

Diary Interventions and Self-monitoring Behaviours in Cancer Survivors. A Rapid Scoping Review Protocol

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Contributions: YE developed main sections of the protocol within the full ENABLE project submitted to the Funder, and revised by co-applicants BN, RE and DS. The present version, revised by YE and JC, follows the requirements of the Joanna Briggs Institute for a scoping review protocol.

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INTRODUCTION

Rationale:

Self-management encompasses an individual's capacity to regulate the symptoms, therapeutic interventions, and the effects including lifestyle adaptations associated with chronic diseases. Barlow adds that 'Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life' [1, p.178].

Self-monitoring tools such as diaries are one of the strategies used to promote self-management behaviours, providing patients with opportunities to reflect on behaviours, raising awareness of symptoms, keeping track of activities or symptoms in real time, facilitating patients' discussions with healthcare professionals, and allowing healthcare professionals to provide suitable advice and support [2-5]. There are different types and modalities of diaries (pen and paper, mobile, and internet) variously being developed for disease-related symptoms, medication, sleep, anxiety and depression, and lifestyle interventions (physical activity and diet). Diaries for cancer patients have been used during primary curative treatment, cancer survivors, and for advanced stages and palliative care.

Currently, much of literature reviews for diaries have focused on its use for patients in intensive care units, but there are no reviews specifically about the use of diaries for

cancer patients. The ENABLE study [6] concentrates on breast cancer patients living with and beyond cancer, known as cancer survivors. The National Cancer Survivorship Initiative (2008) defined a cancer survivor as someone who: has completed initial cancer management and has no apparent evidence of active disease; or is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness (last six months of life); or has had cancer in the past [7].

The purpose of this review is to identify evidence that can be shared and help discussions at two co-design workshops with breast cancer patients and community pharmacists. The workshops will develop an intervention, a patient diary, to support patients in their self-management behaviours and discussions on medication brand changes with community pharmacists. Findings will be used to inform workshop discussions about the most suitable information-recording items for patients to monitor symptoms, enhance self-efficacy, and receive adequate counselling in medication consultations. Additionally, findings will refine the preliminary guiding principles, behavioural analysis and logic model of the intervention development following the Person-Based Approach [8].

Rapid scoping reviews are most pertinent for intervention development studies due to their exploratory nature and ‘broader scope’ to determine what kind of evidence is available on a topic drawing on heterogeneous sources [9]. Given the nature of extant literature and the time constraints for reviewing the evidence, a rapid scoping review is a suitable review method to synthesise the available evidence. This protocol conforms to the five-stage framework laid out by the Joanna Briggs Institute for developing a scoping review protocol [10] which is mapped against items in the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols Checklist (PRISMA-P).

Objective:

This review aims to identify the best available evidence on the use of diaries for cancer patients after active treatment. Findings will inform the co-development of a symptom diary intervention for breast cancer patients to improve medication consultations about hormone therapy brand changes. ENABLE study [6].

What patient diary interventions are available to support self-monitoring behaviours (Co) in cancer survivors (P) after active treatment (C)?

P (population), Co (concept), C (context) framework.

Objectives are to:

- 1) identify and summarise the findings of existing studies on the use of self-monitoring diaries in cancer survivors;
- 2) examine key diary components and outcomes

- 3) identify limitations and gaps in this literature;
- 4) identify practice implications for the use of self-monitoring diaries in cancer survivors

METHODS

Eligibility criteria

Types of participants: Adults who have completed primary treatment for cancer and participated in studies using patient diaries considered likely to be applicable or adapted to hormone therapy for breast cancer. Articles excluded: studies of children and adolescents, palliative care, studies during primary treatment and immediate post treatment rehabilitation.

Concept: the overarching concept of interest is patient diary interventions designed for self-monitoring behaviours in cancer survivors. Further elements of relevance to this review are intervention components and data on people's experiences, views, usability and acceptability. This review will also identify and map adherence and QoL outcomes. Articles excluded: interventions where diaries are used solely with the purpose of reporting symptom scales, episode frequencies (e.g. pain, hot flushes) or tracking time or activities performed, without eliciting further user engagement (i.e. not intended to facilitate patient self-management behaviours or feedback from healthcare professionals).

Context: Studies published in English in the last 20 years (2004-2024), about interventions taking place in primary care settings.

Types of studies: Published peer-reviewed journal articles including systematic reviews, Delphi studies, design and evaluation of interventions, including qualitative, quantitative and mixed-method studies. Pre-prints, conference abstracts and grey literature will be excluded.

Information sources

It will include systematic reviews and primary studies of any design and searches of titles and abstracts in the following electronic databases: Cochrane Library, PubMed, CINAHL, and APA PsycInfo. Due to time constraints, searches will be limited to 1st August 2004 to 31st August 2024. The search terms used for each database will be modified to derive the most meaningful search, using a combination of free text, MeSH and subject headings. Additional key papers will be identified from reference lists, targeted author searches, forward citation searching, and from author expertise.

Search strategy

Search terms

"cancer survivor" OR cancer* OR oncolog* OR post-treatment OR "after treatment"

“self-management” OR “self management” OR “self care” OR “self-care” OR “self-monitor*” OR “self monitor*” OR “self-report*” OR “self report*” OR “self-efficacy”
Adher* OR efficacy OR use OR usability OR accept* OR satisf* OR barriers OR facilitat* OR preferen* OR challeng* OR engagement OR engag*
Diary OR diaries OR “cancer diary” OR “cancer diaries” OR “medication diary” OR “medication diaries” OR “symptom diaries” OR “symptom monitoring diary” OR “patient diary” OR “patient diaries”

Cochrane Library (reviews and trials)

Search #	Concept	Search Terms	Results
#1		((“cancer survivor” OR cancer* OR oncolog* OR post-treatment OR “after treatment”)):ti,ab,kw	244,879
#2		MeSH descriptor: [Cancer survivor] explode all trees	1162
#3		#1 OR #2	332,842
#4		(“self management” OR “self care” OR self NEXT monitor* OR self NEXT report* OR “self-efficacy”):ti,ab,kw	61496
#5		MeSH descriptor: MeSH descriptor: [Self-Management] explode all trees	1378
#6		#4 OR #5	61718
#7		(Adher* OR efficacy OR use OR usability OR accept* OR satisf* OR barriers OR facilitat* OR preferen* OR challeng* OR engagement OR engag*):ti,ab,kw	1105108
#8		MeSH descriptor: [Patient Participation] explode all trees	2196
#9		#7 OR #8	1105657
#10		(Diary OR diaries OR “cancer diary” OR “cancer diaries” OR “medication diary” OR “medication diaries” OR “symptom diaries” OR “symptom monitoring diary” OR “patient diary” OR “patient diaries”):ti,ab,kw	19710
#11		#3 AND #6 AND #9 AND #10	345

Study records

Data management: Citations generated from the search will be stored and managed in Zotero and duplicates will be removed.

Selection processes: Initial screening of all titles and abstracts identified against the inclusion criteria will be conducted by the primary reviewer (JC) with a second reviewer (YE) screening 20%. Disagreements will be resolved through consensus with a third reviewer. The primary reviewer will obtain and read the full text of selected articles and assess suitability for inclusion, with a second reviewer (YE) assessing a random 20% of studies. Unresolved disagreement will be subject to third party review. Reasons for exclusion of studies will be recorded.

Data collection process and data items: The primary reviewer will extract the data using a Microsoft Excel data extraction sheet. YE will check at least 20% of a random sample of extractions for accuracy. Extraction sheet will include:

1. Author, date of publication and country
2. Study design and methodology
3. Cancer type
4. Participant no (sample size)
5. Intervention aim/type
6. Intervention components
7. Diary type/medium
8. Potential barriers and facilitators
9. Behavioural theory used
10. Key findings

Outcomes and prioritization: As this is a rapid scoping review quantitative meta-analysis will not be conducted. Only presentation of intervention outcomes in a descriptive format will be provided to highlight levels of adherence, acceptability or engagement.

Risk of bias: Not usually conducted in scoping reviews.

Scoping synthesis: Analysis of extracted data will initially be descriptive, using coding and tables with key sections of relevance for the study: findings on diary format; self-reporting components; behavioural theory used, barriers and facilitators experienced by patients; healthcare professionals' perspectives; and summary of outcomes (QoL and adherence). To synthesise the descriptive results, analytical themes will be developed

to align findings with the key objectives of the study [11]. This approach will be suitable to synthesise findings from different research designs and with a view to interpret how self-monitoring diaries can effectively support cancer survivors. Themes will be presented in a table and graph to aid interpretation.

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