Adult cancer survivors' experiences of healthcare interactions and unmet needs in healthcare services: A systematic review

Peter Charles Hallett

Master of Clinical Science

The Joanna Briggs Institute

The University of Adelaide

August 2015

Table of Contents –

Abstract

Background:

The cancer survival rate has shown consistent improvement over recent years. This has resulted in an increased focus on the health care needs of cancer survivors. These needs vary as a function of the disease and the time since diagnosis.

Objectives:

The aim of this systematic review was to synthesise the best available evidence of the experiences of disease free adult cancer survivors' interacting with health care practitioners and the healthcare system and the unmet needs they identify in the provision of services.

Methods

A three-step search strategy was utilised in this review to find published and unpublished studies. An initial limited search of PubMed and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference list of all identified reports and articles was searched for additional studies. Studies published in English from 2003 to 2013 were considered for inclusion in this review. The databases searched included: CINAHL, PubMed, Embase, ProQuest Dissertations & Theses A & I and MedNar.

Papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardised critical appraisal instrument from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI).

Results

A total of 3986 articles were identified from the initial search strategy. A further five articles were identified from a review of the reference lists of included articles resulting in a total of 3991 identified articles. After removal of 913 duplicate articles, the titles and abstracts of 3078 records were reviewed and 2924 were excluded. One hundred and fifty four articles were retrieved for full-text review and 138 were excluded. The remaining 16 articles were assessed for methodological quality. A further six articles were excluded on methodological grounds resulting in 10 articles being included in the review. Overall, the methodological quality of the included papers was good will all studies achieving a methodological rating of at least 6/10.

From these articles, 137 findings were extracted and aggregated to form 23 categories. Five synthesised findings were derived: 1) Cancer survivors require comprehensive co-ordination of care and deficits in this care may provoke anxiety and result in a heightened fear of recurrence. 2) Cancer survivors' communication with their health practitioners may be affected by practitioner and system characteristics, which can affect their physical and psychological needs being addressed. 3) Cancer survivors may feel isolated if there is inadequate psychological and social support including preparation for the transition at the end of treatment. 4) Cancer survivors may experience increased distress if they are not provided with adequate information in a timely manner for themselves, their family and partners about issues such as the late effects of treatment. 5) Cancer survivors require information and health practitioner assistance in a number of areas such as physical treatment, body image, and wellness / lifestyle change needs and if this is not provided, adjusting to their health issues may be more challenging.

Conclusions

Patient-centred care consisting of both individual and system issues must be placed at the cornerstone of the delivery of healthcare services to cancer survivors. Through this, adequate care co-ordination may be achieved with appropriate support being available at the transition point at the end of active treatment. The fear of recurrence may be impacting at multiple levels of the survivorship experience and reflects the often unmet need for psychological assistance. There is a need for health professionals to be mindful of not only the physical impact of cancer but the impact on psychological and broader

lifestyle areas, with adequate provision of information and access to appropriate treatment services.

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

I give consent to this copy of my thesis when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968.

The author acknowledges that copyright of published works contained within this thesis resides with the copyright holder(s) of those works.

I also give permission for the digital version of my thesis to be made available on the web, via the University’s digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

Peter Hallett

Acknowledgements

I would like to acknowledge the assistance of Ms Judith Hocking in the methodological review of selected articles for this thesis, the assistance provided by Dr Matthew Stephenson and Assoc Prof Edoardo Aromataris in supervising the preparation of this thesis and Prof Alan Pearson in the preparation of the protocol.

Chapter 1 Introduction

1.1 Context of the review

The survival rate for cancer has increased over recent years with 5-year survival after initial diagnosis increasing from 46% in 1982-1987 to 66% in 2006-2010 (Australian Institute of Health &. Welfare., 2012). This has stimulated increased focus on cancer survivors, survivorship and related issues such as prevention and detection surveillance, management of side effects, care co-ordination and provision of information (Hewitt, Greenfield, & Stovall, 2006). Corner (2008) has called for a broader focus on indicies of cancer burden, rather than only on survival statistics as being the predominant measure of cancer outcomes, to better reflect the compexities of living with cancer and longer illness trajectory.

1.2 Cancer survivors and survivorship

There is not a consistent definition of survivorship in the literature. Mullan (1985), a physician diagnosed with cancer, through his own personal experience and other cancer survivors experiences found the dichotomy of cure and sickness inadequate to encapsulate the experience of being diagnosed with cancer. He conceptualised survival as commencing at initial diagnosis and proposed the “season of survival”. Consisting of three stages; the initial acute survival stage focused on medical treatment; the extended survival period consisting of remission, ending treatment, surveillance scans and/or intermittent therapy and associated with the fear of recurrence; and the final stage of permanent survival where there is either a cure or reduced likelihood of the cancers return. Focused on empowering people affected by cancer, he called for the establishment of a consumer network and specific research into cancer survivorship. This was embraced by an early survivorship organisation, The National Coalition for Cancer Survivorship (NCCS), of which Mullan was a founding member (Rowland, 2007). Established in 1986 to “advocate for quality cancer care for all people touched by cancer”, they defined a cancer survivor as being “from the time of diagnosis and for the balance of life” and survivorship as relating to the continuum of the cancer experience, “living with, through, and beyond a cancer diagnosis” (NCCS, 2015). They were focused on changing the terminology used to refer to cancer patients from “cancer victims” to “cancer survivor” which has occurred with identifying as a cancer victim reduced from 30% in 1994 to 13% in 1998 (Deimling, Bowman, & Wagner, 2007a). Subsequently, they extended their focus to include family, friends and caregivers in the survivor definition. They acknowledge the challenges some people experience with the word “survivor”, and it not being embraced by all, accepting an individual’s right to choose whatever word best fits their personal experience. Prior to this time, the definition of a survivor of cancer was restricted to being disease free at 5 years after their initial diagnosis (Rowland, 2007).

These early origins of the word “survivor” were in advocacy and empowerment. Its usefulness has been criticised as researchers have contributed to uncertainty as each adopts it to define their particular area of study (Twombly, 2004). Recently, the voices of people diagnosed with cancer have been sought to better understand the meaning of the word to them, revealing a diversity of meaning of what it is to be a survivor (Brennan, Butow, Marven, Spillane, & Boyle, 2011; Kaiser, 2008; McGrath, & Holewa, 2012; Shapiro, Angus, & Davis, 1997). The identification with the term “survivor” has varied by cancer diagnosis from 51-95% of breast cancer survivors (Document, Trauth, Key, Flatt, & Jernigan, 2012; Kaiser, 2008) 55% of colorectal cancer patients (Chambers et al., 2012) to 26% of men with prostate cancer (Bellizzi & Blank, 2007). Most haematological malignancy patients disliked the term (McGrath & Holewa, 2012). Mixed findings have been reported with identifying as a survivor and age. Breast cancer survivors diagnosed under 51 years were more likely to associate with survivorship in terms of having a new outlook on life (Documet et al., 2012), whereas the younger colorectal cancer patients (20-49 years) were less likely to identify with the term when compared to older colorectal patients (70-80 years) (Chambers et al., 2012). In contrast, older breast cancer patients were less likely to associate with the term, with some being unfamiliar with the term (Pieters & Heilemann, 2011) or preferring the construct of an aging body rather than being a survivor (Kaiser, 2008) whereas 86-90% of older patients with breast, colorectal or prostate cancer identified with the term (Deimling et al., 2007a).

The meaning people diagnosed with cancer ascribed to the term are varied and multifaceted, with a quarter of patients applying two meanings. Document et al. (2012) explored this with breast cancer survivors and the most common meanings were conquering against an enemy, having a new outlook on life and balancing the awareness of their own mortality with engagement in new activities and life values. Other associations included helping other cancer survivors; accepting life can sometimes be out of their control and dependent on either God or luck; being part of a larger group of survivors and joining an exclusive club. Kaiser (2008) reviewed the layered conceptualisation of the term survivor and its strong association with women affected by breast cancer. Through the dominant narrative associated with femininity, happiness, health and being triumphant while hiding the mastectomy scars and disfigurement that can be associated with the disease (Batt, 1994; King, 2006) these women were highlighted as being deserving women from all walks of life. This enabled women to advocate for greater medical investment in breast cancer to find improved treatments (Kaufert, 1998; King, 2006). This association with femininity and health, with the onset of numerous fun-runs enhanced its appeal, resulting in corporations pledging donations and relabeling products in pink to enhance brand loyalty (King, 2006). Kaiser highlights how some women have turned away for this dominant narrative of being a breast cancer survivor, preferring to identify as thrivers or breast cancer warriors. Some have declined to conceal their mastectomy scars, promoting the acceptance of women’s bodies in all forms and acknowledgement of the breadth of emotions associated with treatment, such as grief and anger not acknowledged in the dominant survivor narrative. This acknowledges a recovery focus through a “restitution narrative” (Frank, 1995) can alienate some, such as those with ongoing effects of cancer (Batt, 1994; Ehrenreich, 2001; Frank, 1995; Mayer, 1993; Potts, 2000; Thomas-MacLean, 2005).

To explore the extent to which women embraced the term survivor, Kaiser (2008) interviewed 39 women who had concluded treatment for breast cancer 3 to 18 months previously. She identified some aligned with the dominant narrative, adopting a fighting image and strength associated with having won the battle and made it through the experience. For some, this was achieved by connecting with their inner strength and generated a sense of pride. Some women were able to have coexisting the fear of recurrence and being a survivor, sometimes conceptualising it as an ongoing war whereas for others, the fear or recurrence and ongoing feeling of being in a battle resulted in them rejecting the term. For some women, the meaning was dynamic, initially being empowering but changing when confronted by the deaths of other breast cancer survivors by expanding it to relate to other life events, characterising themselves as a survivor of life. For some women, the term was incongruent with their experiences, feeling unworthy of the term if they had not been sufficiently near death whereas others rejected the social identity of breast cancer, not wanting to be defined by their illness or reminded of it through pink ribbons.

The process of adopting a survivorship identity is dynamic (Kaiser, 2008) and marked by “defining moments” (Documet et al., 2012) or triggers (Deimling et al., 2007a). Document et al. found these defining moments varied between breast cancer survivors. Most commonly occurring when life was back to normal in terms of physical conditioning and daily routine or completing a process such as surgery or treatment whereas for some, it was when they received confirmation from another they were a survivor. Less frequently reported defining moments were a feeling of spiritual or moral strength, joining a group with other survivors, and the removal of the cancer. Similar results were found by Deimling et al. (2007a) in a heterogeneous sample of breast, colorectal and prostate cancer survivors with identification as a survivor associated with either a reduction or ending of cancer symptoms or treatment side effects or having successful treatment such as surgery; having an optimistic life view; or through discussions with clinical staff. In contrast, experiencing higher treatment and cancer related symptoms increased the likelihood of identifying as a patient rather than as a survivor.

Deimling et al. (2007a) explored the adoption of survivorship identity though a ten-year longitudinal study of mixed cancer survivors. For two thirds, identification as a survivor was an important part of who they were. There was a gradual adoption over time with forty percent adopting a survivorship identity by the end of treatment and a further twenty percent at the 5-year post diagnosis anniversary. Similar results were found with people diagnosed with colorectal cancer with 55% identifying as cancer survivors at 5-years post diagnosis whereas 39% identified as being a person who had had (or have) cancer (Chambers et al., 2012). In contrast, the majority of prostate cancer survivors at an average of 46 months post diagnosis identified with the term "someone who has had prostate cancer" (Bellizzi & Blank, 2007).

There may be positive benefits of adopting a survivorship identity including actively managing their disease, (Deimling et al., 2007a), higher positive affect (Bellizzi & Blank, 2007) and lower levels of depression and anxiety and higher self-esteem (Deimling et al., 2007a), higher personal growth, (Chambers et al., 2013; Helgeson, 2011) interpersonal growth, acceptance, and life satisfaction (Chambers et al., 2012). Adoption of cancer survivor terminology may be part of the person's attempt at meaning making and may be relevant for post-traumatic growth.

1.3 Long term health effects of cancer treatment

Cancer treatments can have debilitating side effects in the acute phase including cancer related fatigue, weight gain, hair loss, nausea, diarrhoea (Shapiro & Recht, 2001), psychological distress (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), anxiety and depression (Derogatis et al., 1983; Walker et al., 2013;) and mild cognitive impairment (Conroy et al., 2013). Some symptoms, such as fatigue, (Mustian, et al,. 2007), neuropathic pain (Fallon, Colvin, & Rowbotham, 2013) and anxiety (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013) may persist after treatment concludes. With increasing survivorship, there are also concerns regarding the long-term effects of cancer treatments, such as radiotherapy and chemotherapy, on the body (Aziz, 2007) and the psychosocial impact (Foster, Wright, Hill, Hopkinson, & Roffe, 2009).

Cancer survivors have poorer health relative to people without cancer (Brown, Brauner, & Minnotte, 1993; Eakin et al., 2006; Hewitt, Rowland, & Yancik, 2003). Lifestyle factors are especially relevant as younger cancer survivors have a higher incidence of smoking and only 30 percent of cancer survivors meet the national physical activity guidelines (Bellizzi, Rowland, Jeffery, & McNeel, 2005). These lifestyle factors such as obesity, poor diet (low in fruit, vegetables and calcium and high in red meat) and inactivity are associated with some cancers or increased mortality (Kushi et al., 2012).

As survival rates have increased there has been increasing focus on improving functional status and quality of life in cancer patients and how this is achieved through interactions between healthcare practitioners and cancer survivors. This has resulted in the adoption of models of care utilised with some other chronic diseases, such as rehabilitation (Silver & Gilchrist, 2011) and patient-centred care (Tsianakas et al., 2012) and self-management/ self-efficacy (Foster et al., 2015). Due to the heterogeneity of cancer patients, different models of care are being developed including cancer survivorship plans, integrated models, separate survivorship clinics and consultative models (Campbell et al., 2011).

1.4 Unmet needs and needs of cancer survivors

The exploration of cancer survivors needs has been addressed from different perspectives with some studies identifying the needs of cancer survivors, some focus on supportive care needs whereas others identify the unmet needs of cancer survivors. Conceptually, there is not a clear definition adopted in the literature regarding an unmet need. Vivar and McQueen (2005) reviewed the concept of “need” and highlighted different disciplines have adopted individual definitions citing its original philosophical origins from Marx and Hegel (Fraser, 1998). Differing concepts have existed including; differences between services necessary to deal with health problems and those actually being received, the absence of sufficient or adequate care or service to address a problem, (Carr & Wolfe, 1976) a gap between an individual’s actual state and goals, (Liss, 1993) perceptions and responses related to achieving and utilising goals, (Heathers, 1955) a difference between actual state and optimal level of health (Vivar & McQueen, 2005) or a necessary or desired action or resource required to achieve optimal well-being (Carey et al., 2012) . Vivar and McQueen highlight the need to differentiate needs from problems and the sequel of illness. They define the existence of a need as the difference between actual state (physical and psychosocial consequences) and optimal state (reduction or absence of sequelae) (Vivar & McQueen (2005).

Health professionals can be poor at discovering patients' needs and concerns for a number of reasons. Patients often do not disclose their concerns, with 80% of patient concerns unidentified by ward nurses in an inpatient chemotherapy setting (Farrell, Heaven, Beaver, & Maguire, 2005) with similar results in hospice settings (Heaven & Maguire, 1997). Patients who are more anxious or depressed are also less likely to disclose their concerns (Heaven & Maguire, 1997). Health care practitioners identify different needs to patient identified needs (Pollock, Wilson, Porock, & Cox, 2007) and may have a bias towards responding to physical symptoms over psychological and sexuality issues (Wilkinson, 1991) for nurses in chemotherapy centres, (Farrell et al., 2005), hospice settings (Heaven, & Maguire, 1997) and hospital wards (Wilkinson, 1991) and oncologists in outpatient clinics (Ford, Fallowfield, & Lewis, 1994). Early identification of patients' concerns is essential as frequent and/ or severity of concerns at time of diagnosis was related to anxiety and depression at 3 and 12 months post diagnosis.

Historically, there has been a lack of standardisation in the assessment, scoring and reporting of unmet needs (Sanson-Fisher et al., 2000) and a lack of needs assessment measures specifically designed for survivors (Hodgkinson, K., Butow, P., Hunt, G. E., Pendlebury, S., Hobbs, K. M., Lo, S. K., & Wain, G. (2007b). Hodgkinson et al., utilised a mixed cancer sample to develop the cancer survivors unmet needs measure (CaSUN). Consisting of five factors, existential survivorship, comprehensive care (health care and multidisciplinary care), information, quality of life and relationships. They also included six positive change items, and 72% of participants identified with at least one of these items. Fifty four percent of survivors identified at least one unmet need with the most significant issues being comprehensive care, existential survivorship and information. The results from their study are detailed in Table 1.

Table 1: Results from the development of the CaSUN measure

	N	Gender	Cancer Type (percentage of total sample)	Stage	Age	Time since Diagnosis	Assessment measure	Unmet Needs
Hodgkinson et al., (2007b)	353	Male (19%); Female (81%)	Breast (59.2%): Gynaecological (16.9%): Prostate (12.2%): Colorectal (9.1%): Other (2.6%)	Disease free	Av Age 59.6 years: Range 26-99 years	Average 2.3 years (Range 1-15 years)	Cancer survivors unmet needs measure (CaSUN) (Hodgkinson et al., 2007b)	. Cancer recurrence concerns (26%) . Up to date information (20%) . Understandable information (18%) . Reduce stress in my life (15%) . Local health care services (15%) . Doctors talk to each other (15%) . Managing health with team (13%) . Complaints addressed (13%) . Best medical care (12%) 0. Information for others (12%)

Early studies of unmet needs have often included heterogeneous samples consisting of mixed cancer types, age, variable time since diagnosis, stage of disease and treatment outcomes such as a curative and palliative treatment. These studies identified that the extent of unmet needs varies over the course of the disease, with higher unmet needs and need for cancer specific information closer to the time of diagnosis or in the treatment phase, (Fiszer, Dolbeault, Sultan, & Bredart, 2014; Harrison, Young, Price, Butow, & Solomon, 2009) whereas in the post treatment phase of care, there remained some treatment related information needs combined with additional information needs about recovery (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Higher unmet needs at time of diagnosis predicted higher unmet needs 6 months post diagnosis (McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010) and were associated with advanced disease, poorer health, living in a rural location, not attending a clinical appointment for more than 6 months and younger age (Butow, Phillips, Schweder, White, Underhill, & Goldstein, 2012; Fiszer et al., 2014; Harrison et al., 2009; Puts, Papoutsis, Springall, & Tourangeau, 2012). There can also be cultural variation with unmet needs. Asian women had lower psychological needs and higher information needs compared to western women (Fiszer et al., 2014) and immigrant cancer survivors have higher unmet information and physical needs than Anglo-Australians (Butow et al., 2013).

Older cancer survivors report more non-cancer related co-morbidities and their symptoms of pain, weakness and reduced energy levels are more related to age-related factors than cancer-related factors (Deimling, Bowman, & Wagner, 2007b). In contrast, younger women tend to have higher unmet needs and more specific needs that relate to menopause, fertility concerns and work considerations (Vivar & McQueen, 2005). This was supported by Geller, Vacek, Flynn, Lord, & Cranmer (2014) who investigated the unmet needs of a mixed group of cancer survivors, predominately diagnosed in stage I or II where 65% of their sample were aged 60 and over. The highest unmet need was relevant for only 15% of the sample. Emotional, social and spiritual areas related to five of the top ten unmet needs and a further three of the top ten unmet needs related to information needs. The remaining two related to physical issues and access to care.

A number of recent systematic reviews have drawn together themes from these earlier studies. Harrison et al. (2009) conducted a systematic review of the unmet supportive care needs for people with all cancers, stages of disease, sample size or study design, and all treatment phases including diagnosis, treatment, advanced and palliative care, and post treatment, follow-up and survivorship phases. The extent of unmet needs showed large variability between different studies, though similar unmet needs were found across breast, melanoma and prostate cancer survivors. Across the different phases of cancer, the most frequent unmet needs related to activities of daily living, psychological, information, psychosocial and physical needs. Anxiety about the fear of recurrence, the post treatment follow-up and survivorship phase activities of daily living remained the highest unmet need and communication, economic, information, physical, psychosocial and supportive care and sexuality were in descending importance. Butow et al. (2012) examined the supportive care needs of cancer patients living in rural and urban settings. There were methodological issues in many studies with a poor definition of ‘rural’, studies often using self-developed assessment tools without psychometric testing and a reliance on cross-sectional designs. They identified higher physical functioning and daily living needs for rural patients, which may reflect a more stoical orientation. Travelling distances for treatment resulted in financial, emotional and relationship challenges. This was offset with the perception of accessing a higher level of clinical expertise in the urban settings. Maguire, Kotronoulas, Simpson, & Paterson, (2015) conducted a systematic review of the supportive care needs of women living with and beyond cervical cancer. The most common needs were fear of cancer recurrence, body image concerns, sexual desire issues, need for more sexuality information, dealing with pain and assistance with relationships. Fiszer et al., (2014) conducted a systematic review of the supportive care needs of women with breast cancer. The highest needs were in the health system / information and psychological domains. Twenty to seventy percent of women identified at least one moderate or high unmet needs. The high ranking specific needs included body image issues, fear of recurrence, being informed about the benefits and side effects of treatment and what you can do to get well, dominated by the fear or recurrence.

Some studies have explored the changes in unmet needs across the cancer continuum. Mohamed et al. (2013) conducted a qualitative study examining the unmet needs of people with muscle invasive bladder cancer treated with radical cystectomy at times along the cancer trajectory; at diagnosis, postoperatively and survivorship. The nature of the unmet needs changed over time. The unmet needs at diagnosis were focused on patient decision-making about surgery and information to support understanding this process. In the postoperative stage, the unmet needs focused on postoperative care including care of the stoma and continence issues. In the survivorship period, at 6 months post operative, unmet needs were more functional in terms of the impact on daily activities and sexual functioning and the emotional and psychological response to the surgery and resultant issues. Millar, Patterson and Desillee (2010) investigated the unmet needs of emerging adulthood cancer survivors at various stages along the treatment and post treatment continuum. Higher unmet needs were reported by survivors still having treatment or within one year of treatment, reporting an average of 25.5 unmet needs. The unmet needs from 1-5 years since treatment averaged 13.2 unmet needs and highlighted the highest unmet need being about focusing on tasks and remembering things and information about what occurs after treatment. Other significant issues included; managing the emotional impact of being a survivor, information about having children, support services and dealing with overprotective parents. At 5 years post treatment and beyond there were an average of 14.5 unmet needs, emotional and adjustment issues were common and some items relating returning to work and study, suggesting reengagement in life was more of an issue at this time. They highlight the need for extended follow up care and the need to interpret unmet needs in a developmental context.

Thorne and Stajduhar (2012) analysed interviews with cancer survivors across the cancer trajectory. They found they experienced confusion and insecurity at the time of transition from primary treatment, associated with feelings of loss, vulnerability and abandonment coinciding with new concerns about work and financial life areas and fears of recurrence and emotional well being. Survivors were advised at the time of diagnosis that cancer treatment required specialised care, which was now incongruent with being transferred back to their primary care physicians at the end of their cancer treatment. This fuelled their fear of recurrence and raised concerns if their primary care physician had the specialist skills to manage their needs. The scheduled structure of their treatment kept their mind busy from fear of recurrence, but this structure was now removed and the meaningful relationships they had developed with their treatment team now felt like personal rejection as they returned to primary care physicians. Survivors felt some healthcare professionals were either unable to or disinterested in assisting them in managing the feelings associated with this transition. However, some health care provider's behaviour assisted patients in this transition such as nonverbal aspects of communication indicating interest and not dismissing, or minimising their concerns at this time of transition. Survivors heightened emotional experience at this time, resulted in some changing the meaning of communication over time, with a more negative message been constructed through the eyes of anxiety, than what was initially construed at the time. Survivors wanted early warning of the transition and emotions that might be experienced at the end of treatment and believed health practitioners should be aware of challenges they might face such as fatigue, emotional reactions and cognitive issues and there should be preparatory discussions with patients in this area. They believed additional information and care pathways could make the transition easier, such as another appointment at the end of treatment. They perceived this as health professionals neglecting to attend to a predictable process, which they should have been aware of, and there was a disconnect between the distress experienced by patients and the level of attention focused on this transition with the need for adequate time for patient consultations to enable a patient-centred focus on survivorship care plans. They thought cancer specialists should not be complicit that a return to a normal life would occur after the conclusion of treatment and conversations about a return of the disease be built in to the management process and given appropriate time and respect.

Thorne and Stajduhar concluded that influential health care relationships need to be managed respectfully which may reduce confusion associated with the end of treatment and improved clarity regarding the roles and responsibilities between specialists and general practitioners and the ability of general practitioners to provide the care they required.

More recently, studies on unmet needs have focused on defined populations and stages along the cancer trajectory with survivors who are disease free, which was more reflective of the inclusion criteria for this thesis. These have included the supportive care needs of breast cancer survivors 2-10 years post diagnosis, (Hodgkinson, et al. 2007c) the unmet supportive care needs of gynaecological cancer survivors, diagnosed at least 1 year prior and free of recurrence, (Urbaniec, Collins, Denson, & Whitford, 2011) the needs of colorectal cancer survivors 2 to 15 years post treatment who were not receiving any active treatment for cancer (Santin, et al., 2015) and the unmet needs of prostate cancer survivors diagnosed 9-24 months earlier with stable disease (Watson et al., 2015). Unmet needs were reported by 39-67% at an average of 8 unmet needs. These studies frequently identified persistent levels of psychological symptoms at rates of 9% to 29% for anxiety, 5% to 20% for depression and 15% for posttraumatic stress disorder and these were related to higher symptom burden and unmet needs. Many survivors also reported positive experiences associated with their diagnosis, with 68-80% of survivors reporting at least one positive item on the CaSUN questionnaire. All studies identified fear of recurrence being an unmet need ranking in the top 3 unmet needs across all studies, and was the highest unmet need in two of the studies, present for 12-32% of survivors. Other common themes across the studies included care co-ordination and communication between health professionals including the timely obtaining of test results.

1.5 Health practitioner communication

The importance of patient-centred communication has been emphasised in numerous cancer treatment guidelines and is critical in enhancing patient outcomes (Greene et al., 2012; Institute of Medicine. (2001); Norris, Pratt-Chapman, Willis, & Reed, 2013). Despite this, the term remains ambiguous due to definition, conceptualisation and assessment challenges (Epstein, Franks, Fiscella, Shields, Meldrum, Kravitz, & Duberstein, 2005; McCormack, et al., 2011; Mead & Bower 2000). Initially developed from the social and behavioural sciences and further refinement in general practice due to limitations of the 'biomedical models' disease focus (Mead & Bower 2000). Ishikawa, Hashimoto and Kiuchi (2013) review the origins of the term from four different sociological theoretical perspectives of functionalism, conflict theory, utilitarianism and social constructionism, which has resulted in different operationalisation and measurement of patient-centeredness. They called for a broader focus on patient-centred communication to be considered as an interaction between the physician and the patient, rather than solely defining it from the perspective of the physician behaviour, also incorporating patient competence (Clayman et al., 2010) in terms of health literacy (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011a; Berkman et al., 2011b; Sorensen et al., 2012).

Gerteis, Edgman-Levitan, and Daley (1993) were some of the earlier advocates of patient-centred care and identified six aspects; respect for patients' values, preferences, and expressed needs; coordination and integration of care; information, communication, and education; physical comfort; emotional support including relieving fear and anxiety; and involvement of family and friends. These have been endorsed in the Institute of Medicine's (IOM) *Crossing the Quality Chasm: A new Health System for the 21st Century* report (IOM, 2001).

Mead and Bower (2000) in their review of the literature distinguished the 'patient-centeredness' model from the 'biomedical model' on five dimensions of; biopsychosocial perspective, the patient as a person, sharing power and responsibility, the therapeutic alliance and the doctor-as-a-person. Together, this incorporates social and psychological factors into illness perception, combined with the individual's experience of illness, its impact on their lifestyle and the personal meaning they attach to their illness. In this model, the doctor-patient relationship is more personable. It is egalitarian and collaborative and based on empathic understanding with mutual influence of the patient upon the doctor and vice versa. They highlight several factors impacting on the doctors ability to adopt a patient-centred approach, including; patient factors, professional context influences, doctor factors, consultation level influences and 'shapers' detailed in Figure 1.

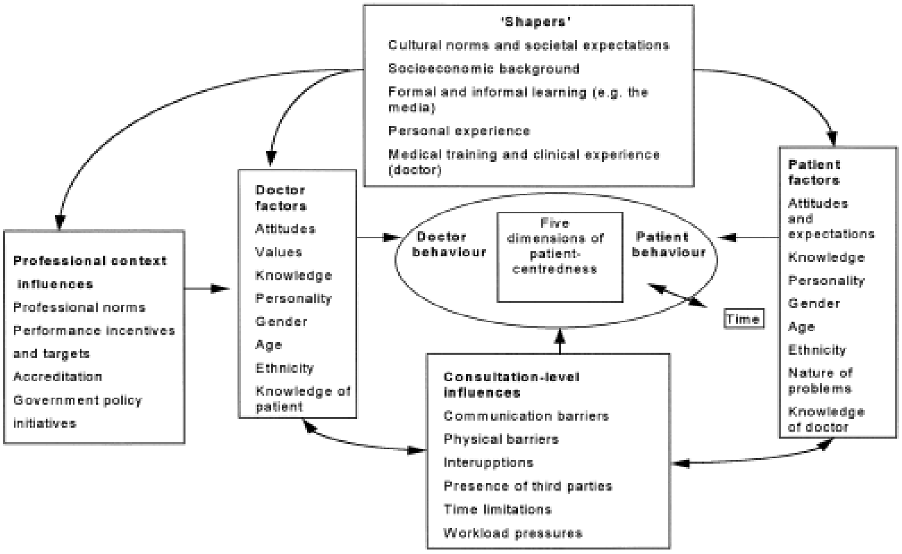


Figure 1 Factors influencing patient-centredness (Mead & Bower, 2000) p 1104

Epstein et al. (2005) drew the distinction between patient-centredness and patient centred care. They described patient centredness as a moral philosophy consisting of the values of; '(1) considering patients' needs, wants, perspectives and individual experiences; (2) offering patients opportunities to provide input into and participate in their care; and (3) enhancing partnership and understanding in the patient-physician relationship. (McWhinney, 1995)' p 1517. Actions that demonstrated patient centredness included interpersonal behaviours, technical interventions and health system innovations and is consistent with the Institute of Medicine's (2001) definition which includes both individual practitioner and health system qualities. Epstein et al. (2005) identify four factors affecting patient centred communication; patient factors, health system factors, relationship factors and clinician factors (See Figure 2).

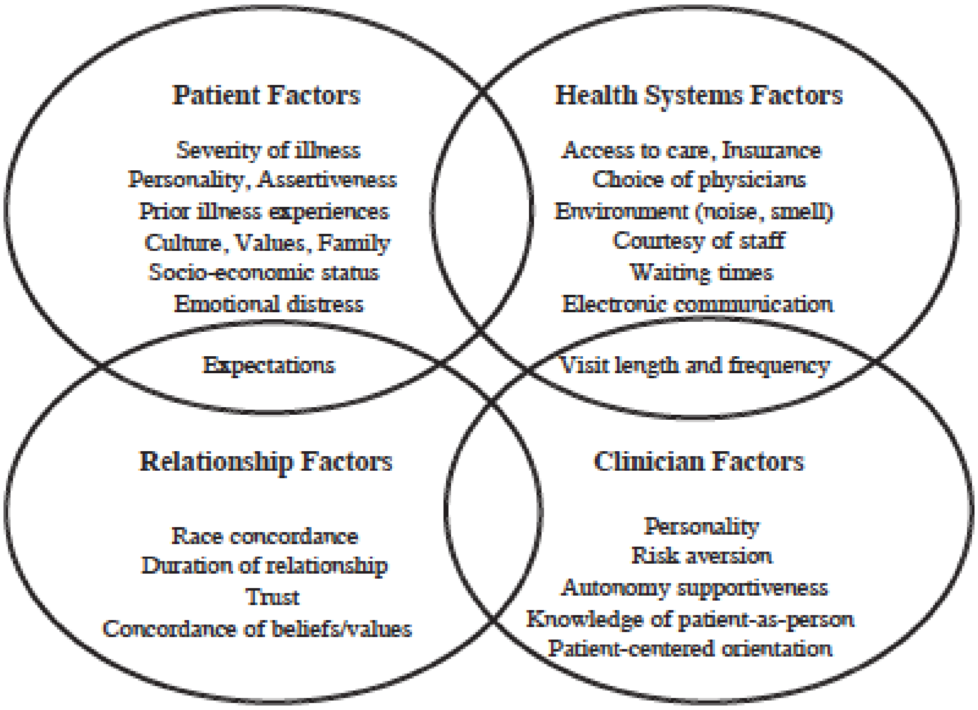


Figure 2: Factors influencing patient-centred communication Epstein et al. (2005) p1517

Epstein and Street (2007) further refined the concept of patient-centred communication, identifying six core functions (See Figure 3) applied across the six stages of the cancer continuum of prevention, screening, diagnosis, treatment, survivorship and end of life. Underpinning the six core functions are patient-centred communication skills and several intrinsic and extrinsic contextual factors, such as; sex, cultural factors, health beliefs, illness representations, knowledge, attitudes, knowledge and the health care system. Through empathy, active listening and self awareness, clinicians seek a shared understanding of the patients’ needs, values, perspective and experiences and how these impact on coping with their cancer diagnosis and subsequent treatment decision making.

The first core function involves fostering the patient-clinician relationship, which is based on trust and rapport with mutual understanding of their respective roles and responsibilities. Clinicians are self-aware and reflective of their own well being. They are mindful of race, ethnicity, language and literacy and the impact these may have on the interaction as they work to engage patients and family to be active in the consultations and decision-making. The second core function of exchanging information is a process where clinicians and patients work to develop a shared understanding of both medical and personal aspects of the health condition. This involves understanding the meaning of the illness to the patient and communicating clinical information, including ‘bad news’ in a compassionate, simple and meaningful way to patients. Effective communication skills can be assisted by visual aids, such as graphs and diagrams to deliver prognostic and clinical information.

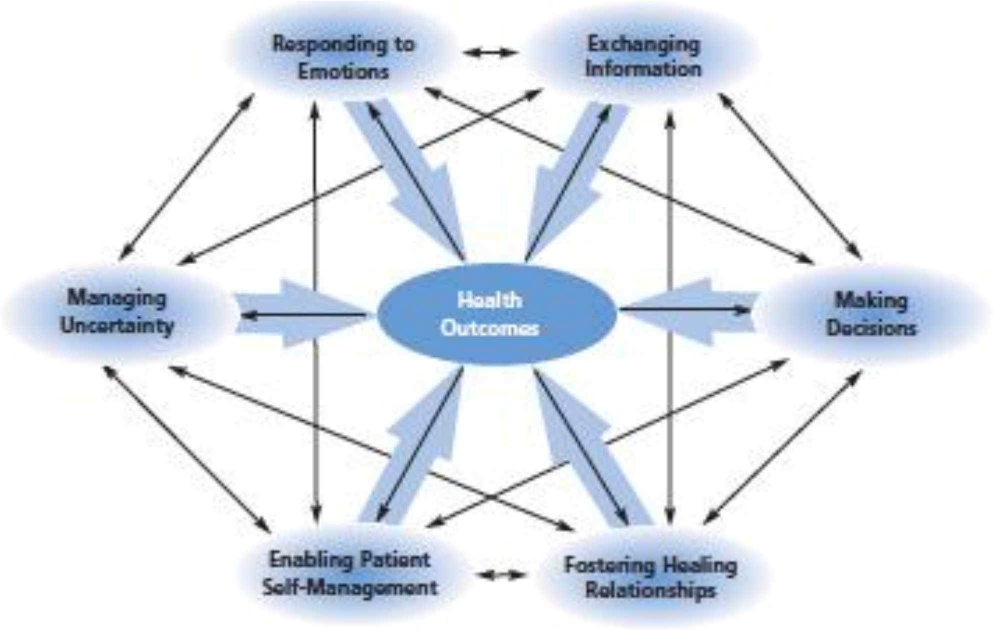


Figure 3: The six core functions of patient-clinician communication (Epstein & Street (2007). p18

The third core function involves clinicians empathically responding to emotions by validating and legitimising patients’ experiences and offering assistance where appropriate. This may include referrals to appropriate services, such as psychotherapy. This function may be affected by environmental factors that impact on communication including limited time and noise and team factors such as permission from management and colleagues to engage in this style of patient interaction (Hope-Stone & Mills, 2001). Clinicians need to be self-aware to enable them to manage their emotional responses. The fourth core function involves managing uncertainty. They highlight the goal to reduce uncertainty for patients where possible, but acknowledge some uncertainty may exist with a cancer diagnosis. They emphasise the complexity of this area in the literature with uncertainty affecting quality of life, perceptions of control and result in emotional distress (Andreassen, Randers, Naslund, Stockeld, & Mattiasson, 2005; Dunn et al., 1993) but can also be self-protective by enabling hope in other situations (Babrow, (2001). Furthermore, reassurance can potentially increase anxiety (McDonald, Daly, Jelinek, Panetta, & Gutman, (1996) for people, especially when provided to survivors spontaneously, before identifying their concerns (Stark et al., 2004). The fifth core function involves making decisions. They proposed a model based on Charles, Gafni and Whelan (1999) consisting of information exchange, deliberation and a shared decision-making process. The health care system supports this process through decision aids such as booklets, web pages, prompt sheets and video recordings. The final core function is enabling patient self-management. This is achieved by clinicians removing barriers to self-management and assisting patients to be more autonomous and provide access to resources. This may involve aspects of advocating for patients and supporting patient autonomy. This approach was similar to Quillin et al. (2009) who advocated adopting a systems model to manage the complexity of the communication needs of cancer patients whereby changes in one aspect of a system may affect other aspects due to their interdependent nature. This helps take account of other factors impacting on communication including the physical environment, organisational aspects of care delivery, and engagement with multiple specialists and maintaining communication between these and the primary care team.

The complexity of these models on patient-centred care has not been matched by patient-reported outcome measures (McCormack et al., 2011). They have predominately been focused on information communication and education over other dimensions of patient-centredness (IOM, 2001) such as ‘physical comfort’ and ‘involvement of family and friends’ and no reliable measure exists to assess all six dimensions (Tzelepis et al., 2014).

Survivors' perceptions of patient-centred communication was facilitated by health practitioners spending time understanding the whole person, spending less time planning, and being flexible to meet concerns throughout the visit (Clayton & Dudley, 2009). This enables the patient to be known as an individual by providers (Thorne, 1999). One example of patient-centred communication is at the 'bad news' consultation. Communication that involved preparing patients for a diagnosis of cancer, having people present at the consultation they wanted, providing clear information, providing written information, discussing patients questions on the day, discussing patients feelings and providing reassurance were associated with lower anxiety. Using the word 'cancer', discussing the severity of the diagnosis, life expectancy, and the impact of cancer on other aspects of the patient's life and encouraging patient involved in treatment decisions was associated with lower depression (Schofield et al., 2003). Patient disclosure of information is facilitated by open directive questions, empathy, clarifying psychological aspects, summarising and making estimated guesses. In contrast, leading questions, focusing on physical problems, providing advice and reassurance inhibited disclosure of information (Maguire, Faulkner, Booth, Elliott, & Hillier, 1996). Communication was not enhanced by the use of screening questions that focused on physical symptoms (Maguire et al., 1996) though using patient reported outcome measures resulted in increased discussion of symptoms with oncologists but there was no impact on discussion of patients' functioning (Takeuchi et al., 2011).

Patient-centred communication is positively related to post visit satisfaction, (Venetis, Robinson, Turkiewicz, & Allen, 2009) lower incidence of mood disturbances three months after diagnosis and patients general and cancer specific psychological health and help in managing anxiety (Arora, 2003; Silliman, Dukes, Sullivan, & Kaplan, 1998). The relationship between patient-centred communication and psychological health has been demonstrated in breast cancer patients who felt well informed when considering surgery had a lower incidence of anxiety and depression compared to those poorly informed (Fallowfield, Hall, Maguire, & Baum, 1990). Less patient-centred communication has been related to poorer psychological adjustment up to 13 months following the ‘bad news’ consultation (Butow et al., 1996; Roberts, Cox, Reintgen, Baile, & Gibertini, 1994). There may also be additional financial cost with poor communication requiring increased duration and frequency of subsequent consultations, pursuing futile treatment in the end stage of life and increased use of complementary and alternative medicine. Other costs in the form of social, emotional and psychological costs to patients and health providers may also be present (Thorne, Bultz, & Baile, 2005).

Observations of doctors and nurses reveals some demonstrate avoidant communication behaviours to maintain distance from patients with a terminal illness, and avoid emotional topics such as prognosis and diagnosis, though they are often unaware of these behaviours. Some of these verbal behaviours include false reassurance and selective attention to the physical rather than psychological needs, subtlety communicating to patients it is not appropriate to raise psychological issues. Some doctors and nurses assume patients will self disclose psychological issues. If they see distress, they may presume they are able to identify the reason, without clarifying, and try to assist by providing physical solutions, such as more pain medication. They may be fearful of evoking strong emotions in patients and lack confidence in knowing how to respond. Many are concerned about getting too close to their patients, feeling overwhelmed due to the strong emotions, and time constraints that might flow from addressing these emotional issues and the psychological impact this might have on them (Hope-Stone & Mills, 2001; Maguire, 1985; Wilkinson, 1991). However, some see the benefits including increased job satisfaction and increased confidence in the care provided to patients (Hope-Stone & Mills, 2001). Similar patterns are evident in the survivorship phase. Clayton and Dudley (2009) studied 60 breast cancer survivors 2 years after treatment and analysed the interactions between breast cancer survivors and their oncologists. Fifty five percent of the time was waiting time such as getting changed and sitting in silence was also a significant component of the visit. Other time involved; exploring illness and symptoms (9%), understanding the patient in context e.g. vacation plans, what children are doing (4%); planning statements e.g. treatment goals and options (2%) and undertaking reassurance (2%).

1.6 Qualitative Synthesis

The synthesis of qualitative data has been a controversial area. (Grypdonck, 2006) identified the value of qualitative research in evidence-based healthcare is that it can elucidate complex processes not identified in the quantitative research. Barnett-Page & Thomas (2009) critically reviewed the different methods for the synthesis of qualitative research including meta-ethnography, grounded theory, thematic synthesis, textual narrative synthesis, meta study, meta-narrative, critical interpretive synthesis, ecological triangulation, framework synthesis and other developing approaches. They identified some confusion that can be created by using different terms for similar approaches. Differing along epistemological assumptions, the extent of iteration, quality assessment problematising the literature, exploration of the similarities and differences between the primary studies and the extent to which they extend beyond the initial primary data and seek to transform it, and the output of the synthesis and its utility. They emphasised the importance of selecting the relevant synthesis approach most appropriate to the researcher's situation.

Dixon-Woods, Booth, and Sutton, (2007) reviewed attempts at qualitative synthesis between 1988 and 2004. They found a lack of clarity regarding the search, appraisal and synthesis methods. In an area that was developing rapidly and was associated with innovative methods, there lacked a consensus of methodology with some techniques being applied inappropriately. Hannes & Macaitis (2012) updated this earlier review and included publications from 2005 to 2008. They identified improved transparency with searching and critical appraisal processes. However, the approach of synthesis remained an area of concern with documented methods of synthesis often being poorly applied by other than the original developer of a method of synthesis.

The meta-aggregation process adopted for this thesis is that recommended by the Joanna Briggs Institute (JBI) which advocated the use of qualitative research to assist in explaining the effectiveness of interventions , the meaningfulness of interventions and from a person centred perspective, ensuring the humanness of the health care experience is given a voice. Based in the philosophy of pragmatism, (Hannes & Lockwood 2011) and modelled on the Cochrane process, (Pearson, 2004), the meta-aggregation process avoids reinterpreting the primary author’s findings and produces practical and usable findings in the form of recommendations, which is in contrast to numerous qualitative synthesis methodologies (Hannes & Lockwood 2011). It allows greater understanding of individual factors such as beliefs, and individual preferences, which may impact on health care utilisation (Joanna Briggs Institute, 2014).

The outcomes from this review will contribute to improved alignment between the expectations and needs of cancer survivors with the services provided to them within the health care system. The results may also contribute to the development of interventions to address the identified unmet needs.

1.7 Methodological basis for the review

This systematic review is necessary to identify the unmet needs of cancer survivors through their interaction with the healthcare system. A preliminary search has been conducted for systematic reviews on this topic. The databases of PubMed, CINAHL, the Cochrane Library and the Joanna Briggs Institute Database of Systematic Review and Implementation Reports were searched. Previous systematic reviews have been conducted to examine the impact of specific cancer on individuals' quality of life, but no qualitative review was found that examined cancer survivors' experience of health care interactions and unmet needs.

The outcomes from this review will contribute to improved alignment between the expectations and needs of cancer survivors with the services provided to them within the health care system. The results may also contribute to the development of interventions to address the identified unmet needs.

1.8 Objective

The aim of this review was to synthesise the best available evidence of adult cancer survivors' experiences interacting with health care practitioners and the health care system and the unmet needs they identify in the provision of services in the healthcare system.

Chapter 2 Methods

2.1 Inclusion criteria

2.2.1 Types of participants

This review considered studies that included adult survivors (18 years and older) of solid tumours, excluding lymphoma, who were under 60 years of age at time of initial diagnosis. For the purpose of this review, a cancer survivor was defined as an individual who has concluded primary treatment and may be in remission or cured, but does not have active advanced disease/ metastatic disease and is not undertaking palliative treatment.

There was significant variability in the literature regarding the reporting of the age of participants; with some reporting age ranges, median ages, age at diagnosis, age at interview, average time since diagnosis and sometimes the age was unclear. For consistency, the age criterion was considered met if; the average age of participants was below 60 years at time of diagnosis or if the average age at time of interview minus the average duration since diagnosis was below 60. This was possible to identify where the study provided information on the age at diagnosis, age at treatment, average duration since diagnosis, median or mean age since diagnosis.

2.1.2 Phenomena of interest

This review considered studies that investigated the experience of cancer survivors, their interactions with the healthcare system and healthcare practitioners, and the unmet needs they experienced in the healthcare system over the course of their survivorship. The health care system included health care practitioners within medicine, nursing, allied health and complementary therapies but excluded alternative therapies.

2.1.3 Context

This review considered studies occurring in any country.

2.1.4 Type of studies

This review considered studies that focused on qualitative data including, but not limited to, study designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

2.2 Search Strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilised in this review. An initial limited search of PubMed and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference list of all identified reports and articles was searched for additional studies. Studies published in English from 2003 to 2013 were considered for inclusion in this review. In 1994, more than half the population was surviving 10 years and 57.9% were surviving five years after a diagnosis of cancer and survivorship issues were becoming increasingly relevant and prevalent in the literature. By 2003, there had been sufficient development of the literature in this area, hence studies published from 2003 onwards were considered for inclusion. The databases searched included:

CINAHL
PubMed
Embase
PsycINFO.

The search for unpublished studies included:

ProQuest Dissertations & Theses, A & I
MedNar.

Initial keywords used were:

Cancer, neoplasm, tumor, cancer survivors, unmet needs, barriers, gaps, qualitative, interviews, focus groups, phenomenology, grounded theory, ethnography, action research and feminist research.

The detailed search strategies used for each of the databases are reported in Appendix I.

To ensure consistency with matching the inclusion criteria against each article, a worksheet was developed and used with the retrieved studies for the full text assessment (Appendix II).

2.3 Assessment of methodological quality

Papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardised critical appraisal instrument from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix III). Prior to the commencement of the critical appraisal, the second reviewer and author agreed that studies would be excluded if they achieved a score of less than 4/10 on this instrument. In addition, studies had to receive a ‘yes’ response to the following two questions from the JBI-QARI tool: Are participants and their voices adequately represented?; Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data? These two questions were perceived to be essential to ensure adequate methodological quality and a clear connection between the voices of the participants and the findings in each study. Any disagreements that arose between the reviewers were resolved through discussion and it was not necessary to seek resolution with a third reviewer.

During the assessment of methodological quality, articles that adopted thematic analysis, or framework analysis, were considered to refer to a method of data analysis (Gale, Heath, Cameron, Rashid and Redwood, 2013; Ward, Furber, Tierney, & Swallow, 2013) rather than a methodology and were rated accordingly. Articles adopting a thematic narrative approach were considered to refer to a broader methodological philosophy and not simply a method of data analysis.

2.4 Data collection

Some studies explored the continuum of treatment, from time of diagnosis; active treatment and post treatment follow up/ survivorship. When this occurred, only that aspect of the article that related to the post treatment follow up/ survivorship phase were included in the review.

Some articles included mixed combinations of participants, with only a subset of participants meeting the inclusion criteria of this thesis. This occurred with respect to the type of cancer and age of participants. Where it was possible to identify the relevant voices of the participants in the article by the authors of the article specifying the type of diagnosis or age of the participant, those extracted findings that met the inclusion criteria of the review were included. Where this was unclear, then the article was excluded from the review.

The identification of unmet needs presented a challenge. Findings that were purely about the lived experience of cancer survivors were excluded. For a study to be included it needed to have findings that had one of the following characteristics; specifically refer to an unmet need, refer to a deficit in care, identify an area that survivors were "less prepared" for than what they wanted to, identify and area that they were "not prepared for", or a statement that referred to what was not helpful.

Data were extracted from papers included in the review using the standardised data extraction tool from JBI-QARI (Appendix IV). The data extracted included specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

The identification of findings was in accordance with the Joanna Briggs institute Reviewers Manual 2014 (JBI, 2014) The author's findings were highlighted in each included study and illustrations in the form of the voices of participants in the study were searched for within the article. When there was a direct link between the authors' findings and the voices of the participants and it was beyond reasonable doubt, the finding was rated as an unequivocal (U) finding. Where the link between the authors findings and the voices of the participants was less direct and lacking a clear association but was plausible, the finding was rated as credible (C). A finding was rated as unsupported when the finding was not supported by the data.

2.5 Data synthesis

Qualitative research findings were pooled using JBI-QARI. This involved the aggregation or synthesis of findings to generate a set of statements that represented that aggregation, through assembling the findings rated according to their quality, and categorising these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings that can be used as a basis for evidence-based practice.

Chapter 3 Results

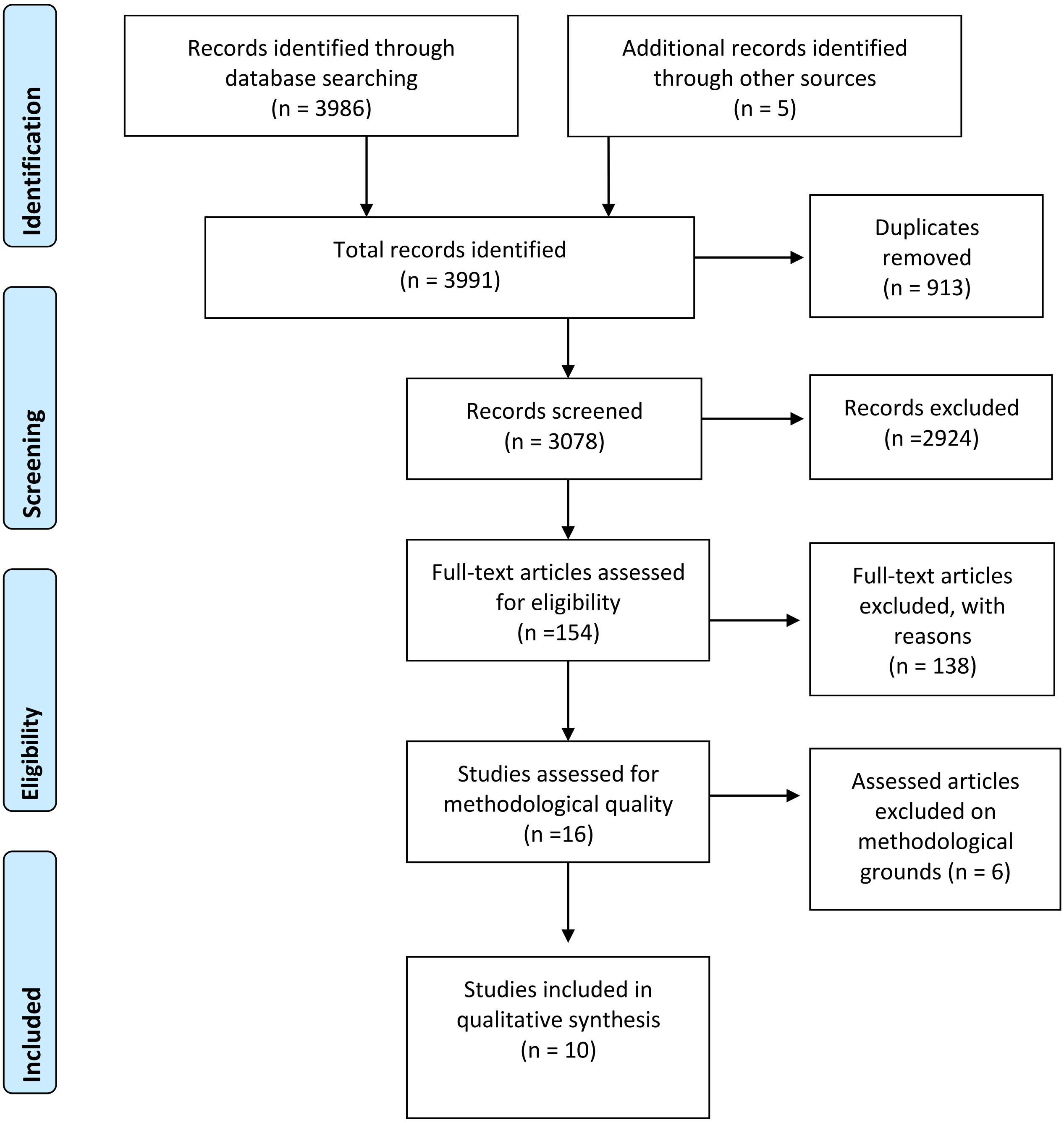
3.1 Search Results and Study Selection

A total of 3986 citations were identified from the search of databases and for unpublished studies. A further five citations were identified from a review of the reference lists of included studies resulting in a total of 3991 identified citations. The results of the search strategy are detailed in Table 2. Following removal of 913 duplicate citations, the titles and abstracts of 3078 records were screened and 2924 were excluded for not meeting the inclusion criteria. One hundred and fifty four articles were retrieved for full-text review and 138 were excluded for not meeting the eligibility criteria. The reasons for exclusion are detailed in Appendix V. The remaining 16 studies were assessed for methodological quality. Six studies were excluded on methodological grounds resulting in 10 studies being included in the review. The reasons for exclusion of the six studies are presented in Appendix VI. The process of study selection and inclusion is summarised in the PRISMA diagram (Figure 4). During this process, authors of seven studies were contacted to seek clarification on the characteristics of their studies, such age of participants and the presence of advanced or metastatic disease in their samples. Of these, two authors did not reply, three replied and their studies were subsequently excluded (Griffiths, 2014; Khan, 2014); McCallum, 2014) for not meeting the inclusion criteria and two studies were included in the methodological assessment for the meta-synthesis (Brennan, 2014; Urquhart, 2014).

Table 2 Results of initial search strategy.

Database	Date searched	Number of articles identified
PubMed	25/1/14	681
CINAHL	25/1/14	319
Embase	25/1/14	2292
PsycINFO	25/1/14	366
Proquest - Dissertations & Theses A&I	25/1/14	129
Mednar	3/11/14	199
Articles identified in reference list of included articles		5
TOTAL		3991

Figure 4: PRISMA Flow Diagram of search results and process of study inclusion.



3.2 Description of Studies

The included studies were heterogeneous with respect to type of cancer, ethnicity, geographical location of the cancer survivors and type of cancer. Eight studies consisted of only female participants (Burns, Costello, Ryan-Woolley, & Davidson, 2007; Galvan, Buki, & Garces, 2009; Lawler, Spathonis, Masters, Adams, & Eakin, 2011; Mollica & Nemeth, 2014; Roundtree, Giordano, Price, & Suarez-Almazor, 2011; Ruddy, Greaney, Sprunck-Harrild, Meyer, Emmons, & Partridge, 2013; Sekse, Raaheim, Blaaka, & Gjengedal, 2010; Thewes, Butow, Girgis, & Pendlebury, 2004;) and two studies were of mixed gender (Easley, Miedema, & Robinson, 2013; Urquhart, Folkes, Babineau, & Grunfeld, 2012). Total included participants across the ten studies were 11 men (5.1%) and 202 women (94.8%). With respect to geographical location, four studies were conducted in the USA (Galvan et al., 2014; Mollica & Nemeth, 2014; Roundtree et al., 2011; Ruddy et al., 2013), two each in Canada (Easley, Miedema, & Robinson, 2013; Urquhart, Folkes, Babineau, & Grunfeld, 2012) and Australia (Lawler et al., 2011; Thewes et al., 2004), one in England (Burns et al., 2007) and one in Norway(Sekse et al., 2010).

There was also heterogeneity with respect to ethnicity. One study consisted of immigrant Latinos, (Galvan et al., 2009), one of African Americans, (Mollica & Nemeth, 2014) and two included a Caucasian sample(Easley et al., 2013; Lawler et al., 2011). Four studies did not specify the ethnicity of participants (Burns et al., 2007; Sekse et al., 2010; Thewes et al., 2004; Urquhart et al., 2012) and two studies had mixed ethnicity. (Roundtree et al., 2011; Ruddy et al., 2013). One study specifically investigated the experience of rural survivors in Australia, (Lawler et al., 2011) three were mixed studies containing 16-33% of rural participants (Easley et al., 2013; Mollica & Nemeth, 2014; Thewes et al., 2004) and six studies were conducted in urban settings. (Galvan et al., 2009; Burns et al., 2007;Roundtree et al., 2011; Ruddy et al., 2013; Sekse et al., 2010; Urquhart et al., 2012). There was also heterogeneity with respect to cancer type. One study investigated each of thyroid cancer survivors, (Easley et al., 2013), gynaecological cancers (Sekse et al., 2010) and cervical cancer (Burns et al., 2007). One study investigated breast and colorectal cancer survivors

(Urquhart et al., 2012) and six studies solely investigated breast cancer survivors (Galvan et al., 2009; Lawler et al., 2011; Mollica & Nemeth, 2014; Roundtree et al., 2011; Ruddy et al., 2013; Thewes et al., 2004).

Table 3 shows the key characteristics of included studies.

Table 3 Characteristics of Included studies

Study	Methodology	Methods	Phenomena of interest	Setting	Geographical	Cultural	Participants	Outcomes/ Authors conclusions
Burns, Costello, Ryan-Woolley, & Davidson, 2007	Descriptive Husserlian phenomenological design	Semi-structured face-to-face interviews adopting topics obtained from the literature, clinical practice and peer discussion.	The lived experiences and concerns of women previously treated for cervical cancer 2–3 years after treatment focusing on their sexuality needs.	A cancer hospital within a National Health Service Trust	North West England	North West England	13 women with a diversity of sexual activity including those; who were sexually active, who were less sexually active and not in a sexual relationship. Eligibility criteria: women with cervical cancer; treated radically 2–3 years previously; current participation in the Late Effects Normal Tissue, Subjective Objective Management Analysis (LENT SOMA) study; disease free; and over the age of 18 years. Exclusion criteria: physical or psychological impairment; and inability to read and understand spoken English.	Cancer treatment for cervical cancer can result in late physical effects, such as bladder and bowel dysfunction, which lead to sexual difficulties and had an impact on their body image and intimate relationships several years after treatment has concluded. They had many evolving unmet information needs after treatment. There is a need for

								communicating the effects of treatment during follow-up care. Further research is required on the advice and type of information women require in follow up care about long-term treatment effects.
Easley, Miedema, & Robinson, 2013	Constructivist Grounded Theory	Semi-structured telephone interviews, collection of sociodemographic information and information about cancer follow up care including improvement recommendations.	Assess the experiences and follow-up care needs of young adult thyroid cancer survivors	Community participants	Canada-9 Urban and 3 rural participants.	Young Caucasian adults	12 adults (11 female, 1 male) average age at diagnosis 32 years (range: 24-37 years). Inclusion criteria: Diagnosed with cancer, aged 18–39 year, 1–5 years post-treatment and able to speak English or French and provide informed consent.	Regardless of disease prognosis, cancer can affect an individual's life. There is a lack of support for young Thyroid cancer patients, which they found challenging as they require as much support as people with other cancers. Health care providers need to recognise

								and acknowledge their physical and psychological needs and assist them to access support services.
Galvan, Buki, & Garces, 2009	Grounded Theory and further analysed using thematic methodology	4 focus groups (acute stage (n=1), reentry stage (n=3), long term survivorship phase (n=1)) and 2 semi-structured interviews (reentry stage). All conducted in Spanish. Administered demographic questionnaire & modified version of the 5-item Acculturation Rating Scale for Mexican Americans	Immigrant Latinas' perceptions of social support, the types and sources of support received, and the influence of social support at various stages of their survivorship experience.	Community participants drawn from a nonprofit, cancer support organisation serving Latina breast cancer survivors	United States of America-mid Atlantic region	English and Spanish speaking immigrant Latina breast cancer survivors of various nationalities (South America, Central America, Mexico, & Caribbean)	22 Latina breast cancer survivors at all stages of survivorship; average age 51 years old (range 35-67) with low levels of formal education and low income. Eligibility criteria: English and Spanish speaking Latina women with a primary breast cancer. All were diagnosed in the treatable stage and had surgery and at least one of chemotherapy and/or radiation therapy. Exclusion criteria: breast cancer recurrence and metastatic cancer	Many support needs were related to financial, linguistic and cultural barriers and health practitioners need to understand these needs and the impact they have on women's treatment selection and adherence and the impact on their quality of life. After treatment, educating family members on the information needs of the needs of the person

								diagnosed with cancer and providing peer support options was recommenced. Those who perceived themselves to have greater social support had better adjustment and lower psychological distress.
Lawler, Spathonis, Masters, Adams, & Eakin, 2011	Methodological approach referred to Strauss & Corbin (1990) and refers to thematic analysis in the discussion. Grounded theory	Telephone based semi-structured interviews	Patient experiences of medical and psychological follow up care after active treatment for breast cancer among Australian rural	Rural community	Participants living in a rural, remote or regional area of Australia at time of diagnosis and treatment.	Caucasian women living in rural, remote or regional areas of Australia	25 female participants - average age 49 years (range 35-69) and 2.5 (range 10 months to 5 years) years since diagnosis. All had breast cancer surgery and at least one form of adjuvant treatment (chemotherapy, radiotherapy, hormone therapy, perception or other treatment). Most travelled more than 300km for treatment with	Rural women were satisfied with their follow up care regimes, but felt isolated when transitioning to follow up care, which was enhanced due to difficulty accessing health professionals, including allied

			women				remainder travelling at least 100 km for treatment. Eligibility criteria: diagnosed with breast cancer in previous 5 years, not currently receiving active treatment (excluding hormone therapy), and living in a rural, remote or regional area of Australia at the time of diagnosis and treatment.	health professionals who could provide lifestyle and psychosocial support programs. There was a need for greater coordination between health professionals, such as utilising eHealth options.
Mollica & Nemeth, 2014	Grounded Theory	Telephone interview	Experience of transition from cancer patient to cancer survivor in African American breast cancer patients	Community setting- recruitment through community and support groups	New York- USA- Charleston, South Carolina and Buffalo. Urban 66%, Rural 33%	African American women between 35-85 years	15 women mean age 51 years. Stage I most frequent category, Inclusion criteria: African American female breast cancer patients, 35-85 years of age, had completed active treatment 6-18 months before the interviews. Exclusion criteria: participants with recurrent breast cancer, metastatic disease, or other primary cancers	After cancer treatment, African American women utilised their faith to help with their transition into survivorship. They experienced persistent physical issues and would have liked to talk to another African American woman. They cited their

								emotional needs were as important as their physical needs and felt unprepared for the transition to survivorship. Heath care practitioners need to have patient centred interventions, such as peer support to aid coping in the transition phase to survivorship.
Roundtree, Giordano, Price, & Suarez-Almazor, 2011	Grounded Theory	Eight focus groups	Participants' opinions and attitudes about their current healthcare utilisation, screening, and information needs.	Participants from the Tumor Registry at the University of Texas MD Anderson Cancer	Within 1 hour of Houston, Texas (USA)	White (84.8%) Black (15.2%) Spanish-Mexican (3%)	33 Breast cancer survivors, mean age 59.7 years (range 42-75). Inclusion criteria: Adult survivors of breast cancer, initially diagnosed in 2000 treated and without a recurrence, English speaking and with the cognitive ability to complete initial screening interview. Survivors for at	Survivors experienced challenges in accessing providers to address their needs and coordinate their care. A holistic approach to healthcare is required and

				Center			least 8 years (interviewed in 2008). Exclusion criteria: participants geographically inaccessible.	providing cancer care treatment summaries to health practitioners caring for patients would aid communication between different providers. Enhanced clinician communication is also required.
Ruddy, Greaney, Sprunck-Harrild, Meyer, Emmons, & Partridge, 2013	Used steps outlined by Strauss and Corbin (1990) Grounded theory	4 focus groups	To identify issues and potential targets for intervention in young women with breast cancer	Dana–Farber Cancer Institute, Boston, Massachusetts	Boston, Massachusetts	White, non-Hispanic 34 (94%) Ashkenazi Jewish 5 (14%)	36 women (mean; age 37.8 years and months since diagnosis 22.3) diagnosed with breast cancer who were either enrolled in the DFCI cohort study ‘‘The Young Women’s Breast Cancer Study’’ or participated in programming for young women at DFCI. Stage I (42%) II (50%) III (8%) Breast surgery 36 (100%) Chemotherapy 31 (86%) Radiation 23 (64%)	Younger breast cancer survivors felt different to older breast cancer survivors in a number of areas. They faced unique challenges in transitioning to survivorship and wanted assistance navigating the health care system, connecting with

							Hormonal therapy (current or past) 16 (44%) Inclusion criteria: 18-42 years of age, able to read English, no known metastatic disease, diagnosed in last 4-years (2007-2011), stage I-III invasive breast cancer	other young survivors, educational material and lists of counsellors.
Sekse, Raaheim, Blaaka, & Gjengedal, 2010	Phenomenological-hermeneutical	Two in-depth interviews with participants 12 months apart.	The lived experience of long-term survivors of gynaecological cancer and their experience of cancer care.	Out-patient gynaecological follow-up clinic at a university hospital	Norway	Living in Norway	16 women (average age at first interview 56 years - range 39-66), diagnosed with gynaecological cancer (cervical (n=2), uterine (n=11) and ovarian (n=3) cancer); Stage I (n=13), Stage II (n=1), stage III (n=2); Treatment type: surgery (n=11); Surgery and radiotherapy (n=2); surgery and chemotherapy (n=3). Inclusion criteria: women free from recidive and metastasis after the first treatment and up to date; 30 to 70 years of age; followed up for approximately 5 years	They experienced a tension between personal growth and a fear of recurrence, living in a changed body and not receiving enough information and guidance after treatment. Psychosocial aspects of follow up care need to be enhanced.

Thewes, Butow, Girgis, & Pendlebury, 2004	Applied qualitative methodologies sampling consistent with (Strauss and Corbin, 1990) and coding using methods described by Miles and Huberman (1994). Grounded Theory	18 Semi-structured telephone interviews. Demographic data was collected using a verbally-administered questionnaire. Clinical data and menopausal status was obtained from medical records.	The needs of breast cancer survivors and identification of the shared and unique psychosocial needs of ‘younger’ and ‘older’ survivors.	Radiation oncology department of a major teaching hospital	Sydney	83.3% urban, 16.7% rural	9 Older and 9 younger women. (Average age at diagnosis 54.9 years-range 29-78 years) and participants had completed their adjuvant treatment on average 13.9 months earlier (range 8-24 months). As the age at Dx was included in the study, only participants aged below 60 at time of diagnosis were included in the data extraction and meta-synthesis. Inclusion Criteria: Women with early stage breast cancer (Stage 1 or Stage 2) in remission, aged 18 years or over and were 6–24 months post completion of their hospital based adjuvant treatment. Exclusion criteria: Non-English speaking women, women with recurrent or metastatic disease or another major physical	Younger women reported more unique needs than older women, especially in relation to access to age-appropriate information, professional counselling, fertility, early menopause and they wanted non-hospital based services and assistance with adopting a health lifestyle. Breast cancer survivors experience psychosocial needs in the 2 years the first 2 years after the end of treatment and clinicians need to identify these unmet needs and assess these at

							illness (e.g. diabetes, heart disease, etc.), and those without a permanent address or contact details.	regular intervals.
Urquhart, Folkes, Babineau, & Grunfeld, 2012	Phenomenology	Semi-structured focus groups (n=19) and interviews (n=4). Data collection continued until data saturation was reached.	Views of breast cancer and colorectal cancer survivors on their routine follow-up care with respect to needs, preferences, and quality of follow-up, and on cancer specialist–led versus family physician-led follow-up care.	Tertiary care cancer centres	Nova Scotia.	Living near Nova Scotia	13 Breast (all female) and 10 colorectal cancer survivors (4 female, 6 male) who had completed primary treatment and currently receiving routine follow-up care by a cancer specialist, a family physician, or both. Inclusion criteria: Diagnosis of invasive cancer within the preceding 12–48 months, no current evidence of disease, and freedom from complications of primary treatment. For colorectal cancer survivors, the diagnosis inclusion criterion was extended to 12–72 months from 12–48 months to improve recruitment. Exclusion criteria: primary	After primary treatment there was a lack of information and preparation for follow up care and insufficient support to address physical, psychological and supportive care needs of survivors. Strategies are needed that provide better information and map out follow-up care to prepare breast cancer and colorectal cancer survivors for post-treatment care and reduce feelings of

							treatment not completed at least 3 months earlier and English language skills insufficient to participate.	abandonment in the transition to follow-up care. There is a need to reassure survivors of their family physician ability to provide quality follow-up care.

3.3 Methodological Quality

Overall, the methodological quality of the included papers was good will all studies achieving a methodological rating of at least 6/10. Two studies achieved a methodological rating of 6/10, five studies were rated 7/10, two studies were rated 8/10 and one study was rated 9/10 (see table 4). The question relating to Q7: “The influence of the research, and vice –versa, is addressed” achieved the lowest methodological rating with no studies meeting this criterion. Q1 “There is congruity between the stated philosophical perspective and the research methodology” and Q6 “There is a statement locating the researcher culturally or theoretically” had two studies (20%) meet these criteria. These areas of lower methodological rating may indicate a reduced level of dependability of the findings. This is further explored in the ConQual summary of findings below. Furthermore, when undertaking the critical appraisal in response to question 2: “There is congruency between the research methodology and the research question or objectives’, three studies did not directly name the research methodology but referenced Strauss and Corbin (1990) with respect to their approach. These articles were considered to be applying Grounded theory.

Table 4 Final Assessment Table

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Easley, Miedema, & Robinson, 2013	U	Y	Y	Y	Y	N	N	Y	Y	Y
Ruddy, Greaney, Sprunck-Harrild, Meyer, Emmons, & Partridge, 2013	U	Y	Y	Y	Y	N	N	Y	U	Y
Lawler, Spathonis, Masters, Adams, & Eakin, 2011	U	Y	Y	Y	Y	N	N	Y	Y	Y
Mollica, & Nemeth, 2014	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Sekse, Raaheim, Blaaka, & Gjengedal, 2010	U	Y	Y	Y	Y	Y	N	Y	Y	Y
Urquhart, Folkes, Babineau, & Grunfeld, 2012	U	Y	Y	Y	Y	N	N	Y	Y	Y

Roundtree, Giordano, Price, & Suarez-Almazor, 2011	U	Y	Y	Y	Y	N	N	Y	Y	Y
Galvan, Buki, & Garces, 2009	U	Y	Y	Y	Y	N	N	Y	U	Y
Thewes, Butow, Girgis, & Pendlebury, 2004	U	Y	Y	Y	Y	N	N	Y	Y	Y
Burns, Costello, Ryan-Woolley, & Davidson, S, 2007	Y	Y	Y	Y	Y	N	N	Y	Y	Y
%	20	100	100	100	100	20	0	100	80	100

3.4 Meta-aggregatative synthesis

One hundred and thirty seven findings were extracted and aggregated to form 23 categories. Five synthesised findings were derived from these categories. The extracted findings from each study are included in Appendix VII). The assessment of the confidence of the synthesised findings and development of a ConQual summary findings table was undertaken in accordance with Munn et al. (2014) methodology. The five synthesised findings on ConQual were rated as low (See table 5). There were 27 unsupported findings.

Table 5: ConQual Summary of Findings

<table>
<tr><td colspan="6">**Systematic review title:** Adult cancer survivors' experiences of healthcare interactions and unmet needs in health care services: A systematic review

Population: Adult survivors (18 years and older) of solid tumours, excluding lymphoma, who were under 60 years of age at time of initial diagnosis. For the purpose of this review, a cancer survivor was defined as an individual who has concluded primary treatment and may be in remission or cured, but does not have active advanced disease/ metastatic disease and is not undertaking palliative treatment.

Phenomena of interest: Experience of cancer survivors, their interactions with the healthcare system and healthcare practitioners, and the unmet needs they experienced in the healthcare system over the course of their survivorship. The health care system included health care practitioners within medicine, nursing, allied health and complementary therapies but excluded alternative therapies.

Context: Studies occurring in any country.</td></tr>
<tr><td>Synthesised Finding</td><td>Type of research</td><td>Dependability</td><td>Credibility</td><td>ConQual Score</td><td>Comments</td></tr>
</table>

Cancer survivors require comprehensive co-ordination of care and deficits in this care may provoke anxiety and result in a heightened fear of recurrence.	Qualitative	Downgrade 1 level*	Downgrade level**	Low	*Downgraded one level due to dependability of primary studies **Downgraded one level due to equivocal findings
Cancer survivors communication with their health practitioners may be affected by practitioner and system characteristics, which can affect their physical and psychological needs being addressed.	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low	*Downgraded one level due to dependability of primary studies **Downgraded one level due to equivocal findings
Cancer survivors may feel isolated if there is inadequate psychological and social support including preparation for the transition at the end of treatment.	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low	*Downgraded one level due to dependability of primary studies **Downgraded one level due to equivocal findings
Cancer survivors may experience increased distress if they are not provided with adequate information in a	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low	*Downgraded one level due to dependability of primary

timely manner for themselves, their family and partners about issues such as the late effects of treatment.					studies **Downgraded one level due to equivocal findings
Cancer survivors require information and health practitioner assistance in a number of areas such as physical treatment, body image, and wellness / lifestyle change needs and which this is not provided adjusting to their health issues may be more challenging	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low	*Downgraded one level due to dependability of primary studies **Downgraded one level due to equivocal findings

3.4.1 Meta-Synthesis Finding 1. Cancer survivors require comprehensive co-ordination of care and deficits in this care may provoke anxiety and result in a heightened fear of recurrence.

Five categories and 35 findings (24 unequivocal and 11 credible) constitute this meta-synthesis finding (See Table 6). Survivors wanted someone devoted to their care to co-ordinate or "map" their care to ensure that they were receiving the appropriate care and help, such as a Breast Care Nurse. They wanted this person to help them to know what questions to ask their health practitioners early in the process, and advocate for them. Survivors wanted this person to be accessible outside of medical appointments and help them navigate the health system, including in the follow-up period to ensure they had undertaken the necessary surveillance tests. The number of health professionals involved in their care was perceived by some to be excessive and sometimes resulted in unnecessary overlap. In contrast, in rural areas access to health professionals was more limited, impacting on patients' choices of health care practitioner. This resulted in some being prepared to travel to access the best specialists and care available, but they would have preferred better co-ordination of their appointments when travelling long distances. They were concerned that these issues resulted in a lack of continuity of care, with them seeing different practitioners at each appointment and retelling their clinical story at each appointment. This impacted upon the clinical handover of information between health care practitioners.

The transition to follow-up care resulted in many of their numerous unmet needs including; receiving appropriate follow up, undertaking the appropriate tests and receiving their results in a timely manner, being aware who could order the required tests, keeping informed on developments in the treatment of their cancer type and determining if any symptoms they experienced needed to be further investigated or if they were normal symptoms of aging. These were viewed through the lens of the fear of recurrence of cancer. These unmet needs made the transition at the end of treatment challenging and anxiety provoking for many and coincided with a loss of support that had been provided by friends and health professionals during the treatment stage. For some, this felt like their safety net had been removed at the same time, as they needed to accept greater personal responsibility for their own health care, causing some to move into "survival mode". The concern about not being taken seriously by some primary care practitioners and others being reluctant to provide them with treatment advice, and seeming to be keen to refer back to the cancer specialists resulted in some survivors not accessing primary care services. Others who wanted ongoing appointments with their oncologists felt guilty for depriving other cancer patients in active treatment of access to an oncologist.

Table 6: Summary of meta-synthesis finding: Cancer survivors require comprehensive co-ordination of care and deficits in this care may provoke anxiety and result in a heightened fear of recurrence.
(U) Unequivocal; (C) Credible

Findings	**Categories**	**Synthesised Findings**
A relationship with a healthcare professional other than their oncologist would have been appreciated before, during, and after treatment to help answer questions outside of medical appointments,…and coordinate follow-up care. (U)	Care co-ordination, access to health professionals	

Accepting greater responsibility for getting the information they needed was also emphasised. However, early in the process, they didn't quite know what to ask (U)	and navigating the health care system	
Better access to health professionals... was needed, especially for rural women who often had to travel long distances. (U)		
Better... organisation of appointments was needed, especially for rural women who often had to travel long distances. (U)		
For several women who were consulting a specialist visiting locally, one drawback perceived was the lack of alternative options if they were dissatisfied with this current provider (C)		
lack of coordination between providers regarding patient records and treatment history (C)		
Limited availability of cancer-related health professionals in rural regions (U)		
Many stated they would value having someone "map" their care, or provide them with a tool that would help them to coordinate and track the care they should be receiving (U)		
Often women perceived there were too many health professionals involved in the delivery of follow-up care and in some instances unnecessary overlap occurred during consultations (U)		
Participants desired assistance, including .....help navigating the healthcare system (U)		
Several women, ...indicated that having access to a BCN or a liaison person central to co-ordinating their follow-up care and acting as a patient advocate would be ideal. It was also suggested that this person could be their primary contact person to help address ongoing questions or concerns (U)		
Some women intimated they would be better off travelling to major towns or cities to access what they perceived to be the ‘best’ specialists and care available. (U)		
Some women receiving public health care experienced a lack of continuity with their health professionals, and had to retrace their clinical history with a different provider at every follow-up appointment (U)		
Some women spoke that they would like more contact with their BCN, but there was no funding for this type of health care provision (U)		
Survivors feared that having to repetitively transfer medical records and explain their medical history to various care providers degraded the quality of their care (C)		

Survivors felt that they had no providers within the healthcare system exclusively devoted to their unique needs. They preferred seeing oncologists, but felt guilty because, in their opinion, patients with active cancer needed oncologists for matters more pressing than theirs. (U)		Cancer survivors require comprehensive co-ordination of care and deficits in this care may provoke anxiety and result in a heightened fear of recurrence.
Survivors overwhelmingly described the transition from active treatment to routine follow-up care as a shift in personal responsibility. That is, they moved from having the oncologist manage their care and treatment (“doing nothing”) to taking responsibility for their cancer-related care (“doing everything”). The shift in responsibility often led to feelings of distress and abandonment after the completion of primary treatment. (U)		
Logistic problems were also a concern including .....delays in receiving test results (U)	Delays in receiving test results and uncertainty about surveillance testing	
Some participants were uncertain about whether FPS could order or prescribe all of the appropriate tests and investigations for cancer follow up. (C)		
They emphasised that knowledge of specific tests and investigations is an arduous element of managing your own care, and that one of their most prominent concerns was being unaware of the types and frequency of tests and investigations that are recommended (U)		
many women spoke about an unmet need to determine whether their symptoms were normal, and a need to receive reassurance that their symptoms were not a sign of recurrence. (C)	Fear of recurrence	
preexisting conditions and other confounders caused confusion about attribution of symptoms, making it difficult for survivors to tell if cancer and its treatment, or other issues (i.e., comorbidity or aging), caused their discomfort and health problems (U)		
Some survivors...felt ...less prepared for the fear of recurrence ..... that comes with the end of treatment (C)		
younger women spoke about the desire to be kept informed about new treatment and research developments. For these women keeping informed was either out of 'interest', or in the case of one younger woman, a form of reassurance or sense of control over possible recurrence (U)		
Although survivors valued participation by their fp in follow-up care, many continued to want specialist-led care. (C)	GP treatment	
crc survivors frequently discussed the fp role as one that ought to work in conjunction with the roles of other care professionals. (C)		

others viewed fp-led care as an obstacle to quick access to cancer care services. (U)		
Some participants were uncertain about whether FPS could order or prescribe all of the appropriate tests and investigations for cancer follow up. (C)		
Survivors sought to have their healthcare needs met by assorted medical professionals including primary care physicians and gynecologists to pharmacists and nurse practitioners. However, these providers were often reluctant to provide advice or treat them, referring them back to cancer specialists (U)		
Some survivors ..felt ... less prepared for the ... loss of safety net that comes with the end of treatment (C)	Transition of care at the end of treatment	
Some survivors...felt ready to combat the physical effects of chemotherapy but less prepared for the... guilt, resulting depression..... that comes with the end of treatment (U)		
The emotional toll of the transition into the survivorship phase was compounded by the fact that participants lost many of the supports that had helped them during treatment. ...... Some women missed seeing their healthcare providers as frequently as they had during treatment (U)		
They also felt dismissed by cancer specialists at the time that transfer of care takes place. (U)		
Transition in care-Returning home after active treatment was described as a difficult time by several women exemplified by feelings of isolation and vulnerability after having been in constant contact with health professionals during the diagnosis and treatment phases (U)		
Uncertainty about their health made it difficult for many women to plan for the future with their partners. Some reported that this became most obvious after finishing treatment. (C)		

3.4.2 Meta-Synthesis Finding 2. Cancer survivors communication with their health practitioners may be affected by practitioner and system characteristics, which can affect their physical and psychological needs being addressed.

This meta-synthesised finding comprised of 18 findings (11 unequivocal and 7 credible), and three categories (See table 7). Cancer survivors wanted sufficient time with health practitioners to allow adequate discussion of their needs and for the communication to be respectful and personable and feel listened to. They wanted the consultations to address their emotional as well as physical needs and be held in an environment that encouraged communication, which for some during the post treatment follow up period, would have preferably been away from the hospital environment. The busyness of some health practitioners, short consultation times and queues of waiting patients resulted in some survivors self-limiting access to services and limiting the topics of discussion with their health practitioner. This inhibited the duration and quality of the interaction, especially in relation to more complex matters, resulting in some questions not being asked by the cancer survivors.

Table 7: Summary of meta-synthesis finding: Cancer survivors communication with their health practitioners may be affected by practitioner and system characteristics, which can affect their physical and psychological needs being addressed.
(U) Unequivocal; (C) Credible

Findings	Categories	Synthesised Findings
A small number of younger women reported a perception that their doctors were only interested in the physical aspects of their recovery, and were therefore reluctant to discuss emotional issues (U)	Communication with health practitioners	Cancer survivors communication with their health practitioners may be affected by practitioner and system characteristics, which can affect their
Acknowledgement and validation of concerns was important to the women, with several reporting they were not listened to or (in one case) believed when communicating side-effects of treatments during follow-up consultations (U)		
complained about communication problems, lack of attention, and lingering questions left unaddressed. (C)		
complaints included ...perceived insensitivity about patients' feelings and opinions regarding treatment (C)		
Questions concerning the consequences of removed reproductive organs were not easily posed. (C)		
Some women perceived their.... provider as not always taking the time to enquire about their wellbeing on a more personal level (U)		
The consultation, with gynaecological examination, blood-tests and focus on facts, was not experienced as an easy setting for raising intimate topics, especially related to sexuality. (C)		
They missed hearing questions such as: 'How do you feel?' (U)		
The hospital environment was not conducive to information giving, particularly about sexuality. (C)	Hospital environment	

Younger survivors tended to view themselves as well, and spoke about the need for support services to be outside of the hospital environment (U)	was not conducive for some conversations with health practitioners	physical and psychological needs being addressed.
because their specialists were so busy, some questions are ‘too trivial’ to ask their doctors in follow-up consultations. (U)	Short consultation times and busyness of health practitioners	
Lack of time for conversations (with health professionals) about what they had been through ...was strongly felt to be missing (U)		
Many survivors reported continued needs to receive information...There was a perception by a small number of women that because their specialists were so busy, some questions are ‘too trivial’ to ask their doctors in follow-up consultations. (U)		
Many women acknowledged health professionals' large workloads and suggested this impacted on the length and quality of consultations. Some women perceived their consultations as rushed (U)		
the lack of time available for discussion (U)		
The short consultation time which was inadequate for deeper conversations (C)		
The short consultation time which was inadequate for deeper conversations, and the queue of patients in the corridor, were other obstacles that were mentioned. (C)		
the timing and pace of information was often limited before and at follow-up outpatient consultations after treatment (U)		

3.4.3 Meta-Synthesis Finding 3. Cancer survivors may feel isolated if there is inadequate psychological and social support including preparation for the transition at the end of treatment.

Thirty-three findings (25 unequivocal and 8 credible), and five categories comprise the meta synthesis finding (See Table 8). Survivors identified unmet needs in relation to psychological and social support for themselves. They wanted support groups to consist of people of a similar age and information to be age-relevant. They wanted contact with other cancer survivors of a similar age, life-stage and ethnicity, with similar cancers and the opportunity to hear their success stories and obtain "straight answers" about treatment. This was important at the time of transition from treatment to follow-up as this was marked by a loss of the support of their treatment teams and some friends. Further isolation occurred in some younger patients who found it difficult to relate to their friends without cancer. Survivors with a curative treatment or a "good prognosis" still wanted to be asked about their support needs to reduce the feeling of being "unworthy" or not requiring support. They desired open discussion about sexual issues, the impact of treatment on their sexuality and the impact of their health issues on their relationships, which was a common unmet need. They were inadequately informed about psychological issues, such as anxiety and depression. Many identified a lack of psychological support, which they were not prepared for and wanted psychological counselling to be offered by practitioners experienced in treating cancer patients. Some wanted their general practitioner to be vigilant to their psychological needs.

Table 8: Summary of meta-synthesis finding: Cancer survivors may feel isolated if there is inadequate psychological and social support including preparation for the transition at the end of treatment.
(U) Unequivocal; (C) Credible

Findings	**Categories**	**Synthesised Findings**
Most participants cited the need for support and communication with another AA woman who had been through treatment for breast cancer. (U)	Communication with other cancer survivors	
Most women desired contact with other cancer survivors (U)		
Participants wished they were able to talk, both during and after treatment, with other breast cancer survivors who were of a similar age and life stage, in order to get "straight answers about the ups and downs of treatment" (C)		
they particularly valued having someone to talk to who had gone through similar experiences (U)		
They wanted to hear the 'success stories' of other younger women (U)		
a number of information needs were unmet, prompting the question of what type of information patients wanted......further knowledge about the effects of treatment on sexuality (U)	Impact on sex, sexuality & relationships	
Breast cancer strained their sexual and emotional connections and caused communication rifts with their partners. Many ...were dismayed at their perceived lack of adequate support to help their		

partners deal with the burden of suddenly becoming a caregiver (U)		
Desired more information on ......the impact of diagnosis and treatment on their personal relationships (C)		
Late effects hindered social activity. Decreases in energy and sex drive—and the tension it triggered between spouses and significant others—topped survivors' list of late effects that must be addressed. (U)		
Most women with a partner stated that they would like sexuality to be discussed at follow-up appointments (C)		
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ...sexual health (U)		
sexual functioning was seldom proactively discussed by practitioners. (U)		
women felt that there was an inadequate provision of information about treatment effects...concerning the possible late effects of treatment, including information about the possible impact on sexuality (U)		
Having the good cancer (i.e.thyroid cancer)....downplayed the diagnosis and experience......feeling that they were perceived as not needing support (U)	Loss of support and unmet support needs	
having the good cancer (i.e.thyroid cancer)....downplayed the diagnosis and experience......They...often felt unworthy of accessing available support programs (U)		
Isolation was strongly connected to the theme of being told that thyroid cancer is the good cancer. Isolation was discussed in relation to three different areas: isolation from ....support programs (U)		
Isolation was strongly connected to the theme of being told that thyroid cancer is the good cancer...being isolated from their peers who did not have cancer because they could not relate to or understand the experience of having a serious illness (U)		
Lack of community-based support programmes was a key concern for many women (U)		
Many survivors spoke about the continued need to keep their family members well informed during their follow-up. One younger woman spoke about the social isolation she experienced after her treatment because of a lack of information for family		

and friends about her diagnosis (U)		Cancer survivors may feel isolated if there is inadequate psychological and social support including preparation for the transition at the end of treatment.
The emotional toll of the transition into the survivorship phase was compounded by the fact that participants lost many of the supports that had helped them during treatment. Participants explained that once they were no longer receiving treatment, some friends and family stopped calling and visiting as often. (U)		
A lack of information on specific areas of follow-up care (for example, ...psychological well-being). (C)	Psychological assistance for self	
Participants did not feel adequately informed about chronic survivorship issues such as... anxiety. (C)		
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ...depression (U)		
Participants voiced many needs after they finished treatment, including the need for psychological support. (U)		
Participants wished for a list of therapists with experience providing counseling for young women with breast cancer (U)		
Some participants reported a need for information about availability of psychological assistance for themselves. (C)		
Some women perceived a need for other types of health professionals to be involved in their follow-up care, such as psychologists (U)		
The process of sorting things out after treatment for gynaecological cancer, such as handling....anxiety, was described as a lonely journey that the women were not prepared for.........Coming to terms with themselves immediately after treatment was a lonely process. (U)		
younger women were more likely than older women to want additional support from professional counsellors during their treatment rather than volunteers.......Younger women felt that although volunteers were 'kind' or 'caring' that they lacked the professional expertise to be able to deal with their counselling needs. One younger woman suggested that psychological support should be a routine part of treatment (C)		
Amongst many younger women, there was a perception that the groups available did not cater to their needs due to their age. (U)	Support group composition and age	

Many participants said that they could not relate to patients and survivors with other types of cancer, and they felt that other patients did not want to hear about their experiences because thyroid cancer treatments typically are well tolerated. (U)	relevant information.	
Participants also expressed difficulty identifying with older adult patients with cancer because of differences based on life stages (C)		
Several younger women felt that the information they received during and after their treatment was not always relevant to women of their age. These women wanted more age-relevant information (U)		

3.4.4 Meta-Synthesis Finding 4. Cancer survivors may experience increased distress if they are not provided with adequate information in a timely manner for themselves, their family and partners about issues such as the late effects of treatment.

Twenty-six findings (18 unequivocal and 8 credible), and three categories comprise this meta-synthesis (See table 9). Survivors had a range of unmet information needs. They wanted material that was specific to their needs and not generic and the timing of this information to match their needs, such as at the transition to follow up care. Many of their concerns related to information about the late side effects of treatment and specifically what physical and psychological symptoms they might expect to occur during the follow up period. They wanted the information to be tangible in the form of pamphlets and videos, but the written information to be supplemented with a discussion with a health practitioner to review the information with them and ensure they had understood the content. They also wanted information available for their partners and family members about access to therapists and increased support for their partners, and the possibility for family members to access someone co-ordinating their care. They wanted information to guide their partners and family and friends about the process of discussing their cancer diagnosis in an appropriate way and how they could discuss their cancer diagnosis with their children both generally and specifically if they carried the BRCA gene. For some, the lack of this information for their partners and family contributed to their isolation.

Table 9: Summary of meta-synthesis finding: Cancer survivors may experience increased distress if they are not provided with adequate information in a timely manner for themselves, their family and partners about issues such as the late effects of treatment.
(U) Unequivocal; (C) Credible

Findings	**Categories**	**Synthesised Findings**
A few women were also interested in easier access to therapists (i.e., lists of experienced providers who were accepting new clients) for partners and other family members (C)	Information and psychological assistance for partners, family and friends	
A relationship with a healthcare professional other than their oncologist would have been appreciated before, during, and after treatment to help answer questions outside of medical appointments, provide support and information to their families (U)		
Breast cancer strained their sexual and emotional connections and caused communication rifts with their partners. Many...were dismayed at their perceived lack of adequate support to help their partners deal with the burden of suddenly becoming a caregiver (U)		
Many survivors spoke about the continued need to keep their family members well informed during their follow-up. One younger woman spoke about the social isolation she experienced after her treatment because of a lack of information for family and friends about her diagnosis (U)		
Women expressed interest in high-quality educational materials ....specifically designed for family members and caregivers (including descriptions of treatments and recommendations regarding what to do/not do for patients and when it is okay/not okay to talk about cancer (C)		
women were also concerned about how their illness affected their children, with many feeling guilty that during treatment they did not have the energy to do things they usually did with their children. Mothers reported that physical changes, including hair loss, were disturbing to their children, and that they generally struggled telling their children about their cancer; in fact, some never did. (U)		
Women who found out that they carried a BRCA mutation voiced concern about how to deal with the possibility that their children may also be carriers (C)		
Desired more information on.... what to expect physically and emotionally after treatment (U)	Late effects and side effects of cancer	
Desired more information on....side effects from treatment (U)		

Information about possible future consequences was strongly felt to be missing (C)	treatment	Cancer survivors may experience increased distress if they are not provided with adequate information in a timely manner for themselves, their family and partners about issues such as the late effects of treatment.
information on expected side effects and longterm consequences after surgery and how to handle them would have been valuable (C)		
Participants also wanted information on what could happen and what their needs might be during the follow-up period (U)		
Participants did not feel adequately informed about chronic survivorship issues such as... how to differentiate side effects from symptoms of recurrence. (C)		
Participants did not feel adequately informed about chronic survivorship issues such as... memory problems (C)		
Participants did not feel adequately informed about chronic survivorship issues such as... what to expect from their bodies ... Many had incorrectly expected they would be able to resume their pre-treatment lives easily, and were distressed to find they could not (U)		
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to …. late effects of treatment. (U)		
Some ... participants reported that they did not receive information from their oncology providers that symptoms may continue past treatment (U)		
there was an inadequate provision of information about treatment effects (U)		
Issues raised by women centred on ... the timing of information giving... (U)	Unmet information needs	
Many survivors reported continued needs to receive information (U)		
Participants also indicated that tangible information— in the form of booklets, brochures, and videos—could not replace a conversation with a real person. Although they valued tangible information, they wanted their care providers to review the information with them to facilitate their understanding and decision-making with respect to the physical and emotional cancer- and treatment-related changes they might experience as cancer survivors. (U)		
Participants specifically expressed desire for educational materials at the time of transition into the survivorship phase of care. (U)		
Participants voiced many needs after they finished		

treatment, including the ...need for resources and more information. (U)		
They felt that discussions and materials were too generic (their specific problems were not addressed) (C)		
Women expressed interest in high-quality educational materials for themselves (U)		
younger women spoke about the desire to be kept informed about new treatment and research developments. For these women keeping informed was either out of 'interest', or in the case of one younger woman, a form of reassurance or sense of control over possible recurrence (U)		

3.4.5 Meta-Synthesis Finding 5. Cancer survivors require information and health practitioner assistance in a number of areas such as physical treatment, body image, and wellness / lifestyle change needs and which this is not provided adjusting to their health issues may be more challenging.

This meta-synthesis finding consisted of seven categories and 25 findings (10 unequivocal and 15 credible) (See table 10). They highlighted both the information component of this assistance as well as contact with a health practitioner to develop strategies. They wanted assistance with nutrition, diet, weight loss and healthy living options. Further information in relation to their body image was also wanted including information on breast reconstruction, prosthetics, and clothes that might aid their adjustment to their changed body. Information about the hormonal effects of treatment was thought to be lacking by many survivors, resulting in them feeling unprepared for entering an early menopause. The impact of treatment on fertility was identified as a challenge and they identified some inconsistencies between different practitioners. Also contraception information was an unmet need. Some were challenged to manage their ostomy and other bladder and bowel side effects of treatment and required assistance in managing this, in addition to the adjustment to the impact of this on their body image and sexuality. Some identified a lack of assistance and information in the management of fatigue. Some were challenged in navigating through return to work issues and the decision-making process surrounding this and learning about the financial and insurance issues while coping with a cancer diagnosis.

Table 10: Summary of meta-synthesis finding: Cancer survivors require information and health practitioner assistance in a number of areas such as physical treatment, body image, and wellness / lifestyle change needs and which this is not provided adjusting to their health issues may be more challenging,
(U) Unequivical; (C) Credible

Findings	Categories	Synthesised Findings
a number of information needs were unmet, ...information about long-term effects of treatment on bladder and bowel function (C)	Bladder and bowel care information and education	
Physical and psychological needs involved issues related to ...bowel function (U)		
The crc participants with ostomy appliances overwhelmingly discussed needs related to their ostomy. Specific issues raised included body image, sexual health, finding appropriate appliances, caring for the ostomy, and costs associated with purchasing ostomy supplies (C)		
desired more information on...weight loss (C)	Body image and weight management	
Information about reconstruction options was also a concern for participants (U)		
Many complained about weight gain during treatment, and that they had not been adequately informed about the high likelihood of this (C)		
With respect to informational support, women wanted to know more about how to cope with their new body image. For example, women reported a need for information about the types of clothes they could wear after surgery, as well as where to obtain breast prostheses. With this information, women could alter their clothing style and feel more attractive (C)		
All of the women who sought information about fertility felt that the information they received was either conflicting or inadequate (U)	Fertility and contraception information	
Desired more information on ...fertility (C)		
Many of the women were upset they had not had more time to explore fertility preservation techniques. The high cost of these techniques and uncertainties about whether they were needed or would be effective added to distress levels, with some women feeling they had very few realistic		

options. These women remained worried about their chances of conceiving in the future, and wished they had had more support around fertility related decisions. (C)		Cancer survivors require information and health practitioner assistance in a number of areas such as physical treatment, body image, and wellness / lifestyle change needs and which this is not provided adjusting to their health issues may be more challenging,
Receiving information about choices for contraception was another major issue for many premenopausal younger women (U)		
A lack of information on specific areas of follow-up care (for example...nutrition (U)	Nutrition information	
Desired more information on....vitamins (C)		
Desired more information on...nutrition (C)		
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to... nutrition. (C)		
Several young women wanted more information about diet, healthy living and possible carcinogens or environmental triggers (U)		
Some women perceived a need for other types of health professionals to be involved in their follow-up care, such as ..... dieticians..... to assist with making lifestyle changes (U)		
Some also expressed dissatisfaction with the information they received from their doctors about the hormonal side effects of their treatments (C)	Readiness for menopause and knowledge of hormonal effects of treatment	
There seemed, however, to be a common experience of feeling unprepared, even shocked. Those who had gone through menopause before the operation described a new, but different menopause because of bodily changes,......Not being prepared for these bodily changes, neither by themselves nor by health care personnel, seemed to lead to an introspection of bodily changes, binded energy and unnecessary uncertainty_ (C)		
many crc survivors frequently reported not seeking professional help for many unmet physical needs (for example, sexual health, bowel function) because they felt they ought to deal with their problems themselves and be content that they were cancer-free (C)	Unmet physical treatment needs, fatigue management and complementary and alternative therapies	
Participants did not feel adequately informed about chronic survivorship issues such as fatigue (C)		
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ... persistent fatigue		

(C)		
A high level of need related to returning to work after their cancer diagnosis and treatment (U)	Work and entitlements to leave & insurance	
it was challenging to learn enough about the financial, insurance, and work leave aspects of treatment while in the throes of a new cancer diagnosis (U)		
some reported that it had been difficult to decide whether or not to continue working. Uncertainties about necessary recovery time often complicated these decisions. (U)		

Chapter 4 Discussion

4.1 Overview of findings

The results from this meta-synthesis are consistent with the quantitative literature highlighting some disease free cancer survivors have persistent unmet needs (Hodgkinson et al. 2007c; Santin et al., 2015; Urbaniec et al., 2011) and physical and practical problems (Brearley et al., 2011). There were also a number of specific unmet information needs and targeted clinical assistance, which had also been highlighted by a number of quantitative studies including; access to high quality information, information to help differentiate symptoms of recurrence from other health symptoms, bladder and bowel functioning, sexuality issues (Flynn et al., 2012; Smith et al., 2013;) fatigue management (Watson et al., 2015), fertility and contraception (Vivar & McQueen, 2005), body image (Hodgkinson et al., 2007a), weight management, nutritional information, impact of menopause (Vivar & McQueen, 2005) work entitlements and complementary and alternative medicine (Hodgkinson et al., 2007a). This suggests an increased array of needs based on lifestyle and coping with the side effects of treatment at the time of transition and into extended survivorship at a time where the support from the health system is reduced and supports patients' research priorities being focused on how to live with the impact of cancer on their life, including the management of practical, social and emotional issues over biological and treatment issues (Corner et al., 2007). These findings from this meta-synthesis continue to identify unmet needs in the four areas of survivorship care identified in the Institute of Medicine's 2006 report '*From cancer patient to cancer survivor: Lost in transition'* of prevention of recurrence, surveillance to detect new cancers or recurrence, treatment and management of side effects of cancer treatment and its sequelae and care co-ordination (Hewitt, et al., 2006).

The theme of patient-centred care/ patient-centred communication and a fear or recurrence permeated a number of the meta-synthesis findings. All individuals come to the experience of being diagnosed with cancer with an individual history characterised by their experience of health care and pre-existing health issues and health beliefs. In addition, they have a range of personal relationships with the significant others in their life and their own life stage in the life cycle, whether they be a single young adult, in a relationship, a parent with young children, or an older adult with grandchildren. Each life stage has various work / recreational and financial responsibilities associated with them. Patients also have their existing health care relationships with their primary physicians. All of these are likely to serve as the foundation at the time of diagnosis, which the individual experience of being diagnosed with cancer is built upon. At time of diagnosis and treatment, the way the experience unfolds for different people, may be further affected by multiple factors including how the person ascribes meaning to their diagnosis, the physical and psychological impact of their diagnosis and treatment on themselves and their close relationships, the residual symptom burden they may experience and the relationships they have developed with health care workers they have met along the course of their cancer treatment.

Superimposed with this individual experience is the unfolding and dynamic changing of needs and unmet needs over the course of the cancer trajectory, moving from being more information based during the diagnosis stage, to information about managing symptoms during the treatment phase and more psychological and existentially based at the time of the post treatment period, often 6-12 months after treatment where the fear of recurrence permeates the ongoing existence for many survivors (Mitchell et al., 2013; Mohamed et al., 2013). Concurrently with these phases of care, are health care relationships, which are dynamic as multiple health professionals assist the survivor for varying durations during the treatment experience entering then exiting their lives. Given the individual nature of the life history, beliefs, experience of a cancer diagnosis and associated health effects, it is only through patient-centred care and communication that these various dimensions can be explored. This then ensures all needs are identified which can then be addressed.

This transition at the end of treatment may reflect the contrast between two concurrent events, one which is task driven and the second which is process driven. Cancer treatment consisting of surgery, radiotherapy and/ or chemotherapy, tends to be more discreet and task natured with a defined start and end point and often based on long standing protocols regarding physiological healing times and duration of follow up visits. In contrast, the experience of adjusting to a cancer diagnosis is more of a process, as it involves experiential aspects of the self, reality testing pre-existing beliefs about perceived functional capacity against actual functional capacity and subsequent readjustment and integration to create a new perception of self (Deimling et al., 2007a; Documet et al., 2012; Kaiser, 2008). This is likely to show significant individual variability in duration, which can only be clarified through effective patient-centred communication.

It may be that the change in the health care relationships, transitioning back to primary care physicians and reducing the intensity of appointments with cancer specialists coincides with this shift in the nature of unmet needs and psychological processing of the experience resulting in heightened anxiety and for some, a feeling of abandonment. There is some support for this in the literature relating to adoption of survivorship identities, post traumatic growth and changes in unmet needs over the course of the cancer trajectory. For example unmet needs for breast cancer patients were highest within one year of diagnosis and 1-3 year survivors compared to 5 year and longer survivors (Park, & Hwang, 2012). This is supported by the gradual adoption of the survivorship identity over time, which can extend to over 5 years for some people (Documet et al., 2012; Deimling et al., 2007a; Kaiser, 2008).

Due to the diversity of the individual experience of being a cancer survivor, the search for a unified solution to managing a survivor’s care lacks the flexibility to help address the unmet needs that some cancer survivors have and various approaches may be required to adequately address the needs of survivors (Grant, Economou, Ferrell, & Uman, 2012). Patient-centred communication seems to be one of the cornerstones of care to assist these transition points for cancer survivors with health practitioners willing to listen and respond to the psychological impact of the cancer experience on the individual. The feeling of abandonment that some survivors report experiencing at the end of treatment, is interesting to hypothesise if this is in some part a manifestation of the discomfort some health care practitioners may feel in discussing the emotional impact of cancer on individuals or a focus on the physical aspect of their treatment. Through patient-centred communication, an individually tailored solution to address survivors' needs may be developed throughout their engagement with the health system, where cancer survivors want to be more than a patient, but to have relationships with health professionals that are real and long lasting (Epstein & Street, 2007). The results of the meta-synthesis are consistent with the six-stage patient centred communication model identified by Epstein and Street (2007). Consisting of fostering the patient-clinician relationship, exchanging information to develop a shared understanding of medical and personal aspects of the health condition, empathically responding to emotions by validating and legitimising patients' experiences and offering assistance where appropriate, managing uncertainty, making decisions and enabling patient self-management.

Taplin and Rodgers (2010) highlighted the complexity of cancer care with multiple transitions at differing stages including diagnosis through to end of life care and the multi-layered aspect of care consisting of multiple organisations, differing medical specialists, primary care physicians, and other health practitioners and the care at times moving back and forth between primary care to specialists. These interfaces of care and co-ordination involve both human and organisational interfaces and are essential for the cancer care to be successful and meet patients' needs. This meta-synthesis identified unmet needs to manage the complexity of the health system, such as by having someone to help them navigate the health care system at the gaps which occur at these interfaces, such as transitioning into post treatment care and having the general practitioner manage their care, knowing what follow up care was required including surveillance testing, or ensuring they received tests results in a timely way. Taplin emphasised the predominance of research focused on the provision of care and a lack of focus on the interfaces between the different aspects of care. Carey, Clinton-McHarg, Sanson-Fisher, Campbell, and Douglas (2011) also drew attention to the main focus on individual factors rather than other predictors of outcomes of cancer patients and the need to look broader and examine characteristics of treatment centres, such as structure, organisation or delivery of care. Furthermore, Hope-Stone and Mills (2011) have also cited the impact of environmental factors including limited time and noise impact on communication. These meta-synthesis findings reinforce the broader conceptualisation of patient-centred communication, with organisational factors such as the length of consultations and the busyness of health professionals and environmental factors, such as the location of a consulting room away from the hospital environment impacting on the questions patients chose to ask. This, in combination with health practitioners being poor at identifying patient concerns and psychological needs, makes the preparation for survivorship particularly perilous and not surprisingly, has been associated with high levels of unmet needs and low levels of patient satisfaction.

The findings of this meta-synthesis are consistent with issues that patients experience with care co-ordination in the transition from primary treatment to follow up care (Corner, Wagland, Glaser, & Richards, 2013). There is significant variability in the models of follow up care being pursued. Campbell et al. (2011) examined adult cancer survivorship care in eight of the LIVESTRONG centres of excellence network. They found multiple models of care within organisations, which provided flexibility in matching the most suitable model to the survivor. Some models included disease specific approaches, consultative approaches (e.g. survivorship/ transition clinics (McCabe & Jacobs, 2008) transition models (immediate post treatment), long-term models and integrative models embedded in the oncology team. The care provided to survivors involved medical (e.g. test results, physical examination) and psychosocial aspects (e.g. counselling) for up to two years post treatment. Whilst there was a commitment to provide treatment summaries and survivorship care plans, access to adequate tools, time and staffing resulted in these sometimes not being developed collaboratively between the survivor and health practitioner. The need for greater focus on health promotion and wellness was highlighted as the main focus was on counselling relating to diet, exercise and smoking cessation. There was little use of self-management tools for health promotion and only one program had a group exercise program and one had a telephone peer support program. Foster and Fenlon (2011) supported the importance of self-management and self-management support from health professionals, employers, friends and family and on-line resources, which was at times unavailable. They found low self confidence impacted on the ability of people diagnosed with cancer to access support, which may impact on their ability to effectively self-manage and negatively affect their recovery.

The need for adequate clinical handover was identified in this meta-synthesis. Mayer, Gerstel, Leak, and Smith (2012) identified inadequacies with the clinical handover of information. They found some cancer survivors' experience difficulty understanding and recalling information presented verbally in consultations about their diagnosis and treatment plan. Some survivors were unclear who to call for different problems after treatment had concluded and some developed their own rules to manage this uncertainty. Due to variability in the adequacy and timeliness of the communication between different doctors, many were left being the source of information to hand over to the relevant doctor (Mayer et al., 2012) and felt confused when different clinicians provided different recommendations (Brennan et al., 2011). There is ample support from cancer survivors for survivorship care plans, with most wanting them at the start of treatment and with it being updated at the end of treatment with the addition of health promotion information and an indication of what a reoccurrence may appear as to aid differentiating symptoms of recurrence from other symptoms. The updated plan they wanted near the end of treatment, but not on the last day of treatment ended, and for it to be in print form and delivered via a face to face meeting with the provider most familiar with them. They preferred clear information about their diagnosis, treatment summary, care team, symptoms to watch for, surveillance guidelines and recommendations regarding follow up care. In addition survivors wanted details of what provider to call in relation to what symptoms (Brennan et al., 2011; Mayer et al., 2012). They also wanted the survivorship care plan to contain information about breast reconstruction options (for breast cancer survivors) (Brennan et al., 2011).

The concerns from some survivors about primary care physicians managing the care of cancer survivors raised in this meta-synthesis is also supported in the broader literature (Thorne and Stajduhar, 2012). Breast cancer survivors are satisfied with follow up care from their oncologist. While most are supportive of shared care arrangements with their general practitioner and breast cancer nurse, providing they have adequate knowledge and training, some were unsure if they wanted their GP to provide this care. They highlighted some positive aspects with breast care nurses potentially being more approachable, have more time for conversations about psychological and sexuality issues and a different perspective (Brennan et al., 2011). Breast cancer survivors wanted their person overseeing their follow up care to be the same person at each follow up visit and have been involved throughout their cancer experience and have a long term relationship with them to ensure continuity of care, with adequate time for consultations (Brennan et al., 2011). Primary care physicians have confirmed issues with clinical handover of information, sometimes relying on patients to update them in treatment due to delays in receiving information (Mayeret al., 2012). Hoekstra, Heins and Korevaar (2014) identified the needs of cancers survivors from their general practitioner. Most commonly related to psychosocial needs and a person to provide warmth and emotional support, who they could discuss sensitive topics they felt unable to discuss with their specialists. Survivors saw the general practitioner as being important to treat non-cancer related health issues, preventative health and treatment effects from their cancer treatment. Many saw the GP as a source of information about cancer and the effects of cancer in plain English language.

The fear of recurrence permeates the survivorship phase for many cancer survivors and is one of the most common unmet needs across different types of cancer and was also prominent in this meta-synthesis (Beesley, Eakin, Steginga, Aitken, Dunn, & Battistutta, 2008; Fiszer et al., 2014; Harrison et al., 2009; Kaiser, 2008; Maguire et al., 2015). It may be that fear of recurrence is at the heart of a number of these issues, such as care-co-ordination with some apprehension about general practitioners having the necessary training and skill to undertake the required tests, in comparison with their oncologists. It is interesting to hypothesise if patient centred communication has a role here as well, in that if the primary care physician has shown a personal interest in the survivor and followed their treatment throughout the time they were managed by their oncologists, would the survivor have greater confidence in being cared for by their general practitioner in the follow up post treatment period. This is supported by Thind, Liu, and Maly, (2011) finding that breast cancer survivors' ability to ask their family physician questions and rating them higher on the ability to explain aspects of their care was related to higher levels of satisfaction with their family physicians treatment. Further research to explore the nature of patients' ratings of their primary care physician competence in communication and technical skills and the survivors own anxiety level may further clarify some of these potential interactions. It may be that if a strong relationship with the primary care physician was lacking it may affect the survivors' anxiety levels at the time of transition and further research in this area is warranted. The fear of recurrence may be driving the behaviour of many survivors and when there is a lack of clarity regarding the follow up care or it is perceived to be inadequate, this may trigger fear of recurrence anxiety.

There are heightened levels of psychological distress in patients diagnosed with cancer, with cancer survivors having a higher incidence of anxiety (Mitchell et al., 2013). This need was supported in this meta-synthesis. The time of transition is a vulnerable and isolating time and the loss of the personable communication from their treatment team can result in feelings of abandonment. The unmet needs of sexual issues is consistent with the literature of most cancer survivors identifying discussions with health professionals about the impact of treatment on their sexuality was important, but usually lacking (Flynn et al., 2012) and the need for this information to be discussed in the context of the impact on their relationships is consistent with desires for partners to be included in these conversations (Flynn et al., 2012).

The nature of this distress can vary over the different stages of treatment. Despite this high level of psychological distress with up to one-third of people being affected, the number of distressed patients who access treatment remains low at under half (Carlson et al., 2004). Adequate provision of information may be able to address some of these needs. Husson et al. (2011) found that this can aid psychological adjustment as patients satisfied with their information needs being fulfilled and receiving high quality and clear information had lower levels of anxiety and depression. These information needs must be based in patient-centred communication to aid identification of unmet needs, which can then assist in the adequate planning of the transition into the extended survivorship phase after active treatment to reduce the emotional disruption to survivors.

4.2 Limitations to the review

A review of the included studies shows a high percentage of female participants and an overrepresentation of breast cancer patients. This may limit the generalisability of the findings. There was a lack of illustrations for some findings, resulting twenty-seven author's findings being unsupported. With either better research or reporting, additional unmet needs may have been identified.

4.3 Implications for practice

There are a number of implications for practice that can be drawn from this thesis. Patient-centred communication in its broadest concept must be placed at the cornerstone of all treatment of people with cancer. This creates an environment where the impact of a cancer diagnosis and the meaning of it to the individual can be explored and the specific needs of cancer survivors can be identified and strategies to address them developed. Consideration of the broader environmental and systems issues that impact on communication, such as health professional's busyness, the scheduled duration of appointments and the location where appointments occur, must be given greater consideration. Consideration of the provision of a broader range of information for cancer survivors, beyond their physical treatment, to include psychological support, lifestyle issues and the longer-term impact of cancer treatment. This information giving may take the form of professional consultations or through resources, such as brochures, webpages or DVD's. This also needs to be extended to the needs of their family members and friends. Cancer survivors need to have multiple options for their survivorship care to be tailored to their individual needs. Health professionals need to be mindful about issues with clinical handover and ensuring adequate continuity of care and the timely communication and handover of clinical information. Specific recommendations arising from this systematic review are detailed below. Recommendations have been assigned a JBI Grade of Recommendation (Appendix VIII).

> Patient-centred communication must be placed at the cornerstone of all treatment of people with cancer. (Grade A)
>
> Cancer survivors need improved co-ordination of their care including adequate clinical handover and help navigating the health system. They require clarity regarding which health professional is responsible for the management of their care, and adequate preparation and support in achieving the transition beyond the end of active treatment. (Grade A)
>
> Consideration of the broader impact of systems, such as duration of patient appointments and the environment have on patient communication must be considered by organisations providing cancer care services. (Grade A)
>
> The fear of recurrence and psychological needs of cancer survivors and their broader relationships need to be identified when present and opportunities to address them presented. Health practitioners need to be vigilant for signs of fear of recurrence and ask about this as a concern at the time of transitioning survivors at the end of active treatment. (Grade A)
>
> Greater focus of the psychological impact of cancer on the individual and their close relationships and adequate access to psychological and peer support is required for cancer survivors, rather than a predominant focus on physical symptoms by health professionals. (Grade A)
>
> Increased information is required for cancer survivors that is specific and tailored to their needs and addresses topics such as the late effects of treatment. (Grade A)

> Cancer survivors require both information and access to appropriate health professionals for a range of broader health 'lifestyle' issues, such as body image and weight management, nutrition, fertility and contraception, menopause and hormonal effects of treatment, complementary therapies, bladder and bowel care, fatigue management and information about insurance and work entitlements. (Grade B)

4.4 Implications for research

Further research is required to explore the specific characteristics that differentiate when survivors are content for their primary care physicians to provide follow up care and when they are not and if patient-centred communication and anxiety in the form of fear of recurrence contributed to these perceptions of survivors. The relationship between anxiety and other aspects of health care delivery, such as the model of survivorship plan requires further development. Further longitudinal studies investigating the fear of recurrence and care co-ordination relationship are required. With respect to patient-centred communication, there is a need to investigate broader environmental and system factors, rather than a predominance on individual factors in the delivery of cancer survivorship care.

References

Andreassen, S., Randers, I., Naslund, E., Stockeld, D., & Mattiasson, A. C. (2005). Family members' experiences, information needs and information seeking in relation to living with a patient with oesophageal cancer. *Eur J Cancer Care (Engl), 14*(5), 426-434. doi: 10.1111/j.1365-2354.2005.00602.x

Arora, N. K. (2003). Interacting with cancer patients: the significance of physicians' communication behavior. *Soc Sci Med, 57*(5), 791-806.

Australian Institute of Health &. Welfare., (2012). Cancer survival and prevalence in Australia: period estimates from 1982 to 2010. Cancer Series no. 69. Cat no. CAN 65. Canberra: AIHW.

Aziz, N. M. (2007). Late Effects of Cancer Treatments *Cancer Survivorship: Today and Tomorrow* (pp. 54-76).

Babrow, A. S. (2001). Uncertainty, value, communication, and problematic integration. *Journal of Communication, 51*(3), 553-573. doi: 10.1093/joc/51.3.553

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC medical research methodology, 9*(1), 1-11. doi: 10.1186/1471-2288-9-59

Batt, S. (1994). *Patient no more: The politics of breast cancer*. Charlottetown, Canada: Best Gagne.

Beesley, V., Eakin, E., Steginga, S., Aitken, J., Dunn, J., & Battistutta, D. (2008). Unmet needs of gynaecological cancer survivors: implications for developing community support services. *Psychooncology, 17*(4), 392-400. doi: 10.1002/pon.1249

Bellizzi, K. M., & Blank, T. O. (2007). Cancer-related identity and positive affect in survivors of prostate cancer. *J Cancer Surviv, 1*(1), 44-48. doi: 10.1007/s11764-007-0005-2

Bellizzi, K. M., Rowland, J. H., Jeffery, D. D., & McNeel, T. (2005). Health behaviors of cancer survivors: examining opportunities for cancer control intervention. *J Clin Oncol, 23*(34), 8884-8893. doi: 10.1200/jco.2005.02.2343

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011a). Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med, 155*(2), 97-107. doi: 10.7326/0003-4819-155-2-201107190-00005

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., . . . Viswanathan, M. (2011b). Health literacy interventions and outcomes: an updated systematic review. *Evid Rep Technol Assess (Full Rep)*(199), 1-941.

Brearley, S. G., Stamataki, Z., Addington-Hall, J., Foster, C., Hodges, L., Jarrett, N., . . . Amir, Z. (2011). The physical and practical problems experienced by cancer survivors: a rapid review and synthesis of the literature. *Eur J Oncol Nurs, 15*(3), 204-212. doi: 10.1016/j.ejon.2011.02.005

Brennan, M. E., Butow, P., Marven, M., Spillane, A. J., & Boyle, F. M. (2011). Survivorship care after breast cancer treatment--experiences and preferences of Australian women. *Breast, 20*(3), 271-277. doi: 10.1016/j.breast.2010.12.006

Brennan, M. (2014) Personal communication 6 August 2014

Brown, B. W., Brauner, C., & Minnotte, M. C. (1993). Noncancer deaths in white adult cancer patients. *J Natl Cancer Inst, 85*(12), 979-987.

Butow, P. N., Bell, M. L., Aldridge, L. J., Sze, M., Eisenbruch, M., Jefford, M., . . . Goldstein, D. (2013). Unmet needs in immigrant cancer survivors: a cross-sectional population-based study. *Support Care Cancer, 21*(9), 2509-2520. doi: 10.1007/s00520-013-1819-2

Butow, P. N., Kazemi, J. N., Beeney, L. J., Griffin, A. M., Dunn, S. M., & Tattersall, M. H. (1996). When the diagnosis is cancer: patient communication experiences and preferences. *Cancer, 77*(12), 2630-2637. doi: 10.1002/(sici)1097-0142(19960615)77:12<2630::aid-cncr29>3.0.co;2-s

Butow, P. N., Phillips, F., Schweder, J., White, K., Underhill, C., & Goldstein, D. (2012). Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. *Support Care Cancer, 20*(1), 1-22. doi: 10.1007/s00520-011-1270-1

Campbell, M. K., Tessaro, I., Gellin, M., Valle, C. G., Golden, S., Kaye, L., . . . Miller, K. (2011). Adult cancer survivorship care: experiences from the LIVESTRONG centers of excellence network. *J Cancer Surviv, 5*(3), 271-282. doi: 10.1007/s11764-011-0180-z

Carey, M. L., Clinton-McHarg, T., Sanson-Fisher, R. W., Campbell, S., & Douglas, H. E. (2011). Patient or treatment centre? Where are efforts invested to improve cancer patients' psychosocial outcomes? *Eur J Cancer Care (Engl), 20*(2), 152-162. doi: 10.1111/j.1365-2354.2010.01211.x

Carey, M., Lambert, S., Smits, R., Paul, C., Sanson-Fisher, R., & Clinton-McHarg, T. (2012). The unfulfilled promise: a systematic review of interventions to reduce the unmet supportive care needs of cancer patients. *Support Care Cancer, 20*(2), 207-219. doi: 10.1007/s00520-011-1327-1

Carlson, L. E., Angen, M., Cullum, J., Goodey, E., Koopmans, J., Lamont, L., . . . Bultz, B. D. (2004). High levels of untreated distress and fatigue in cancer patients. *Br J Cancer, 90*(12), 2297-2304. doi: 10.1038/sj.bjc.6601887

Carr, W., & Wolfe, S. (1976). Unmet needs as sociomedical indicators. *Int J Health Serv, 6*(3), 417-430.

Chambers, S. K., Baade, P., Meng, X., Youl, P., Aitken, J., & Dunn, J. (2012). Survivor identity after colorectal cancer: antecedents, prevalence and outcomes. *Psychooncology, 21*(9), 962-969. doi: 10.1002/pon.1991

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med, 49*(5), 651-661.

Clayman, M. L., Pandit, A. U., Bergeron, A. R., Cameron, K. A., Ross, E., & Wolf, M. S. (2010). Ask, understand, remember: a brief measure of patient communication self-efficacy within clinical encounters. *J Health Commun, 15 Suppl 2*, 72-79. doi: 10.1080/10810730.2010.500349

Clayton, M. F., & Dudley, W. N. (2009). Patient-centered communication during oncology follow-up visits for breast cancer survivors: content and temporal structure. *Oncol Nurs Forum, 36*(2), E68-79. doi: 10.1188/09.onf. e68-e79

Conroy, S. K., McDonald, B. C., Smith, D. J., Moser, L. R., West, J. D., Kamendulis, L. M., . . . Saykin, A. J. (2013). Alterations in brain structure and function in breast cancer survivors: effect of post-chemotherapy interval and relation to oxidative DNA damage. *Breast Cancer Res Treat, 137*(2), 493-502. doi: 10.1007/s10549-012-2385-x

Corner, J., Wright, D., Hopkinson, J., Gunaratnam, Y., McDonald, J. W., & Foster, C. (2007). The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *Br J Cancer, 96*(6), 875-881. doi: 10.1038/sj.bjc.6603662

Corner, J. (2008). Addressing the needs of cancer survivors: issues and challenges. *Expert Rev Pharmacoecon Outcomes Res, 8*(5), 443-451. doi: 10.1586/14737167.8.5.443

Corner, J., Wagland, R., Glaser, A., & Richards, S. M. (2013). Qualitative analysis of patients' feedback from a PROMs survey of cancer patients in England. *BMJ Open, 3*(4). doi: 10.1136/bmjopen-2012-002316

Deimling, G. T., Bowman, K. F., & Wagner, L. J. (2007a). Cancer survivorship and identity among long-term survivors. *Cancer Invest, 25*(8), 758-765. doi: 10.1080/07357900600896323

Deimling, G. T., Bowman, K. F., & Wagner, L. J. (2007b). The effects of cancer-related pain and fatigue on functioning of older adult, long-term cancer survivors. *Cancer Nurs, 30*(6), 421-433. doi: 10.1097/01.NCC.0000300168.88089.2b

Derogatis, L. R., Morrow, G. R., Fetting, J., Penman, D., Piasetsky, S., Schmale, A. M., . . . Carnicke, C. L., Jr. (1983). The prevalence of psychiatric disorders among cancer patients. *JAMA, 249*(6), 751-757.

Dixon-Woods, M., Booth, A., & Sutton, A.J. (2007). Synthesizing qualitative research: a review of published reports. *Qualitative Research, 7*(3), 375-422. doi: 10.1177/1468794107078517

Documet, P. I., Trauth, J. M., Key, M., Flatt, J., & Jernigan, J. (2012). Breast cancer survivors' perception of survivorship. *Oncol Nurs Forum, 39*(3), 309-315. doi: 10.1188/12.onf.309-315

Dunn, S. M., Patterson, P. U., Butow, P. N., Smartt, H. H., McCarthy, W. H., & Tattersall, M. H. (1993). Cancer by another name: a randomized trial of the effects of euphemism and uncertainty in communicating with cancer patients. *J Clin Oncol, 11*(5), 989-996.

Eakin, E. G., Youlden, D. R., Baade, P. D., Lawler, S. P., Reeves, M. M., Heyworth, J. S., & Fritschi, L. (2006). Health status of long-term cancer survivors: results from an Australian population-based sample. *Cancer Epidemiol Biomarkers Prev, 15*(10), 1969-1976. doi: 10.1158/1055-9965.epi-06-0122

Ehrenreich, B. (2001). Welcome to Cancerland: a mammogram leads to a cult of Pink Kitsch. *Harper’s Magazine,* 43–53.

Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., & Duberstein, P. R. (2005). Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med, 61*(7), 1516-1528. doi: 10.1016/j.socscimed.2005.02.001

Epstein R.M., & Street R.L., Jr. (2007). Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering.: National Cancer Institute.

Fallon, M. T., Colvin, L., & Rowbotham, D. J. (2013). Neuropathic pain in cancer. *British Journal of Anaesthesia, 111*(1), 105-111. doi: 10.1093/bja/aet208

Fallowfield, L. J., Hall, A., Maguire, G. P., & Baum, M. (1990). Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *BMJ, 301*(6752), 575-580.

Farrell, C., Heaven, C., Beaver, K., & Maguire, P. (2005). Identifying the concerns of women undergoing chemotherapy. *Patient Educ Couns, 56*(1), 72-77. doi: 10.1016/j.pec.2003.12.008

Fiszer, C., Dolbeault, S., Sultan, S., & Bredart, A. (2014). Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psychooncology, 23*(4), 361-374. doi: 10.1002/pon.3432

Flynn, K. E., Reese, J. B., Jeffery, D. D., Abernethy, A. P., Lin, L., Shelby, R. A., . . . Weinfurt, K. P. (2012). Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology, 21*(6), 594-601. doi: 10.1002/pon.1947

Ford, S., Fallowfield, L., & Lewis, S. (1994). Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *Br J Cancer, 70*(4), 767-770.

Foster, C., Breckons, M., Cotterell, P., Barbosa, D., Calman, L., Corner, J., . . . Smith, P. W. (2015). Cancer survivors' self-efficacy to self-manage in the year following primary treatment. *J Cancer Surviv, 9*(1), 11-19. doi: 10.1007/s11764-014-0384-0

Foster, C., & Fenlon, D. (2011). Recovery and self-management support following primary cancer treatment. *Br J Cancer, 105 Suppl 1*, S21-28. doi: 10.1038/bjc.2011.419

Foster, C., Wright, D., Hill, H., Hopkinson, J., & Roffe, L. (2009). Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *Eur J Cancer Care (Engl), 18*(3), 223-247. doi: 10.1111/j.1365-2354.2008.01001.x

Frank, A. W. . (1995). *The wounded storyteller*. Chicago: The University of Chicago Press.

Fraser, I. (1998). *Hegel and Marx. The concept of need.* Edinburgh: Edinburgh University Press.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol, 13*, 117. doi: 10.1186/1471-2288-13-117

Geller, B. M., Vacek, P. M., Flynn, B. S., Lord, K., & Cranmer, D. (2014). What are cancer survivors' needs and how well are they being met? *J Fam Pract, 63*(10), E7-16.

Gerteis, M. , Edgman-Levitan, S, & J, Daley. (1993.). *Through the Patient’s Eyes. Understanding and Promoting Patient-centered Care.* San Francisco, CA: Jossey-Bass,.

Grant, M., Economou, D., Ferrell, B., & Uman, G. (2012). Educating health care professionals to provide institutional changes in cancer survivorship care. *J Cancer Educ, 27*(2), 226-232. doi: 10.1007/s13187-012-0314-7

Greene, F.L., Dickson-Witmer, D., Edge, S. B., Winchester, D.P., Dickerson, D., Dreyer, S., . . . Van Loon, S. (2012). Cancer Program Standards 2012: Ensuring Patient-Centered Care. CHICAGO, IL: AMERICAN COLLEGE OF SURGEONS

Griffiths, J. (2014). Personal communication 28 August 2014

Grypdonck, M.H. F. (2006). Qualitative Health Research in the Era of Evidence-Based Practice. *Qual Health Res, 16*(10), 1371-1385. doi: 10.1177/1049732306294089

Hannes, K., & Lockwood, C. (2011). Pragmatism as the philosophical foundation for the Joanna Briggs meta-aggregative approach to qualitative evidence synthesis. *J Adv Nurs, 67*(7), 1632-1642. doi: 10.1111/j.1365-2648.2011.05636.x

Hannes, K., & Macaitis, K. (2012). A move to more systematic and transparent approaches in qualitative evidence synthesis: update on a review of published papers. *Qualitative Research, 12*(4), 402-442. doi: 10.1177/1468794111432992

Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N., & Solomon, M. J. (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer, 17*(8), 1117-1128. doi: 10.1007/s00520-009-0615-5

Heathers, G. (1955). Acquiring dependence and independence: a theoretical orientation. *J Genet Psychol, 87*(2), 277-291.

Heaven, C. M., & Maguire, P. (1997). Disclosure of concerns by hospice patients and their identification by nurses. *Palliat Med, 11*(4), 283-290.

Helgeson, V. S. (2011). Survivor centrality among breast cancer survivors: implications for well-being. *Psychooncology, 20*(5), 517-524. doi: 10.1002/pon.1750

Hewitt M., Greenfield S., Stovall E. eds. . (2006). From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, D.C.: The National Academies Press.

Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer survivors in the United States: age, health, and disability. *J Gerontol A Biol Sci Med Sci, 58*(1), 82-91.

Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G. E., Stenlake, A., Hobbs, K. M., . . . Wain, G. (2007a). Long-term survival from gynecologic cancer: psychosocial outcomes, supportive care needs and positive outcomes. *Gynecol Oncol, 104*(2), 381-389. doi: 10.1016/j.ygyno.2006.08.036

Hodgkinson, K., Butow, P., Hunt, G. E., Pendlebury, S., Hobbs, K. M., Lo, S. K., & Wain, G. (2007b). The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psychooncology, 16*(9), 796-804. doi: 10.1002/pon.1137

Hodgkinson, K., Butow, P., Hunt, G. E., Pendlebury, S., Hobbs, K. M., & Wain, G. (2007c). Breast cancer survivors' supportive care needs 2-10 years after diagnosis. *Support Care Cancer, 15*(5), 515-523. doi: 10.1007/s00520-006-0170-2

Hoekstra, R. A., Heins, M. J., & Korevaar, J. C. (2014). Health care needs of cancer survivors in general practice: a systematic review. *BMC Fam Pract, 15*, 94. doi: 10.1186/1471-2296-15-94

Hope-Stone, L. D., & Mills, B. J. (2001). Developing empathy to improve patient care: a pilot study of cancer nurses. *Int J Palliat Nurs, 7*(3), 146-150. doi: 10.12968/ijpn.2001.7.3.8913

Husson, O., Mols, F., & van de Poll-Franse, L. V. (2011). The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol, 22*(4), 761-772. doi: 10.1093/annonc/mdq413

Institute of Medicine. (2001). Crossing the Quality Chasm: A New Health System for the 21st Century. (2001). National Academy Press. Washington D.C. : National Academy Press.

Joanna Briggs Institute. (2014). *Joanna Briggs Institute Reviewers' Manual 2014 Edition*. Adelaide: The Joanna Briggs Institute.

Ishikawa, H., Hashimoto, H., & Kiuchi, T. (2013). The evolving concept of "patient-centeredness" in patient-physician communication research. *Soc Sci Med, 96*, 147-153. doi: 10.1016/j.socscimed.2013.07.026

Khan, N. (2014). Personal communication 8 August 2014

Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer. *Soc Sci Med, 67*(1), 79-87. doi: 10.1016/j.socscimed.2008.03.036

Kaufert, P. A. (1998). Women, resistance, and the breast cancer movement. In M. M. Lock & P. A. Kaufert (Eds.), *Pragmatic women and body politics* (pp. 287–309). Cambridge: Cambridge University Press.

King, S. (2006). *Pink Ribbons, Inc. Breast cancer and the politics of philanthropy*. Minneapolis: University of Minnesota Press.

Kushi, L. H., Doyle, C., McCullough, M., Rock, C. L., Demark-Wahnefried, W., Bandera, E. V., . . . Gansler, T. (2012). American Cancer Society Guidelines on nutrition and physical activity for cancer prevention: reducing the risk of cancer with healthy food choices and physical activity. *CA Cancer J Clin, 62*(1), 30-67. doi: 10.3322/caac.20140

Liss, P.E. (1993). *Health care need: meaning and measurement*. Aldershot: Averbury.

Maguire, P. (1985). Barriers to psychological care of the dying. *Br Med J (Clin Res Ed), 291*(6510), 1711-1713.

Maguire, P., Faulkner, A., Booth, K., Elliott, C., & Hillier, V. (1996). Helping cancer patients disclose their concerns. *Eur J Cancer, 32A*(1), 78-81.

Maguire, R., Kotronoulas, G., Simpson, M., & Paterson, C. (2015). A systematic review of the supportive care needs of women living with and beyond cervical cancer. *Gynecol Oncol, 136*(3), 478-490. doi: 10.1016/j.ygyno.2014.10.030

Mayer, D. K., Gerstel, A., Leak, A. N., & Smith, S. K. (2012). Patient and provider preferences for survivorship care plans. *J Oncol Pract, 8*(4), e80-86. doi: 10.1200/jop.2011.000401

Mayer, M. (1993). *Examining myself: One woman's story of breast cancer treatment and recovery*. Boston: Faber and Faber.

McCabe, M. S., & Jacobs, L. (2008). Survivorship care: models and programs. *Semin Oncol Nurs, 24*(3), 202-207. doi: 10.1016/j.soncn.2008.05.008

McCallum, M. (2014). Personal communication 14 August 2014

McCormack, L. A., Treiman, K., Rupert, D., Williams-Piehota, P., Nadler, E., Arora, N. K., . . . Street, R. L., Jr. (2011). Measuring patient-centered communication in cancer care: a literature review and the development of a systematic approach. *Soc Sci Med, 72*(7), 1085-1095. doi: 10.1016/j.socscimed.2011.01.020

McDonald, I. G., Daly, J., Jelinek, V. M., Panetta, F., & Gutman, J. M. (1996). Opening Pandora's box: the unpredictability of reassurance by a normal test result. *BMJ, 313*(7053), 329-332.

McDowell, M. E., Occhipinti, S., Ferguson, M., Dunn, J., & Chambers, S. K. (2010). Predictors of change in unmet supportive care needs in cancer. *Psychooncology, 19*(5), 508-516. doi: 10.1002/pon.1604

McGrath, P., & Holewa, H. (2012). What does the term 'survivor' mean to individuals diagnosed with a haematological malignancy? Findings from Australia. *Support Care Cancer, 20*(12), 3287-3295. doi: 10.1007/s00520-012-1453-4

McWhinney, I. R. . (1995). Why we need a new clinical method. In M. Stewart, Brown, J.B, Weston, W.W, & I. R. McWhinney, McWilliam, C.L. & Freeman, T.R. (Eds.), (Eds.), *Patient-Centred Medicine: Transforming the Clinical Method* (pp. pp. 1–18). Thousand Oaks, CA:: Sage.

Mead, N., & Bower, P. (2000). Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med, 51*(7), 1087-1110.

Miles, M.B., & A.M., Huberman. (1994). *Qualitative Data Analysis An Expanded Sourcebook*. London: Sage.

Millar, B., Patterson, P., & Desille, N. (2010). Emerging adulthood and cancer: how unmet needs vary with time-since-treatment. *Palliat Support Care, 8*(2), 151-158. doi: 10.1017/s1478951509990903

Mitchell, A. J., Ferguson, D. W., Gill, J., Paul, J., & Symonds, P. (2013). Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncol, 14*(8), 721-732. doi: 10.1016/s1470-2045(13)70244-4

Mohamed, N. E., Chaoprang Herrera, P., Hudson, S., Revenson, T. A., Lee, C. T., Quale, D. Z., . . . Diefenbach, M. A. (2014). Muscle invasive bladder cancer: examining survivor burden and unmet needs. *J Urol, 191*(1), 48-53. doi: 10.1016/j.juro.2013.07.062

Mullan, F. (1985). Seasons of survival: reflections of a physician with cancer. *N Engl J Med, 313*(4), 270-273. doi: 10.1056/nejm198507253130421

Munn, Z., Porritt, K., Lockwood, C., Aromataris, E., & Pearson, A. (2014). Establishing confidence in the output of qualitative research synthesis: the ConQual approach. *BMC Med Res Methodol, 14*, 108. doi: 10.1186/1471-2288-14-108

Mustian, K. M., Morrow, G. R., Carroll, J. K., Figueroa-Moseley, C. D., Jean-Pierre, P., & Williams, G. C. (2007). Integrative nonpharmacologic behavioral interventions for the management of cancer-related fatigue. *Oncologist, 12 Suppl 1*, 52-67. doi: 10.1634/theoncologist.12-S1-52

National Coalition for Cancer Survivorship (NCCS). (2015). webpage. Retrieved 12 April 2015, 2015

Norris, L., Pratt-Chapman, M., Willis, A., & Reed, E.A. (2013). Guide for Quality Delivering Survivorship Care Washington D.C.: The George Washington University Cancer Institute.

Park, B. W., & Hwang, S. Y. (2012). Unmet needs of breast cancer patients relative to survival duration. *Yonsei Med J, 53*(1), 118-125. doi: 10.3349/ymj.2012.53.1.118

Pearson, A. (2004). Balancing the evidence: incorporating the synthesis of qualitative data into systematic reviews. *JBI Reports, 2*(2), 45-64. doi: 10.1111/j.1479-6988.2004.00008.x

Pieters, H. C., & Heilemann, M. V. (2011). "Once you're 82 going on 83, surviving has a different meaning": older breast cancer survivors reflect on cancer survivorship. *Cancer Nurs, 34*(2), 124-133. doi: 10.1097/NCC.0b013e3181ef77b5

Pollock, K., Wilson, E., Porock, D., & Cox, K. (2007). Evaluating the impact of a cancer supportive care project in the community: patient and professional configurations of need. *Health Soc Care Community, 15*(6), 520-529. doi: 10.1111/j.1365-2524.2007.00711.x

Potts, L. K. (2000). Publishing the personal: autobiographical narratives of breast cancer and the self. In L. K. Potts (Ed.), *Ideologies of breast cancer* (pp. 98–127). London: Macmillan Press Ltd.

Puts, M. T., Papoutsis, A., Springall, E., & Tourangeau, A. E. (2012). A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment. *Support Care Cancer, 20*(7), 1377-1394. doi: 10.1007/s00520-012-1450-7

Quillin, J. M., Tracy, K., Ancker, J. S., Mustian, K. M., Ellington, L., Viswanath, V., & Miller, S. M. (2009). Health care system approaches for cancer patient communication. *J Health Commun, 14 Suppl 1*, 85-94. doi: 10.1080/10810730902806810

Roberts, C. S., Cox, C. E., Reintgen, D. S., Baile, W. F., & Gibertini, M. (1994). Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. *Cancer, 74*(1 Suppl), 336-341.

Rowland, J. H. (2007). Survivorship Research: Past, Present, and Future *Cancer Survivorship: Today and Tomorrow* (pp. 28-42).

Rutten, L. J., Arora, N. K., Bakos, A. D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns, 57*(3), 250-261. doi: 10.1016/j.pec.2004.06.006

Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer, 88*(1), 226-237.

Santin, O., Murray, L., Prue, G., Gavin, A., Gormley, G., & Donnelly, M. (2015). Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors. *Eur J Oncol Nurs*. doi: 10.1016/j.ejon.2015.01.009

Schofield, P. E., Butow, P. N., Thompson, J. F., Tattersall, M. H., Beeney, L. J., & Dunn, S. M. (2003). Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol, 14*(1), 48-56.

Shapiro, C. L., & Recht, A. (2001). Side effects of adjuvant treatment of breast cancer. *N Engl J Med, 344*(26), 1997-2008. doi: 10.1056/nejm200106283442607

Shapiro, S., Angus, L., & Davis, C. (1997). Identity and meaning in the experience of cancer: three narrative themes. *J Health Psychol, 2*(4), 539-554. doi: 10.1177/135910539700200410

Silliman, R. A., Dukes, K. A., Sullivan, L. M., & Kaplan, S. H. (1998). Breast cancer care in older women: sources of information, social support, and emotional health outcomes. *Cancer, 83*(4), 706-711.

Silver, J. K., & Gilchrist, L. S. (2011). Cancer rehabilitation with a focus on evidence-based outpatient physical and occupational therapy interventions. *Am J Phys Med Rehabil, 90*(5 Suppl 1), S5-15. doi: 10.1097/PHM.0b013e31820be4ae

Smith, A. B., King, M., Butow, P., Luckett, T., Grimison, P., Toner, G. C., . . . Olver, I. (2013). The prevalence and correlates of supportive care needs in testicular cancer survivors: a cross-sectional study. *Psychooncology, 22*(11), 2557-2564. doi: 10.1002/pon.3323

Sorensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health, 12*, 80. doi: 10.1186/1471-2458-12-80

Stark, D., Kiely, M., Smith, A., Morley, S., Selby, P., & House, A. (2004). Reassurance and the anxious cancer patient. *Br J Cancer, 91*(5), 893-899. doi: 10.1038/sj.bjc.6602077

Strauss, A.L., & Corbin, J.M. (1990). *Basics of qualitative research : grounded theory procedures and techniques*. Newbury Park, California: Sage Publications

Takeuchi, E. E., Keding, A., Awad, N., Hofmann, U., Campbell, L. J., Selby, P. J., . . . Velikova, G. (2011). Impact of patient-reported outcomes in oncology: a longitudinal analysis of patient-physician communication. *J Clin Oncol, 29*(21), 2910-2917. doi: 10.1200/jco.2010.32.2453

Taplin, S. H., & Rodgers, A. B. (2010). Toward improving the quality of cancer care: addressing the interfaces of primary and oncology-related subspecialty care. *J Natl Cancer Inst Monogr, 2010*(40), 3-10. doi: 10.1093/jncimonographs/lgq006

Thind, A., Liu, Y., & Maly, R. C. (2011). Patient satisfaction with breast cancer follow-up care provided by family physicians. *J Am Board Fam Med, 24*(6), 710-716. doi: 10.3122/jabfm.2011.06.100288

Thomas-MacLean, R. (2005). Beyond dichotomies of health and illness: life after breast cancer. *Nurs Inq, 12*(3), 200-209. doi: 10.1111/j.1440-1800.2005.00268.x

Thorne, S. E. (1999). Communication in cancer care: what science can and cannot teach us. *Cancer Nurs, 22*(5), 370-378; quiz 378-379.

Thorne, S. E., Bultz, B. D., & Baile, W. F. (2005). Is there a cost to poor communication in cancer care?: a critical review of the literature. *Psychooncology, 14*(10), 875-884; discussion 885-876. doi: 10.1002/pon.947

Thorne, S. E., & Stajduhar, K. I. (2012). Patient perceptions of communications on the threshold of cancer survivorship: implications for provider responses. *J Cancer Surviv, 6*(2), 229-237. doi: 10.1007/s11764-012-0216-z

Twombly, R. (2004). What's in a name: who is a cancer survivor? J Natl Cancer Inst, 96(19), 1414-1415. doi: 10.1093/jnci/96.19.1414

Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C., Griffin, M., & Wiseman, T. (2012). Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Support Care Cancer, 20*(11), 2639-2647. doi: 10.1007/s00520-012-1470-3

Tzelepis, F., Rose, S. K., Sanson-Fisher, R. W., Clinton-McHarg, T., Carey, M. L., & Paul, C. L. (2014). Are we missing the Institute of Medicine's mark? A systematic review of patient-reported outcome measures assessing quality of patient-centred cancer care. *BMC Cancer, 14*, 41. doi: 10.1186/1471-2407-14-41

Urbaniec, O. A., Collins, K., Denson, L. A., & Whitford, H. S. (2011). Gynecological cancer survivors: assessment of psychological distress and unmet supportive care needs. *J Psychosoc Oncol, 29*(5), 534-551. doi: 10.1080/07347332.2011.599829

Urquhart, R. (2014). Personal communication 14 August 2014

Venetis, M. K., Robinson, J. D., Turkiewicz, K. L., & Allen, M. (2009). An evidence base for patient-centered cancer care: a meta-analysis of studies of observed communication between cancer specialists and their patients. *Patient Educ Couns, 77*(3), 379-383. doi: 10.1016/j.pec.2009.09.015

Vivar, C. G., & McQueen, A. (2005). Informational and emotional needs of long-term survivors of breast cancer. *J Adv Nurs, 51*(5), 520-528. doi: 10.1111/j.1365-2648.2005.03524.x

Walker, J., Holm Hansen, C., Martin, P., Sawhney, A., Thekkumpurath, P., Beale, C., . . . Sharpe, M. (2013). Prevalence of depression in adults with cancer: a systematic review. *Ann Oncol, 24*(4), 895-900. doi: 10.1093/annonc/mds575

Ward, D. J., Furber, C., Tierney, S., & Swallow, V. (2013). Using Framework Analysis in nursing research: a worked example. *J Adv Nurs, 69*(11), 2423-2431. doi: 10.1111/jan.12127

Watson, E., Shinkins, B., Frith, E., Neal, D., Hamdy, F., Walter, F., . . . Rose, P. (2015). Symptoms, unmet needs, psychological well-being and health status in prostate cancer survivors: implications for redesigning follow-up. *BJU Int*. doi: 10.1111/bju.13122

Wilkinson, S. (1991). Factors which influence how nurses communicate with cancer patients. *J Adv Nurs, 16*(6), 677-688.

Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psychooncology, 10*(1), 19-28.

Appendix I: Detailed database search strategy

PubMed

(neoplasms[mh] OR neoplasm*[tw] OR cancer*[tw] OR tumor*[tw] OR melanoma*[tw] OR sarcoma*[tw] OR carcinoma*[tw] OR tumour*[tw]) AND (Disease-free survival[mh] OR surviv*[tw] OR survivorship[tw] OR remission*[tw] OR cure[tw] OR cures[tw] OR curative[tw] OR disease-free[tw]) AND (health services needs and demand [mh:noexp] OR needs[tw] OR unmet[tw] OR gaps[tw] OR barrier* [tw] OR satisfaction[tw]) AND (qualitative research[mh] OR focus groups [mh] OR qualitative[tw] OR interview*[tw] OR focus group[tw] OR phenomenology[tw] OR grounded theory[tw] OR ethnography[tw] OR action research[tw] OR feminist research[tw])

CINAHL

(MH Neoplasms+ OR TI neoplasm* OR AB neoplasm* OR TI cancer OR AB cancer OR TI tumo#r* OR AB tumo#r* OR TI melanoma* OR AB melanoma* OR TI sarcoma* OR AB sarcoma* OR TI carcinoma* OR AB carcinoma*) AND (MH “cancer survivors+” OR TI “Disease-free” OR AB “Disease-free” OR TI surviv* OR AB surviv* OR TI survivorship OR AB survivorship OR TI remission* OR AB remission* OR TI cure OR AB cure OR TI cures OR AB cures OR TI curative OR AB curative) AND (MH “health services needs and demand+” OR MH “information needs+” OR TI needs OR AB needs OR TI unmet OR AB unmet OR TI gaps OR AB gaps OR TI barrier* OR AB barrier* OR TI satisfaction OR AB satisfaction) AND (MH “qualitative studies+” OR MH “focus group+” OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI “focus group” OR AB “focus group” OR TI phenomenology OR AB phenomenology OR TI “grounded theory” OR AB “grounded theory” OR TI ethnography OR AB ethnography OR TI “action research” OR AB “action research” OR TI “feminist research” OR AB “feminist research”)

Embase

(Neoplasm/exp OR neoplasm:ti,ab OR cancer:ti,ab OR tumor:ti,ab OR melanoma:ti,ab OR sarcoma:ti,ab OR carcinoma:ti,ab OR tumour:ti,ab) AND (“Cancer survivor”:de OR “disease free survival”:de,ti,ab OR “cancer regression”/exp OR “cancer regression”/exp OR surviv*:ti,ab OR survivorship:ti,ab OR remission*:ti,ab OR cure:ti,ab OR cures:ti,ab OR curative:ti,ab OR “disease-free”:ti,ab) AND (“health service”/exp OR needs:ti,ab OR unmet:ti,ab OR gaps:ti,ab OR barrier*:ti,ab OR satisfaction:ti,ab) AND (“qualitative research”/exp OR “qualitative research”:ti,ab OR qualitative:ti,ab OR interview*:ti,ab OR “focus group”:ti,ab OR phenomenology:ti,ab OR “grounded theory”:ti,ab OR ethnography:ti,ab OR “action research”:ti,ab OR “feminist research”:ti,ab)

PsycINFO –

(neoplasms.sh OR neoplasms.mp OR neoplasms.ti,ab OR neoplasm.ti,ab OR cancer.ti,ab OR tumor.ti,ab OR melanoma.ti,ab OR sarcoma.ti,ab OR carcinoma.ti,ab OR tumour.ti,ab) AND (Cancer survivor.ti,ab OR Disease free.ti,ab OR surviv*.ti,ab OR survivorship.ti,ab OR remission*.ti,ab OR cure.ti,ab OR cures.ti,ab OR curative.ti,ab) AND (Health care services.mp OR health services.ti,ab OR need.ti,ab

OR needs.ti,ab OR unmet.ti,ab OR gaps.ti,ab OR barrier*.ti,ab OR satisfaction.ti,ab) AND (qualitative research.mp OR focus group.ti,ab OR qualitative.ti,ab OR interview*.ti,ab OR focus group .ti,ab OR phenomenology.ti,ab OR grounded theory.ti,ab OR ethnography.ti,ab OR action research.ti,ab OR feminist research.ti,ab OR grounded theory.mp OR interviews.mp)

Proquest - Dissertations & Theses A&I

(AB,TI(neoplasms) OR AB,TI(neoplasm*) OR AB,TI(cancer*)OR AB(cancer*) OR AB,TI(tumor*) OR AB,TI(melanoma*) OR AB,TI(sarcoma*) OR AB,TI(carcinoma*) OR AB,TI(tumour*)) AND (AB,TI("Disease free survival") OR AB,TI(surviv*) OR AB,TI(survivorship) OR AB,TI(remission*) OR AB,TI(cure) OR AB,TI(cures) OR AB,TI(curative) OR AB,TI("disease free")) AND (AB,TI("health care services") OR AB,TI (need) OR AB,TI(needs) OR AB,TI(unmet) OR AB,TI(gaps) OR AB,TI(barrier*) OR AB,TI(satisfaction)) AND (AB,TI("qualitative research") OR AB,TI("focus group") OR AB,TI(qualitative) OR AB,TI(interview*) OR AB,TI(phenomenology) OR AB,TI ("grounded theory") OR AB,TI(ethnography) OR AB,TI("action research") OR AB,TI("feminist research"))

Mednar
(cancer OR neoplasm OR tumor OR cancer survivor) AND (unmet needs OR barriers OR gaps) AND (qualitative OR interviews OR focus group)

Appendix II: Study Selection Checklist

Included /Excluded

Reference:

SEARCH CRITERIA FOR CANCER SYSTEMATIC REVIEW – JANUARY 2014
(tick if criteria met)

☐**published from 2003**

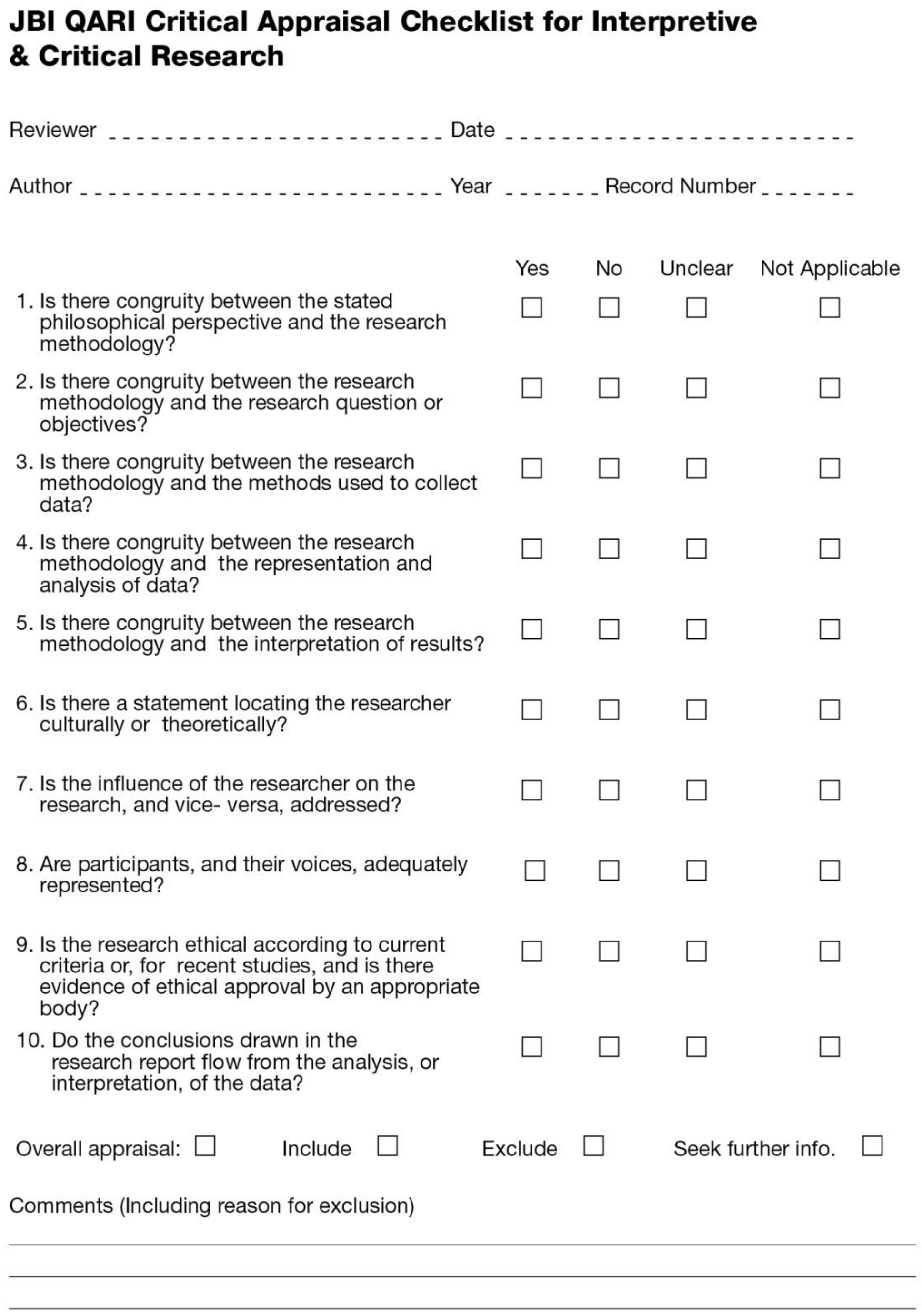
☐**adults >18 years old**
☐**survivors of solid tumours excluding lymphoma**
☐**under 60 years old at time of initial diagnosis**
☐**primary treatment concluded**
☐**may be in remission or cured**
not have
    ☐**not advanced disease**
    ☐**not metastatic disease**
    ☐**not palliative treatment**

☐**Experience of cancer survivors**
☐**Their interaction with the health care system and health practitioners**
☐**Their unmet needs**

Included: Yes/ No → Of NO, Reason:________________
____
____

Notes:____
____
____

Appendix III: QARI Appraisal Checklist



JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _ Date _

Author _ Year _ _ _ _ _ _ _ Record Number _ _ _ _ _ _ _

	Yes	No	Unclear	Not Applicable
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 representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between 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?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

Appendix IV: QARI Data Extraction Instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer - Date -

Author - Year -

Journal - Record Number - - - - - - - - - - - - - - - - - -

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes ☐ No ☐

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete Yes ☐ No ☐

Appendix V: Retrieved studies that did not fulfil the eligibility criteria of the review

DeMarco, R. F., et al. (2004). "Nurse experiences as cancer survivors: part I-personal." Oncol Nurs Forum **31**(3): 523-530.	Includes lymphoma and/or haematological disease
Gorman, J. R., et al. (2011). "Young breast cancer survivors: Their perspectives on treatment decisions and fertility concerns." Cancer Nurs **34**(1): 32-40.	Includes lymphoma and/or haematological disease and under age
Dagostino, N. M. and K. Edelstein (2013). "Psychosocial challenges and resource needs of young adult cancer survivors: Implications for program development." J Psychosoc Oncol **31**(6): 585-600.	Includes lymphoma and/or haematological disease
Gorlick, A., et al. (2013). "Internet-based interventions for cancer-related distress: Exploring the experiences of those whose needs are not met." Psychooncology.	Includes lymphoma and/or haematological disease and some with metastatic disease
Bolte, S. (2010). "The impact of cancer and its treatments on the sexual self of young adult cancer survivors and as compared to their healthy peers." Dissertation Abstracts International Section A: Humanities and Social Sciences **71**(6-A): 2219.	Includes lymphoma and/or haematological disease and some patients in stage IV
D'Agostino, N. M. and K. Edelstein (2013). "Psychosocial Challenges and Resource Needs of Young Adult Cancer Survivors: Implications for Program Development." J Psychosoc Oncol **31**(6): 585-600.	Includes lymphoma and/or haematological disease
Hauken, M. A., et al. (2013). "Meeting reality: Young adult cancer survivors' experiences of reentering everyday life after cancer treatment." Cancer Nurs **36**(5): E17-E26.	Includes lymphoma and/or haematological disease
Hodgkinson, K., et al. (2007). "After cancer: the unmet supportive care needs of survivors and their partners." J Psychosoc Oncol **25**(4): 89-104.	Includes lymphoma and/or haematological disease
Kent, E. E., et al. (2012). ""You're too young for this": Adolescent and young adults' perspectives on cancer survivorship." J Psychosoc Oncol **30**(2): 260-279.	Includes lymphoma and/or haematological disease
Klemm, P. (2008). "Late effects of treatment for long-term cancer survivors: Qualitative analysis of an online support group." CIN - Computers Informatics Nursing **26**(1): 49-58.	Includes lymphoma and/or haematological disease
Maiedema, B., et al. (2004). "Cancer follow-up care in New Brunswick: cancer surveillance, support issues and fear of recurrence." Can J Rural Med **9**(2): 101-107.	Includes lymphoma and/or haematological disease
Miedema, B., et al. (2013). "Do current cancer follow-up care practices meet the needs of young adult cancer survivors in Canada? A qualitative inquiry." Current Oncology **20**(1): 14-22.	Includes lymphoma and/or haematological disease
Miedema, B., et al. (2013). "Comparing urban and rural	Includes lymphoma

young adult cancer survivors' experiences: a qualitative study." Rural Remote Health **13**: 2324.	and/or haematological disease
Miedema, B., et al. (2004). "Cancer follow-up care in New Brunswick: cancer surveillance, support issues and fear of recurrence." Canadian Journal of Rural Medicine **9**(2): 101-107.	Includes lymphoma and/or haematological disease
Mikkelsen, T. H., et al. (2008). "Cancer rehabilitation: Psychosocial rehabilitation needs after discharge from hospital? A qualitative interview study." Scand J Prim Health Care **26**(4): 216-221.	Includes lymphoma and/or haematological disease
Rabin, C., et al. (2013). "Intervention format and delivery preferences among young adult cancer survivors." Int J Behav Med **20**(2): 304-310.	Includes lymphoma and/or haematological disease
Thompson, K., et al. (2009). "Adolescents & young adults: issues in transition from active therapy into follow-up care." European Journal of Oncology Nursing **13**(3): 207-212.	Includes lymphoma and/or haematological disease and some still receiving treatment
Wilson, K., et al. (2013). "Follow-up care in cancer: Adjusting for referral targets and extending choice." Health Expectations: An International Journal of Public Participation in Health Care & Health Policy **16**(1): 56-68.	Includes lymphoma and/or haematological disease and only 3/12 post initial diagnosis and some still receiving treatment
Gibson, F., et al. (2005). "Follow up after childhood cancer: a typology of young people's health care need." Clinical Effectiveness in Nursing **9**(3-4): 133-146.	Includes lymphoma and/or haematological disease
Hordern, A. and A. Street (2007). "Issues of intimacy and sexuality in the face of cancer: the patient perspective." Cancer Nurs **30**(6): E11-18.	Includes lymphoma and/or haematological disease
Beehler, G. P., et al. (2013). "Lasting impact: Understanding the psychosocial implications of cancer among military veterans." J Psychosoc Oncol **31**(4): 430-450.	Includes lymphoma and/or haematological disease and can include people with advanced disease
Thorne, S. E. and K. I. Stajduhar (2012). "Patient perceptions of communications on the threshold of cancer survivorship: Implications for provider responses." Journal of Cancer Survivorship **6**(2): 229-237.	Includes lymphoma and/or haematological disease and stage unclear
Amir, Z., et al. (2008). "Cancer survivors' views of work 3 years post diagnosis: a UK perspective." European Journal of Oncology Nursing **12**(3): 190-197.	Includes lymphoma and/or haematological disease and stage unclear
Balling, K. A. (2003). "Surviving childhood cancer: The impact on transition to emerging adulthood." Dissertation Abstracts International: Section B: The Sciences and Engineering **63**(11-B): 5154.	Includes lymphoma and haematological disease
Ekwall, E., et al. (2003). "Important aspects of health care for women with gynecologic cancer." Oncol Nurs Forum **30**(2): 313-319.	Primary Rx not completed and/or active treatment continuing for

	some
Loh, S. Y., et al. (2007). "Perceived barriers to self-management in Malaysian women with breast cancer." Asia-Pacific Journal of Public Health **19**(3): 52-57.	Primary Rx not completed
Chawla, N. (2011). South Asian Women with Breast Cancer: Navigating Cancer Care and the Role of Social Capital in Obtaining Cancer Resources. Ann Arbor, University of California, Los Angeles. **3486606:** 224.	No phenomena of interest
Colbourne, L. C. (2005). Testicular and prostate cancer: Explaining the treatment and post treatment experience of couples. Ann Arbor, University of Southampton (United Kingdom). **C823360:** 1.	No phenomena of interest
Dolce, M. C. (2009). Experiences of cancer patients, survivors, and caregivers with health care providers in the context of online health information and resources, New York University. **Ph.D.:** 273 p.	No phenomena of interest
Edwards, T. A. (2006). "Surviving breast cancer: Exploring the significance and meaning for african american women." Dissertation Abstracts International: Section B: The Sciences and Engineering **67**(3-B): 1697.	No phenomena of interest
Fernandes-Taylor, S. and J. R. Bloom (2011). "Post-treatment regret among young breast cancer survivors." Psychooncology **20**(5): 506-516.	No phenomena of interest
Fitch, M. I., et al. (2007). "Breast cancer information dissemination strategies -- finding out what works." Canadian Oncology Nursing Journal **17**(4): 206-211.	No phenomena of interest
Flynn, K. E., et al. (2012). "Patient experiences with communication about sex during and after treatment for cancer." Psychooncology **21**(6): 594-601.	No phenomena of interest
Furness, P., et al. (2006). "Coming to terms: a grounded theory of adaptation to facial surgery in adulthood." J Health Psychol **11**(3): 453-466.	No phenomena of interest
Galbraith, M. E., et al. (2012). "What men say about surviving prostate cancer: complexities represented in a decade of comments." Clin J Oncol Nurs **16**(1): 65-72.	No phenomena of interest
Gaudine, A., et al. (2003). "The experience of waiting and life during breast cancer follow-up." Research & Theory for Nursing Practice **17**(2): 153-168.	No phenomena of interest
Gorlick, A. (2011). Evaluating Use of an Online Intervention for Cancer Patients with Distress. Ann Arbor, Loma Linda University. **1534618:** 102.	No phenomena of interest
Gorman, J. R., et al. (2012). "How do you feel about fertility and parenthood? The voices of young female cancer survivors." Journal of Cancer Survivorship **6**(2): 200-209.	No phenomena of interest
Gould, J., et al. (2006). "'Nothing fit me': Nationwide consultations with young women with breast cancer." Health Expectations **9**(2): 158-173.	No phenomena of interest

Martinez, G. P. (2006). "Breast cancer as a life process: Psychosocial experiences of Latina and White (non-Latina) long-term breast cancer survivors." Dissertation Abstracts International Section A: Humanities and Social Sciences **66**(9-A): 3477.	No phenomena of interest
Rust, C. and C. Davis (2011). "Health literacy and medication adherence in underserved African-american breast cancer survivors: a qualitative study." Soc Work Health Care **50**(9): 739-761.	No phenomena of interest
Clayton, M. F. and W. N. Dudley (2009). "Patient-centered communication during oncology follow-up visits for breast cancer survivors: content and temporal structure." Oncol Nurs Forum **36**(2): E68-79.	No phenomena of interest
Fitzpatrick, T. R. and J. Remmer (2011). "Needs, expectations and attendance among participants of a cancer wellness centre in Montreal, Quebec." Journal of Cancer Survivorship **5**(3): 235-246.	No phenomena of interest
Ashing-Giwa, K. T., et al. (2006). "Understanding the breast cancer experience of Latina women." J Psychosoc Oncol **24**(3): 19-52.	No phenomena of interest
Allen, J. D., et al. (2007). "African-American men's perceptions about prostate cancer: implications for designing educational interventions." Social Science & Medicine **64**(11): 2189-2200.	No phenomena of interest
Bache, R. A., et al. (2012). "African and Black Caribbean origin cancer survivors: A qualitative study of the narratives of causes, coping and care experiences." Ethnicity and Health **17**(1-2): 187-201.	No phenomena of interest
Beatty, L., et al. (2008). "The psychosocial concerns and needs of women recently diagnosed with breast cancer: a qualitative study of patient, nurse and volunteer perspectives." Health Expectations **11**(4): 331-342.	No phenomena of interest
Beaver, K. and K. Booth (2007). "Information needs and decision-making preferences: comparing findings for gynaecological, breast and colorectal cancer." European Journal of Oncology Nursing **11**(5): 409-416.	No phenomena of interest
Bender, J. L. (2011). The Web of Care: A Multi-Method Study Examining the Role of Online Communities as a Source of Peer-to-Peer Supportive Care for Breast Cancer Survivors. Ann Arbor, University of Toronto (Canada). **NR78128:** 291.	No phenomena of interest
Bender, J. L., et al. (2013). "What is the role of online support from the perspective of facilitators of face-to-face support groups? A multi-method study of the use of breast cancer online communities." Patient Education & Counseling **93**(3): 472-479.	No phenomena of interest
Canales, M. K., et al. (2011). "Multi-generational Perspectives on Health, Cancer, and Biomedicine: Northeastern Native American Perspectives Shaped by Mistrust." Journal of Health Care for the Poor &	No phenomena of interest

Underserved **22**(3): 894-911.	
Davidge, K. M., et al. (2010). "Qualitative assessment of patient experiences following sacrectomy." J Surg Oncol **101**(6): 447-450.	No phenomena of interest
de Leeuw, J., et al. (2011). "Discharge advice in cancer patients: posttreatment patients' report." Cancer Nurs **34**(1): 58-66.	No phenomena of interest
Hodgkinson, K., et al. (2007). "The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure)." Psychooncology **16**(9): 796-804.	No phenomena of interest
James-Martin, G., et al. (2013). "Information needs of cancer patients and survivors regarding diet, exercise and weight management: a qualitative study." Eur J Cancer Care (Engl).	No phenomena of interest
Juraskova, I., et al. (2003). "Post-treatment sexual adjustment following cervical and endometrial cancer: A qualitative insight." Psychooncology **12**(3): 267-279.	No phenomena of interest
Kazer, M. W., et al. (2011). "The experiences of unpartnered men with prostate cancer: A qualitative analysis." Journal of Cancer Survivorship **5**(2): 132-141.	No phenomena of interest
Kim, B. and D. M. Gillham (2013). "The experience of young adult cancer patients described through online narratives." Cancer Nurs **36**(5): 377-384.	No phenomena of interest
Kwok, C. and K. White (2011). "Cultural and linguistic isolation: the breast cancer experience of Chinese-Australian women - a qualitative study." Contemp Nurse **39**(1): 85-94.	No phenomena of interest
Lee, R. J., et al. (2011). "Facilitating reproductive choices: The impact of health services on the experiences of young women with breast cancer." Psychooncology **20**(10): 1044-1052.	No phenomena of interest
Lopez-Class, M., et al. (2011). "Quality of life among immigrant latina breast cancer survivors: realities of culture and enhancing cancer care." Journal of Cancer Education **26**(4): 724-733.	No phenomena of interest
Martin, F., et al. (2013). "Development and qualitative evaluation of a self-management workshop for testicular cancer survivor-initiated follow-up." Oncol Nurs Forum **40**(1): E14-E23.	No phenomena of interest
Martinez, G. P. (2005). Breast cancer as a life process: Psychosocial experiences of Latina and White (non-Latina) long-term breast cancer survivors. Ann Arbor, University of Michigan. **3186702:** 204-204 p.	No phenomena of interest
Matulonis, U. A., et al. (2008). "Long-term adjustment of early-stage ovarian cancer survivors." International Journal of Gynecological Cancer **18**(6): 1183-1193.	No phenomena of interest
Miedema, B. and J. Easley (2012). "Barriers to rehabilitative care for young breast cancer survivors: A	No phenomena of interest

qualitative understanding." Supportive Care in Cancer **20**(6): 1193-1201.	
Migliara, C. L. (2010). The experience of aftercare for women diagnosed with breast cancer and are in remission for at least six months: A qualitative inquiry. Ann Arbor, Capella University. **3432506:** 97.	No phenomena of interest
Rivers, B. M., et al. (2012). "Understanding the psychosocial issues of african american couples surviving prostate cancer." Journal of Cancer Education **27**(3): 546-558.	No phenomena of interest
Roberts, K. and C. Clarke (2009). "Future disorientation following gynaecological cancer: women's conceptualisation of risk after a life threatening illness." Health, Risk & Society **11**(4): 353-366.	No phenomena of interest
Rosedale, M. (2009). "Survivor loneliness of women following breast cancer." Oncol Nurs Forum **36**(2): 175-183.	No phenomena of interest
Royak-Schaler, R., et al. (2008). "Exploring patient-physician communication in breast cancer care for African American women following primary treatment." Oncol Nurs Forum **35**(5): 836-843.	No phenomena of interest
Rust, C. and C. Davis (2013). "Chemobrain in underserved African American breast cancer survivors: a qualitative study." Clin J Oncol Nurs **17**(2): E29-34.	No phenomena of interest
Semple, C. J., et al. (2008). "Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer." J Adv Nurs **63**(1): 85-93.	No phenomena of interest
Song, L., et al. (2012). "Patient-healthcare provider communication: Perspectives of African American cancer patients." Health Psychology **31**(5): 539-547.	No phenomena of interest
Sprung, B. R., et al. (2011). "The lived experience of breast cancer patients and couple distress." Journal of the American Academy of Nurse Practitioners **23**(11): 619-627.	No phenomena of interest
Tam Ashing, K., et al. (2003). "Understanding the breast cancer experience of Asian American women." Psychooncology **12**(1): 38-58.	No phenomena of interest
Tamminga, S. J., et al. (2012). "Breast cancer survivors' views of factors that influence the return-to-work process--a qualitative study." Scand J Work Environ Health **38**(2): 144-154.	No phenomena of interest
Tanna, N., et al. (2012). "Breast cancer patient stories project." Menopause Int **18**(4): 128-133.	No phenomena of interest
TeBrake, M. L. (2010). A time to question: A study of the information needs of postmenopausal breast cancer patients regarding endocrine therapy. Ann Arbor, Queen's University (Canada). **MR70072:** 113.	No phenomena of interest
Tighe, M., et al. (2011). "Coping, meaning and symptom experience: A narrative approach to the overwhelming impacts of breast cancer in the first year	No phenomena of interest

following diagnosis." European Journal of Oncology Nursing **15**(3): 226-232.	
Tsuchiya, M., et al. (2012). "Information provision and problem-solving processes in Japanese breast cancer survivors with lymphoedema symptoms." Scand J Caring Sci **26**(1): 53-60.	No phenomena of interest
Van Bogaert, D., et al. (2012). "The Development of an eHealth tool suite for prostate cancer patients and their partners." J Support Oncol **10**(5): 202-208.	No phenomena of interest
van der Spek, N., et al. (2013). "Meaning making in cancer survivors: a focus group study." PLoS One **8**(9): e76089.	No phenomena of interest
Volker, D. L., et al. (2013). "A double whammy: Health promotion among cancer survivors with preexisting functional limitations." Oncol Nurs Forum **40**(1): 64-71.	No phenomena of interest
Winterling, J., et al. (2009). "Expectations for the recovery period after cancer treatment--a qualitative study." Eur J Cancer Care (Engl) **18**(6): 585-593.	No phenomena of interest
Khan, N. F., et al. (2011). "A qualitative study of unmet needs and interactions with primary care among cancer survivors." Br J Cancer **105**(SUPPL. 1): S46-S51.	Includes advanced disease
Penrose, R., et al. (2012). "Fertility and cancer - A qualitative study of Australian cancer survivors." Supportive Care in Cancer **20**(6): 1259-1265.	No phenomena of interest
Shin, D. W., et al. (2011). "Knowledge, attitudes, and practice on second primary cancer screening among cancer survivors: A qualitative study." Patient Educ Couns **85**(1): 74-78.	No phenomena of interest
So, W. K. W., et al. (2013). "Perceived unmet supportive care needs and determinants of quality of life among head and neck cancer survivors: a research protocol." J Adv Nurs **69**(12): 2750-2758.	No phenomena of interest
Sun, V., et al. (2014). "From diagnosis through survivorship: health-care experiences of colorectal cancer survivors with ostomies." Supportive Care in Cancer: 1-8	No phenomena of interest
Lewis, L. (2006). "Round table: survivor-focused practice models." Cancer Nurs **29**(2 Suppl): 86-90.	No phenomena of interest
Buki, L. P., et al. (2008). "Latina breast cancer survivors' lived experiences: Diagnosis, treatment, and beyond." Cultural Diversity and Ethnic Minority Psychology **14**(2): 163-167.	No phenomena of interest
Campbell, M. K., et al. (2011). "Adult cancer survivorship care: Experiences from the LIVESTRONG centers of excellence network." Journal of Cancer Survivorship **5**(3): 271-282.	No phenomena of interest
Rosedale, M. (2007). Women's lived experience more than one year following breast cancer and their understanding of the meaning of loneliness, New York University. **Ph.D.:** 135 p.	No phenomena of interest

Anderson, D. J., et al. (2011). "Younger and older women's concerns about menopause after breast cancer." Eur J Cancer Care (Engl) **20**(6): 785-794.	No phenomena of interest
Barnet, M. and T. Shaw (2013). "What do consumers see as important in the continuity of their care?" Supportive Care in Cancer **21**(9): 2637-2642.	No phenomena of interest
Brooks, C. M. (2009). Aboriginal Women's Visions of Breast Cancer Survivorship: Intersections of Race(ism)/Class/Gender and "...Diversity as We Define It*". Ann Arbor, The University of Saskatchewan (Canada). **NR92138:** 298.	No phenomena of interest
Sorensen, L. and P. Graham-Dickerson (2005). "Latina breast cancer survivors: informational needs." Communicating Nursing Research **38**: 449-449.	No phenomena of interest
Haq, R., et al. (2013). "Designing a multifaceted survivorship care plan to meet the information and communication needs of breast cancer patients and their family physicians: results of a qualitative pilot study." BMC Med Inform Decis Mak **13**: 76.	No phenomena of interest
Abbott, R. (2013). Head & Neck Cancer Survivorship: A qualitative study of experience and suggestions for improvement. Ann Arbor, Icahn School of Medicine at Mount Sinai. **1546126:** 39.	Over age limit
Chouliara, Z., et al. (2004). "Older people with cancer: Perceptions and feelings about information, decision-making and treatment - A pilot study." European Journal of Oncology Nursing **8**(3): 257-261.	Over age limit
Boydell, K. M., et al. (2008). "I'll show them: The social construction of (in)competence in survivors of childhood brain tumors." Journal of Pediatric Oncology Nursing **25**(3): 164-174.	Under age limit stage unclear and unclear if have completed primary treatment
Harper, F. W. K., et al. (2013). ""It's up to you and God": Understanding health behavior change in older African American survivors of colorectal cancer." Translational Behavioral Medicine **3**(1): 94-103.	Over age limit
Jones, J. M., et al. (2012). "Experiences of care delivery: endometrial cancer survivors at end of treatment." Gynecol Oncol **124**(3): 458-464.	Over age limit
McCaughan, E. and O. McSorley (2007). "Consumers' and professionals' perceptions of a breast cancer review clinic." J Adv Nurs **60**(4): 419-426.	Over age limit
Wenzel, J., et al. (2012). "Cancer support and resource needs among African American older adults." Clin J Oncol Nurs **16**(4): 372-377.	Over age limit
Letts, C., et al. (2010). "Exploring the impact of prostate cancer on men's sexual well-being." J Psychosoc Oncol **28**(5): 490-510.	Over age limit
Duffey-Lind, E. C., et al. (2006). "Transitioning to survivorship: a pilot study." Journal of Pediatric Oncology Nursing **23**(6): 335-343.	Under age limit

Maliski, S. L., et al. (2003). "The aftermath of lung cancer: balancing the good and bad." Cancer Nurs **26**(3): 237-244.	Over age limit
Mohamed, N. E., et al. (2014). "Muscle invasive bladder cancer: Examining survivor burden and unmet needs." Journal of Urology **191**(1): 48-53.	Over age limit
Ball, M., et al. (2013). "Men's Experience with Sexual Dysfunction Post-rectal Cancer Treatment: A Qualitative Study." Journal of Cancer Education **28**(3): 494-502.	Over age limit and not on unmet needs
Grimison, P., et al. (2013). "Are visiting oncologists enough? A qualitative study of the needs of Australian rural and regional cancer patients, carers and health professionals." Asia Pac J Clin Oncol **9**(3): 226-238.	Includes recurrent disease
Hagan, T. L. and H. S. Donovan (2013). "Ovarian Cancer Survivors' Experiences of Self-Advocacy: A Focus Group Study." Oncol Nurs Forum **40**(2): 140-147.	Includes recurrent disease and some still having primary treatment
Fernandes-Taylor, S. (2010). Provider communication, self-reported health, and post-treatment regret among young breast cancer survivors. Ann Arbor, University of California, Berkeley. **3413364:** 86.	Includes recurrent disease
Ashing-Giwa, K. T., et al. (2004). "The impact of cervical cancer and dysplasia: A qualitative, multiethnic study." Psychooncology **13**(10): 709-728.	Includes recurrent disease
Ashing-Giwa, K. T., et al. (2006). "Survivorship: A Qualitative Investigation of Latinas Diagnosed with Cervical Cancer." J Psychosoc Oncol **24**(4): 53-88.	Includes recurrent disease
Leng, J., et al. (2012). "Identifying the informational and psychosocial needs of Chinese immigrant cancer patients: A focus group study." Supportive Care in Cancer **20**(12): 3221-3229.	Includes recurrent disease and some still having active treatment
Moradian, S., et al. (2012). "Iranian cancer patients and their perspectives: A qualitative study." Eur J Cancer Care (Engl) **21**(3): 377-383.	Includes recurrent disease
Napoles-Springer, A. M., et al. (2009). "Developing a culturally competent peer support intervention for Spanish-speaking Latinas with breast cancer." Journal of Immigrant and Minority Health **11**(4): 268-280.	Includes recurrent disease and some still having active treatment
Tanjasiri, S. P., et al. (2011). "Needs and experiences of Samoan breast cancer survivors in Southern California." Hawaii Med J **70**(11 Suppl 2): 35-39.	Includes recurrent disease and some still having primary treatment
Walton, L. M., et al. (2010). "Gynaecologic cancer patients' needs and experiences of supportive health services in New Zealand." Psychooncology **19**(2): 201-208.	Includes recurrent disease and some still having active treatment
Naik, A. D., et al. (2013). "Cancer survivor rehabilitation and recovery: protocol for the Veterans Cancer Rehabilitation Study (Vet-CaRes)." BMC Health	Includes recurrent disease

Serv Res **13**: 93.	
Griffiths, J., et al. (2007). "Meeting the ongoing needs of survivors of rarer cancer." European Journal of Oncology Nursing **11**(5): 434-441.	Includes recurrent disease and lymphoma patients
Neese, L. E., et al. (2003). "Finding help for sexual problems after prostate cancer treatment: A phone survey of men's and women's perspectives." Psychooncology **12**(5): 463-473.	Includes recurrent disease and over age limit
Burg, M. A., et al. (2009). "The potential of survivorship care plans in primary care follow-up of minority breast cancer patients." J Gen Intern Med **24 Suppl 2**: S467-471.	Several areas not specified
Davis, C., et al. (2009). "Social workers as patient navigators for breast cancer survivors: what do African-American medically underserved women think of this idea?" Soc Work Health Care **48**(6): 561-578.	Several areas not specified
Easley, J. and B. Miedema (2012). "Rehabilitation after breast cancer: recommendations from young survivors." Rehabil Nurs **37**(4): 163-170.	Several areas not specified
Hewitt, M. E., et al. (2007). "Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians." Journal of Clinical Oncology **25**(16): 2270-2273.	Several areas not specified
Kantsiper, M., et al. (2009). "Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers." J Gen Intern Med **24 Suppl 2**: S459-466.	Several areas not specified
Marbach, T. J. and J. Griffie (2011). "Patient preferences concerning treatment plans, survivorship care plans, education, and support services." Oncol Nurs Forum **38**(3): 335-342.	Several areas not specified
McCallum, M., et al. (2012). "Sexual health and gynecological cancer: Conceptualizing patient needs and overcoming barriers to seeking and accessing services." Journal of Psychosomatic Obstetrics and Gynecology **33**(3): 135-142.	Several areas not specified
Walker, T., et al. (2008). "The road we travel: Maori experience of cancer." New Zealand Medical Journal **121**(1279): 27-35.	Several areas not specified
Mosavel, M. and K. Sanders (2011). "Needs of low-income African American cancer survivors: multifaceted and practical." Journal of Cancer Education **26**(4): 717-723.	Several areas not specified
O'Brien R, Rose PW, Campbell C, Weller D, Neal RD, Wilkinson C, et al. Experiences of follow-up after treatment in patients with prostate cancer: a qualitative study. BJU Int. 2010 Oct;106(7):998-1003. PubMed PMID: 20230391. Epub 2010/03/17. eng.	Unclear if completed primary treatment and stage of disease
Buki LP, Garces DM, Hinestrosa MC, Kogan L, Carrillo IY, French B. Latina breast cancer survivors' lived	Not on unmet needs on the lived experience.

experiences: diagnosis, treatment, and beyond. Cultural diversity & ethnic minority psychology. 2008 Apr;14(2):163-7. PubMed PMID: 18426289. Epub 2008/04/23. eng.	
von Friederichs-Fitzwater MM, Denyse T. The unmet needs of African American women with breast cancer Advances in Breast Cancer Research. 2012;1:1-6. Epub http://dx.doi.org/10.4236/abcr.2012.11001 Published Online April 2012 (http://www.SciRP.org/journal/abcr).	Included people with recurrent disease
Allen JD, Savadatti S, Levy AG. The transition from breast cancer 'patient' to 'survivor'. Psycho-oncology. 2009 Jan;18(1):71-8. PubMed PMID: 18613299. Epub 2008/07/10. eng.	On the lived experience, rather than on unmet needs
Adams E, Boulton M, Rose P, Lund S, Richardson A, Wilson S, et al. Views of cancer care reviews in primary care: a qualitative study. The British journal of general practice : the journal of the Royal College of General Practitioners. 2011 Apr;61(585):173-82. PubMed PMID: 21439175. Pubmed Central PMCID: PMC3063046. Epub 2011/03/29. eng.	Included some lymphoma participants and some have advanced disease.

Appendix VI: Studies excluded following assessment of methodological quality

Reference	**Cancer type**	**Reason for exclusion**
Cappiello, M., et al. (2007). "Breast cancer survivors: Information and support after treatment." Clin Nurs Res **16**(4): 278-293.	Breast cancer	Low methodological quality rating of 3/10 (Q8.9.10)
Anderson, A. S., et al. (2013). "Lifestyle issues for colorectal cancer survivors--perceived needs, beliefs and opportunities." Support Care Cancer **21**(1): 35-42.	Colorectal	Low methodological quality rating of 3/10 (Q8.9.10)- Utilises framework analysis which is a method of data analysis rather than a methodology
Oshima, S., et al. (2013). "Care-seeking behavior of Japanese gynecological cancer survivors suffering from adverse effects." BMC Womens Health **13**: 1.	Gynaecological	Low Methodology quality rating of 2/10 (Q9.10) with a lack of the voices of participants represented in the article. Utilises Thematic Analysis - more of a method of analysis rather than a methodology
Singh-Carlson, S., et al. (2013). "Breast cancer survivorship and South Asian women: understanding about the follow-up care plan and perspectives and preferences for information post treatment." Curr Oncol **20**(2): e63-79.	Breast	Low methodological quality rating of 3/10 (Q8.9.10)
Thompson, H. S., et al. (2006). "Posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent: an exploratory qualitative study." Cancer Nurs **29**(6): 478-487.	Breast	Low methodological quality rating of 2/10 (Q8.10)
Brennan, M. E., et al. (2011). "Survivorship care after breast cancer treatment--experiences and preferences of Australian women." Breast **20**(3): 271-277.	Breast	Low methodological quality rating of 3/10 (Q8.9.10)

Appendix VII: Extracted findings from included articles

Findings for: Mollica, M, Nemeth, L. - Cancer Nursing (2014)

Finding	Illustration from Study	Evidence
Some survivors...felt ready to combat the physical effects of chemotherapy but less prepared for the... guilt, resulting depression..... that comes with the end of treatment	“I went into a depression I think a little bit, because you experience a lot of anxiety, it’s very emotional, there is a lot of fear and being overwhelmed, things happening right behind each other. Guilt, um, that I survived and other’s didn’t, happiness that it’s over, and sadness that I lost the support I had.” p 5	Unequivocal
Some ... participants reported that they did not receive information from their oncology providers that symptoms may continue past treatment	“I would have loved to have seen someone come into my room as I was ending treatment, while I was taking my last few chemos, and said to me, I was a survivor, I’ve been there, and here is what you can expect.” p 5..."I wish I had more energy-I’m just not where I should be. This is stuff that is ongoing long after you finish treatment. Even though the chemo is over, and radiation is over, you still have lasting effects. I am tired all of the time." p5...."I’ve been off of chemo for over a year...and it hasn’t gone away. With the neuropathy, it’s hard to button your clothes with your hands, it makes you hurt on your soles. You have a problem with cooking because your hands aren’t sensitive to hot and cold. You drop things, you burn yourself." p5	Unequivocal
Participants voiced many needs after they finished treatment,including the need for psychological support.	"I went into a depression I think a little bit, because you experience a lot of anxiety, it’s very emotional, there is a lot of fear and being overwhelmed, things happening right behind each other. Guilt, um, that I survived and other’s didn’t, happiness that it’s over, and sadness that I lost the support I had." p 5	Unequivocal
Participants voiced many needs after they finished treatment, including the ...need for resources and more information.	“I would have loved to have seen someone come into my room as I was ending treatment, while I was taking my last few chemos, and said to me, I was a survivor, I’ve been there, and here is what you can expect.” p 5	Unequivocal

Participants voiced many needs after they finished treatment, including ... the need to giveback.	No illustration identified in the article	Unsupported
Most participants cited the need for support and communication with another AA woman who had been through treatment for breast cancer.	"I would have loved to have seen someone come into my room as I was ending treatment, while I was taking my last few chemos, and said to me, I was a survivor-I've been there, and here is what you can expect. You get a lot from the doctors, but what you don't get is someone who has been there and is a strong black woman like yourself. You really need that voice that has been through it." p5	Unequivocal
Some survivors ..felt ... less prepared for the ... loss of safety net that comes with the end of treatment	"I went into a depression I think a little bit, because you experience a lot of anxiety, it's very emotional, there is a lot of fear and being overwhelmed, things happening right behind each other. Guilt, um, that I survived and other's didn't, happiness that it's over, and sadness that I lost the support I had." p 5 "More of the mental issues. Being young and being a mom, and dealing with that whole lifestyle of being a mom, being sick, and just trying to deal with that part. So for me, at the end of my treatment, I was believed to be over it, but for me at the same time, just dealing with the mental part of it." p 5-6	Credible
Some survivors...felt ...less prepared for the fear of recurrence ..... that comes with the end of treatment	"I went into a depression I think a little bit, because you experience a lot of anxiety, it's very emotional, there is a lot of fear" p 5	Credible

Findings for : Lawler, S, Spathonis, K, Masters, J, Adams, J, Eakin, E. - Supportive Care in Cancer (2011)

Finding	Illustration from Study	Evidence
Some women perceived a need for other types of health professionals to be involved in their follow-up care, such as psychologists	"Probably everyone who has had cancer and gone through treatment should really be seeing a psychologist" p 1978	Unequivocal
Transition in care-Returning home after active treatment was described as a difficult	"What I found was that the cotton-wool-type situation that you find yourself in when you're under the	Unequivocal

time by several women exemplified by feelings of isolation and vulnerability after having been in constant contact with health professionals during the diagnosis and treatment phases	treatment regime...As soon as that was removed from my life, I really felt extremely isolated and vulnerable because it just sort of ended there. ...I really felt that I was set a cast on a very big ocean, with lots of things to contemplate because you really don't have time to think." p 1977	
Often women perceived there were too many health professionals involved in the delivery of follow-up care and in some instances unnecessary overlap occurred during consultations	"I'd happily only see one doctor now, once a year rather than the two or the three. I know the gynaecologist he's sort of looking after more of the side-effects of the drugs (Tamoxifen) that I'm on than the cancer at the time……But, um, yeah like I said for me I feel it's a waste of time seeing both the radiation (sic, radiologist) and the surgeon. I think one would be sufficient for follow-up." p1978	Unequivocal
some women felt communication between their doctors was often lacking	No illustration identified in the article	Unsupported
Some women perceived a need for other types of health professionals to be involved in their follow-up care, such as ..... dieticians..... to assist with making lifestyle changes	"I had to ask to see a dietician cause I had put on a lot of weight. Um, and that was concerning me and causing me stress...but that was all instigated by me" p1978	Unequivocal
Better access to health professionals... was needed, especially for rural women who often had to travel long distances.	"I believe if the public hospitals have the capacity and the power to identify the rural patients, and therefore understand that you know they have made a significant journey to be here, they have to make a significant journey to get back, you know, can they not be seen in priority, particularly when it's just a review-type situation." p 1978	Unequivocal
Some women spoke that they would like more contact with their BCN, but there was no funding for this type of health care provision	"One of the breast care nurses from the area health group was very, very good. In fact she pops around occasionally. But like everything else she doesn't have the funding to provide full support for, you know, rural people who need it." p 1978	Unequivocal
Several women, ...indicated	"…the ideal thing would be to have	Unequivocal

that having access to a BCN or a liaison person central to co-ordinating their follow-up care and acting as a patient advocate would be ideal. It was also suggested that this person could be their primary contact person to help address ongoing questions or concerns	your own breast care nurse that's involved from day one. I mean you don't need to see them every week or even every month but if you know that there's someone who knows you (participant 2)." p 1978	
Limited availability of cancer-related health professionals in rural regions	"I understand that (my town) doesn't have enough people that you're not going to get specialists to come here," p 1979	Unequivocal
For several women who were consulting a specialist visiting locally, one drawback perceived was the lack of alternative options if they were dissatisfied with this current provider	"She (sic, BCN) never came again … I have met her since and I said "don't ever bother coming again because you've got no idea what you did to me"… no compassion or anything and to think that I needed a back up." p 1978	Credible
Acknowledgement and validation of concerns was important to the women, with several reporting they were not listened to or (in one case) believed when communicating side-effects of treatments during follow-up consultations	"… he said 'but you're not going off the drug'. I'm not telling you that I want to go off the drug. I don't want to go off the drug in fact I'm happy to take the drug forever, but what I want is acknowledgment that this is what it is doing. He finally did acknowledge that okay I agree with you it does have these issues, but you're not going off it. … He couldn't see that it was just validation I was after." p 1979	Unequivocal
Some women receiving public health care experienced a lack of continuity with their health professionals, and had to retrace their clinical history with a different provider at every follow-up appointment	"…cause I'm with a public hospital… you're on a team and you just get whoever you see that day… Yes, I think I've seen the whole team.... …they'd come in and sit down and say 'hello how are you, I don't think we've met before have we?' and you'd say 'yep'. You know, you don't remember who I am and therefore you're just a number." p 1979	Unequivocal
Many women acknowledged health professionals' large workloads and suggested this impacted on the length and quality of consultations.	"I feel the consultations are rushed. You get in, check your blood pressure, write out the request for a mammogram, write out the pathology request, write out your script, everything OK. Good, off you	Unequivocal

Some women perceived their consultations as rushed	go." p 1979	
Some women perceived their.... provider as not always taking the time to enquire about their wellbeing on a more personal level	"I don't feel that you are invited to just sit and chat with how you're doing." p 1979	Unequivocal
Lack of community-based support programmes was a key concern for many women	"I know it's very difficult when you're as isolated as I was out there and, well probably not alone, there's probably other women in very small towns, but to find… get some sort of a group going of ladies who are close by who you could talk to.... Cause you have nothing…(participant 10)." p 1978-80	Unequivocal
Most women desired contact with other cancer survivors	"I'm a resourceful person in myself, so I explored opportunities…I tapped into a women's health service that had received a grant… that was, you know, going to pay for a telephone call every 6 weeks to hook up for an hour and a half, women in remote areas. And that was a really nice opportunity to, just to be on the end of the phone …it's not confrontational, you're not looking at somebody, and that was really good but that was another thing that I had to go and get (participant 5)." p 1979	Unequivocal
Some women perceived a need for other types of health professionals to be involved in their follow-up care, such as ..... physiotherapists, to assist with making lifestyle changes	No illustration identified in the article	Unsupported
Better... organisation of appointments was needed, especially for rural women who often had to travel long distances.	"I believe if the public hospitals have the capacity and the power to identify the rural patients, and therefore understand that you know they have made a significant journey to be here, they have to make a significant journey to get back, you know, can they not be seen in priority, particularly when it's just a review-type situation." p 1978	Unequivocal
Some women perceived a	No illustration identified in the	Unsupported

need for other types of health professionals to be involved in their follow-up care, such as .....complementary, or alternative medicine	article	
Some women intimated they would be better off travelling to major towns or cities to access what they perceived to be the 'best' specialists and care available.	"I've always been of the opinion that I would much rather go to where good specialists are even if it costs me money, um to know that I'm getting the best possible care and expertise" p 1979	Unequivocal

Findings for : Galvan, N, Buki, LP, Garces, DM. - Journal of Psychosocial Oncology (2009)

Finding	Illustration from Study	Evidence
Participants also reported feeling uncomfortable being intimate with their partners and discussed the need for them to learn about and understand the changes that survivors experience	No Illustration identified in the article	Unsupported
With respect to informational support, women wanted to know more about how to cope with their new body image. For example, women reported a need for information about the types of clothes they could wear after surgery, as well as where to obtain breast prostheses. With this information, women could alter their clothing style and feel more attractive	"[information about where to go and how to pay for it] is the help that one needs the most . . . at least that's the thing that I feel I have needed the most, particularly because one does not know where to go." p 374	Credible
Information about reconstruction options was also a concern for participants	"We wish we knew where women could get reconstructive surgery." p 373	Unequivocal
Some participants reported a need for information about availability of psychological assistance for themselves.	"Well, in the beginning, when I didn't know about the support group, I felt very isolated, as if I were the only one struggling with this illness" p 374	Credible

Some participants reported a need for information about availability of psychological assistance for ... their male partners.	No illustration identified in the article	Unsupported
women in committed heterosexual relationships expressed a need for couples counseling to improve their communication and address changes in their sexual relations as a result of the breast cancer experience.	"Well, in the beginning, when I didn’t know about the support group, I felt very isolated, as if I were the only one struggling with this illness,"	Unsupported
Women whose male partners provided emotional support, such as by expressing acceptance of body changes (e.g., scarring and weight gain), were more likely to accept their new body image, to feel self-confident, and to perceive their breast cancer experience as positive, than those who did not have this support.	"Well, in the beginning, when I didn’t know about the support group, I felt very isolated, as if I were the only one struggling with this illness" p 374	Unsupported

Findings for : Easley, J, Miedema, B, Robinson, L. - Oncology Nursing Forum (2013)

Finding	Illustration from Study	Evidence
having the good cancer (i.e.thyroid cancer)....downplayed the diagnosis and experience......They...often felt unworthy of accessing available support programs	“They call it the ‘good’ cancer. And I’m like, how can it be the good cancer? . . . I didn’t lose my hair . . . and we don’t look like we have cancer. And that’s why it’s very hard for us to find support because we haven’t gone through chemotherapy. We don’t have scars from radiation. You know? People forget.” p 598	Unequivocal
Many participants said that they could not relate to patients and survivors with other types of cancer, and they felt that other patients did not want to hear about their experiences because thyroid cancer treatments typically are well tolerated.	“So for me to go to [the Cancer Support Centre] . . . I didn’t feel like I belonged there. I didn’t feel like I had cancer because no one recognized it like that. I would go in and then I was like, this isn’t for me because . . . I could walk in there and they’d be like, ‘Yeah, right.’ Because that’s the reputation that thyroid cancer has. . . . It’s not that no one believes you, it’s just that it’s the good cancer, so who cares?” p 598	Unequivocal
Participants also expressed difficulty identifying with older adult patients with cancer because of differences based on life stages	“They have lots of group therapy [at the Health Care Centre], but again, it’s people who have got serious cancer who are dying. They really don’t want to hear about my little survival story when they are dying.” p599	Credible
Isolation was strongly connected to the theme of being told that thyroid cancer is the good cancer...being isolated from their peers who did not have cancer because they could not relate to or understand the experience of having a serious illness	“The physical thing is so easy to explain to my friends. I have low energy, whereas the psychological component is a little different. I guess for me, psychologically, I felt . . .I didn’t have a lot of support at the time, and so that I felt very lonely. . . . I wouldn’t say that I was depressed or anything, but definitely just lonely and just having to kind of deal with it all on my own at the time with no one that I could relate to.” P 599	Unequivocal
Isolation was strongly connected to the theme of being told that thyroid cancer is the good cancer. Isolation was discussed in relation to three different areas: isolation from	“They have lots of group therapy [at the Health Care Centre], but again, it’s people who have got serious cancer who are dying. They really don’t want to hear about my little survival story when they are dying.” P 599	Unequivocal

....support programs		
Having the good cancer (i.e.thyroid cancer)....downplayed the diagnosis and experience......feeling that they were perceived as not needing support	“I think as soon as the radiation stuff was done, I was done to [healthcare providers]. To the medical profession, I was finished, and I was so not finished. I felt like I have a minor cancer, so . . . I feel like there’s a class of patients that’s like the real cancer patient [laughs]. And they would get, you know, different kind of care.” P598	Unequivocal

Findings for : Ruddy, KJ, Greaney, ML, Sprunck-Harrild, K, Meyer, ME, Emmons, KM, Partridge, AH. - Journal of Adolescent and Young Adult Oncology (2013)

Finding	**Illustration from Study**	**Evidence**
Breast cancer strained their sexual and emotional connections and caused communication rifts with their partners. Many...were dismayed at their perceived lack of adequate support to help their partners deal with the burden of suddenly becoming a caregiver	‘‘We both felt very, very alone, because we were both so busy, trying to be strong for each other, that we didn’t open up as much as we probably should have, and we each felt like we had gone through it very separately. Despite, like, giving outward support and everything, we each felt like, ‘If I tell you how scared I am and how I’m about to lose my %#*$, you might lose your %#*$, too,’ and you know, he felt like he couldn’t do that to me because I was sick; and I felt like I couldn’t do that to him, because I knew he was suffering.’’ p155....‘‘I think that’s part of why my marriage fell apart.he listened, he took notes, he asked questions, he did all the right things on the surface. But then, you know, we’d get home and he’d be like, ‘When are you going to get better? When is it going to be my turn? When are we going to have sex again? When can my life get back to normal?’’’ p155...."It would be helpful for them to say ‘There are going to be issues that are going to come up. You might find it useful to find a therapist.’’’ P 157	Unequivocal
Women who found out that they carried a BRCA	‘‘The BRCA1 gene, I have it, and my sister was diagnosed with breast	Credible

mutation voiced concern about how to deal with the possibility that their children may also be carriers	cancer right when we were figuring that out (and she had the gene as well). And then, suddenly, the light bulb went off in my daughter's head, my fifteen-year old, and she said, 'Mommy, what am I to expect?' I had to be upfront with her and just say, 'When you get to your twenties they're going to keep an eye on you a little bit more than they would somebody that doesn't have this risk' for a fifteen-year old to really understand that is hard.'' P155	
Desired more information on exercise	''I just wish that there was more information in a nicely easy-to-read packet, that someone would say, 'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z' when you are going through all of this, it is overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your convenience to read, it [would be] invaluable.'' p 157...''You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.'' p 157	Unsupported
Many of the women were upset they had not had more time to explore fertility preservation techniques. The high cost of these techniques and uncertainties about whether they were needed or would be effective added to distress levels, with some women feeling they had very few realistic options. These women remained worried about their chances of	''I didn't have a lot of time to make a choice because I had to enroll in a study to get chemo. I felt very, very rushed even though I did a lot of research to educate myself. My insurance wouldn't cover it, and I couldn't afford $15,000 to harvest eggs. So I just had to take a chance.'' p155....''The fertility issue is a big issue, and to have to make a decision on that in that head space, I think, is really challenging there's so much pressure. 'Oh, my God, I have to decide if I want to have kids in 5	Credible

conceiving in the future, and wished they had had more support around fertility-related decisions.	years, right this minute!' Which is a really weird place to be in where you're thinking about your own mortality.'' p 155	
Many complained about weight gain during treatment, and that they had not been adequately informed about the high likelihood of this	''The weight is brutal, and I hate it.'' p 156	Credible
Some also expressed dissatisfaction with the information they received from their doctors about the hormonal side effects of their treatments	''You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.'' p 157	Credible
They felt that discussions and materials were too generic (their specific problems were not addressed)	''I just wish that there was more information in a nicely easy-to-read packet, that someone would say, 'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z' when you are going through all of this, it is overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your convenience to read, it [would be] invaluable.'' p 157	Credible
sexual functioning was seldom proactively discussed by practitioners.	"Regarding discussing sexual functioning: ''Had I never said anything, I think they just would have assumed that everything was fine.'' p 156	Unequivocal
Many reported that it was hard to decide whom (if anyone) at work to tell about their cancer because they were not sure how colleagues would react	No illustration identified in the article	Unsupported
it was challenging to learn enough about the financial, insurance, and work leave aspects of treatment while in the throes of a new	''I was challenged with navigating through the whole FMLA you know, kind of making sense of, 'Okay, what is covered? What is considered sick leave?' And it was a lot of phone	Unequivocal

cancer diagnosis	calls, trying to figure that out. And I just wish that it would just be a lot more seamless, because I was going through treatment, not sure when am I gonna get my paycheck, how much time should I take off, and such.'' p156	
Participants did not feel adequately informed about chronic survivorship issues such as... what to expect from their bodies ... Many had incorrectly expected they would be able to resume their pre-treatment lives easily, and were distressed to find they could not	''I think the misconception is 'Once I get through all this, I want to go back to normal.' Like, that's the goal to be 'back to what I was, before.' It's not like that. You are completely changed and different and, you know, I kind of just took that expectation off myself, because I felt you can't go back.'' p 157...''You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.'' p 157	Unequivocal
The emotional toll of the transition into the survivorship phase was compounded by the fact that participants lost many of the supports that had helped them during treatment. ...... Some women missed seeing their healthcare providers as frequently as they had during treatment	''I felt like you were just set adrift. And, it was sad because, during the whole process, there's so much support, and it almost seems like everyone disappears....Some women missed seeing their healthcare providers as frequently as they had during treatment'' p157	Unequivocal
Participants wished they were able to talk, both during and after treatment, with other breast cancer survivors who were of a similar age and life stage, in order to get "straight answers about the ups and downs of treatment"	''Right after you're done with chemo, or, the period when you're done with treatment, if people haven't had chemo or radiation or whatever, and then you're just sort of supposed to be normal, but you're not quite normal. My oncologist actually said they used to have support groups just for people during this transition time. I don't know what happened to those support groups.'' ''I always find myself on the younger side of everything.[with] people that are MUCH older and didn't have kids that are at a similar age, and so, that's been very difficult.'' p 157	Credible

A relationship with a healthcare professional other than their oncologist would have been appreciated before, during, and after treatment to help answer questions outside of medical appointments, provide support and information to their families	‘‘I guess the other thing which would be really helpful, would have been to have one person who I kind of felt was my case manager. My oncologist is super duper, but because is so super duper I you know, I get like ten minutes with him and then that’s it. And he’s very careful, he’s like, ‘Any questions.?’ but I don’t want to pressure him with anything else, all the time and my nurse practitioner was like, ‘This is more of an OB question,’ ‘That’s more of a surgery question,’ so I’d go off and ask the other person they can ask the other person, but it’s very tiring to do that. So, it would have been very helpful for me to have one person who was my kind of appointed question asking person, rather than this Rolodex of business cards.’’ p157	Unequivocal
Desired more information on ......the impact of diagnosis and treatment on their personal relationships	‘‘[I wish someone had said,] ‘Here’s a list of therapists. You might want to go down, see if some of them click, you might find them useful to talk to.’ I’m like a complete and utter mess I know that it’s normal and they didn’t really tell me that. It would be helpful for them to say ‘There are going to be issues that are going to come up. You might find it useful to find a therapist.’’’ p 157	Credible
Desired more information on....side effects from treatment	"You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.’’ p157	Unequivocal
Desired more information on ...fertility	‘‘The fertility issue is a big issue, and to have to make a decision on that in that head space, I think, is really challenging there’s so much pressure. ‘Oh, my God, I have to decide if I want to have kids in 5 years, right this minute!’ Which is a really weird place to be in where you’re thinking about your own mortality.’ p 156	Credible
desired more information on...weight loss	‘‘I just wish that there was more information in a nicely easy-to-read packet, that someone would say,	Credible

	'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z' when you are going through all of this, it is overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your convenience to read, it [would be] invaluable.'' p 157...''You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.'' p 157	
Desired more information on....vitamins	''I just wish that there was more information in a nicely easy-to-read packet, that someone would say, 'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z' when you are going through all of this, it is overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your convenience to read, it [would be] invaluable.'' p 157...''You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.'' p 157	Credible
Desired more information on...nutrition	''I just wish that there was more information in a nicely easy-to-read packet, that someone would say, 'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z' when you are going through all of this, it is	Credible

	overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your convenience to read, it [would be] invaluable.'' p 157 ''You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.'' p 157	
Desired more information on.... what to expect physically and emotionally after treatment	"I'm like a complete and utter mess I know that it's normal and they didn't really tell me that." p 157	Unequivocal
Women expressed interest in high-quality educational materials for themselves	''I just wish that there was more information in a nicely easy-to-read packet, that someone would say, 'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z' when you are going through all of this, it is overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your convenience to read, it [would be] invaluable.'' p 157 ''You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.'' p 157	Unequivocal
Women expressed interest in high-quality educational materials ....specifically designed for family members and caregivers (including descriptions of treatments and	''I just wish that there was more information in a nicely easy-to-read packet, that someone would say, 'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z' when you are going through all of this, it is	Credible

recommendations regarding what to do/not do for patients and when it is okay/not okay to talk about cancer	overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your convenience to read, it [would be] invaluable.'' p 157.....''I think people, generally, are trying to support you, and they don't know that telling you their death stories, you know, makes you think about death.'' p 157	
Some felt that online information about statistics ...would be particularly reassuring, and they were not aware of existing resources of this type.	No illustration identified in the article	Unsupported
Some felt that ... survivorship care follow-up plans would be particularly reassuring, and they were not aware of existing resources of this type.	No illustration identified in the article	Unsupported
Participants specifically expressed desire for educational materials at the time of transition into the survivorship phase of care.	''I just wish that there was more information in a nicely easy-to-read packet, that someone would say, 'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z' when you are going through all of this, it is overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your convenience to read, it [would be] invaluable.'' p157	Unequivocal
Participants wished for a list of therapists with experience providing counseling for young women with breast cancer	''[I wish someone had said,] 'Here's a list of therapists. You might want to go down, see if some of them click, you might find them useful to talk to.' p 157	Unequivocal
A few women were also	''[I wish someone had said,] 'Here's	Credible

interested in easier access to therapists (i.e., lists of experienced providers who were accepting new clients) for partners and other family members	a list of therapists. You might want to go down, see if some of them click, you might find them useful to talk to.’ I’m like a complete and utter mess. I know that it’s normal and they didn’t really tell me that. It would be helpful for them to say ‘There are going to be issues that are going to come up. You might find it useful to find a therapist.’’’ p 157	
The emotional toll of the transition into the survivorship phase was compounded by the fact that participants lost many of the supports that had helped them during treatment. Participants explained that once they were no longer receiving treatment, some friends and family stopped calling and visiting as often.	‘‘I felt like you were just set adrift. And, it was sad because, during the whole process, there’s so much support, and it almost seems like everyone disappears. It’s like this big bandwagon, ‘Yay! Here’s some meals, here’s this, here’s all the support groups and the social worker.’ But then it’s over! And then you have this expectation that you’re supposed to be glad you’re alive, and grateful, and it’s past you, but it is totally not.’’ p157	Unequivocal
Participants desired assistance, including .....help navigating the healthcare system	"‘‘I guess the other thing which would be really helpful, would have been to have one person who I kind of felt was my case manager…. So, it would have been very helpful for me to have one person who was my kind of appointed question asking person, rather than this Rolodex of business cards.’’" p 157	Unequivocal
Participants did not feel adequately informed about chronic survivorship issues such as... memory problems	‘‘They’re telling me these things that happened, and I can’t remember It’s just, that chemo brain, or it’s just shut everything out. My 5 year old already knows, ‘Yeah, you can’t remember.’’’ p 156	Credible
Participants did not feel adequately informed about chronic survivorship issues such as... anxiety.	‘‘By the end, you feel like you’ve been beat up and abused. And you’re TIRED. And you’re like, sort of emotionally raw, and I feel like THAT’S the time when there need to be more supports out there.’’	Credible
Participants did not feel adequately informed about chronic survivorship issues such as fatigue	‘‘I’m almost thinking, ‘Should I tell [my kids] that I go to bed at 9:00 now, instead of reading my book till 1:00?’.Because, is that fatigue? Or is that just the new me?’’ p 156	Credible
Uncertainty about their	‘‘By the end, you feel like you’ve	Credible

health made it difficult for many women to plan for the future with their partners. Some reported that this became most obvious after finishing treatment.	been beat up and abused. And you're TIRED. And you're like, sort of emotionally raw, and I feel like THAT'S the time when there need to be more supports out there.'' p 157	
women were also concerned about how their illness affected their children, with many feeling guilty that during treatment they did not have the energy to do things they usually did with their children. Mothers reported that physical changes, including hair loss, were disturbing to their children, and that they generally struggled telling their children about their cancer; in fact, some never did.	''I did feel guilty. I'd make myself go to bed at 8:00.they were doing homework, and you could hear stuff going on, and I was doing what I could to stay as normal as possible, but I definitely had to make that time for myself.'' ''I remember not being able to pick up my son, and then, when I did, I couldn't feel him anymore on my chest.'' ''My little one didn't like me to go without my hat on should she see me without it, it would upset her.'' p 155	Unequivocal
some reported that it had been difficult to decide whether or not to continue working. Uncertainties about necessary recovery time often complicated these decisions.	"I was going through treatment, not sure when am I gonna get my pay check, how much time should I take off, and such.'' p 156	Unequivocal
Participants did not feel adequately informed about chronic survivorship issues such as... how to differentiate side effects from symptoms of recurrence.	''You could almost do a pamphlet head to toe chemo brain, loss of sensation, sexual functions, joint hurts, real pain this is stuff that you might experience because I never knew that.'' p 157	Credible
A relationship with a healthcare professional other than their oncologist would have been appreciated before, during, and after treatment to help answer questions outside of medical appointments,…and coordinate follow-up care.	''I guess the other thing which would be really helpful, would have been to have one person who I kind of felt was my case manager. My oncologist is super duper, but because is so super duper I you know, I get like ten minutes with him and then that's it. And he's very careful, he's like, 'Any questions.?' but I don't want to pressure him with anything else, all the time and my nurse practitioner was like, 'This is more of an OB question,' 'That's more of a surgery question,' so I'd go off and ask the	Unequivocal

	other person they can ask the other person, but it's very tiring to do that. So, it would have been very helpful for me to have one person who was my kind of appointed question asking person, rather than this Rolodex of business cards.'' p157	

Findings for : Sekse, RJT, Raaheim, M, Blaaka, G, Gjengedal, E. - Scandinavian Journal of Caring Sciences (2010)

Finding	Illustration from Study	Evidence
The short consultation time which was inadequate for deeper conversations, and the queue of patients in the corridor, were other obstacles that were mentioned.	'I felt like, well, 'Now you're done… through… out you go!' p 804	Credible
There seemed, however, to be a common experience of feeling unprepared, even shocked. Those who had gone through menopause before the operation described a new, but different menopause because of bodily changes,......Not being prepared for these bodily changes, neither by themselves nor by health care personnel, seemed to lead to an introspection of bodily changes, binded energy and unnecessary uncertainty	''When they removed my uterus and all that, they removed my temperature control.'' p 803	Credible
The process of sorting things out after treatment for gynaecological cancer, such as handling....anxiety, was described as a lonely journey that the women were not prepared for.........Coming to terms with themselves immediately after treatment was a lonely process.	''I felt like, well, 'Now you're done… through… out you go!'' p 804...'My mental state may have been different if I'd had someone to talk things over with afterwards!…You have many thoughts in your head, right…and you can't air them and relieve yourself of your burdens… so I think that talking with health personnel would have been of considerable help!' p 804	Unequivocal
information on expected side effects and longterm	"These things (guidance and information) are in fact so important	Credible

consequences after surgery and how to handle them would have been valuable	that they define whether you feel okay or not afterwards, because you are able to choose a position, an identity – so you don't float around in uncertainty." p 804	
Lack of time for conversations (with health professionals) about what they had been through ...was strongly felt to be missing	"My mental state may have been different if I'd had someone to talk things over with afterwards!…You have many thoughts in your head, right…and you can't air them and relieve yourself of your burdens… so I think that talking with health personnel would have been of considerable help!'" p 804	Unequivocal
They missed hearing questions such as: 'How do you feel?'	''How do you feel?'' 804	Unequivocal
Accepting greater responsibility for getting the information they needed was also emphasised. However, early in the process, they didn't quite know what to ask	'I just didn't know what to ask about! Everything was new to me (…) Maybe I should have asked, but then and there I didn't know… I see it now …I didn't realize that there were questions that needed to be asked!' p 804	Unequivocal
The short consultation time which was inadequate for deeper conversations	"I felt like, well, 'Now you're done… through… out you go!" "My mental state may have been different if I'd had someone to talk things over with afterwards!…You have many thoughts in your head, right…and you can't air them and relieve yourself of your burdens… so I think that talking with health personnel would have been of considerable help!' p 804	Credible
Information about possible future consequences was strongly felt to be missing	"These things (guidance and information) are in fact so important that they define whether you feel okay or not afterwards, because you are able to choose a position, an identity – so you don't float around in uncertainty. This is the time, after cancer, when essential choices are made." p 804	Credible
The process of sorting things out after treatment for gynaecological cancer, such as handling bodily changes …was described as a lonely journey that the	No illustration identified in the article	Unsupported

women were not prepared for		
Questions concerning the consequences of removed reproductive organs were not easily posed.	‘I wasn’t open enough when I was there…I couldn’t manage it… I was so nervous!’ p 804	Credible
The consultation, with gynaecological examination, blood-tests and focus on facts, was not experienced as an easy setting for raising intimate topics, especially related to sexuality.	‘I wasn’t open enough when I was there…I couldn’t manage it… I was so nervous!’ p 804	Credible
There was also much suspense associated with each follow–up control. The experience of receiving a ‘stamp’ was poignant: ‘Cured’ or ‘Still sick’. Questions related to anything else seemed irrelevant at the time.....The medical focus on cancer was important, but not sufficient, in handling the women’s everyday lives and coming to terms with themselves after cancer.	‘I wasn’t open enough when I was there…I couldn’t manage it… I was so nervous!’ p 804	Credible

Findings for : Thewes, B. Butow, P. Girgis, A. Pendlebury, S. - Psycho-Oncology (2004)

Finding	**Illustration from Study**	**Evidence**
many women spoke about an unmet need to determine whether their symptoms were normal, and a need to receive reassurance that their symptoms were not a sign of recurrence.	"Following treatment. . . there are certain landmarks that people go through. . . it would be nice to be able to keep in touch with someone, to chat or to have someone to just hold your hand during those times." p 183	Credible
concerns about how work related stressors might affect their health. One young woman spoke about her concerns about getting back into a 'vicious cycle' of work/family pressures and stress.	‘vicious cycle’ p 182	Unsupported
All of the women who	"The major concern for me was	Unequivocal

sought information about fertility felt that the information they received was either conflicting or inadequate	fertility, not getting the information that I needed about what could be done. That was a huge issue for me, probably one of the worst things" P 183	
Receiving information about choices for contraception was another major issue for many premenopausal younger women	"There is no consistency in information [about fertility] and, leading off that, contraception. The fact that I won't be able to go back on the Pill raises new questions. How is it going to be safe? It was especially difficult during the time that I knew was a bad time to conceive. It has placed strains on our [marital] relationship" P 183	Unequivocal
A small number of younger women reported a perception that their doctors were only interested in the physical aspects of their recovery, and were therefore reluctant to discuss emotional issues	"I haven't labored the point [my needs for emotional support] too much because I figured it was something I had to do on my own. What they [doctors] are really keen to see is physical improvement or to make sure there is no recurrence of the cancer (Anthea, 51 years)." P 183	Unequivocal
Amongst many younger women, there was a perception that the groups available did not cater to their needs due to their age.	"I 've been to one meeting, and I wouldn't go to another. I left because I was very young. I was the youngest one there. I'd hear 'ooh look how young she is' and that kind of thing. It's like well, I don't want to be here either, you know. In a sense I felt a bit alienated. . .I just wanted to be with a group of women my age, and whether it be a bitch session or a cry session, just to get things off your chest, that's what I would have liked." P 184	Unequivocal
They wanted to hear the 'success stories' of other younger women	"You want to hear stories about women who had it [breast cancer] around the same age as you, who've gone through chemotherapy, who've had kids and that they are fine and the kids are fine." P 184	Unequivocal
Younger survivors tended to view themselves as well, and spoke about the need for support services to be outside of the hospital environment	"'you don't want to live in that [cancer] world anymore' (Anne, 29 years). Another young woman said I knew of one [group] at the hospital but I didn't want to go back to that hospital atmosphere. It was the ideas that went with venues like that, also I thought it was sort of more political	Unequivocal

	than dealing with the needs you wanted [addressed]." P 184	
younger women were more likely than older women to want additional support from professional counsellors during their treatment rather than volunteers.......Younger women felt that although volunteers were 'kind' or 'caring' that they lacked the professional expertise to be able to deal with their counselling needs. One younger woman suggested that psychological support should be a routine part of treatment	"I haven't labored the point [my needs for emotional support] too much because I figured it was something I had to do on my own. What they [doctors] are really keen to see is physical improvement or to make sure there is no recurrence of the cancer" P 183	Credible
because their specialists were so busy, some questions are 'too trivial' to ask their doctors in follow-up consultations.	"Often times you go into the waiting room and you see other people who are so much worse off than you that you think it is hardly worth mentioning it." P 185	Unequivocal
Many survivors spoke about the continued need to keep their family members well informed during their follow-up. One younger woman spoke about the social isolation she experienced after her treatment because of a lack of information for family and friends about her diagnosis	"Recently, I've had people ring me who didn't ring me for months afterwards who have said to me 'I just didn't know what to say', they didn't know how to react! I think it would be good to have even a pamphlet or something like that to give them." P 185	Unequivocal
younger women spoke about the desire to be kept informed about new treatment and research developments. For these women keeping informed was either out of 'interest', or in the case of one younger woman, a form of reassurance or sense of control over possible recurrence	"It would be nice to be more informed about the new drugs . . .and to know some of the positive things happening in breast cancer research. I've got to the situation now where I think if I do get a recurrence, hopefully there are new drugs evolving, and if I 'm unlucky enough to get a recurrence one of them will be effective." P 185	Unequivocal
Several young women wanted more information	"I 'm reading now a lot about Asian women who have a lot of bean curd	Unequivocal

about diet, healthy living and possible carcinogens or environmental triggers	in their diet and lower levels of breast cancer, I suppose I would like to be able to explore that a bit more in a more structured way." P 186	
Several younger women felt that the information they received during and after their treatment was not always relevant to women of their age. These women wanted more age-relevant information	"There isn't a lot of information about breast cancer for women my age. It seems as though there are so many statistics for post-menopausal women, [for women my age] it seems to be a completely different ball game." P 186	Unequivocal
Many survivors reported continued needs to receive information	"The doctors and the hospital should be able to give you something that you can take home, so that you can look at it and put it to one side and pick it up again later if you need it." p185	Unequivocal
The need to access physiotherapy services following their treatment to assist them in dealing with arm problems	No illustration identified in the article	Unsupported
Many survivors reported continued needs to receive information...There was a perception by a small number of women that because their specialists were so busy, some questions are 'too trivial' to ask their doctors in follow-up consultations.	"Often times you go into the waiting room and you see other people who are so much worse off than you that you think it is hardly worth mentioning it" p 185	Unequivocal

Findings for : Roundtree, AK. Giordano, SH. Price, A. Suarez-Almazor, ME. - Supportive Care in Cancer (2011)

Finding	**Illustration from Study**	**Evidence**
Logistic problems were also a concern including inconvenience making appointments	No illustration identified in the article	Unsupported
Logistic problems were also a concern including .....delays in receiving test results	"They send you a letter in the mail, and they thought they found something and I wasn't leaving until they decided to repeat this test. You know you can never be that busy... if they think they have found something repeat it. Or work them in, I mean I would have stayed here all day. I	Unequivocal

	didn't want to have to wait...Just to relieve my mind." p 1926	
Survivors felt that they had no providers within the healthcare system exclusively devoted to their unique needs. They preferred seeing oncologists, but felt guilty because, in their opinion, patients with active cancer needed oncologists for matters more pressing than theirs.	"If I had a choice, I would come [to the cancer center] for everything. I just feel like that [my oncologist] has so many patients,…if I started to come here for every little thing, I could be taking up some time that they could be taking care of somebody [with] more critical needs." P 1925	Unequivocal
They also felt dismissed by cancer specialists at the time that transfer of care takes place.	"I had already been dismissed by the radiologist a couple of years ago, and then by the surgeon 1 year ago and then my oncologist [who] said you are doing well and we are going to send you to…the survivorship clinic." p 1925	Unequivocal
Survivors sought to have their healthcare needs met by assorted medical professionals including primary care physicians and gynecologists to pharmacists and nurse practitioners. However, these providers were often reluctant to provide advice or treat them, referring them back to cancer specialists	"The other thing that is hard too is primary care...[Healthcare providers] usually don't want to deal with you anymore and if it is any little old thing they say you need to go to your oncologist." p 1925	Unequivocal
Survivors feared that having to repetitively transfer medical records and explain their medical history to various care providers degraded the quality of their care	"I think some things may be slipping through the cracks" p 1925	Credible
complained about communication problems, lack of attention, and lingering questions left unaddressed.	"[W]hen I was going to my gynecologist, it was just difficult to relay what information they actually wanted or if that was something that we needed to look into more."	Credible
lack of coordination between providers regarding patient records and treatment history	"Either there has to be a gigantic education process of general practitioners in the market place about how to work with cancer patients or … look down the	Credible

	survivorship path and how to deal with [it].” p 1925 "I think some things may be slipping through the cracks" p 1925	
complaints included ...perceived insensitivity about patients’ feelings and opinions regarding treatment	“Either there has to be a gigantic education process of general practitioners in the market place about how to work with cancer patients or … look down the survivorship path and how to deal with [it]........The other thing that is hard too is primary care...[Healthcare providers] usually don’t want to deal with you anymore and if it is any little old thing they say you need to go to your oncologist.” p 1925	Credible
Other complaints included ...billing department errors	No illustration identified in the article	Unsupported
Other complaints included ...frequency of visits with mid-level providers rather than physicians.	No illustration identified in the article	Unsupported
preexisting conditions and other confounders caused confusion about attribution of symptoms, making it difficult for survivors to tell if cancer and its treatment, or other issues (i.e., comorbidity or aging), caused their discomfort and health problems	“I am getting to where my back and legs hurt when I stoop to try and get something and then get back up. But I don’t think that mine are cancer related or chemo related as much as if it would have happened if I would have gone through menopause naturally.” p 1925	Unequivocal
Late effects hindered social activity. Decreases in energy and sex drive—and the tension it triggered between spouses and significant others—topped survivors’ list of late effects that must be addressed.	“[I experience] the lack of even wanting even the desire to have sex...Because I am single, it’s a big issue. [M]en take that as a response that I don’t even like them.” p 1927	Unequivocal

Findings for : Urquhart, R. Folkes, A. Babineau, J. Grunfeld, E. - Current Oncology (2012)

Finding	Illustration from Study	Evidence
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of	“Nearly everybody gets depressed.... Nobody told me to expect that.” p 297	Unequivocal

which were largely unmet by their care providers. Physical and psychological needs involved issues related to ...depression		
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ... memory loss	No illustration identified in the article	Unsupported
With respect to self-management, bc and crc survivors both described feeling guilty for contacting professionals about their post-primary treatment concerns	No Illustration identified in the article	Unsupported
many crc survivors frequently reported not seeking professional help for many unmet physical needs (for example, sexual health, bowel function) because they felt they ought to deal with their problems themselves and be content that they were cancer-free	“And then I’m saying, ‘Oh my god, what are you complaining about?’ It could be so much worse and I’m lucky ... but it’s still an adjustment.” p 297....“It’s shocking that you had to be, like, you had to constantly be on alert. You had to be the one seeking people rather than people coming.”—p 297	Credible
Participants frequently discussed communication issues related to language use (for example, medical jargon); ....consistency, currency, and timing of information	No illustration identified in the article	Unsupported
A lack of information on specific areas of follow-up care (for example...nutrition	"[On healthy eating] “You have read it yourself ... you need somebody ... to sit down and explain it to me: ‘You need to eat so many vegetables a day’ because ... of what they do for me and how they help me rebound from cancer." p 297	Unequivocal
Information overload	No Illustration identified in the article	Unsupported
Participants also indicated that tangible information—	"[On healthy eating] “You have read it yourself ... you need somebody ...	Unequivocal

in the form of booklets, brochures, and videos—could not replace a conversation with a real person. Although they valued tangible information, they wanted their care providers to review the information with them to facilitate their understanding and decision-making with respect to the physical and emotional cancer- and treatment-related changes they might experience as cancer survivors.	to sit down and explain it to me: 'You need to eat so many vegetables a day' because ... of what they do for me and how they help me rebound from cancer." p 297	
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to …. late effects of treatment.	"Can you tell me what to expect? Can you tell me, you know, what would be some normal things? ... I'm smart enough to recognise that this is just a guideline, but could you tell me something, because this is all new to me, and I have no idea where to even begin." p 297	Unequivocal
Most participants reported difficulties accessing allied health professionals to help with those needs	No Illustration identified in the article	Unsupported
A high level of need related to returning to work after their cancer diagnosis and treatment	"The transition back to being [in the] office from 9 to 5 is, I found, very difficult because ... I am never going to have the energy that I had before.... I go home, and I go to bed." p 297	Unequivocal
The crc participants with ostomy appliances overwhelmingly discussed needs related to their ostomy. Specific issues raised included body image, sexual health, finding appropriate appliances, caring for the ostomy, and costs associated with purchasing ostomy supplies	"I have more issues with this [ostomy] than with the cancer. It's stupid, but I think it's just, it's a reminder of what I went through. If I had surgery and just a scar and that would have been it, I think it would have been a lot better. So, I'm fighting through this. It's getting better.... It's more up here [mental] than the physical." p 297	Credible
They emphasised that	"I cried because I was abandoned. I	Unequivocal

knowledge of specific tests and investigations is an arduous element of managing your own care, and that one of their most prominent concerns was being unaware of the types and frequency of tests and investigations that are recommended	got used to somebody making my appointments, my tests, and my mammograms ... my family doctor ... he wasn't really that aware of my problems. Who was going to find more cancer? ... Are there tests that I had to look for, for myself?" p 297..."I would like to have like a tracking, like for a courier package, you can go online and see, okay, your test is here ... and this is when you can expect it." p 297	
Many stated they would value having someone "map" their care, or provide them with a tool that would help them to coordinate and track the care they should be receiving	"I would like to have like a tracking, like for a courier package, you can go online and see, okay, your test is here...and this is when you can expect it." p 297	Unequivocal
Participants also wanted information on what could happen and what their needs might be during the follow-up period	"Can you tell me what to expect? Can you tell me, you know, what would be some normal things? ... I'm smart enough to recognise that this is just a guideline, but could you tell me something, because this is all new to me, and I have no idea where to even begin." p 297	Unequivocal
Some participants were uncertain about whether FPS could order or prescribe all of the appropriate tests and investigations for cancer follow up.	"[My family physician is] not a surgeon. That's about the only thing.... As far as my other ailments ... he takes excellent care of me." p 297	Credible
Survivors overwhelmingly described the transition from active treatment to routine follow-up care as a shift in personal responsibility. That is, they moved from having the oncologist manage their care and treatment ("doing nothing") to taking responsibility for their cancer-related care ("doing everything"). The shift in responsibility often led to feelings of distress and abandonment after the	"I cried because I was abandoned. I got used to somebody making my appointments, my tests, and my mammograms ... my family doctor ... he wasn't really that aware of my problems. Who was going to find more cancer? ... Are there tests that I had to look for, for myself?" p 297	Unequivocal

completion of primary treatment.		
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ...sexual health	“The radiation messed me up. Basically, I’m probably one step away from Viagra. The sex drive just isn’t there.” p 297	Unequivocal
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to exercise.	No illustration identified in the article	Unsupported
A lack of information on specific areas of follow-up care (for example, ...psychological well-being).	“I cried because I was abandoned. I got used to somebody making my appointments, my tests, and my mammograms ... my family doctor ... he wasn’t really that aware of my problems. Who was going to find more cancer? ... Are there tests that I had to look for, for myself?” p 297	Credible
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to... nutrition.	"[On healthy eating] “You have read it yourself ... you need somebody ... to sit down and explain it to me: ‘You need to eat so many vegetables a day’ because ... of what they do for me and how they help me rebound from cancer.” p 297	Credible
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ... weight	No illustration identified in the article	Unsupported

management.		
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ... persistent fatigue	“The transition back to being [in the] office from 9 to 5 is, I found, very difficult because ... I am never going to have the energy that I had before.... I go home, and I go to bed.” p 297	Credible
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ...lymphedema	No illustration identified in the article	Unsupported
Physical and psychological needs involved issues related to ...bowel function	“I have more issues with this [ostomy] than with the cancer. It’s stupid, but I think it’s just, it’s a reminder of what I went through. If I had surgery and just a scar and that would have been it, I think it would have been a lot better. So, I’m fighting through this. It’s getting better.... It’s more up here [mental] than the physical.” p 297	Unequivocal
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to ...pain	No illustration identified in the article	Unsupported
Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological	No illustration identified in the article	Unsupported

needs involved issues related to ...sleep		
participants wanted their care providers to be personable	No illustration identified in the article	Unsupported
they particularly valued having someone to talk to who had gone through similar experiences	"When you speak to someone who has had [cancer], they understand. To talk to someone who hasn't had the experience, they don't know what you're talking about.... They haven't been through it." p 297	Unequivocal
Although survivors valued participation by their fp in follow-up care, many continued to want specialist-led care.	"[My family physician is] not a surgeon. That's about the only thing.... As far as my other ailments ... he takes excellent care of me." p 297	Credible
crc survivors frequently discussed the fp role as one that ought to work in conjunction with the roles of other care professionals.	"My assumption is that [my family physician] is knowledgeable to know enough about what I'll be going through. If not, she will put the referral in to another doctor anyway."p 297	Credible
others viewed fp-led care as an obstacle to quick access to cancer care services.	"If something happened, I would feel like I could get in. That's my sense, and I don't even think about it, but just the fact that I, like, if I have to go through my family doctor, it would take longer because I would be out of the system." p 297	Unequivocal
Only 2 crc participants explicitly expressed concerns about staying within the cancer system.	No illustration identified in the article	Unsupported
Some participants were uncertain about whether FPS could order or prescribe all of the appropriate tests and investigations for cancer follow up.	"[My family physician is] not a surgeon. That's about the only thing.... As far as my other ailments ... he takes excellent care of me." p 297	Credible

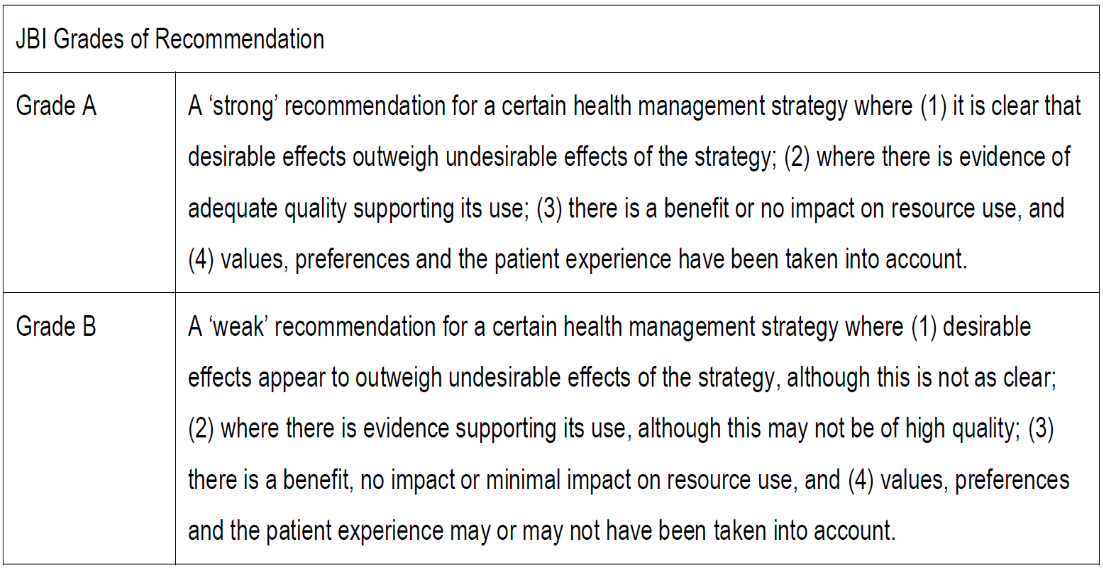
Findings for : Burns, M. Costello, J. Ryan-Woolley, B. Davidson, S. - European Journal of Cancer Care (2007)

Finding	Illustration from Study	Evidence
women felt that there was an inadequate provision of information about treatment	"No, no. But I wish they had of done because having sex is the main issue as well. If someone would have said	Unequivocal

effects...concerning the possible late effects of treatment, including information about the possible impact on sexuality	to me at the beginning or the end of the treatment OK everything looks fine, it shouldn't affect your sexual activities then I'd be fine but nothing like that is ever mentioned." p 369	
Issues raised by women centred on ... the timing of information giving...	"If someone would have said to me at the beginning or the end of the treatment OK everything looks fine, it shouldn't affect your sexual activities then I'd be fine but nothing like that is ever mentioned." p 369	Unequivocal
there was an inadequate provision of information about treatment effects	"To tell me perhaps what the complications are, what the treatment can do .... I had none of that, there was nothing about it." p369	Unequivocal
the timing and pace of information was often limited before and at follow-up outpatient consultations after treatment	"You see at the clinic you're concerned with the patients that are coming in and out and there's that many, you don't want to take too much time with the doctor because there's a lot of people there coming and going " p 368	Unequivocal
Most women with a partner stated that they would like sexuality to be discussed at follow-up appointments	"At the moment, I've no inclination that way (for sexual activity) what so ever, it can put a strain on your marriage because obviously your husband is still wanting to be sexually active when you don't want to be. So it can be a problem. Well it can be a big problem." p 368	Credible
The hospital environment was not conducive to information giving, particularly about sexuality.	"You see at the clinic you're concerned with the patients that are coming in and out and there's that many, you don't want to take too much time with the doctor because there's a lot of people there coming and going and those little rooms are not exactly made for talking." p 368	Credible
a number of information needs were unmet, ...information about long-term effects of treatment on bladder and bowel function	"To tell me perhaps what the complications are, what the treatment can do .... I had none of that, there was nothing about it." p369	Credible
a number of information needs were unmet, prompting the question of what type of information patients wanted......further knowledge about the effects of treatment on sexuality	"To tell me perhaps what the complications are, what the treatment can do and what you can and can't do, sexual activities or physical activities. I had none of that, there was nothing about it." p 369	Unequivocal

the lack of time available for discussion	"You see at the clinic you're concerned with the patients that are coming in and out and there's that many, you don't want to take too much time with the doctor because there's a lot of people there coming and going and those little rooms are not exactly made for talking." p 369	Unequivocal

Appendix VIII: JBI Grades of Recommendation



JBI Grades of Recommendation	
Grade A	A ‘strong’ recommendation for a certain health management strategy where (1) it is clear that desirable effects outweigh undesirable effects of the strategy; (2) where there is evidence of adequate quality supporting its use; (3) there is a benefit or no impact on resource use, and (4) values, preferences and the patient experience have been taken into account.
Grade B	A ‘weak’ recommendation for a certain health management strategy where (1) desirable effects appear to outweigh undesirable effects of the strategy, although this is not as clear; (2) where there is evidence supporting its use, although this may not be of high quality; (3) there is a benefit, no impact or minimal impact on resource use, and (4) values, preferences and the patient experience may or may not have been taken into account.