Experiences of adult cancer patients in a patient navigation program: a qualitative systematic review protocol

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Review question/objective
The aim of the project is to conduct a comprehensive review of scholarly literature detailing the experiences of adult cancer patients in patient navigation programs.

The specific questions are:
1) What are the experiences of patients with cancer in patient navigation programs?
2) How do patient navigators impact the challenges patients encounter in the cancer care continuum?

Background
A patient navigation program is a model of care which requires a trained individual to provide individualized and assistive care to adult oncology patients, to help them overcome barriers and to achieve continuity of care as they experience the complex healthcare system.¹ The aim of patient navigation is to achieve safe and patient-centered care in the healthcare continuum.² The care provided by a patient navigator includes assisting patients to overcome barriers to healthcare, patient education, counseling and care coordination. Some examples of care coordination include setting up appointments with various departments and ensuring that the investigations needed and doctors’ appointments coincide on the same day.

The first patient navigation program was initiated in Harlem, New York, in the early 1990s as a means to overcome barriers preventing an underserved group; namely the poor and uninsured, in getting timely access to healthcare for cancer screening, diagnosis, treatment and supportive care.¹³ Patient navigation was based originally in the community and the first navigators were non-healthcare trained Harlem

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Since then, patient navigation as a patient-centered healthcare delivery model has evolved and has been embraced by numerous institutions to achieve continuity of care for patients diagnosed with complex diseases, throughout the whole spectrum of cancer care.\cite{1,3,4}

Cancer has remained the top cause of death in Singapore for the last three years, accounting for 30% of total deaths.\cite{5} The incidence of cancer diagnosis in Singapore continues on an upward trend, with the Singapore Cancer Registry reporting that the most frequently diagnosed cancers from 2007 to 2011 among adult males were colorectal, lung and prostate cancer and breast, colorectal and lung cancers for adult females.\cite{6}

Advancement in cancer research has resulted in many patients undergoing a combination of concurrent treatment modalities involving various specialists. This has contributed to the myriad of complex issues that patients with cancer have to deal with. These commence as soon as they are diagnosed and can persist throughout treatment, survivorship or end of life.\cite{7,8}

Jacobsen,\cite{9} reported that distress is present among 30 to 75% of cancer patients, but this is often not identified by oncology care providers.\cite{7} Apart from distress due to the cancer diagnosis, patients' experiences with the healthcare system as they undergo multiple treatment modalities and investigations can further exacerbate the distress felt by patients.\cite{10} Patients with cancer are often prepared for the ‘big issues’, for example surgery and treatment plans of radiation or chemotherapy. However, the ‘smaller issues’ of day to day events or external environmental factors can aggravate the distress felt by patients and it is vital to help patients overcome these ‘smaller issues’. Some examples of these issues may include a lack of caregivers for patients’ young children, lack of information and the need to find their way around the healthcare system in terms of physical locations of different departments, as well as processes of the healthcare system as they undergo investigations, consultation with their healthcare team and treatment.\cite{10}

The role of patient navigator can be taken on by lay persons who are trained as navigators, or by different healthcare professionals, however the appropriate person to fulfill the role is dependent upon the needs of the patient group requiring assistance.\cite{3} The role of a navigator has been likened to that of a case manager, with principles of case management found within the patient navigation program framework.\cite{2,11}

Some examples of these include: coordinating different aspects of care and services required by the patient, assessing and addressing patients’ psychosocial needs and providing resources as needed.\cite{1} The distinction of patient navigation from case management is the focus on a single health condition for patient navigation.\cite{1} Patient navigators aim to assist patients overcome personal and logistic barriers that may exist for the diagnosis and treatment of the specific health condition. Collaborative efforts are made with the patients and their caregivers to help patients make sense of the care trajectory from their own perspective, rather than to simply achieve quality of service, optimal utilization of hospital resources and lower costs, which are usually goals in case management.\cite{1,2} In a review conducted to explore oncology patients’ outcomes with oncology nurses as navigators, Case reported that oncology nurses as navigators not only improved the coordination of care and reduced barriers encountered by patients, they also contributed to a ‘safe passage’ of care for them, as the oncology nurse navigators used their expertise and knowledge to conduct risk assessment to identify and manage complications early for patients with cancer.\cite{12} In addition, the patient navigators also linked the patients with various resources needed, for example, other healthcare providers, community and social services, symptom management...
and social support.\textsuperscript{7,13} Through providing information and resources and assisting patients to make sense of their treatment plans, patient navigation can result in better self-care by patients and thus reduce the need for unnecessary visits to the emergency department or unplanned hospitalizations. This reduces unnecessary burden on limited healthcare resources and aids better coping by patients, which indirectly translates to better patient satisfaction.\textsuperscript{7,11,14}

Despite the use of patient navigation as a model of care in many institutions, the effectiveness of patient navigation programs in cancer care remains inconclusive due to a paucity of randomized controlled trials (RCTs), small sample sizes and combining patient navigation with other interventions that may have resulted in inconclusive outcomes.\textsuperscript{15} Stemming from this lack of patient navigation studies, many centers have begun to initiate studies using well designed RCTs with large sample sizes to address these gaps.\textsuperscript{15} It is, however, salient to note that qualitative research findings can complement the outcomes of studies focusing on the effectiveness of interventions, giving voices to patients in regards to their experiences of this novel care delivery model and thus broaden the understanding of the patient navigation experience. The role of qualitative research is thus vital in the translation to evidence based practice.\textsuperscript{16}

Since the inception of the patient navigation program and especially in recent years, there has been an increased amount of literature surrounding patient navigation, in part due to the accelerated uptake of patient navigation as a patient-centered care delivery model in many institutions.\textsuperscript{17} It is therefore timely to review and synthesize existing qualitative literature so as to provide an up-to-date summary of the topic.

An initial search in evidence-based databases has revealed a recent submission of a systematic review protocol focusing on quantitative studies investigating the effectiveness of patient navigation programs.\textsuperscript{18} A systematic review of scholarly studies of the experiences of adult patients in patient navigation programs has not been conducted. The findings from this review will therefore contribute to a more comprehensive understanding of the effectiveness of patient navigation programs and will inform institutions with newly established programs. This will help to improve the quality of care of patients newly diagnosed with cancer, through understanding patients’ and healthcare workers’ experiences with the program.

**Inclusion criteria**

**Types of participants**

Inclusion criteria

The types of participants of interest are adult cancer patients aged 18 years and over who are receiving or have received standard cancer care, for example, chemotherapy, radiation therapy and/or hormonal therapy and are in a patient navigation program or had been in a hospital patient navigation program.

Exclusion criteria

Studies examining patient navigation programs targeted at the following will be excluded: improving screening rates for cancer, timeliness from positive screening to diagnosis and recruitment and retention for clinical trials, because the patients will not have experienced the complexities of the healthcare system at this point and thus have not had relevant experience.
**Types of intervention(s)/phenomena of interest**

The phenomena of interest are the experiences of adult cancer patients who used patient navigation programs in hospital and the impact of patient navigators on the challenges the patients encountered in the cancer care continuum.

**Types of studies**

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, action research and exploratory studies.

**Search strategy**

A three-step search strategy will be used for this review. An initial limited search will be conducted using PubMed and Science Direct, with key words such as ‘patient navigation’, ‘patient navigator’ and ‘cancer’ to find potentially relevant articles. This will be followed by analysis of the text words contained in the title and abstract and of the index terms used to describe the article. An expanded search will commence in step two using all identified keywords and index terms specific to each included database. Step three will involve searching through the reference lists of identified articles for additional relevant studies.

The databases to be searched include:

1) CINAHL
2) Web of Knowledge
3) Embase
4) Medline
5) PsycINFO
6) ProQuest Dissertations and Theses
7) Network Digital Library and Theses

The search strategy will aim to find both published and unpublished studies in the English language, from the year 1990 onwards, because patient navigation programs first commenced in the year 1990. Articles will be included based on whether they meet the inclusion criteria. Initially, identified papers will be assessed by two independent reviewers for relevance based on the title or abstract using broad inclusion criteria, i.e. patient navigation, cancer, patients’ experiences and qualitative methods using the tool in Appendix I. Full text articles will be sought when necessary. This will serve to exclude irrelevant non-qualitative papers and papers that do not fit the criteria. The process of study selection will be presented using the PRISMA flow diagram as shown in Appendix II.
Assessment of methodological quality

The studies will be evaluated for their methodological quality by two independent reviewers before inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute (JBI): Qualitative Assessment and Review Instrument (QARI) (Critical Appraisal Checklist for Interpretive & Critical Research attached in Appendix III). The instrument consists of 10 criteria that establish the nature and appropriateness of the methodological approach, specific methods and the representation of the voices or meanings of study participants. Any disagreements that may arise between the reviewers will be resolved through discussions or with a third reviewer.

Data collection

Data extraction and synthesis will be conducted using standardized data extraction and synthesis tools from JBI-QARI, developed for meta-aggregation of qualitative research studies. Before the commencement of data extraction, the standardized data extraction instrument (as shown in Appendix IV) from JBI-QARI will be read through by both reviewers and each criterion discussed to ensure common interpretation of the question. Extraction of data will then be done independently by the two reviewers and any disagreement will likewise be resolved by discussion or with a third reviewer. Qualitative data extracted from papers included in the review using the standardized data extraction tool from JBI-QARI will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives. Primary authors will be contacted for missing information and unclear data.

Data synthesis

Data synthesis will begin with the identification of findings from included papers. Findings are the themes, metaphors or concepts primary study authors raised in their analyses. The papers will be read and re-read to identify the findings and entered in QARI (level 1 finding). Once the findings have been identified, similar findings are categorized together as a form of pooling based on like meaning (level 2). These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative form.

Conflicts of interest

No potential conflicts of interest noted.

Acknowledgements

I would like to extend my gratitude to Dr Emily Ang and Dr Dora Lang from National Cancer Institute, Singapore for their support given during the development of this protocol, which was conducted as part of the school curriculum.
References

Appendix I: Assessment of study for eligibility

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Satisfied</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Studies</strong></td>
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<tr>
<td>Qualitative studies that meet the inclusion criteria including, but not limited to, designs such as phenomenology, grounded theory, action research and exploratory studies.</td>
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<tr>
<td><strong>Type of participants</strong></td>
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<tr>
<td>Adult patients with cancer in patient navigation program.</td>
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<td>Years are unlimited</td>
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<tr>
<td><strong>Inclusion</strong></td>
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<tr>
<td>Adult cancer patients more than 18 years of age who are receiving or have received cancer care and are in a patient navigation program or had been in a hospital patient navigation program</td>
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<tr>
<td><strong>Exclusions:</strong></td>
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<tr>
<td>Studies surrounding patient navigation program targeted at the following: improving screening rates for cancer; timeliness from positive screening to diagnosis; and recruitment and retention for clinical trial</td>
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<tr>
<td><strong>Phenomena of Interest</strong></td>
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<tr>
<td>Patient navigation programs in hospital</td>
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<td><strong>Type of outcome measures</strong></td>
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<td>Patients’ experiences</td>
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<td>Impact on cancer care continuum</td>
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</table>
Appendix II: PRISMA 2009 flow diagram for studies selection

Records identified through database searching
(n = )

Additional records identified through other sources
(n = )

Records after duplicates removed
(n = )

Records screened
(n = )

Records excluded
(n = )

Full-text articles assessed for eligibility
(n = )

Full-text articles excluded, with reasons
(n = )

Studies included in qualitative synthesis
(n = )
Appendix III: Appraisal instruments

QARI appraisal instrument

**JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research**

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not Applicable</th>
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</thead>
<tbody>
<tr>
<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</td>
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<td>2. Is there congruity between the research methodology and the research question or objectives?</td>
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<td>3. Is there congruity between the research methodology and the methods used to collect data?</td>
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<td>4. Is there congruity between the research methodology and the representation and analysis of data?</td>
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<td>5. Is there congruity between the research methodology and the interpretation of results?</td>
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<td>6. Is there a statement locating the researcher culturally or theoretically?</td>
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<td>7. Is the influence of the researcher on the research, and vice-versa, addressed?</td>
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<td>8. Are participants, and their voices, adequately represented?</td>
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<td>9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?</td>
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<td>10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
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Overall appraisal: [ ] Include [ ] Exclude [ ] Seek further info. [ ]

Comments (Including reason for exclusion)

________________________________________________________________________
________________________________________________________________________
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Appendix IV: Data extraction instruments

QARI data extraction instrument

**JBI QARI Data Extraction Form for Interpretive & Critical Research**

<table>
<thead>
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<th>Reviewer</th>
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<tr>
<td>Author</td>
<td>Year</td>
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<tr>
<td>Journal</td>
<td>Record Number</td>
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**Study Description**

Methodology

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Method

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Phenomena of interest

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Setting

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Geographical

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Cultural

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Participants

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Data analysis

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Authors Conclusions

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Comments

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Complete: Yes ☐ No ☐
<table>
<thead>
<tr>
<th>Findings</th>
<th>Illustration from Publication (page number)</th>
<th>Evidence</th>
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<td>Unequivocal Credible Unsupported</td>
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Extraction of findings complete  Yes [ ]  No [ ]