ABSTRACT

Introduction Patient-centred care is valued by patients and providers. As management of cancer becomes increasingly complex, the value of providing care that incorporates an individual’s values and preferences along with demographic and tumour factors is increasingly important. To improve care, patients with cancer need easily accessible information on the outcomes important to them. The patient-centred outcome, days at home (DAH), is based on a construct that measures the time a patient spends alive and out of hospitals and healthcare institutions. DAH is accurately measured from various data sources and has shown construct validity with many patient-centred outcomes. There is significant heterogeneity in terms used and definitions for DAH in cancer care. This scoping review aims to consolidate information on the outcome DAH in cancer care and to review definitions and terms used to date to guide future use of DAH as a patient-centred care, research and policy tool.

Methods and analysis This scoping review protocol has been designed with joint guidance from the JBI Manual for Evidence Synthesis and the expanded framework from Arksey and O’Malley. We will systematically search MEDLINE, Embase and Scopus for studies measuring DAH, or equivalent, in the context of active adult cancer care. Broad inclusion criteria have been developed, given the recent introduction of DAH into cancer literature. Editorials, opinion pieces, case reports, abstracts, dissertations, protocols, reviews, narrative studies and grey literature will be excluded. Two authors will independently perform full-text selection. Data will be extracted, charted and summarised both qualitatively and quantitatively.

Ethics and dissemination No ethics approval is required for this scoping review. Results will be disseminated through scientific publication and presentation at relevant conferences.

INTRODUCTION

Patient-centred care is important and desired by patients and providers. It is a holistic approach to healthcare that seeks to treat patients as unique individuals by incorporating patient and family values, perspectives and expectations into a shared decision-making model. Patient-centred care was initially introduced over 50 years ago as a contentious shift in philosophy of care. Today, there is clear consensus across major medical organisations and institutions on its utility and value in reaching the goal of high-quality care. Accordingly, the WHO has released a global strategy towards improved healthcare by focusing on ways to implement patient-centred care. The value of patient-centred care as a philosophy is no longer disputed, but challenges remain in ensuring care is delivered with this framework in mind.

In oncology, the value of providing patient-centred care resides in tailoring care to individual goals and needs that are known to vary according to demographics, tumour biology, values and preferences. In addition, many patients with cancer prefer being active participants in shared decision making. To improve care provided to patients with cancer by leveraging principles of patient-centred care, clinicians need accurate metrics that are meaningful to both patients and providers to support counselling, decision-making and preparedness for treatments.

The patient-centred outcome, days at home (DAH), is meaningful to patients and
accurately measured, and has construct validity for many provider-important and patient-important outcomes.\textsuperscript{11–13} DAH assesses the time a patient spends alive and out of hospitals and healthcare institutions and is measured in units of days, a metric that is simple and understood by patients and providers. DAH relates to the construct of time toxicity, a concept emerging in oncology from recognition of the significant time spent attending treatments, appointments or managing toxicities from therapy.\textsuperscript{14} The outcome DAH was first used in 2005 in a randomised control trial in the field of cardiology, being introduced only recently into the oncology literature.\textsuperscript{15 16} Since its first use, DAH has been shown to have construct validity with many traditional outcome measures such as morbidity and mortality, along with other patient-centred outcomes.\textsuperscript{11 12 16 17} Given that measurement of DAH is feasible using various data sources, from trials to administrative health data, it has potential to be a meaningful research, policy and clinical tool in cancer care.

Several terms have been applied to the construct captured by DAH in the literature including but not limited to DAH, time at home, days spent at home, days alive and out of hospital, days alive and at home, home time and healthy DAH.\textsuperscript{11–13 16 18–20} Accordingly, definitions have been inconsistent. In addition, some researchers opt to measure its inverse, which has been termed institution days or time toxicity.\textsuperscript{14} The heterogeneity in both terms used and definitions point to the need for a better understanding of its use to date to inform future applications. A preliminary search for existing reviews on the construct captured by DAH was performed on 25 October 2022 on MEDLINE with no prior reviews retrieved. Therefore, we aim to perform a scoping review to consolidate the current information on the patient-centred outcome DAH in cancer care, review outcome definitions and provide an overview of how it has been used in the oncology literature to date. This work is conducted with a view to guide future use of the outcome DAH in patient-centred cancer research, clinical decision making and policy, such as quality monitoring and resource allocation.

### Table 1 Inclusion and exclusion criteria.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcome</td>
<td>Measurement of outcome ‘DAH’ or equivalent* No measurement of outcome DAH or equivalent*</td>
</tr>
<tr>
<td>Exposure</td>
<td>Include all interventions along the cancer care continuum following a diagnosis including systemic therapy, radiation therapy and surgery Interventions outside of the context of cancer care</td>
</tr>
<tr>
<td>Population</td>
<td>Age ≥18 years Active or prior diagnosis of malignancy Age &lt;18 years No cancer diagnosis</td>
</tr>
</tbody>
</table>

*Defined as a composite outcome, recording time a patient spends alive and out of hospitals and institutions. Inverse measures recording time spent in hospitals and institutions will also be included. DAH, days at home.

### Table 2 MEDLINE search strategy

<table>
<thead>
<tr>
<th>Search number</th>
<th>Terms and subject headings</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(Days at home or time at home or “days alive and out of hospital” or “days alive and out of the hospital” or “days alive out of hospital” or days alive out of the hospital or days alive at home or “days alive and at home” or home time or healthy days at home or time spent at home or “time spent alive and out of hospital” or “time spent alive and out of the hospital” or “time spent alive and at home” or time toxicity or opportunity cost* or institution day* or institution time or time in institution* or time spent away from home or time spent away from the home)). tw,kf.</td>
<td>2978</td>
</tr>
<tr>
<td>2</td>
<td>exp Neoplasms/</td>
<td>3763405</td>
</tr>
<tr>
<td>3</td>
<td>(cancer* or tumo?r* or malignan* or mass or neoplasm*).tw,kf.</td>
<td>3946538</td>
</tr>
<tr>
<td>4</td>
<td>2 or 3</td>
<td>5131651</td>
</tr>
<tr>
<td>5</td>
<td>1 and 4</td>
<td>342</td>
</tr>
</tbody>
</table>
METHODS AND ANALYSIS
This scoping review protocol has been designed with joint guidance from the JBI Manual for Evidence Synthesis and the expanded framework from Arksey and O’Malley.²¹–²³ Reporting of the scoping review will adhere to the Preferred Reporting Items for Systematic reviews and Meta-Analyses Extension for Scoping Reviews.²¹ ²⁴ This review has been registered with Open Science Framework (https://osf.io/xzpj7).

Objectives
The scoping review will answer the following research questions:
► How has the construct ‘DAH’ been termed and defined as an outcome in cancer care?
► How has the construct DAH been used as an outcome measure in cancer care?
► In what context has DAH been validated in cancer care?

Eligibility criteria
See table 1 for inclusion and exclusion criteria. The relatively recent introduction of this construct into the scientific literature necessitates broad inclusion criteria to have wide capture of what has been reported on to date.

Population
The population of interest includes studies reporting on adults (≥18 years) with a current or past cancer diagnosis. All cancer types will be included.

Concept
The outcome DAH is inconsistently termed and defined in the literature. For the review, DAH has been defined as a composite outcome, recording the time a patient spends alive and out of hospitals and healthcare institutions. Healthcare institutions include oncology centres, emergency departments, rehabilitation centres, long-term care homes and other healthcare facilities. The use of the term DAH in this review refers to all variables measuring the same construct, acknowledging the variability in terms and definitions used. We will also include studies measuring the inverse of DAH, such as institution days, which speaks to the same underlying construct. DAH may be operationalised as a continuous variable or as a proportion of a predefined number of days. The definition used for this review seeks to encompass all applications of a construct that uses hospital and healthcare institution days as a patient-centred metric to reflect the overall treatment burden on patients.

Context
To capture literature studying the outcome DAH in cancer care; studies evaluating any interventions in the diagnosis, management and follow-up of cancer care will be included. This will include all forms of systemic therapy, radiation therapy and surgery for the purposes of cancer treatment.

Study details
A broad list of study designs will be included. We will include randomised and non-randomised trials, prospective and retrospective cohort studies, case–control studies, cross-sectional studies, quasi-experimental studies and case series of 10 or more participants. There will be no publishing year restrictions. Grey literature will be excluded. All geographical regions and languages will be included; however, the literature search will only be performed in English.

Search strategy and information sources
The search strategy was developed for MEDLINE through consultation with a librarian at the University of Toronto. The search was adopted with aid from a librarian for use in two additional databases: Embase and Scopus. Additional text words may be added to the search in an iterative manner as reviewers explore the evidence base. A list of text words were chosen based on a preliminary literature
review. Terms analogous to DAH were included to ensure broad capture. See table 2 for the full search strategy for MEDLINE. Search strategies for additional databases are provided in the online supplemental tables. The search is proposed to be completed between 1 January 2023 and 1 March 2023.

Study selection

Study selection will follow guidelines as set out by the *JBI Manual for Evidence Synthesis* and the expanded Arksey and O’Malley framework. An initial pilot testing phase of eligibility criteria will be completed on a random sample of 25 titles and abstracts by two independent reviewers. The team of reviewers will review selection results, discuss discrepancies and modify eligibility criteria as necessary. Management of search results will be completed via Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia). Once inter-rater reliability of 75% or greater is achieved, study selection will begin. The first stage of study selection will involve title and abstract examination based on inclusion and exclusion criteria by two independent reviewers. The second stage will involve full-text review by two independent reviewers. Disagreements between both stages will be addressed through consensus or by consultation with the research team. Inclusion and exclusion criteria will be reviewed and may be modified following the pilot testing phase and iteratively throughout the search during research team meetings. See figure 1 for study selection flowchart.

Data extraction

Data extraction tables have been designed by the research team with guidance from the *JBI Manual for Evidence Synthesis* and Arksey and O’Malley with research objectives in mind. See table 3 for preliminary extraction tables. Data extraction will follow an iterative process as outlined by expert guidelines, with updates to tables as deemed necessary by the research team. As a pilot step, two independent reviewers will extract data from the first 10 studies into preliminary tables, as recommended by expert guidance. Results from pilot data extraction will be reviewed by the research team, and changes to the tables will be made as necessary, guided by research objectives.

Data analysis

In keeping with scoping review objectives and methodology, data analysis will include a descriptive numerical analysis followed by a thematic analysis. A descriptive numerical summary using tables and charts will describe proportions of study characteristics as guided by study objectives and data extraction. Key study characteristics will include study design, aims and validation. The nature and distribution of studies assessing the outcome DAH will provide insight into its scope and use in the cancer literature to date. Potential implications on research, policy or clinical use will be discussed.

Patient and public involvement

Patient and service user engagement is known to enhance the relevance, validity, quality and applicability of research. Patients and service users are essential partners in research, not only providing unique insight into lived experience of illness but also helping to determine research plans and outputs. Following the patient and service user engagement framework, we have engaged patients, service users, healthcare professionals (HCPs) and health decision makers to obtain additional sources of information, perspectives and applicability to the study. Two patient partners with lived experience of cancer (EK and JD) are members of the research team and have been involved from inception and will participate in all parts of the study to ensure clinical relevance. Consultations with stakeholders will also be used to share preliminary findings, validate and identify any gaps in our findings, and to inform future research efforts.

Ethics and dissemination

This scoping review protocol outlines a method to systematically search and map the literature on DAH for cancer care. Since this review will only include published data, ethics approval will not be sought. This scoping review will constitute the first stage in developing clinical tools to integrate DAH information into cancer care. Terminology, definitions and measures of DAH will inform the building of predictive tools and decision aids for personalised cancer care delivery. This is necessary to create tools that go beyond typical prognostication and provide patients with information on outcomes that are most relevant to their experience to support decision making and preparedness for treatment. Moreover, the information generated by this review can also be used by health systems, patient organisations, researchers and HCPs to plan cancer care delivery, clinical trial design and conduct, and assessment of health services.

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Contributors TR, AB-S, NGC and JH conceived the idea and developed the research questions and study methods. TR and JH drafted the protocol. TR and AB-S conceived and executed the search strategy. TR, AM, AJ, AB-S, VB, AAB, FCW, EK, JD, NGC and JH contributed meaningfully to the editing and critical review of this protocol and approved the final manuscript.

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Patient and public involvement  Patients and the public were involved in the design, conduct, reporting or dissemination plans of this research. Refer to the Methods and analysis section for further details.

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Ethics approval  Not applicable.

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REFERENCES


