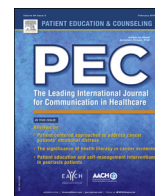




Contents lists available at ScienceDirect

## Patient Education and Counseling

journal homepage: [www.elsevier.com/locate/pateducou](http://www.elsevier.com/locate/pateducou)



Medical decision making

# Family involvement in cancer treatment decision-making: A qualitative study of patient, family, and clinician attitudes and experiences

Rebekah Laidsaar-Powell<sup>a,\*</sup>, Phyllis Butow<sup>a</sup>, Stella Bu<sup>a</sup>, Cathy Charles<sup>b</sup>, Amiram Gafni<sup>b</sup>, Alana Fisher<sup>a</sup>, Ilona Juraskova<sup>a</sup>

<sup>a</sup> Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), School of Psychology, The University of Sydney, New South Wales, Australia

<sup>b</sup> Department of Clinical Epidemiology and Biostatistics and Centre for Health and Policy Analysis (CHEPA), McMaster University, Hamilton, Ontario, Canada

### ARTICLE INFO

#### Article history:

Received 20 August 2015

Received in revised form 20 January 2016

Accepted 22 January 2016

**This paper is dedicated to the memory of the late Professor Cathy Charles, whose insightful ideas, questions, and comments have been an integral part of this program of research. We will miss Cathy greatly, and acknowledge and appreciate her ground-breaking contributions of the field of medical decision-making.**

#### Keywords:

Cancer  
Family caregivers  
Communication  
Decision-making  
Triadic  
Qualitative

### ABSTRACT

**Objective:** Little is known about how family are involved in cancer treatment decision-making. This study aimed to qualitatively explore Australian oncology clinicians', patients', and family members' attitudes towards, and experiences of, family involvement in decision-making.

**Methods:** Semi-structured interviews were conducted with 30 cancer patients, 33 family members, 10 oncology nurses and 11 oncologists. Framework analysis methods were used.

**Results:** Three main themes were uncovered: (i) how family are involved in the decision-making process: specific behaviours of family across 5 (extended) decision-making stages; (ii) attitudes towards family involvement in the decision-making process: balancing patient authority with the rights of the family; and (iii) factors influencing family involvement: patient, family, cultural, relationship, and decision.

**Conclusion:** This study highlighted many specific behaviours of family throughout the decision-making process, the complex participant attitudes toward retaining patient authority whilst including the family, and insight into influencing factors. These findings will inform a conceptual framework describing family involvement in decision-making.

**Practice implications:** Clinicians could ascertain participant preferences and remain open to the varying forms of family involvement in decision-making. Given the important role of family in the decision-making process, family inclusive consultation strategies are needed.

© 2016 Elsevier Ireland Ltd. All rights reserved.

## 1. Introduction

Family members (usually a partner, adult child, parent, or sibling but not excluding other family/friends) regularly attend cancer consultations [1,2] and can provide emotional support, contribute information, and participate in medical decision-making [3]. Quantitative studies show that a majority of cancer patients (49–84%) and family members (FMs) (54–59%) prefer family participation in decision-making to some extent [4–9]. Similarly, oncologists also appreciate family involvement, whilst recognising potential issues such as family dominance [10].

To date, a limited number of studies [11–15] have explored qualitative accounts of family involvement in cancer treatment

decision-making. Hilton [12] and Ohlen et al. [14] interviewed cancer patients and FMs and reported that family involvement in decision-making can range from passive to active, and may be influenced by demographic, relationship, and disease factors [11]. Reust and Mattingly [15] and Hubbard [13] identified some common family behaviours (e.g., informational support, advocacy, sounding board) during cancer treatment decision-making. However, a number of limitations are evident in the existing literature. Few studies have described the range of specific behaviours of family during the decision-making process. Additionally, two of the studies were conducted over 20 years ago and results may not reflect the current state of consultation communication and decision-making [12,15]. Ohlen's [14] study described only complementary and alternative medicine decision-making, which may differ from decision-making dynamics for conventional treatment. Additionally, no previous studies have qualitatively reported the attitudes and experiences of oncologists and oncology nurses.

\* Corresponding author at: School of Psychology, Level 6, Chris O'Brien Lifehouse (C39Z), The University of Sydney, NSW 2006 Australia. Fax: +61 2 9036 5223.

E-mail address: [rebekah.laidsaar-powell@sydney.edu.au](mailto:rebekah.laidsaar-powell@sydney.edu.au) (R. Laidsaar-Powell).

Thus this study aimed to provide a comprehensive view of family involvement in cancer treatment decision-making, both within and outside of the consultation. We aimed to elicit the attitudes and experiences of Australian oncology clinicians (oncologists and nurses), cancer patients, and FMs of cancer

patients regarding: (i) participants' experiences of how family are involved in decision-making; (ii) participants' attitudes towards family involvement in decision-making; and (iii) participant perceptions of factors influencing the extent of family involvement in decision-making.

**Box 1. Overview of oncologist interview items**

**OVERVIEW OF ONCOLOGIST INTERVIEW ITEMS**

Attitudes towards FMs in consultations

- What do you think about having FMs participate in consultations?
- Are some FMs more/less helpful than others?

FM roles in the consultation

- What roles have you observed FMs assume in a consultation?

Family involvement in decision-making

- What do you think about FM being involved in the decision-making process?
- Are there any challenges including FMs in decision-making?
- What strategies (if any) do you use to overcome these challenges?

Family involvement in decision-making stages

- How is information about different options discussed in consultations which include a FM?
- Once the information had been discussed, what happens when different options (if available) are being weighed up within consultations? Are preferences discussed, if so by who?
- When it comes down to making the decision, what is the influence of the family?

Family involvement in decision-making (barriers and facilitators)

- What do you think prevents FMs from participating in treatment decision-making?
- What do you think helps FMs participate in treatment decision-making?
- Can you think of any strategies to manage or enhance family involvement in decision-making?

**OVERVIEW OF PATIENT INTERVIEW ITEMS**

Patient experiences and attitudes

- Why did your FM come along to cancer consultations with you?
- What is it like having a FM attend cancer consultations?
- Can you describe some of the specific things that your FM did in the consultation(s) ?
- Was there anything that was hard about having a FM in a consultation?

Decision-making

- Could you tell me about how your FM was involved when you were making the decisions?
- What would you say was your FM's level of involvement in the decision?

Benefits and challenges

- What are the benefits of including FMs in medical decisions?
- What are the challenges of including FMs in medical decisions?

Barriers and facilitators

- Did anything help your FM to participate when you were making decisions about your treatment?
- Was there anything that prevented or stopped your FM from participating when you were making decisions about your treatment?

Strategies

- Can you think of anything that can be done to improve consultations with a patient, FM, and doctor?

Download English Version:

<https://daneshyari.com/en/article/6152445>

Download Persian Version:

<https://daneshyari.com/article/6152445>

[Daneshyari.com](https://daneshyari.com)