



Karel de Grote Hogeschool

## **BNB Oncologie**

Studiegebied Gezondheidszorg Academiejaar 2017-18

# Bachelorproef

An integrative review regarding the development and delivery of survivorship care plans by health care providers

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Word count: 4.812

## Preface

The end of the most packed academic year of my life is nearing. Relatives, friends, colleagues and even new acquaintances of mine have considered me insane in combining the thesis of my MSc in Nursing (15 ECTS), the BSc in Oncology (60ECTS), and the preparatory course for the MSc Management and Health Care Policy (22ECTS) in one year. Months have passed filled with courses, practical trainings and my student job (20%) as a radiotherapy nurse in Aalst. During these months I have not only experienced great amount of stress but also encountered beautiful moments which have motivated me to keep going.

The oncology setting has always interested me greatly. The complexity of the pathology and the effects that cancer has on the individual, the relatives and the society in general is challenging, yet fascinating to unravel. When searching PubMed for possible topics for this review, I wanted to address a gap in the literature which would prove beneficial for the oncology setting. It is astonishing that countless years pass by while the needs of cancer survivors are neglected. Hence, I sincerely hope that this work will not be easily forgotten.

I would like to express my gratitude to my parents who are proud of what I have already accomplished and who back me in the hardest of choices. Furthermore, many thanks to my colleagues and the head nurse Kathleen Vandamme at the Radiotherapy ward in the OLV Aalst Hospital, and my supervisors during my practical trainings Aline Depraet, Christine De Bosschere and Chantal Delava for providing me with wisdom and realistic life lessons. In addition, I am grateful to prof. dr. Ann Van Hecke and prof. dr. Dimitri Beeckman for providing me with the unique experience of travelling abroad in Dublin for four months last year, an experience which motivated me to write this thesis in English. Next to address are my roommates at the student residence, Home Boudewijn. Apologies for the times that I could not be present at the most fun parties of the year. However, I plan on making things right next semester during my Erasmus in Rome at the Università Cattolica del Sacro Cuore for the last year as a fulltime student. Last but not least, a sign of gratitude to Erly Vandenabeele for being my promotor this year. I wish that I could have planned more appointments with you, as I really enjoyed sharing our point of views and interests. It was however impossible for me to start earlier on this paper. I hope that you, and the other readers will enjoy my dissertation.

## Abstract

Het 'Institute of Medicine' (IOM) heeft in 2005 de implementatie van een zorgplan voor overlevers van kanker voorgesteld als een manier om de kloof tussen actieve therapie en opvolging te dichten. Er is echter geen consensus wie hiervoor verantwoordelijk moet zijn. Daarom werd een integrative review opgesteld waarin de attitudes van belanghebbenden over deze zorgplanning geïdentificeerd werden.

PubMed en Cinahl werd doorzocht in combinatie met het consulteren van referentielijsten en citaten. De studies diende ofwel kwalitatief, (quasi-) experimenteel of observationeel te zijn. Bovendien diende de publicaties te dateren van januari 2005 tot mei 2018, en niet geschreven te zijn in een taal anders dan het Nederlands, Engels, Duits of Frans. De attitudes van elke belanghebbende in verband met de zorgplanning van overlevers met kanker (tussen 18 en 65 jaar) werden geïncludeerd. Bijgevolg werden de studies beoordeelt op hun kwaliteit aan de hand van de bijhorende checklists. In totaal werden 1452 zoekresultaten gescreend op abstract en titel. Na exclusie bleven er 82 documenten over. Na het doornemen van deze teksten werden er 19 artikels weerhouden, waarvan zeven kwalitatieve, één mixed method, zeven cross-sectionele en één gerandomiseerde klinische studie. De kwaliteit van de studies was acceptabel (n=16) tot goed (n=3).

De barrières van gebrek aan tijd, terugbetalingen, ondersteuningssystemen, opleiding, materialen, personeel, leiderschap en zekerheid over de resultaten werden geïdentificeerd. Bovendien waren de overlevers (n=1), artsen (n=4), verpleegkundigen (n=5) en sleutelfiguren (n=1) voorstander voor een taakdelegatie van de zorgplanning aan verpleegkundigen. Desondanks de voorstellen van de IOM is het gebruik van het zorgplan relatief laag. Een nieuw zorgmodel waarin de oncoloog, huisarts en verpleegkundig specialist samenwerken is nodig om tegemoet te komen aan de stijgende vraag van de overlevers van kanker enerzijds en de geidentificeerde barrières anderzijds.

De beperkingen zijn dat enkel twee databanken geconsulteerd werden, terwijl het zoeken naar grijze literatuur gelimiteerd werd tot het screenen van referentielijsten en het zoeken naar citaten. Bovendien werd de studie-selectie en de kwaliteitsbeoordeling uitgevoerd door een beginnend onderzoeker. Omwille van deze opmerkingen is het onzeker in welke mate de resultaten de realiteit betrouwbaar weerspiegelen.

## Abstract

In 2005, the Institute of Medicine (IOM) has proposed the survivorship care plan as a way in bridging the gap between active treatment and follow-up for the cancer survivor. However, there is no consensus which care provider should take responsibility for the care planning. Therefore, an integrative review was conducted in which the barriers and facilitators regarding survivorship care planning were summarized.

A literature search in PubMed and Cinahl was performed in combination with reference list scanning and citation searching. Studies were eligible if they were qualitative, (quasi-)experimental or observational and published after January 2005 to May 2018. The attitudes of every stakeholder regarding care planning among survivors aged older than 18 and younger than 65 was considered. Articles in a language other than English, French, German and Dutch were excluded. Included studies were quality appraised with according checklists. A total of 1452 records were screened on title and abstract. Consequently, 82 articles were assessed for full text analysis. Of these, 19 articles of which seven qualitative, one mixed method, one randomized controlled trial and seven cross-sectional studies were included. The quality of the studies was deemed adequate (n=16) to good (n=3).

Various barriers were identified such as lack of time, funding, support systems, training, resources, personnel, leadership and certainty of the outcomes. In addition, survivors (n=1), physicians (n=4), nurses (n=5) and key leaders in oncology (n=1) are in favor for task delegation of the survivorship care planning to a survivorship nurse. Despite the recommendations of the IOM, the uptake of survivorship care planning is lagging. In addition, a new model of care in which the medical oncologist, advanced practice nurse and general practitioner work together is needed to meet the increasing demand of survivors.

The limitations of this review are that only two databases were consulted, while searching for grey literature was limited to citation searching and scanning of reference lists. Additionally, the study selection and quality appraisal was performed independently by one novice researcher. Lastly, the available literature was scarce, of which only one RCT was retrieved. As a result, it is unsure to determine the overall validity of the summarized results.

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### **Problem statement**

During the past decade, advancements in detection, prevention and novel treatments of cancer has caused a decline in cancer-related mortality. However, along with the increasing numbers of cancer survivors, the long-term side effects of their treatment become apparent (DeSantis et al. 2014). Therefore, increasing attention has been given by the Institute of Medicine (IOM) in 2005 with the report of Cancer Patient to Cancer Survivor: Lost in Transition of The institute (Hewitt and Greenfield 2005). In this report, the IOM sheds light on the fragmentation of health care, knowledge deficit of providers, presence of financial barriers, a lack of evidence based survivorship and a poor integration in practice. Currently, most cancer patients are referred back to their primary care provider (PCP) when they complete their treatment. Yet, it is during the survivorship stage that patients need at least equal guidance from health care professionals in supporting their psychical and psychological unmet needs (Klemanski et al. 2016, DeSantis et al. 2014, Hewitt and Greenfield 2005).

In response, the IOM advocates the development and implementation of survivorship care plans (SCP). This is a tailored treatment summary and plan for the cancer survivor which is recommended by various international guidelines to be supplied to every patient at the completion of their treatment (Brennan et al. 2014). Models of SCP include information concerning long-term complications, signs of recurrence, resources, self-management strategies, healthy lifestyle, physical therapy, and rehabilitation (DeSantis et al. 2014, Mayer et al. 2015). Both primary care physicians and patient groups support SCP, however their implementation is lagging mainly due to the costs, lack of evidence, limited use of personnel, time and communication systems (Brennan et al. 2014, Mayer et al. 2015, Klemanski et al. 2016). As such, only around 10-20% of oncologists have provided a SCP to their patients. Furthermore, survivors are confused which provider is responsible for their follow-up (Klemanski et al. 2016).

This raises the question which care provider is most suitable to prepare and deliver the care plan to the survivor (Hewitt and Greenfield 2005, van de Poll-Franse et al. 2017). Therefore, the goal of this integrative review was to systematically make an inventory of the perception of survivors, medical specialists, nurses and other stakeholders regarding the preparation and delivery of the SCP.

### Methodology

#### Search strategy

The electronic databases of Pubmed and Cinahl have been searched with the following free text words: (1) cancer, (2) neoplasms, (3) survivor, (4) survivorship, (5) care plan, (6) care planning, (7) treatment summary, (8) treatment summaries, (9) follow up, (10) coordination of care, (11) patient care planning, (12) providers, (13) nurse, (14) physician, (15) oncologist, and (16) health personnel. These keywords have been identified through consultation of relevant systematic reviews. A combination of free text and database specific major headings were used of which the specific query's and results can be seen in table 1 further below. Additional publications and grey literature were retrieved by scanning reference lists and searching citations. To evaluate the handled search strategy, reference lists were screened in the included studies. A last search was performed on 01/05/2018.

#### **Eligibility criteria**

In order to be included, the participants had to be care providers or other relevant stakeholders. The population of interest are cancer survivors aged older than 18 and younger than 65 due to the distinct issues of younger or older cancer survivors (Hewitt and Greenfield 2005). The focus had to be regarding the barriers and facilitators of preparing and/or providing a SCP to the survivor. As the attention to SCP has greatly increased due to the IOM report in 2005, articles starting from January 1<sup>st</sup> of 2005 were included (Mayer et al. 2015). Articles in any language other than English, French, German and Dutch, were excluded. Only primary studies were considered, more specifically (quasi-)experimental, observational and qualitative studies.

The term cancer survivor can be ambiguous and culture-dependent. In the North-American setting it most often refers to either the patient who has finished active treatment or who is diagnosed with cancer and is still alive, whereas the Europeans declare someone a cancer survivor when he has been cancer free for at least five years (Wronski 2015). The Commission on Cancer (CoC) recommends that every cancer patient who finishes active treatment should receive a SCP (van de Poll-Franse et al. 2017). Therefore, the term cancer survivor in this study implies those in transition to follow-up care.

### Search outcomes

The search strategy was initially crafted for the PubMed database with previously stated keywords and the MeSh terms: (1) neoplasms; (2) patient care planning; and (3) health personnel. The search queries were consequently modified for the Cinahl database.

Table	1:	Search	Query's
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Database	Query (01/05/2018)	Items
		found
PubMed	(cancer OR "Neoplasms"[Mesh]) AND (survivor OR survivorship) AND	1016
	("Patient Care Planning"[Mesh] OR "care plan" OR "care planning" OR	
	"treatment summary" OR "treatment summaries" OR "follow up" OR	
	"coordination of care") AND (providers OR nurse OR physician OR	
	oncologist OR "Health Personnel"[Mesh])	
Cinahl	(cancer OR neoplasms OR "MH Neoplasms+") AND (survivor OR	422
	survivorship OR "MH Survivors+" OR "MH cancer survivors") AND	
	("patient care planning" OR "care plan" OR "care planning" OR	
	"treatment summary" OR "treatment summaries" OR "follow up" OR	
	"coordination of care" OR "MH Patient Care Plans+" OR "MH Nursing	
	Care Plans+") AND (providers OR nurse OR physician OR oncologist)	

#### **Study selection**

Once the search strategy was tested and finalized, studies were screened by the researcher in two steps. Firstly, the title and abstract of the articles were evaluated for eligibility. Consecutively, the full texts of the remaining records were screened. Studies not corresponding to suggested inclusion criteria, were excluded.

All the eligible literature was saved in Endnote X7 citation manager. A flowchart was constructed. In case the full text was not available, the author was contacted to obtain the publication. If the article remained unobtainable, it was taken into consideration for purchase. A list of excluded full text publications has been provided in appendix 1.

#### Data extraction and quality assessment

Data from eligible studies are presented in a standardized form in table 2 below. The extraction form was pilot tested by the researcher to identify whether the form had to be improved or not. The citation, study design, population, method of data collection and results of each individual study is noted. The developed form was evaluated by an independent researcher guiding the author of this review.

The quality appraisal of potentially eligible studies was performed independently by the researcher of which the assessment forms have been classified in appendix 2. The choice for the tool was based on the review of Zeng et al. (2015). The Cochrane Collaboration's tool for assessing risk of bias was used for randomized controlled trials (RCTs) (Higgins et al. 2011). In addition, the Agency for Healthcare Research and Quality (AHRQ) checklist was chosen for the cross-sectional studies (Zeng et al. 2015, Rostom et al. 2004, Slim et al. 2003). Lastly, the Joanna Briggs Institute's Qualitative Assessment and Review Instrument (JBI-QARI) was considered for qualitative research evaluation whereas the Mixed Methods Appraisal Tool (MMAT) was deemed appropriate for mixed method research (Pace et al. 2012, Lockwood C 2017).

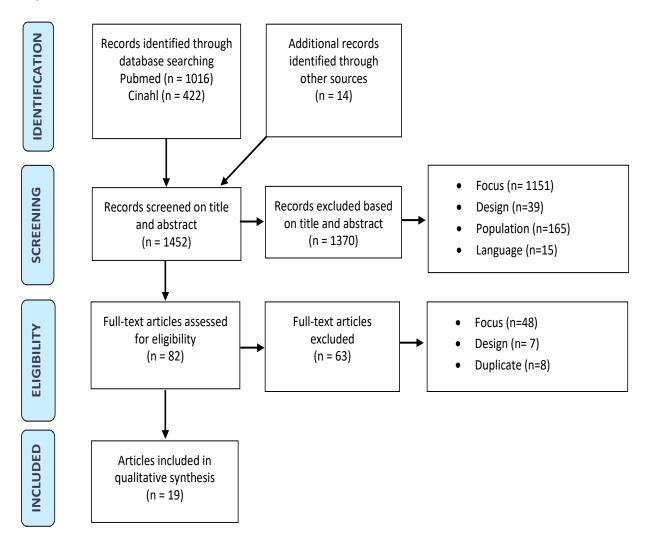
## Data synthesis

The results have been qualitatively synthesized and narratively reported. On basis of the formed body of evidence, an answer to the research question was formulated. Lastly, recommendations for clinical practice, education, policy and further research have been stated.

## **Results**

#### **Study selection**

Fig.1 Decision flowchart for identified studies



The search strategy resulted in a total of 1452 hits comprising of 1016 and 422 results from PubMed and Cinahl, respectively. An additional fourteen studies were identified by search for grey literature. The articles were screened for title and abstract in which 82 studies were selected for full-text assessment after exclusion of 1370 records based on discrepant focus (n=1151), design (n=39), younger or older target population (n=165) or language other than English, Dutch, German or French (n=15). Consequently, an additional 63 articles were excluded of which the majority of studies focused mainly on the follow-up in general (n=34), or on aspects of SCP other than the pre-specified attitudes (n=14). Moreover, several commentary papers or review articles (n=7) and duplicates (n=8) were exempted from analysis. A list of excluded studies can be retrieved in appendix A.

#### Study characteristics

A total of nineteen articles were deemed fit for analysis. The characteristics of the studies have been presented in table 2 below. Around seven of the studies were qualitative in nature, one mixed method approach, and eleven quantitative designs of which ten cross-sectional studies and one RCT. Data for the qualitative research was obtained through focus groups (n=2), individual interviews (n=2), document reviews (n=1), semi-structured telephone interviews (n=4), unstructured survey (n=1) and site visits (n=1) whereas quantitative data was collected by use of written questionnaires (n=6), online surveys (n=5) and structured telephone interviews (n=2).

The included studies predominantly inquired in the views of oncological providers, more specifically medical oncologists (n=14), radiation oncologists (n=5), hematologists (n=1), urologists (n=1), gynecologists (n=3) and surgeons (n=2). In addition, more than half of the studies involved the perceptions of registered nurses (n=12) and advance practice nurses (n=9), while a handful of articles included focus on PhD's (n=2), key leaders in survivorship care (n=1), community representatives (n=1), administrative staff and project coordinators (n=3), and clinical social workers (n=2). Noticeably, lesser attention was devoted to the primary care providers (n=1) and the cancer survivors themselves (n=3).

#### **Risk of bias within studies**

The quality assessment forms can be retrieved in table 1 to 5 in appendix 2. One study was evaluated by the Cochrane risk of bias tool in which the risk of bias was deemed mediocre. More specifically, the process of allocation concealment and blinding of the outcome assessment was not described. However, blinding of personnel and of the outcome is hardly an option in this case, since the intervention arm was trained in the use of SCP, whereas the control arm continued their practice as usual. Consequently, the quality of the mixed method study was high, even though the influence of the researcher on the data and vice versa was inadequately addressed.

The quality of the seven qualitative studies was adequate (n=5) to good (n=2). Statements which shed light on the cultural and theoretical position of the researcher were absent in all seven articles. Furthermore, the philosophical perspective was unclear in five of the cases. The oldest study of Hewitt et al. (2007) scored lowest due to inadequate reporting of the philosophical perspective, the theoretical and cultural position of the researcher and his influence on the data, and the unclearness regarding ethical board approval.

Lastly, the cross-sectional studies were conducted sufficiently. However, the data collection instruments were inadequately or not validated in five of the ten studies, while information regarding the control for confounding was absent in five studies.

## Table 2: data extraction form of the included studies

Nr.	Author	Design	Population	Data collection	Results
1	(Hewitt et al. 2007)	Descriptive qualitative design	Medical oncologists (n=12), radiation oncologists (n=4), urologists (n=3), gynecologist (n=1)	Focus groups and individual interviews	MO prefer not to use SCP owing to the lack of reimbursement and time.
			Advanced practice nurses (n=14), ambulatory office-based nurses (n=8) and combination (n=12)		ANP already are more likely to use a survivorship care based program due to medical staff being preoccupied with patients in active treatment than those in follow-up. Nurses are confident in their knowledge skills and use of patients medical file to develop SCP and agree that this can be seen as their role in accordance with their training and experience. Lack of reinforcement from attending physician in attaining this role, lack of time and lack of reimbursement are viewed as barriers
2	(Baravelli et al. 2009)	Cross-sectional design	Medical oncologists (n=30) Nurses (n=64)	Written questionnaire followed by structured telephone interviews	Doctors were less in favor for including psychosocial and practical aspects in the SCP in comparison to the nurses and survivors. Most physicians indicated that they should prepare the SCP (57%) whereas 55% of the nurses ought themselves to be most suitable to deliver the information. Regarding the delivery, 57% of the oncologists indicate they should discuss the SCP in comparison of 66% of the nurses.
3	(Brennan et al. 2010)	Cross-sectional design	Breast surgeons, medical oncologists, radiation oncologists, breast physicians and breast care nurses (n=217)	Online semi- structured survey	Unclear among respondents whether using a SCP costs or saves time.

4	(Watson et al. 2010)	Cross-sectional design	Oncologists (n=100)	Online structured survey	73% of oncologists think a SCP is useful, whereas only 58% indicate that it would be useful for the survivor. The barriers of difficulty in making the plan (40%), time constraints (38%) and need for standardized format (23%) were noted.
5	(Campbell et al. 2011)	Mixed method design	Medical oncologists (n=9), nurses (n=11), PhDs (n=4), community representatives (n=5), administrative and project coordinators (n=10)	Document reviews, telephone interviews (n=39), online surveys (n=40) and site visits (n=3)	Lack of funding, time, resources, personnel and medical record abstraction Already task delegation of preparing the SCP to nurse practitioners and administrative staff. Respondents find strong support from senior leadership and the allocation of staff and finances important facilitators.
6	(Marbach and Griffie 2011)	Descriptive qualitative design	Prostate, genitourinary and skin; breast and gynecologic; gastrointestinal, sarcoma, and head and neck; brain, pancreatic and lung cancer survivors (n=40)	Focus groups (n=4)	Patients indicate that they have trust in nurses to prepare and deliver their SCP.
7	(Chubak et al. 2012)	Descriptive qualitative design	Key leaders in survivorship care (n=40)	Telephone interviews	Use of SCP is not familiar to care providers (25%). General concerns regarding the benefits and costs of providing SCP.
8	(Faul et al. 2012)	Grounded theory qualitative design	Medical oncologists, radiation oncologists, registered nurse, physician assistant, clinical social worker (n=7)	Semi-structured interviews	SCP are seen as a duplication of current existing care. The time investment, lack of reimbursement and absence of an electronic medical platform have a negative influence on the sustainability of SCP. The use of a SCP takes too much time and effort and should be delegated to a designated health care professional, such as a nurse.

9	(Merport et al. 2012)	Cross-sectional design	Oncologists, radiation oncologists and hematologists (n=108)	Mailed structured survey	Only 14% actually prepare SCP for their patients. In addition, 47% mention the lack of training, 46% lack of template and 40% lack of reimbursement for the time spent
10	(Birken et al. 2013)	Cross-sectional design	Registered nurses (n= 7), administrators (n=6), nurse practitioners (n=3), medical oncologists (n=2), PhDs (n=2), Social workers (n=2)	Structured online and postal survey	Reports of insufficient time, resources, staff and training by 75% of the respondents. Absence of supportive electronic system and of a designated survivorship nurse.
11	(Dulko et al. 2013b)	Cross-sectional design	Oncologists, advanced practice professionals and nurses (n=16)	Telephone survey	Lack of time preparing or gathering information due to fragmented use of medical records The APP should prepare the SCP and deliver it with or without the oncologist.
12	(Birken et al. 2014a)	Cross-sectional design	Registered nurses, nurse practitioners, and other clinical staff (n=77)	Written questionnaire	Lack of resources (76%), difficulty in using SCP (29%) and unsupportiveness for SCP by physician champions and managers (24%)
13	(Birken et al. 2014b)	Descriptive qualitative design	Medical oncologists (n=4), nurses (n=5), patient navigators (n=3), patient educator (n=1)	Semi-structured interview	Unsure whether SCP help the transition to survivorship care and whether patients actually use them. Difficulty in dedicating time to the use of SCP except when specifically hired to do so. Lack of external benefits such as funding. Lack of resources such as staff and materials. Lack of support and recognition from influential leaders. Respondents are confident in using SCP and belief its congruity with their role.

14	(Blanch-Hartigan et al. 2014)	Cross-sectional design	Oncologists (n=1130)	Mailed survey	More likely to provide a SCP when they have had a specific training (OR 1,72: CI95%, 1.22 – 2.44).
15	(Collie et al. 2014)	Descriptive qualitative design	Breast (n=36) and head-and- neck cancer survivors (n=21) Nurses (n=9) and medical oncologists (n=3)	Unstructured survey and telephone interviews	Survivors appreciate having an additional moment with qualified nurses to discuss their SCP. General concern among the nurses and physicians that preparing and providing SCP may not fit in their schedule. Nurses suggest the great benefit of integrating SCP into the electronic medical file. The task of preparing the SCP could be delegated to a clerical staff before the nurse discusses it with the patient.
16	(Lester et al. 2014)	Cross-sectional design	Registered and advanced practice nurses (n=223)	Online survey	Less than 50% of nurses have adequate knowledge concerning survivorship issues. The higher the education, experience, age, and function (advanced practice nurse or research nurse) the more knowledgeable.
17	(Nicolaije et al. 2014)	Pragmatic clustered RCT	Gynecologists, gynecologic oncologists, oncology nurses (n=43)	Written questionnaire	75% of the providers indicate that the oncology nurse should deliver the SCP, whereas 20% prefer delivery by the physician. None chose for the PCP. Providers claim that time should be made available to prepare and provide the SCP, and that oncology nurses could lower the burden of physicians by carrying out this task.
18	(Salz et al. 2014)	Cross-sectional design	Medical and radiation oncologists, nurse practitioners, clinical nurse specialists, and physician assistants (n= 245)	Written questionnaire	<ul> <li>Lack of personnel (69%) and lack of time to prepare a SCP (64%) are the two most reported barriers.</li> <li>40% of the respondents have the opinion that developing SCP should be the responsibility of a single person.</li> <li>74% think that a template with pre-specified fields should be used to reduce difficulty and time.</li> <li>Respondents desire additional training with, among others, emphasis on the supporting evidence of SCP use.</li> </ul>

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19	( J	Descriptive qualitative design	Head and neck medical oncologists, radiation oncologists and surgeons (n=6), nurse practitioners and administrative support staff (n=5), survivors (n=4) and primary care providers (n=9)	Semi-structured telephone interviews	It is unclear which professional in the oncology team should be responsible for the preparation of the SCP. The SCP should be electronically accessible through the health record and should be frequently updated.
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#### **Results of individual studies**

#### Survivors

During four focus groups with each ten survivors with different cancers, the conclusion was that survivors trust a nurse in preparing and delivering the SCP (Marbach and Griffie 2011). They appreciate the extra time with a qualified nurse greatly (Collie et al. 2014). However, a clear preference regarding the preparation and delivery is absent (Zullig et al. 2018).

#### Oncology physicians

Only 14% of the physicians mention they use a SCP (Merport et al. 2012). There are various barriers in using SCP which have been identified in the literature.

- (1) Perception of SCP as a duplication of care and that it is not useful for the provider and the survivor (n=2) (Watson et al. 2010, Faul et al. 2012)
- (2)Lack of reimbursement (n=4) (Campbell et al. 2011, Faul et al. 2012, Hewitt et al. 2007, Merport et al. 2012);
- (3) Lack of time (n=10) (Birken et al. 2013, Brennan et al. 2010, Campbell et al. 2011, Collie et al. 2014, Dulko et al. 2013b, Faul et al. 2012, Hewitt et al. 2007, Nicolaije et al. 2014, Salz et al. 2014, Watson et al. 2010);
- (4) Difficulty of making the plan, lack of template and electronic support (n=8)
  (Birken et al. 2013, Collie et al. 2014, Dulko et al. 2013b, Faul et al. 2012, Merport et al. 2012, Salz et al. 2014, Watson et al. 2010, Zullig et al. 2018);
- (5) Lack of training (n=4) (Birken et al. 2013, Blanch-Hartigan et al. 2014, Merport et al. 2012, Salz et al. 2014)
- (6) Lack of resources and personnel(n=3) (Birken et al. 2013, Campbell et al. 2011, Salz et al. 2014)

In general, it remains unclear who should be responsible for the SCP (Zullig et al. 2018). Because of the excess time required to develop SCP, various studies (n=4) state that this task should be delegated to a clinical staff member such as a nurse (Birken et al. 2013, Dulko et al. 2013b, Faul et al. 2012, Nicolaije et al. 2014) or to a clerical staff who prepares the SCP before the nurse delivers it (Collie et al. 2014). One of the reasons is that physicians are less inclined to integrate psychosocial and practical aspects when delivering SCP, in contrast to nurses (Baravelli et al. 2009). Notwithstanding, most of the physicians (57%) in the study of Baravelli et al. (2009) hold on to the opinion that they should prepare and deliver the SCP.

#### Nurses

Equivalent to the barriers reported by the physicians, nurses have the perception that the reimbursement for preparing and delivering the SCP are inadequate and that there simply is insufficient time (n=7) (Brennan et al. 2010, Campbell et al. 2011, Collie et al. 2014, Dulko et al. 2013b, Hewitt et al. 2007, Nicolaije et al. 2014, Salz et al. 2014). Furthermore, they mention the requirement for templates and an integration in the electronic medical file (n=4) (Collie et al. 2014, Dulko et al. 2013b, Salz et al. 2014, Zullig et al. 2018) and a lack in training and knowledge (n=2), which is less prominent in APN (Lester et al. 2014, Salz et al. 2014). Lastly, support from the treating physician is missing (n=2) while strong leadership from senior professionals is needed (Campbell et al. 2011, Hewitt et al. 2007).

Similar as before, it is unclear who should assume responsibility regarding the SCP (Zullig et al. 2018). In the study of Baravelli et al. (2009) 55% of the nurses indicate that they are most suitable to prepare the SCP, while 66% think they should be the one who delivers it to the patient. Considering previous mentioned barriers, five studies state that it could be beneficial if this task were to be delegated to the nurses (Birken et al. 2013, Campbell et al. 2011, Dulko et al. 2013b, Faul et al. 2012, Nicolaije et al. 2014). Another possibility is that a clerical staff prepares the SCP and the nurse delivers it (Collie et al. 2014). In the study of Hewitt et al. (2007), APN are already more inclined to use survivorship care programs due to previous experiences in which physicians are more occupied with patients who are in active treatment than those who have transitioned to followup. Furthermore, the nurses are confident in their experience, knowledge and skills to develop SCP and think that this is a task which aligns the most with their profession (Hewitt et al. 2007). In comparison with physicians, nurses devote more attention to psychosocial and practical issues which the survivor must cope with (Baravelli et al. 2009).

#### Key leaders

There is a general skepticism among policy members and PhD's concerning the benefits and costs of SCP and the lack of familiarity among oncology providers (Chubak et al. 2012). Furthermore, the barriers of insufficient time, resources, staff and training, an absence of electronic support and a survivorship nurse are mentioned (Birken et al. 2013)

## Other staff members

Two studies mention the possibility of delegating the preparation and/or delivery of the SCP to administrative staff considering the time and effort of physicians and nurses (Campbell et al. 2011, Faul et al. 2012)

## **Discussion**

#### Summary of evidence

According to the IOM, a SCP is an effective method in enhancing the (1) prevention of recurrent or second cancers, (2) surveillance of late medical and psychosocial effects, (3) interventions for the consequences of cancer (related treatment) and, (4) coordination of care between specialists and primary care providers (Hewitt and Greenfield 2005). However, at current time it remains unclear which care provider should develop and discuss the SCP (Hewitt and Greenfield 2005, Zullig et al. 2018). Therefore, the aim of this integrative review was to gather the perceptions of survivors, physicians, nurses, key leaders and other staff members to evaluate who should be the responsible professional.

In general, the barriers of (1) lack of funding, (2) lack of time, (3) lack of tools and systems to aid in the development, (4) lack of training, and (5) lack of resources and personnel, were noted by the physicians, nurses, policy members and opinion leaders. In addition, (6) physician's express uncertainty regarding the usefulness for practice and survivor, while the nurses find that (7) strong leadership and support is needed but missing. Moreover, previously mentioned policy members and opinion leaders are skeptical regarding the use, benefits and feasibility of SCP (Birken et al. 2013, Brennan et al. 2010, Campbell et al. 2011, Collie et al. 2014, Dulko et al. 2013a, Faul et al. 2012, Hewitt et al. 2007, Lester et al. 2014, Merport et al. 2012, Nicolaije et al. 2014, Salz et al. 2014, Watson et al. 2010, Zullig et al. 2018).

Due to these barriers the use of a survivorship nurse is often considered a viable solution in offloading the physicians of their clinical work (Birken et al. 2013, Dulko et al. 2013b, Faul et al. 2012, Nicolaije et al. 2014). However, this mindset is not shared among every physician as a large portion are hesitant to lose part of their responsibility (Baravelli et al. 2009). Similar conflicting findings can be seen among the nurses who claim that they are not knowledgeable enough to perform this task, do not have the support from the attending physician, and that it does not fit in their competence profile and timetable (Brennan et al. 2010, Campbell et al. 2011, Collie et al. 2014, Dulko et al. 2013b, Hewitt et al. 2007, Lester et al. 2014, Nicolaije et al. 2014, Salz et al. 2014). Therefore, they believe that the physician should assume this responsibility (Salz et al. 2014). In contrast, other studies

report samples of nurses who in fact are enthusiastic in attaining a role which incorporates survivorship care planning, while the most recent study of (Zullig et al. 2018) could report no decisive preferences of interviews from multiple oncologist specialists and nurses (Baravelli et al. 2009). Nonetheless, examples already exist in which APN perform survivorship related tasks (Hewitt et al. 2007). These nurses are more confident, knowledgeable, experienced and skilled than registered nurses (Hewitt et al. 2007, Lester et al. 2014, Salz et al. 2014). They hold on to the opinion that this task aligns more with their profession than of a physician due to their distinct competences in providing psychosocial care (Baravelli et al. 2009).

#### Implications for policy

The number of cancer survivors keeps increasing, concurrently with the demand for oncology services. As a result, it is estimated that the demand will surpass the capacity of traditional medical oncologist-provided survivorship care, leading to a shortage of workforce by 2025 (LaGrandeur et al. 2018, Rosenzweig et al. 2017). In contrast, the amount of APN keeps increasing (Corcoran et al. 2015). Therefore, it is evident that new models of care are implemented to sustain survivorship care. Especially now, as institutions will be required to supply every cancer patient finishing treatment with a SCP in order to certify for accreditation (van de Poll-Franse et al. 2017, Zullig et al. 2018).

However, in spite of the recommendations of the IOM and initiatives of other institutions, actual use of SCP remains noticeably low in which only 10% of oncologists prepare SCP and 13% of PCP indicate ever receiving one (Blanch-Hartigan et al. 2014). The hardship of implementation is due to significant barriers such as lack of awareness, time, tools, personnel, collaboration, leadership and responsibility (Birken et al. 2014b, Klemanski et al. 2016). Governments, insurance companies, policy members and other stakeholders should therefore focus on mitigating these barriers by (1) raising awareness and educating care providers concerning the benefits of SCP; (2) providing the necessary resources, funding's and reimbursements; (3) facilitating an integration in the electronic health record and providing templates (HER); (4) empowering PCP to request SCP; (5) encouraging patients to inform themselves by patient advocate groups; and (6) supporting strong leadership and a shared care model (Klemanski et al. 2018, Zabora et al. 2015).

A shared care model entails care-coordination between the oncologist, PCP and specialized cancer nurses in which the roles and responsibilities are clearly described (Baravelli et al. 2009, LaGrandeur et al. 2018). Survivors, cancer specialists as well as PCP are in support for a greater responsibility and involvement of PCP in the follow-up. This can be achieved by delegating the tasks of general and psychosocial care, health promotion, management of cancer- and treatment related side effects and provision of information (Hebdon et al. 2015, Meiklejohn et al. 2016). As such, the PCP is responsible for wellness and psychosocial care while the oncologists focusses on cancer care (Hebdon et al. 2015). In addition, including survivorship nurses could free up time for the oncology providers while increasing productivity, patient satisfaction and costeffectiveness (Birken et al. 2013, Spears et al. 2017). Patients indicate that nurses express more empathy and provide more psychological support and coaching compared to physicians (Corcoran et al. 2015, Rosenzweig et al. 2017). Furthermore, APN are confident, skilled and experienced in performing survivorship related tasks such as physical examination, history taking, discussing symptoms of recurrence and surveillance. They may therefore be most suitable in the follow-up in general, while registered nurses can specifically aid in the development and discussion of care plans with the APN, physician and survivor (Klemp 2015, Lester et al. 2014, Spears et al. 2017). The SCP could herein act as a method of linking tertiary with primary care and providing the GP with timely and individualized patient information in order to sustain the patient's trajectory and care coordination (Hebdon et al. 2015, Meiklejohn et al. 2016).

Major contributions for survivorship care has largely originated from the US, Canada and the UK. Moreover, other countries in the EU have net yet established sustainable survivorship models, including Belgium (Keesing et al. 2015, Rowland et al. 2013). Recently, initiatives have been taken by the non-governmental organization (NGO) "Kom op tegen Kanker" such as the dissemination of the report "Zorgen na kanker" (2017) regarding the testimony of 782 Flemish cancer survivors pertaining their unmet needs and follow-up. The lack of coordination and transition of care is apparent and relatable to the existing literature. As such, around 75% consult their specialist or PCP when they have questions, although their PCP is often not experienced in oncology or was not involved in the patient's cancer treatment. Furthermore, patients report a lack of systematic monitoring of

their physical and psychosocial issues after their treatment, consequently feeling abandoned and frustrated. The NGO desires to use this report to commence negotiations with the ministry of health care and welfare and policy members, and to formulate specific recommendations by the end of 2019 (Neefs 2017). Reintegration of the cancer survivor, providing individualized care and enhancing transmural coordination are goals which have been specified in their operational plan for 2017 – 2021 (KOTK 2017).

### Implications for nursing practice and education

The steps to achieve implementation of a shared care model in which the survivorship nurses prepare and provide the SCP need to be planned and executed strictly. This is necessary as it pertains a second-order change in which the care system itself needs to be transformed, along with the individual values, norms and goals of the stakeholders (Kezar 2001). The implementation model of Grol and Wensing (2012) is deemed most suitable and consists of five phases: orientation, apprehension, acceptance, change, and integration. The specific steps are summarized below according to the PDCA cyclus of Deming (Sokovic et al. 2010)

### Plan and Do

- (1) Thoroughly analyze the problem by conducting systematic reviews concerning the definition, outcomes and components of the innovation project.
- (2) Develop validated and patient reported quality indicators by consulting experts and stakeholders.
- (3) Construct an implementation plan with realistic short and long-term goals, clearly delineated tasks, procedures and responsibilities.
- (4) Assess the team functioning, culture, barriers and facilitators by use of observations, interviews and surveys. Identify the motivators and involve the target population (Ouwens et al. 2007, Ouwens et al. 2008).
- (5) Provide charismatic and transformational leadership in which a common goal is identified and a bottom-up involvement is stimulated (Mackie and Darvill 2016).
- (6) Conduct preliminary testing to assess the feasibility of the plan.
- (7) A variety of interventions need to be considered and aimed at individuals, organizations, work processes and the society. Examples are financial incentives, task and function differentiation, use of feedback and reminders,

electronic support systems, dissemination of educative materials, organization of trainings and meetings, employing opinion leaders, empowering patients and mass media.

#### Check and Act

- (1) Ensure that the effects of the interventions can be reliably measured by setting up (quasi-)experimental or observational studies.
- Regularly evaluate and provide feedback to stakeholders, policy members, managers and personnel (Evans et al. 2013).
- (3) Take steps to avoid falling back into old habits and facilitate an integration in routine procedures.
- (4) Adjust the goals in accordance with the progression of the implementation.

This review has partially fulfilled step one and ten in which the barriers and facilitators have been systematically identified. It is evident that the implementation of an innovation like this will require years of work.

Next to the implementation of shared care in practice is the integration of survivorship care into the training programs for health care professionals. The growing number of cancer survivors necessitates changes in the academic curricula so that it aligns with the recommendations of the IOM (Klemp 2015, Lester et al. 2014). The curriculum should not only focus on understanding the medical and psychosocial needs that cancer survivors might cope with, but also include aspects of survivorship care planning (DeSantis et al. 2014).

### Implications for research

Firstly, the scarcity of evidence poses difficulties in establishing a curriculum for care providers, as survivorship care planning is just one of the many tasks of a survivorship nurse (Rosenzweig et al. 2017). Current curricula often lack comprehensive cancer-related education (Lester et al. 2014).

Secondly, RCTs often include distal patient-reported outcomes which are mildly influenced by SCP use, and lack stakeholder relevant outcomes (Birken et al. 2018). This explains the conflicting results in which no significant difference in adherence, number of visits to the cancer center or PCP, quality of life, satisfaction, distress, coordination of care, or clinical examinations among the survivors could be indicated (Birken et al. 2018, LaGrandeur et al. 2018, van de Poll-Franse et al. 2017). Birken et al. (2018) state following outcome categories through interviews

with stakeholders (1) communication and role clarity, (2) providers' educational and informational needs, (3) provider anxiety, (4) efficient discharge to primary care, (5) survivors educational and informational needs, (6) survivors fear and anxiety and (7) self-management of the survivor.

Lastly, evidence is lacking concerning the ideal form, content, timing and method of delivery of the SCP (Klemanski et al. 2016, LaGrandeur et al. 2018, van de Poll-Franse et al. 2017). Furthermore, there still is uncertainty regarding the outcomes of the models of survivorship care, the delineation of the specific tasks of each clinical member, and how early survivorship care should be introduced to the patient (Klemp 2015, LaGrandeur et al. 2018, Hebdon et al. 2015). The need for well-established RCTs which are reported according to the CONSORT statement and which include stakeholder relevant outcomes are necessary (Moher et al. 2001). In addition, the STROBE checklist is recommended when conducting cross-sectional research, whereas the SPQR is suitable for qualitative research (O'Brien et al. 2014, Von Elm et al. 2007).

### Limitations

Even though this review was conducted systematically and reporting was done according to the checklist of PRISMA, it may have been that possible eligible studies were overlooked (Moher et al. 2009). More specifically, only two databases were consulted and searching for grey literature was limited to citation searching and reference list screening, thereby possibly introducing publication bias. Moreover, the review was conducted by one novice researcher, thus subjectivity may be higher than when two independent researchers would have performed the data selection and quality appraisal. Lastly, only one RCT was deemed eligible, apart from ten cross-sectional, one mixed method, and eight qualitative studies. Although the results are not highest level of evidence, the integrative design allow for a deeper understanding of this healthcare phenomenon (Whittemore and Knafl 2005).

## Conclusion

Since 2005, cancer survivorship has gained significant attention in the United States and more recently the European continent. People diagnosed with cancer survive longer periods of time, with most of them requiring long term support for the late effects of cancer and its treatment. This poses new challenges for the health care system, in which reforms are necessary to accommodate the needs of this unique patient population. However, almost fifteen years later, survivors still feel abandoned with their unmet needs while research fails to incorporate the outcomes which really matter to stakeholders. In addition, the curricula of care providers lack thoroughness in the issues of cancer survivorship and the implementation of shared care and care planning is hampered by organizational constraints.

The need for change is urgent, as the demand will surpass the available resources. As such, governments and institutions need to establish a model of shared care comprising of the medical oncologist, the general practitioner and the advanced practice nurse. Herein, the SCP acts as a formal document which links tertiary with primary care for the survivor.

This integrative review was conducted to systematically determine which care provider should be responsible for the care planning. Various studies address the benefits of implementing survivorship nurses owing to their relevant competences. Furthermore, existing scarce resources can be used more efficiently, in which duplication of care is avoided and more time can be spent on survivorship care. This body of evidence may thus prove beneficial in implementing a shared care model.

## **Conflict of interest**

No conflict of interest declared.

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## **Appendices**

## Appendix 1: List of excluded studies

- Anvik, T., Holtedahl, K.A. & Mikalsen, H. (2006) "When patients have cancer, they stop seeing me"--the role of the general practitioner in early follow-up of patients with cancer--a qualitative study. *BMC Fam Pract*, 7, 19.
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## **Appendix 2: Quality assessment forms**

Table 1: Quality assessment of RCTs with the Cochrane risk of bias tool

	Selec	tion bias	Perform	ance bias	Detection bias	Attrition bias	Reporting bias	Other bias	
Study	Adequate sequence generation	Allocation concealment	Blinding of patient	Blinding of personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting		
(Nicolaije et al. 2014)	+	?	+	-	?	+	+	?	

**Abbreviations:** + low risk for bias; - high risk of bias; ? unclear risk of bias

Table 2: Quality assessment of mixed method studies with the with the Mixed Methods Appraisal Tool (MMAT)

Author	Qualitative component	Quantitative component	1	2	3	4	5	6	7	8	9	10
(Campbell et al. 2011)	Qualitative description	Cross-sectional	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

**Abbreviations:** 1. Are there clear qualitative and quantitative research questions (objectives), or a clear mixed methods question (objective)? 2. Do the collected data allow to address the research question (objective)? 3. Are the sources of qualitative data relevant to address the research question (objective)? 4. Is the process for analyzing qualitative data relevant to address the research question (objective)? 5. Is appropriate consideration given to how findings relate to the context in which the data were collected? 6. Is appropriate consideration given to how findings relate to the sampling strategy relevant to address the quantitative research question? 8. Is the sample representative of the population understudy? 9. Are measurements appropriate? 10. Is there an acceptable response rate?

1

Table 3: Quality assessment of qualitative research with the Joanna Briggs Institute's Qualitative Assessment and Review Instrument (JBI-QARI)

Author	1	2	3	4	5	6	7	8	9	10
(Hewitt et al. 2007)	Unclear	Yes	Yes	Yes	Unclear	No	No	No	No	Yes
(Marbach and Griffie 2011)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
(Faul et al. 2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
(Birken et al. 2014b)	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
(Collie et al. 2014)	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
(Chubak et al. 2012)	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
(Zullig et al. 2018)	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

**Abbreviations:** 1. Is there congruity between the stated philosophical perspective and the research methodology? 2. Is there congruity between the research methodology and the research question or objectives? 3. Is there congruity between the research methodology and the methods used to collect data? 4. Is there congruity between the research methodology and the research methodology and the interpretation of results? 6. Is there a statement locating the researcher culturally or theoretically? 7. Is the influence of the researcher on the research, and vice-versa addressed? 8. Are participants, and their voices, adequately represented? 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis, or interpretation of the data?

Table S2. Quality Ass Author		Quality Indicators From AHRQ												
(Publication Year)	1	2	3	4	5	6	7	8	9	10	11			
(Baravelli et al. 2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Not applicable			
(Brennan et al. 2010)	Yes	Yes	Yes	Yes	Not applicable	No	Not applicable	No	Not applicable	Yes	Not applicable			
(Birken et al. 2013)	Yes	Yes	Yes	Yes	Not applicable	No	Not applicable	No	Not applicable	Yes	Not applicable			
(Dulko et al. 2013b)	Yes	Yes	Yes	Yes	Not applicable	No	Not applicable	No	Not applicable	Yes	Not applicable			
(Birken et al. 2014a)	Yes	Yes	Yes	Yes	Not applicable	No	Not applicable	Yes	Not applicable	Yes	Not applicable			
(Blanch-Hartigan et al. 2014).	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	Not applicable	Yes	Not applicable			
(Lester et al. 2014).	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	Not applicable	Yes	Not applicable			
(Salz et al. 2014)	Yes	Yes	Yes	Yes	Not applicable	Yes	Not applicable	Yes	Yes	Yes	Not applicable			
(Watson et al. 2010)	Yes	Yes	Yes	Yes	Not applicable	No	Yes	No	Yes	Yes	Not applicable			
(Merport et al. 2012)	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	Not applicable	Yes	Not applicable			

Table 4: Quality assessment of cross-sectional studies with the Agency for Healthcare Research and Quality (AHRQ) checklist

**Abbreviations:** 1. Define the source of information (survey, record review); 2. List inclusion and exclusion criteria for exposed and unexposed subjects (cases and controls) or refer to previous publications; 3. Indicate time period used for identifying patients; 4. Indicate whether or not subjects were consecutive if not population-based; 5. Indicate if evaluators of subjective components of study were masked to other aspects of the status of the participants; 6. Describe any assessments undertaken for quality assurance purposes; 7. Explain any patient exclusions from analysis; 8. Describe how confounding was assessed and/or controlled; 9. If applicable, explain how missing data were handled in the analysis; 10. Summarize patient response rates and completeness of data collection; 11. Clarify what follow-up, if any, was expected and the percentage of patients for which incomplete data or follow-up was obtained