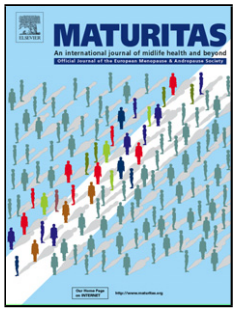
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# Advance care planning within survivorship care plans for older cancer survivors: a systematic review.

Running head: Advance care planning in older cancer survivors.

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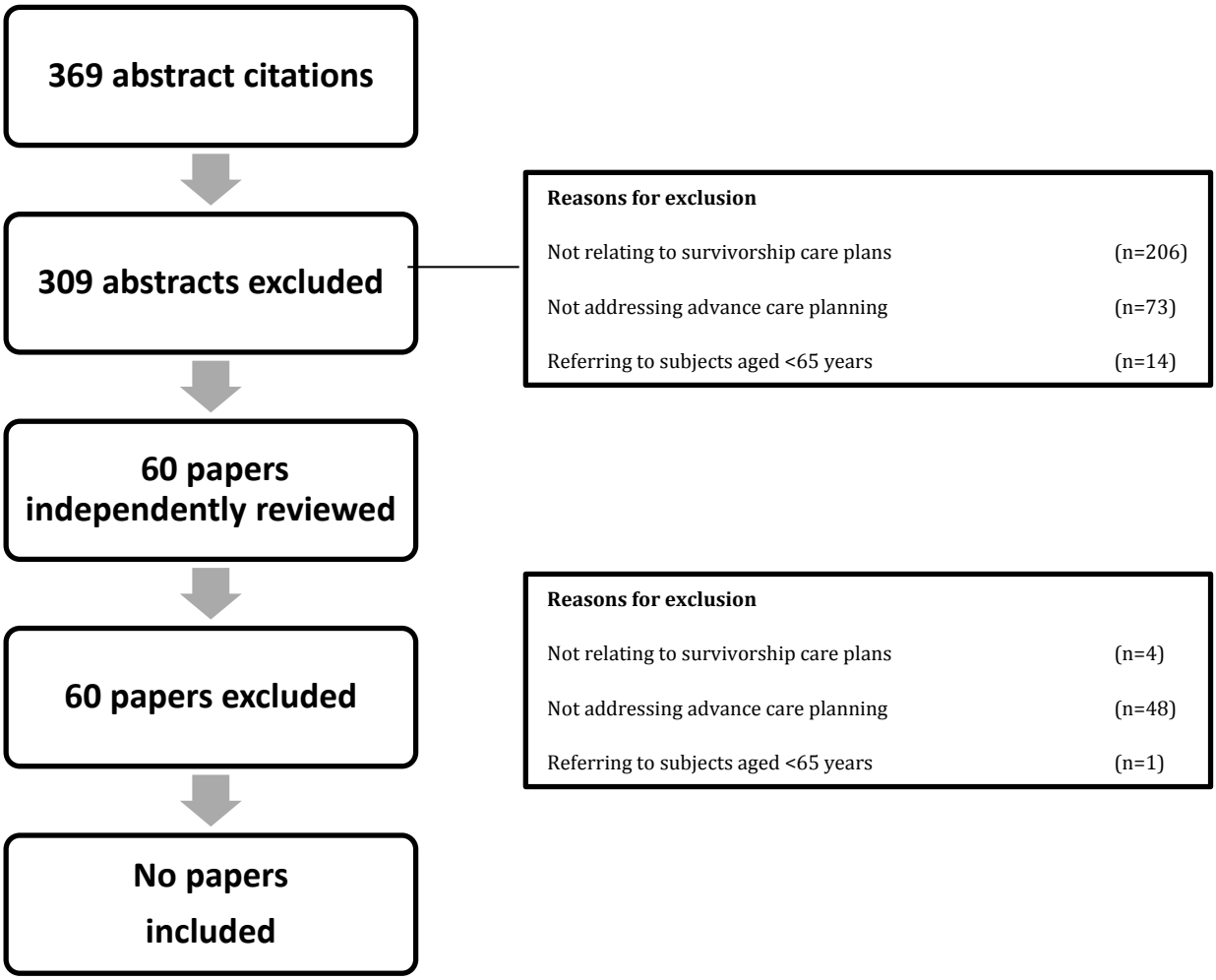
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**Graphical abstract: Advance care planning within survivorship care plans for older cancer survivors: a systematic review.**



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**Highlights**

- We reviewed the evidence for advance care planning, including advance care directives in survivorship care plans, among older cancer survivors.
- No papers were found that met inclusion criteria, with only one survivorship care plan including mention of an advance care directive.
- Despite increasing numbers of older and frail cancer survivors, there is little evidence for the use of advance care planning after cancer.
- Future studies should establish their acceptability and utility among older cancer survivors.

## Abstract

Advances in the medical treatment of cancer have increased the number of survivors, particularly among older adults, who now represent the majority of these. Survivorship care plans (SCPs) are documents that cancer patients receive summarising their care, usually at the end of treatment but preferably from initial diagnosis. These may increase patient satisfaction and represent an opportunity to initiate preventative strategies and address future care needs. Advance care planning (ACP), incorporating advance healthcare decision-making, including formal written directives, increases satisfaction and end-of-life care. This paper systematically reviews evaluations of ACP within SCPs among older (≥65 years) cancer survivors. No studies meeting the inclusion criteria were identified by search strategies conducted in PubMed/MEDLINE and the Cochrane databases. One paper examined cancer survivors' mainly positive views of ACP. Another discussed the use of a SCP supported by a 'distress inventory' that included an advance care directive (living will) as an issue, though no formal evaluation was reported. Although ACP is important for older adults, no study was found that evaluated its role within survivorship care planning. Despite the risk of recurrence and the potential for morbidity and mortality, especially among older cancer survivors, ACP is not yet a feature of SCPs.

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**Keywords:** advance care planning; survivorship care plan; cancer survivors; older adults; advance care directives; systematic review.

## Introduction

With improved treatment more patients are surviving cancer [1]. This includes older patients, who now represent the majority of cancer survivors [1,2]. Robust post-cancer treatment should involve multi-modal, tailored supports that address individual's needs and predicted risks [3], especially in the case of older patients who have different requirements to younger cancer survivors [4]. Providing cancer survivors with information in the form of a survivorship care plan (SCP) is important to improve and enhance delivery of this care. While useful for patients of all ages, survivorship care planning may be particularly important for older adults who because of higher levels of frailty [5] and multi-morbidity [6] have increasingly complex care needs.

SCPs, either written or delivered in an computerised (online) format (e.g. the LIVESTRONG$^{TM}$ SCP developed in 2007), function as a communication tool to enhance person-centred quality of care, collaborative decision making and post-treatment surveillance, and were recommended for all cancer survivors in the United States Institute of Medicine report '*From cancer patient to cancer survivor: Lost in the Transition*' [7] and more recently by the American College of Surgeons Commission on Cancer [4]. Reflecting this, centres in North America have the most experience with survivorship care planning though they are now in use in many countries [8]. SCPs improve engagement with patients' general practitioners [9, 10], facilitate discussion between patients and their families [10, 11] and are associated with higher levels of satisfaction [12], knowledge [13] and self-reported understanding by survivors [11,12].

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Elements perceived as being important by patients to incorporate into a SCP include a watch list of symptoms and signs, a treatment summary and preventative healthcare recommendations [14,15], though only half of SCPs provide all these elements and often without sufficient detail [8]. Despite recommendations from several bodies, their proposed potential benefits and a near universal desire among survivors for information in the form of a SCP [15,16], few patients report having received one [15]. Use varies from as high as 35% of American women with breast cancer in one centre surveyed between 2004 and 2011 [17], to less than 20% of a sample of patients with different cancers in a study in Australia [15] to only 11% in an American sample of brain tumour survivors [18]. This may be because the evidence behind their effectiveness remains unclear [12]. In particular, while suggested, there is no definitive evidence that they increase uptake of recommended surveillance screening [19] or that they improve outcomes for cancer survivors [12]. Some studies indicate that they may even increase anxiety, perceived symptom burden and unnecessary contact with healthcare professionals [20].

Despite the need for positivity in the face of a cancer diagnosis, it is also important for healthcare professionals and patients to be cognisant that cancer survivorship, particularly for older patients, is associated with reduced life expectancy with 40% of patients living less than five years after diagnosis [21]. Further, cancer survivorship is not defined by success of treatment and SCPs are also recommended for those with a new diagnosis or those with advanced stage disease living with cancer [22]. Many of those who progress or experience recurrence will receive palliation or end-of-life care and will be required to make decisions surrounding treatment, though they may often lack the ability to do this by that stage [23]. Advance care planning (ACP), which involves communication between individuals, families and professionals, to support, discuss and plan for future healthcare decisions in the event that an individual loses capacity [24], can help reduce the burden on patients and proxy decision

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makers. ACP may result in the completion of an advance care directive (ACD) reflecting the persons' preferences for their healthcare including end-of-life care in writing, if and when that time comes. Based on the limited evidence, ACP improves patient and relative satisfaction, the quality of death and dying, while respecting autonomy [24], and is generally well received by both patients [25] and healthcare professionals [26]. There is also evidence that dedicated ACP programmes such as 'Let Me Decide' are cost effective [27] and may reduce unnecessary healthcare use [28]. Yet, few patients receive ACP or complete an ACD [29].

Despite the increasing use of SCPs, there is very little evidence for the use of survivorship care planning in older patients with cancer [4]. Given this and the growing recognition of the importance of ACP in those with potentially life limiting conditions, the objective of this systematic review is to summarise the evidence for the inclusion of advance care planning decisions and ACDs within SCPs among older cancer survivors.

## Methods

### Search Strategy and Selection Criteria

A systematic review of the literature was conducted using PubMed/MEDLINE and the Cochrane Central Register of Controlled Trials. The search was conducted before March 2017. Databases were searched using the following search terms, which are detailed further in Table 1:

Advance directive* OR Advance care directive* OR Healthcare directive* OR Health care directive* OR Advance care plan* OR Advance care decision* OR Patient care plan* OR Care plan* OR Nursing care plan* AND Cancer* OR Oncology OR Neoplasm* AND Survivor* OR "Survivorship care plan*" AND Elderly OR Aged OR Older adult* OR Older person* OR Geriatric*.

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The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used [30].

Papers were included if they met all the following criteria:

(i) An original study excluding case studies, letters to the editor or conference proceedings. Review papers or those describing the results of surveys of opinion were searched for relevant papers,

(ii) Describing the evaluation of ACP within a multi-faceted SCP or long-term follow-up care plan that specifically includes reference to the process of ACP (i.e. active communication between patients, carers or family members and healthcare professionals that recognise, prepare for, discuss and document (i.e. written ACD) future healthcare decisions. Those presenting a survey of experience or satisfaction with SCPs without reference to ACP were excluded.

(iii) Sampling cancer survivors (across the spectrum of a diagnosis of cancer i.e. from initial diagnosis to those who were undergoing or had completed treatment, which may have included surgery, chemotherapy or radiotherapy, and from patients living with advanced cancer to those in complete remission with 'no evidence of disease' [22], excluding secondary cancer survivors i.e. carers, family and friends), aged ≥65 years (i.e. older adults).

(iv) Reported in English.

The selection of relevant papers is presented in a PRISMA flow diagram in Figure 1. The titles and abstracts of the selected articles were screened for inclusion criteria and the full papers of those meeting these were then reviewed. In total, 369 abstracts were reviewed. No

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duplicates were found. Of these, 309 citations were excluded for different reasons, the most common being that the paper did not relate to SCPs (n=206) or address the issue of ACP if it discussed or evaluated survivorship care planning. Of the remaining citations 60 papers were reviewed.

## Results

No papers met the inclusion criteria for this review i.e. no paper described the evaluation of ACP as part of the wider process of survivorship care planning with older cancer survivors. Two papers, not meeting the criteria, were relevant to the topic. One paper presented the views of ACP among a small sample (n=18) of survivors with a haematological malignancy (leukaemia or lymphoma), surveyed at least six months and up to one year after receiving a haematopoietic cell transplant, which included some older patients (≥65), though the median age was only 47 (range 33-67) years [31]. Of these, all but one discussed some element of ACP and half made a 'living will'. The ACP intervention was not documented as part of a formal SCP. The researchers found that cancer survivors engaging with ACP felt less anxiety. Although half who had discussed mortality with their family found it upsetting, all but one would recommend ACP to those undergoing similar treatment [31].

Another paper describing an American cancer centre's revised action plan with an emphasis on psychosocial concerns, for a small sample of 26 patients, documented the presence of an ACD, included as a 'living will' as an issue coupled with 'power of attorney' in a 'distress inventory' under the heading of 'financial/practical needs' [32]. This inventory was used to support the development and implementation of a SCP. While the SCP was considered by the authors to improve psychosocial care for patients no details were provided on outcomes nor was reference made to the process or utility of recording whether the patient had an ACD as part of survivorship care planning. It was not possible to conduct a

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methodological review to assess the quality of papers, given the lack of data and suitable papers available.

## Discussion

This paper systematically evaluates the evidence for a role for advance decision-making and the implementation of advance care plans or directives within SCPs for older cancer survivors. The results show that there is a paucity of data available on the utility or effectiveness of including ACP and more specifically advance care directives within a SCP. While survivorship care planning has been recommended by several organisations for more than ten years, uptake has been variable and research into the process limited. Further, none of these advocate for the inclusion of ACP discussions or the formal implementation of an ACD [4,7,8,33]. Most studies published on the topic of survivorship care planning focus on surveys of opinion and practice, possibly reflecting the early stages of experience and evidence with using SCPs. The most frequent preventative actions prompted by survivorship care planning were lifestyle changes (diet and exercise) [34] rather than long-term or anticipatory planning for future healthcare requirements.

This review found only one reference to ACP within a SCP [32], although this did not evaluate the SCP. A second paper describing ACP decisions in haematological malignancy survivors did not include reference to survivorship care planning or the use of a SCP [31] and captured the views of a young cohort whose experiences may not entirely reflect those of older patients. However, the study did suggest that ACP is acceptable to most cancer survivors, across a range of age groups from those in their early thirties to late sixties [31].

The field of survivorship care does not as yet appear to place importance on the use of advance directives with cancer survivors. Reflecting this, the validated Cancer Survivors' Unmet Needs (CaSUN) measure, the most widely used measure of unmet need in cancer

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survivors, does not directly include the requirement to make anticipatory decisions or provisions for future healthcare needs [35], though the item "*I need help to try to make decisions about my life in the context of uncertainty*" [36] might suggest that this is something that patients do consider, albeit indirectly. Likewise when surveyed, most requested the inclusion of strategies to deal with the fear of cancer recurrence [37] suggesting that this is something that they are keenly aware of. Advance directives and SCPs are both forms of anticipatory care planning, which can reduce unplanned hospitalisations for older, frail patients [38] and promote autonomy and shared decision-making in those with advanced cancer [39].

The emerging subspecialty of geriatric oncology, already spearheading the use of comprehensive geriatric assessment (CGA) in older cancer patients [40] is likely to act as a catalyst for introducing the discussion and encouraging the uptake of ACDs as part of SCP. The Cancer and Ageing Research Group in collaboration with the National Cancer Institute and the National Institute on Ageing have recently advocated this approach, recommending the development of standardised SCPs for older cancer survivors based on CGA [41]. Although the evidence is yet to be established, studies examining the effectiveness of geriatric assessment are on-going and will likely help establish the role of CGA in promoting positive outcomes among these patients [41]. However, these do not as yet include ACP [41], despite the shorter life expectancy and high levels of co-morbidity [42,43,44] and reoccurrence in older patients with some cancers [45]. Indeed, few if any guidelines specifically address these issues in older cancer survivors [44]. This is despite the fact that evidence suggests that those with comorbidity had a greater desire for additional information [46].

Several challenges exist to the use of SCPs that have implications for the introduction of advance directives. The most important of these are the resource constraints related to the

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manpower, time and costs required to deliver both survivorship care planning [47,48,49] and ACP [26]. A lack of training, experience and confidence among healthcare professional are also barriers to both [26,50,51]. Evidence suggests that like ACP discussions [26], SCPs may not be acceptable to all patients, particularly given that a small minority prefer not to receive any information at end of treatment [15]. The optimal timing of survivorship care planning is uncertain and should be carefully considered, particularly as many older cancer survivors experience anxiety regarding the symbolic nature of a cancer diagnosis in terms of their own mortality and likelihood of recurrence and may not wish to discuss it openly [52]. Three-six months after treatment is suggested as an appropriate timeline [48,53,54], though some advocate that it should be initiated early at diagnosis, well before end of treatment and modified throughout the course of the illness [8,55]. Further, it is unclear if cancer survivors wish to incorporate ACP within SCPs. The construct of survivorship is less clear to many older cancer survivors with some regarding it as opportunity, while others see it is a reminder of vulnerability [56] and a source of anxiety [52]. It may be that survivorship itself is better conceptualised among younger patients whose expectations of treatment and surviving cancer are different to previous generations [56]. Older cancer survivors place emphasis on issues relating to quality of life after cancer [57] with a focus on practical issues, which are included in some but not all SCPs, such as stress reduction, managing concerns regarding recurrence and the impact of cancer treatment on their partner and personal relations [58].

Where survivorship care planning is best delivered is not established with little evidence supporting the superiority of primary or secondary (clinic) care [59], though patients express more confidence in specialists suggesting that advance planning discussions may be best initiated by cancer specialists [60,61]. Community providers require additional resources to implement ACP and are unclear on their role [49]. Thus, advanced nurse practitioners may be best placed to facilitate this and encourage discussion about and uptake

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of both SCPs and ACP in these older cancer survivors, particularly when frailty and multi-morbidity are recognised [54,62]. Personal (face-to-face) contact with trained staff is acceptable and preferable to many patients [63] and has been shown to improve adherence with SCPs [16]. Thus, it could be a useful format for delivering ACP where desired. Improving healthcare professionals training and understanding of survivorship care planning and the role that ACP could have in this is also important [51]. Finally, the optimal vehicle for implementing SCPs with older adults is also unclear. Although Information technology (web-based applications) solutions already support the implementation of survivorship planning and are now replacing written SCPs [23], the use of these approaches has not been documented for older survivors. Nevertheless because of complex and fluctuating health states older survivors may benefit most from the regular updating afforded by these [23,64].

Overall, the construct of ACP is similar to survivorship care planning, focusing on discussions around patients future healthcare needs [24], and is consistent with the taxonomy of health related values identified by older multi-morbid cancer survivors, which includes the importance of a balance between quality and quantity of life, and their desire to actively participate in care decisions [57]. At a minimum the offer should be available to patients to promote choice, autonomy and informed decision-making. Thus, future research should now confirm the benefits of survivorship care planning, assess the priorities of older cancer survivors and attempt to appreciate their understanding of the need and desire for a SCPs as well as the optimal timing and setting of such discussions. This research should then investigate the effects of ACP on costs and important healthcare outcomes such as the uptake of post-treatment cancer surveillance, cancer recurrence rates and the use of healthcare resources, particularly among older cancer survivors with an advance directive in place.

Limitations of this review are that it only included articles written in English, which may have resulted in the omission of important studies. Further, only two sources were

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reviewed for papers, potentially limiting the results. Despite these, the findings highlight the gaps that exist in the literature.

## Conclusion

In summary, survivorship care planning incorporates many important elements that could potentially improve the care and wellbeing of older cancer survivors, who already represent the majority of cancer survivors [1,2]. While these typically include post-treatment summaries, diet, nutritional and exercise recommendations, and schedules for surveillance for recurrence, they do not yet address the important issue of ACP. This review could not find any evidence for the evaluation of a SCP that incorporated the construct on ACP or a formal written advance directive but did find some evidence that ACP is acceptable for cancer survivors [31]. At present high quality evidence for the use, benefits and risks of ACP within a SCP for older cancer survivors is lacking and further research is required, particularly given the expected increase in treatment options and numbers of frail, multi-morbid older patients receiving and benefiting from cancer therapies. However, even without supporting evidence, it would seem appropriate to consider instigating an ACP discussion with older cancer survivors to coincide with the creation of a SCP, a 'geriatric-centred care plan' [17]. In this sense, constructs around survivorship and ACP are not mutually exclusive and should not be treated as such for older patients. We suggest that SCPs should be tailored to the characteristics of individual older cancer survivors whose needs and openness to the concept may vary considerably [46] but are generally positive [31]. Irrespective, increasing awareness of the need for SCPs and ACP in cancer survivors, particularly older persons with advanced disease and comorbidity, is required to provide patients and their families with the option to implement these important anticipatory healthcare plans and promote independent living.

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## Contributors

RO'C contributed to data collection, analyzed and interpreted the data, and drafted the manuscript.

NC contributed to data collection.

RO'S contributed to data collection and review.

RH contributed to data collection and review.

EW contributed to data collection.

AHL contributed to data collection.

TK contributed to data collection.

AC contributed to data collection.

CMcG contributed to data collection.

DWM conceived and designed the review, and drafted the manuscript.

All authors saw and approved the final manuscript.

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## Ethical approval

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## Provenance and peer review

This article has undergone peer review.

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**Conflict of interest**

The authors declare that they have no conflict of interest.

## Conflict of Interest Statement

The authors report no other conflict of interest.

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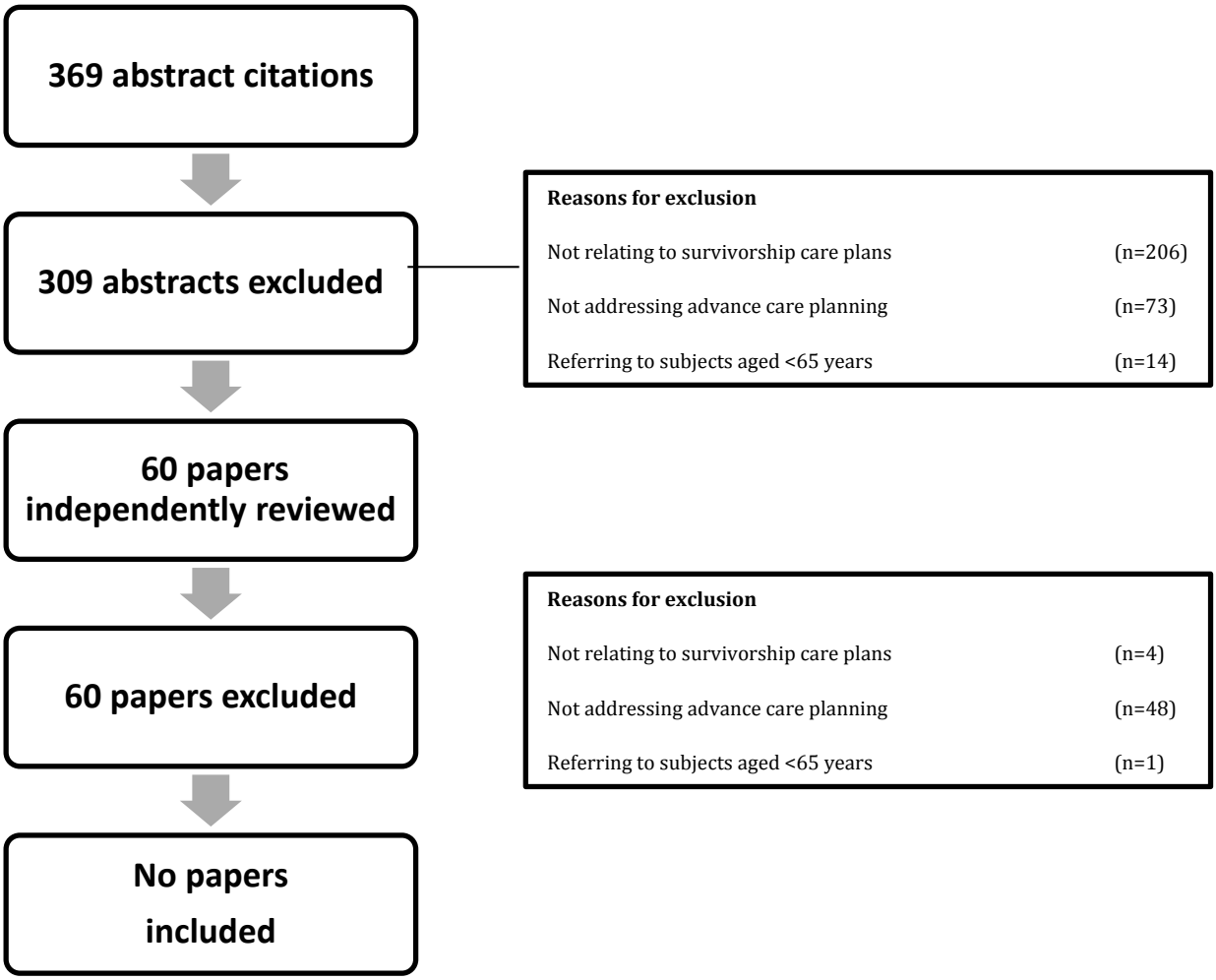
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Figure 1. PRISMA flow diagram of the search strategy.



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**Table 1. Search strategy**

| Search Details | PubMed Citations | Cochrane Citations | Total Citations |
|---|---|---|---|
| **Search #1**: Advance directive* OR Advance care directive* OR Healthcare directive* OR Health care directive* OR Advance care plan* OR Advance care decision* OR Patient care plan* OR Care plan* OR Nursing care plan* | 52,288 | 6,020 | 58,308 |
| Search #2: Cancer* OR Oncology OR Neoplasm* | 3,567,298+ | 3,008 | 3,570,306+ |
| Search #3: Survivor* OR "Survivorship care plan*" | 88,260 | 702 | 88,962 |
| Search #4: Elderly OR Aged OR Older adult* OR Older person* OR Geriatric* | 4,672,266 | 8,734 | 4,681,702 |
| **#1 AND #2** | 5,974 | 2,106 | 8,080 |
| **#1 AND #3** | 592 | 542 | 1,134 |
| **#1 AND #4** | 13,536 | 5,840 | 19,376 |
| **#2 AND #3** | 30,079 | 277 | 30,356 |
| **#1 AND #2 AND #3** | 452 | 218 | 670 |
| **#1 AND #2 AND #3 AND #4** | 152 | 217 | 369 |
| Number of abstracts reviewed excluded from combined searches | 152 | 217 | 369 |
| Number of abstracts excluded from combined searches | 103 | 206 | 309 |
| Number of articles reviewed from combined searches | 49 | 11 | 60 |
| Number of articles included | 0 | 0 | 0 |