinical practice or patients. Engaging patients could make research more relevant and/or meaningful, and thus more attractive for patients and clinicians [2–5]. Lastly, when research is publicly funded, patients have a right to be involved in the research process, both as taxpayers and as beneficiaries/users of research [6,7].

Patients can have different roles in research. Typically clinical research includes patients as study subjects; another role is as study advisors or committee members on grant review panels. A relatively new development around the world is to engage patients and the public more in research by making them team members; this is known as patient and public involvement (PPI). In Canada, the Canadian Institutes of Health Research (CIHR) has developed a patient engagement framework and defined patient engagement as "*meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context patient-oriented research may also engage people who bring the collective voice of specific, affected communities*" [8]. While in the literature the terms patient engagement, involvement, and patient participation have been used interchangeably, we will use the CIHR definition in the current review to be inclusive of the role patients can play in all phases of research.

In the current overview we examined the evidence with regard to: 1) the history of patient engagement in research and frameworks developed; 2) impact of patient engagement on patient and research outcomes; 3) use of patient engagement in geriatrics and oncology, 4) recommendations for successful engagement; and 5) gaps in the literature that should be studied further. An expert librarian (APA) developed a search strategy in Medline based on the searches of recent systematic reviews of patient engagement [2,9,10]; of the identified relevant articles, and references lists were examined to find more articles.

* Corresponding author at: Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, 155 College Street suite 130, Toronto, Ontario M5T 1P8, Canada.
E-mail address: martine.puts@utoronto.ca (M.T.E. Puts).

http://dx.doi.org/10.1016/j.jgo.2017.05.002
1879-4068/

2. History of Patient Engagement Research

The first move towards patient engagement took place in the United Kingdom in 1996. The National Institute for Health Research funded the development of a national group to support active public involvement in the national health system, public health and social care research [11]. In Australia in 2002, the National Health and Medical Research Council (NHMRC) and the Consumers' Health Forum of Australia (CHF) released a Statement on Consumer and Community Participation in Health and Medical Research (the Statement on Participation) [12] which contended that consumers could have valuable input on research and that collaboration was encouraged. In 2010, the Scottish Government launched a National Dementia Strategy with a prominent place for PPI, which led to the development of the Scottish Dementia Research Interest Register of patients who are willing to be contacted for research [13,14]. In the USA, the Patient-Centered Outcomes Research Institute (PCORI) was founded in 2010 as part of the Affordable Care Act to engage patients in research [15]. In Canada, the Strategy for Patient Oriented Research (SPOR) was developed in 2011 [7].

2.1. Patient Engagement Frameworks Developed

A systematic review by Shippee et al. [9] looking at patient and service user engagement in research developed a framework based on a synthesis of the literature that divided engagement into three phases of research: preparatory, execution and translation. In the preparatory phase patients can help identify research gaps, prioritize research questions and participate in funding decisions. Patients can participate in the design of a study by providing input on inclusion criteria, selection of methods and relevant outcomes, as well as input on the intervention and the informed consent procedure and materials. During the execution of the study they can be involved in the recruitment of participants; the collection of data; the analysis of data, including providing input on subgroups to be analyzed; and the interpretation of the findings. Lastly, patients can play an important role in the dissemination of findings, helping to translate and deliver meaningful messages to their peers [16]. So far, most research that includes patients and service users has done so at the preparatory phase and the translation phase; patient involvement is rarely reported for the execution phase of research [9,17–22].

The Canadian Institutes of Health Research (CIHR) Patient Engagement Framework has identified four guiding principles for patient engagement: Inclusiveness, Support, Mutual Respect, and Co-Build [8]. These are very similar to the four engagement principles developed by PCORI in their engagement rubric [23]. The CIHR has identified six desired outcomes for successful patient engagement [8]: 1) Inclusive Mechanisms and Processes (e.g. patients should be involved on all levels and research led by patients is supported); 2) Multi-Way Capacity Building (e.g. training and support for researchers, patients and health care providers is needed to work together); 3) Multi-Way Communication and Collaboration (e.g. a safe and respectful environment to promote honest discussion is needed); 4) Experiential Knowledge Valued as Evidence (e.g. experiences of patients and families is valued); 5) Patient-Informed and Directed Research (e.g. the research uses a collaborative approach); and 6) A Shared Sense of Purpose (e.g. the team works together towards patient-oriented outcomes).

PCORI has listed sample engagement plans for researchers to use to develop their own project [24]. A roadmap has also been developed for patient and family engagement in health care, policy and research [25]. PCORI has identified five actions that include: 1) co-create proposals with patients and their families; 2) conduct research to support patient and family engagement; 3) partner with patients and their families to design the process and outcomes; 4) develop return-on-investment metrics to measure outcomes, benefits and costs of engagement; and 5) look beyond peer-reviewed publications to disseminate findings.

Marlett et al. [26,27] developed the Set-Collect-Reflect methodological framework for patient and community engagement. Set refers to setting the study directions with participants. Collect refers to data collection and Reflect refers to reviewing the findings together. This approach uses the Patient and Community Engagement Research (PaCER) method of peer-to-peer research and includes a 12-month internship. Two recent studies [28,29] using the PaCER method in patients with osteoarthritis and patients who had been admitted to the Intensive Care Unit and their caregivers showed that it was feasible to examine patient experiences and areas of the care journey that need improvement. An important and novel finding was that the patients were able to carry out the study. Moreover, in the ICU study by Gill et al. [28], the research data were analyzed by the patients and by the research team independently, and both reported similar findings. While both studies included adults aged 65 years and over, neither reported the number of health conditions these patients had. Thus, while the PaCER approach seems to be very promising, it should be investigated whether it would be feasible in older adults with cancer receiving cancer treatments.

A recent systematic review by Domecq et al. [2] included 142 studies, including 8 systematic reviews and meta-analyses, but found no studies that compared the best ways to engage patients and concluded that there is currently no evidence to support one method of engaging patients in research over another.

3. Impact of Patient Engagement

3.1. Impact on Patients

In a systematic review of the impact of patient and public involvement on health care users, researchers and communities [10], 65 papers were included, mostly from the UK and the USA. The review showed there were several personal benefits for patients getting involved. These consisted of feeling listened to and empowered, feeling valued, feeling part of a team, having improved access to information, being able to engage with researchers (which helped the patients understand research better and develop a more positive attitude towards research), and gaining a number of skills such as public speaking, group working and interviewing [10].

Negative impact of engagement was also reported by patients, including frustration due to feeling not valued or listened to, feeling marginalized, feeling not being taken seriously, and apprehension about engaging in something different. These findings were similar to those in a review by Backhouse et al. among older adults living in residential settings [10,30]. Furthermore, patients have reported increased emotional burden due to having to recall their own experiences and listening to those of other patients [10].

3.2. Impact on Researchers

In a systematic review on the impact of patient engagement [10], 35 papers were identified that studied the impact on researchers. The benefits of engaging patients included the research team gaining new insights into the research issues and a greater understanding of patients' needs, a finding supported by the systematic review of Domique et al. [2].

Including patients on the team also led to greater diversity and sometimes even less workload for researchers, whose role changed from researcher to advisor. However, the most commonly identified challenges were needing more time to engage patients, having to work on patient relationships, and needing more funds to implement patient engagement [2,10]. Researchers also sometimes felt uncomfortable when patients' ideas did not match their expert vision, particularly when researchers and patients had a different vision of what constitutes good research [2,10]. Sensory and communication difficulties, the fluctuating health state of patient participants, cognitive impairment,

Please cite this article as: Puts MTE, et al, Patient engagement in research with older adults with cancer, J Geriatr Oncol (2017), http://dx.doi.org/10.1016/j.jgo.2017.05.002