

Article details: 2017-039	
Title	A qualitative analysis of the role of patient and physician advocacy in improving wait times for cancer care
Authors	Maria Mathews PhD, Donna Bulman PhD, Dana Ryan MA
Reviewer 1	Dr. Serge Daneault
Institution	Direction de santé publique, Montréal-Centre, Montréal, Que.
General comments (author response in bold)	<p>The number of participants is high and raises the possible problem of lack of deepness in the analysis. The reasons for that are not presented but I suspect that saturation purpose can be an explanation to the number of recruited. It has to be clearly stated. Otherwise, it could be the result of too large or imprecise questions that can generate more much data unrelated to the objectives of the study. The initial interview grid must be presented in annex.</p> <p>Participants were recruited to ensure a minimum number of interviews in each cell of our recruitment strata. We have clarified that interviews continued until data saturation was reached and no new themes emerged among the participants' responses.</p> <p>The interviews were done in-person or by phone. Maybe, the data collected were influenced by the kind of interviews performed. This point has to be documented among limitations on the interpretation section.</p> <p>We have clarified that most interviews (58 of 60) were done by phone and added a statement in the limitations about potential impact of differences in interview mode.</p> <p>Sixty-eight persons approached refused to participate to the study. This proportion is high and relatively rare for this kind of study. The characteristics of refusing patients and reasons for refusal need to be given and put in relations with the characteristics of participants.</p> <p>We have clarified the number of survey respondents who were identified as potential respondents and the number of contacted patients who participated in an interview. We have also noted the reasons why patients declined to participate.</p> <p>In the interpretation segment, some reflections are missing as the explanations of waiting time, the ethic to gain some advantage to be more demanding over patients which stay in the waiting queue, etc. It is also surprising that the participants do not give some data on consequences of waiting on their suffering or wellbeing. Maybe, the authors cannot report that because of the word count limitations but they have to be mentioned.</p> <p>We have added a sentence in the interpretation section on the impact of advocacy actions on the patients' well-being.</p> <p>I do not understand why retrospective interviews is a limitation of this study. It seems to me that interviews are inevitably retrospective. The problem of retrospectivity is that the data reflect the experiment and emotions about these experiences more than the real facts which are unrevealed by this kind of design.</p> <p>We have changed the wording of this statement to remove the term "retrospective" from the limitations section. It could be pertinent to tackle the divergent cases or less prominent themes of the analysis.</p> <p>We have included divergent examples in the results.</p> <p>The main problem of this study is its lack of results validation. Are some patients interviewed a second time in order to verify if they were agreeing with the emerging results? Are focus group held in order to validate main findings? This point refers to the triangulation process essential to the validation of this kind of study (See Miles, Huberman & Saldana. Qualitative Data Analysis, 3rd Ed, 2014).</p> <p>We noted that we used members checking during the interview to verify participants' responses. We also triangulate our findings with other studies (described in the interpretations section).</p>
Reviewer 2	Ann Del Bianco PhD
Institution	Adjunct Professor, Faculty of Environmental Studies, York University, Toronto, Ont.
General comments (author response in bold)	<p>Given that one of the aims of this study was to describe wait times, I was expecting to see a section addressing this in the Introduction and Results. Perhaps providing some background on what the literature considers/defines as average or reasonable wait times in Newfoundland and Labrador may serve as a springboard – drawing from your previous studies could also assist in this regard. Describing wait times should be explored more explicitly, especially in light of the fact that the second aim explores efforts to improve timeliness of care, suggesting that the amount of time it currently takes to access care is too long.</p> <p>We have clarified that the purpose of the article is to describe patients' perspectives of their efforts to improve the timeliness of their care.</p> <p>We have summarized our findings from our larger study that specifically examined wait times and included these papers in the references</p> <p>The way the study is currently worded suggests that the period of time between the onset of symptoms to the start of treatment was examined. However, the study addresses both satisfied and dissatisfied wait experiences for diagnosis but applies this to advocacy efforts any time along this spectrum. Perhaps separating advocacy efforts by different periods (i.e. i) onset of symptoms; ii) diagnosis; iii) treatment) would be beneficial. Also, as noted, only patients' satisfaction with wait times for diagnosis were presented in the Table. The addition of satisfaction of wait times at the onset of symptoms (if available) and the start of treatment in the Table is suggested. I would recommend parsing these out more clearly throughout the manuscript.</p> <p>We have clarified that satisfaction with wait times refers to satisfaction with overall wait times.</p> <p>In introducing each quotations, we have described the context to describe the stage in the care seeking process the in which the quotation takes place (e.g. before diagnosis, waiting for surgery etc.)</p> <p>We have summarized our findings from our larger study that examines interval specific wait times in greater detail By including breast, colorectal, lung, and prostate cancers, a fairly even number of participants from each sex from the most frequent types of cancer in Canada were recruited. It would however be worthwhile to include a breakdown of participants by cancer type and stage of disease (if available) in the Table. I would recommend that the corresponding text also elaborate on any differences by cancer type and/or stage of disease. For instance, was advocacy (self, friends and family, and/or health care team) more prevalent amongst those who were more symptomatic, had a poor prognosis or late stage disease, or had been diagnosed with a cancer associated with low survival rates? Similarly, although some elaboration was provided on how rural patients and those with insider knowledge were able to get timelier appointments, it would be interesting to know if or how age, sex, or marital status may have played a role.</p> <p>We have included stage of disease in Table 1.</p> <p>We have summarized our findings from our larger study that examines predictors of wait times and wait time-related satisfaction (including interval age, sex, or marital status).</p> <p>Given that thematic analysis was used I was expecting to see the results split up more explicitly according to major themes under each of the headings provided in the Results.</p> <p>We have created a table that presents the results by each major theme.</p> <p>Page 1, Line 10 and Page 4, Line 11: Recommend replacing the word "caregiver" with family members or friends, since not all excerpts sound like they come from caregivers (for example see Page 11, lines 11-35).</p> <p>We have replaces caregivers with "friends, or health care providers".</p> <p>Page 5: Consider adding the heading "Introduction"</p>

The heading has been added.

Page 5, Lines 25-27: notes few studies examined the patients' perspectives – consider citing these articles

We have added these references and discussed cancer specific studies in the interpretation section

Page 5, line 51: reads "... that was carried out larger study..." consider revising to "... that was carried out as part of a larger study..."

The statement has been revised.

Page 6, lines 13-14: Consider indicating how many satisfied and unsatisfied clients were included in the sample. Also, the use of the word "client" is introduced here – it is unclear if this includes other people (i.e. family members, friends etc.), or if this has been used as another word for "patient". If it is the latter, to avoid confusion, consider using the word "patient" again.

We have included the numbers and percentages of satisfied and unsatisfied patients in the sample. We have also changed the word "client" to "patient".

Page 6, lines 33-34: Given that interviews were conducted both in person and by phone and that there was a wide range in the length of time of interviews, it may be worthwhile to mention if those interviewed by phone were shorter or longer and/or if there was any difference in the quality of data obtained by the different collection techniques. If there were no differences, a brief sentence noting this with a reference supporting it is suggested.

We have added information about the number of interview conducted in person and by phone. In the limitations, we have discussed the potential influence of different modes of interviewing.

Page 6, line 34: It is unclear if only twelve of the sixty interviews were transcribed or if the number "12" was accidentally inserted in front of the word "transcribed". If the former, all interviews should have been transcribed, if the latter please remove the number "12".

This typographical error has been removed.

Page 7- Lines 3&4: reads "... a coding template was developed [18, 20] and with NVIVO software, used to code all interviews [19]." Consider revising to clearly describe the use of NVIVO (i.e. for both developing a coding template and to code all interviews).

We have revised this sentence.

Page 7- Line 17: in brackets consider inserting (47% response rate)

The response rate has been included as a percentage.

Page 7- Line 20: currently reads "...demographic characteristics and wait times for diagnosis..." – please revise to "...demographic characteristics and satisfaction with wait times for diagnosis..."

This statement has been revised.

Page 7- Lines 32 &34: Consider numbering findings (i.e. 1. having tests for symptoms; 2. Following up on test results; 3. Arranging appointments themselves)

This statement has been revised to include numbers.

Page 7, Line 39: Please correct typo "tests"

This typographical error has been corrected.

Page 7, Line 41: Based on the excerpts provided as illustrations, consider revising "participants perceived that delays stemmed from..." to "participants perceived that delays they had already experienced stemmed from..."

We have revised this sentence.

Page 8, Line 22 to Page 10, Line 7: the majority of the section "Efforts by the Patient to reduce Waits" provides insight and examples relating to patients arranging appointments themselves, perhaps a bit more elaboration on the other two areas would also be interesting. Also, there is a paragraph on page 9 (Lines 8-28) that describes access to care for rural patients that could result in earlier appointments – could this have had an impact on the results of the study given that nearly half the sample consisted of rural patients?

We have added additional examples with quotations to the results.

We have summarized our findings from our larger study. These studies examine urban rural differences in wait times.

Page 10, Line 13: begins with "Family members may", consider revising to "Family members and/or friends may..."

We have revised this sentence.

Page 11, Line 48: Please revise the typo "...letter on the his behalf..." to "...letter on his behalf..."

This typographical error has been fixed.

Page 13, Lines 6- 8: Consider rewording the sentence to state that just over half of participants made attempts to reduce wait time and improve access to care rather than stating that they were commonplace.

We have reworded this statement.

Page 13, Lines 27-46: Explanation and Comparison with Other Studies: Consider including a paragraph or two explaining and citing other articles that speak to the advocacy roles that patients, family members and friends take – not only health care professionals.

We have expanded the paragraphs comparing the study results with other studies.

Page 14, Line 10: To remain consistent, consider revising "insider-knowledge" to "insider knowledge"

We have made the suggested change.

Page 14, Line 13: There is a word missing – "...the health system" should read "the health care system"

We have added this word to the sentence.

I fully appreciate the difficulty compressing a report of a study of this nature into a very strict word limit. Although the authors have accomplished that, they have had to provide the reader with a fairly superficial overview of what was done and learned from this study.

We have moved quotations into a table which has allowed us to provide additional details about the methods and expand the interpretation section.

Page 10, Line 37: Based on the information provided about patients from rural settings, was ID445 Rural rather than Semi-urban?

We have verified that the label for ID445 is correct.

Page 13, Line 53: Although some recall bias relating to the symptomatic period may exist, perhaps patient files could be pulled (if possible) to see how long a patient actually waited for appointments between diagnosis and treatment to rule out some of the recall bias.

Recall bias described in the limitations is not specific to wait time dates, but rather to participants ability to remember events in the past.

We have summarized our findings from our larger study, other articles describe wait times in detail. These studies examine urban rural differences in wait times.

It would be helpful if appointments were described better throughout the manuscript in the lead up to excerpts so that the reader can follow along more easily. For instance, on page 10, lines 15-18 it is unclear what kind of appointment the patient was waiting for. Is the dissatisfaction in wait time for a diagnostic test or in securing an appointment for treatment? These should be clearly parsed out, perhaps as separate sections (as noted in Major Comments #2).

	<p>The focus of the article is to describe examples of advocacy. We have summarized our findings from our larger study; other articles describe wait times in detail. These studies describe wait times relative to specific treatment milestones.</p> <p>Please double check the number and corresponding percentage of dissatisfied vs. satisfied wait times as they differ from a previously published study utilizing what appears to be the same sample (Mathews, M., Ryan, D., and Bulman, D. (2015). What does satisfaction with wait times mean to cancer patients? BMC Cancer, 15 (1013) doi: 10.1186/s12885-015-2041-z).</p> <p>The focus of the article is to describe examples of advocacy. We have summarized our findings from our larger study; other articles describe wait times in detail. These studies describe wait times relative to specific treatment milestones.</p> <p>In this study, we have clarified that satisfaction refers to overall satisfaction with wait times.</p>
Reviewer 3	Dr. Sally Thorne
Institution	University of British Columbia School of Nursing, Vancouver, BC
General comments (author response in bold)	<p>The writing style in the findings section seems to overly generalize where it seems more likely there would have been some diversity with the sample. Eg "patients insisted, "participants believed" [note also that patients and participants are used interchangeably].</p> <p>We have reviewed the manuscript to limit the generalizations where possible</p> <p>The use of coding notations may not be quite as useful as intended, as the reader is not given the full context to know how to interpret the system eg (ID 337, Rural, Satisfied, Lung Cancer, Male). However, if the "satisfied" aspect was meant as a device to cue the team to a binary of satisfaction with advocacy (the focus of this analysis), then it may further underscore the need to avoid the use of expressions that appear to overly homogenize "the patient perspective" within this study sample.</p> <p>We have provided more information on the coding notations.</p> <p>Because the findings are organized by the agent of the effort to reduce wait time (patients, families and friends, members of health care team), the report essentially provides examples from the data set, rather than offering any sense of what was gleaned from the more thematic analysis process described in the methods section. The section on interpretation provides a very brief summary of what are considered main findings, again not extending the analysis beyond the superficial, but rather confirming that the findings fit with available understandings from the literature.</p> <p>We have expanded the interpretation.</p> <p>p. 6 line 35 - typo? "12transcribed"</p> <p>This typographical error has been fixed.</p> <p>p. 7 line 4 – NVIVO should likely be written as NVivo[®]</p> <p>This has been fixed.</p> <p>p. 7 line 6- unclear what "field notes" pertains to, since this was not an observational study</p> <p>We have removed the mention of "field notes" from the statement.</p> <p>p. 7 line 11 – "identifying individuals" likely should read "identifying features"</p> <p>This statement has been changed.</p>
Reviewer 4	Ms. Mihaela C. Munteanu
Institution	Drexel University, Philadelphia, Pa.
General comments (author response in bold)	<p>To make the manuscript stronger please show what exactly are the healthcare implications to the system or healthcare policy or medical education in Canada or other countries, or costs in Canada? Choose at least one item (policy, system, etc) as it would be very applicable especially since so much rich data was available here. For example, so what if a patient is his or her advocate to healthcare?</p> <p>We have identified a specific implication for medical education.</p> <p>The discussion section could be made a bit more comprehensive re literature review. I understand the limit in number of words may be an issue.</p> <p>We have included more literature in the section.</p> <p>Are there any points that can be made or are there differences in themes from coding between satisfied and dissatisfied interviewees?</p> <p>We have commented on differences between satisfied and dissatisfied patients</p> <p>line 12 - rec'd to add pls a range of age since your N is large; either here or in your table attached</p> <p>We are not sure what this comment means. Age is presented in the table</p> <p>line 34 - number 12 should be deleted?</p> <p>This has been deleted.</p> <p>line 36-37 - attach pls template protocol for semi structured questions as an appendix or an online supplement.</p> <p>We have attached the interview guide.</p> <p>line 53 - how many, and did you handle discourse among raters?</p> <p>We added a sentence stating that disagreements in coding were resolved by consensus.</p> <p>Summarize the themes and subthemes in a diagram with colors found from NVivo and study members in a diagram and then let the reader know which ones will be discussed if not all will be described.</p> <p>We presented the results in a table format.</p> <p>We have summarized other articles from our larger study, including those that present other findings from the qualitative interviews.</p> <p>line 53 - would add if this method was cited before or please add the reference of the method in text</p> <p>References for the methods were cited in the original manuscript.</p>