The development and testing of patient reported outcomes – Cancer Instrument

Research Team:

Dr Carol Reid, Griffith University. Australia
Professor Alexandra McCarthy, University of Auckland, New Zealand
Professor Monika Janda, The University of Queensland, Australia
Lee Jones, Queensland University of Technology, Institute of Health and Biomedical Innovation (IHBI)
Introduction

- In Australia, PROMs are an emerging method of assessing the quality of health care. They are not yet embedded in routine measurement at regional, jurisdictional or national level.

- Internationally, such routine and consistent measurement is being developed or is already embedded in the health systems of several Organisation for Economic Co-operation and Development (OECD) countries.\(^1\)
Introduction (continued)

- Patient-centred approaches, through actively working with consumers to ensure their needs are being met, can result in improved safety, quality and cost-effectiveness, as well as improved patient and staff satisfaction.

- There is clear evidence that: ‘...patient centred care has significant benefits associated with clinical quality and outcomes, the experience of care, the business and operations of delivering health services, and the work environment’\(^2\).
Version 2 of the National Safety and Quality Health Service (NSQHS) Standards is under development by the Commission. Emphasis throughout Version 2 is on the achievement of a greater level of patient-centeredness in health service organisations. This should also assist in the evaluation of the outcomes of treatments and services.
Patient feedback and involvement in service design and delivery is a prerequisite to inform streamlined and responsive cancer care⁴.

Globally, Cancer health care services do not routinely or robustly assess patient-reported outcomes to evaluate the care they provide despite their agreement with the ideals of patient-centred care in accordance with Institute of Medicine (IOM) domains³.
Background continued

- According to the IOM, these domains encompass the following principles:
  - Respect for the values, preferences and expressed needs of patients
  - Coordination and integration
  - The provision of information, communication, and education
  - Ensuring physical comfort
  - The provision of emotional support and relieving fear and anxiety
  - Involving family and friends in care\(^5\).
Background (continued)

- The endorsement of these factors by the IOM reflects increasing recognition at political and service levels that ensuring optimal outcomes is not the exclusive domain of health professionals.

- Consumers and their carers have the right and responsibility to understand what is required for their care, how they could self-manage their care if they choose to do so, and to be involved in decision-making processes if they wish.
Background Continued

- Patient feedback ideally captures patients’ individual perceptions of the quality of care provided\(^5\).
- Patient self-reported outcomes are considered the most pertinent means with which to collect these data\(^5\).
- The Institute of Medicine (IOM)\(^5\) recommends that care be measured across the six (6) domains in order to comprehensively evaluate its quality and whether it meets patient needs\(^5,6\).
So why is this important?
Background Continued

- The IOM argues that cancer-specific patient-reported outcome measures need to be developed and then *routinely used to evaluate and inform* service changes to enhance the quality of care for cancer patients⁵.
There are many tools available for measuring specific cancer groups.

- You may know some of these already:
  - APECC
  - Cancer Care Coordination Questionnaire for Patients
  - Cancer Patient Information Importance and Satisfaction Tool
  - EORTC IN-PATSAT
  - Indicators (Head & Neck Cancer)
  - Indicators (Non-small Cell Lung Cancer)
    - ✓ ✓ ✓ ✓ ✓ ✓
  - PainCQ
  - Patient Satisfaction with Cancer Care 7
We have developed the Patient Reported Outcomes–Cancer (PRO-C) instrument in response to these issues.

The PRO-C is designed to measure the IOM domains in the cancer care setting.
Goal of the study

- This is the second study in this program of research

- The goal was to design a brief, reliable and flexible measure that met IOM recommendations for outcome measurement in cancer care.

- It is the first time that such a measure has been developed.
Aims

- The **aim** of this study was, through exploratory factor analysis and confirmatory factor analysis, to examine the psychometric properties of the PRO - C in a typical cohort of ambulatory cancer patients treated at Cancer Services, in a large quaternary hospital in Australia.
Objectives

- The objectives are to determine the
- a) dimensionality
- b) construct validity,
- c) internal consistency reliability, and
- d) test-retest reliability of the PRO - C.
Sample and Sample size

- **Sample:**
  - Adults > 18 years attending ambulatory chemotherapy or radiotherapy clinics at hospital with a new or recurrent diagnosis of any cancer.

- **Sample size:** A sample size of 330 participants was required for the study. (10 participants per item on the scale plus attrition rates)

- 414 participants were recruited.
Methods: Recruitment

- Following HREC approval:

- Ambulatory clinics in the cancer service were chosen to recruit the participants.

- A Project Officer was responsible for the recruitment and data collection.
PRO – C Instrument

- There are 28 IOM domain-specific items.

- Scale of 1-10 (where 1 = strongly disagree, 10 = strongly agree).

- The numbers and examples of statements in each domain include:

  - Respect for the values, preferences and expressed needs of patients (8 items: e.g., I was involved in decision-making about my treatment; My preferences were respected).

  - Care coordination and integration (4 items: e.g., The health professionals involved in my care coordinated the different aspects of my care well; The health professionals involved in my care communicated with each other well).
PRO – C Instrument

- The provision of information, communication, and education (5 items; e.g., I understand what is likely to happen over the course of my treatment; The different health professionals involved in my care always gave me similar information).

- Ensuring physical comfort (4 items; e.g., My physical needs were managed within a reasonable time; The care I received helped me to more easily undertake my normal daily activities).

- The provision of emotional support and the relief of fear and anxiety (4 items: e.g., My concerns about my cancer were discussed; My concerns about the financial impact of my treatment were discussed).

- Involving family and friends in care (3 items e.g., My family and friends were made to feel welcome; My family and friends were able to meet with members of the health care team to discuss their concerns about my care).
METHODS: Data Analysis

- **The PRO - C instrument: Phase 1** of the PRO - C was tested for:
  - Face and content validity (with 10 clinicians and 30 chemotherapy patients)
  - Content validation index (CVI), with all items achieving an excellent CVI between 75-100%.
  - The PRO - C’s acceptability and feasibility were also determined, in terms of time taken to complete (usually 5-10 minutes) and number of missing questions (none).
Data Analysis (continued)

- PRO - C instrument development, **Phase 2:**

- 414 patients were recruited to confirm the dimensionality of the PRO - C using exploratory factor analysis. The response rate was 70%.

- The original study recorded standard patient demographics and medical history.

- Data analysis was completed in June 2017.
Results

- Preliminary results show the PRO - C assumptions underpinning the domain structure are sound with the six domain α’s ranging from 0.73 to 0.8
- 24 of the 28 domain-specific items fit the hypothetical model well.
- The four items that did not load in the exploratory factor analysis have been revised
- All 28 items have been modified from the original 1-10 range of responses to 1-5,
- The ‘not applicable’ option was deleted.
Conclusion

- The PRO-C is the first instrument to measure patient-reported outcomes in the cancer chemotherapy setting according to IOM recommendations.

- The next step in PRO-C development is to confirm instrument reliability.

- This procedure will indicate the instrument’s local relevance, and its potential to guide interventions in cancer service redesign, irrespective of service context.

- This will enable responsive, timely service redesign.

- If the PRO-C proves reliable, it could be digitised and linked to patient records.
Conclusion (continued)

- Importantly: The PRO - C has the potential to guide cancer service interventions and redesign, irrespective of where care is delivered, in a way that is responsive to patients’ needs.

- If validated for this population, the PRO - C is expected to support ACSQHC V2 standards (due in 2019) because it is well known, “Patient centred care has significant benefits associated with clinical quality and outcomes, the experience of care, the business and operations of delivering health services, and the work environment”.
Conclusion (continued)

- Phase 3 (Further testing of the tool) of the study is about to commence in New Zealand

- Phase 4 (Further testing of the tool) is about to commence in Australia.
References


Thank you