Cancer and identity: An exploration of people's understanding of cancer identities and their mass media representations

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KEY TO ABBREVIATIONS

ACS   American Cancer Society

AIHW   The Australian Institute of Health and Welfare

FIT   Faecal immunochemical test

GBD   Global Burden of Disease

GP   General practitioner

IARC   International Agency for Research on Cancer

NCI   National Cancer Institute (The United States of America[1])

NCCS   National Coalition for Cancer Survivorship (The United States of

                America[1])

NGO   Non-government organisation

PBS   Pharmaceutical Benefits Scheme (Australia[1])

SCS   Singapore Cancer Society

USA   The United States of America

[1]The country is specified for organisations whose country affiliation is not obvious from their names.

ABSTRACT

With the increasing length of cancer survivorship, a rising number of clinicians and researchers are turning their focus to the long-term outcomes or side effects of cancer and its treatments, including the impact on an individual's identity – which is defined as an individual's self-construal that is inclusive of how one construes oneself in the present, past and future (Weinreich, 2003). The aims of the research project presented in this thesis were (1) to examine the understandings of individuals with cancer and the community for cancer identities (and in particular the "survivor" identity); and (2) to investigate media representations of individuals diagnosed with cancer that may not only affect the formation of cancer identities in these individuals, but also influence public perceptions and policies. To address these aims, four independent but related studies were conducted.

Study 1 addressed the first aim through a systematic review of 24 independent studies, consolidating the current literature about the understanding and endorsement of various cancer identities, in particular the "cancer survivor" identity, in individuals diagnosed with cancer. Analysis of these studies revealed that though "cancer survivor" is a widely accepted term, not everyone diagnosed with the disease would take on the label.

Study 2 presented the findings of an online survey that examined lay understandings of cancer identities and survivorship in a sample of 263 crowdsourced adult residents of United States of America (USA) who self-reported not having been diagnosed with cancer. The term "cancer survivor" was mostly viewed as an individual who has beaten cancer, is cancer-free and/or is in remission, an understanding resembling that of individuals diagnosed with cancer rather than reflecting the views of health professionals. Only 57.4% of the respondents considered someone

who is 5 years in remission to be a "cancer survivor" and some felt that the term was unnecessary or unhelpful.

Study 3 addressed the second aim in a sample of Australian print newspapers published in 2015; Study 4 explored the possibility of cultural differences whereby the Australian study was replicated, using a selection of Singaporean newspapers, which allowed for cross-national cultural comparisons. In both countries, certain cancers were over-represented in the media whereas others were under-reported. The most common portrayal of an individual diagnosed with cancer was that of a female adult under the age of 50 and diagnosed with breast cancer. Although psychosocial issues were the second most frequently mentioned sequelae of cancer, cancer identity issues were not as frequently reported ($n = 9$ [Australia]; $n = 2$ [Singapore]). In line with the findings of Study 1, individuals with a cancer diagnosis reported having a lack of cancer identity or refusing to consider the cancer experience as being central to their lives. The "cancer survivor" identity was mostly used by journalists to describe people who have finished treatment, have survived cancer, or are in remission, and also used to describe those who are carrying out cancer-related activities such as fundraising or advocating for better care of those currently undergoing treatment. As hypothesised, Singaporean newspapers had significantly more human interest stories than Australian newspapers, possibly reflecting the greater collectivism of Singaporean culture.

In conclusion, this research project highlighted the different understanding of cancer identities within two different populations (individuals with cancer and lay people), an understanding that was reflected in the media studies but not shared by advocacy groups or policymakers. With the term "cancer survivor" being shown not to be endorsed by everyone diagnosed with cancer, the various sectors involved in cancer care should take caution when using it – or use alternative terms that are more sensitive and acceptable. The mismatches between print media depictions of cancer and the actual statistics, and the under- or over-representation of certain

cancers, demonstrated the need for accurate dissemination of information from researchers and health professionals to the public when using the media. Future research conducted in non-English speaking countries will be helpful to extend the current findings, because they might have a different understanding for the term "cancer survivor" and/or use other more culturally-accepted terms, and the way cancer and the individuals diagnosed with it are presented in the media will give an indication of public perceptions in those countries.

DECLARATION

I, Sze Yan Cheung, 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.

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Sze Yan Cheung

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CHAPTER 1: PREFACE

Cancer is a general name for more than 100 related non-communicable diseases involving a variety of malignant tumours characterised by limitless cell division capacity (Hanahan & Weinberg, 2000; National Cancer Institute [NCI], 2015) . They are able to spread or metastasize to other parts of the body because they can sustain proliferative signalling while evading growth suppressors, avoiding programmed cell death (apoptosis), and sustaining formation of new blood vessels (angiogenesis; Hanahan & Weinberg, 2000).

Although cancer remains a leading cause of morbidity and mortality worldwide (International Agency for Research on Cancer [IARC] , 2014) survival rates have increased in recent decades due to advances in screening, early diagnosis and more effective treatments (Rowland, 2008; Saracci & Wild, 2015). A cancer diagnosis is no longer considered an automatic death warrant (Bellizzi & Blank, 2007). Hence, there is increasing attention from clinicians and researchers to the long-term outcomes or side effects of cancer and its treatments, including the longer-term impact on an individual's identity.

In 1985, Mullan first suggested the usage of the term "survivor" as a replacement for the terms "sickness" and "cure", proposing that an individual becomes a survivor at the point of a cancer diagnosis when he or she has to rethink about life and make adjustments to it. Since then, this term has been embraced by the mass media and advocacy groups, and in more recent years, by researchers and policymakers and has often replaced negatively-connoted terms like "victim" and "patient" to encourage empowerment (Bellizzi & Blank, 2007). There is some evidence that the extent to which the cancer experience has been integrated into an individual's identity – which is defined as an individual's self-construal that is inclusive of how one construes oneself in the present, past and future (Weinreich, 2003) – can affect psychological well-being. For example, Deimling and colleagues (2007) found that early adoption of a "cancer survivor" identity was significantly related

to lower levels of anxiety and depression. However, despite widespread usage of the term "cancer survivor", not everyone who has been diagnosed with cancer identifies with it, and some feel that the term is inappropriate or even offensive (Kaiser, 2008; Khan, Harrison, Rose, Ward, & Evans, 2012; McGrath & Holewa, 2012). In addition, there has been a lack of consensus regarding how the term "survivor" should be defined and much debate revolving around its usage (Bell & Ristovski-Slijepcevic, 2013; Khan, Rose, & Evans, 2012). To understand this term and its potential impact, there is a need to extend the current internal debates between health professionals and agencies by listening to and incorporating the perceptions and values of individuals diagnosed with cancer, their significant others and the community.

The mass media is a persuasive force, shaping both public opinions and public policies (McCombs, 2002; Soroka, Lawlor, Farnsworth, & Young, 2012). Other fields of research have consistently shown that the media plays a role in shaping identity, one of the most prominent examples being the influence of conventional media images of "thin-ideal" models and celebrities (Bessenoff, 2006; Irving, 1990; Stice & Shaw, 1994). In modern cancer discourse, popular magazines and advocacy groups have most often focussed on individuals with inspiring and almost heroic experiences and outcomes, not necessarily shared by everyone with a cancer diagnosis. As a result , some individuals with cancer diagnoses may choose not to adopt the identity of "cancer survivor" because the prominent images portrayed within the media do not appear to represent them, or because "survivor" does not fit with their prognosis (Gubar, 2012). Importantly, the health communication literature has shown that health outcomes can be affected by the quality of communication between an individual and the doctor (Ong, et al., 1995). If health professionals choose to use cancer identity terminology such as "survivor" that has the potential to be either rejected or misinterpreted by patients, it may lead to miscommunication and lack of rapport, and patients becoming less engaged with their treatment teams and plans.

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Furthermore, inaccurate media portrayals of cancer, its treatments, and the individuals diagnosed with it can potentially influence news consumers to form inaccurate perceptions. For example, an American study found that media representations of the various cancers were not only related to public perceptions of cancer and its incidence rates, but also the government's amount of funding for those cancers (Jensen et al., 2014). In Australia, for example, media coverage of Kylie Minogue's (an Australian singer) cancer diagnosis at age 36 led to an increase in mammography screenings in Australian women who were not within the at-risk age bracket (i.e. 50 – 65 years of age; S. Chapman, McLeod, Wakefield, & Holding, 2005).

Content analytic research has revealed that certain cancers (e.g. breast cancer) are very likely to be reported by the mass media whereas others are under-reported (MacKenzie, Chapman, Johnson, McGeechan, & Holding, 2008; Williamson, Jones, & Hocken, 2011). Moreover, media reporting has been shown to be misleading at times, either by reporting inaccurate statistics or depicting individuals who were not necessarily representative of the population being discussed (Jones, 2004; MacKenzie, Chapman, Barratt, & Holding, 2007; MacKenzie, Chapman, Holding, & McGeechan, 2007; MacKenzie, Chapman, Holding, & Stiven, 2010). Therefore, there is a need to disseminate accurate cancer information to reduce possible confusion around the disease, to ensure that health services are correctly utilised, and to correct negative attitudes towards individuals diagnosed with cancer.

The aims of the research project presented in this thesis were (1) to examine the understandings of individuals with cancer and the community about cancer identities (and in particular the "survivor" identity); and (2) to investigate media representations of individuals diagnosed with cancer, which might not only affect the formation of cancer identities in these individuals, but also influence public perceptions and policies.

A review of the literature on cancer and survivorship is presented in Chapter 2. Various impacts of cancer and its treatments are outlined, followed by a discussion of several identity theories. Next, identity issues faced by individuals diagnosed with cancer are examined in greater detail. The influence of the mass media on the understanding of a particular disease and those diagnosed with it is then discussed alongside communication theories. Finally, previous cancer-related media research is presented.

The understanding of cancer identities, in particular the "cancer survivor" identity, in individuals diagnosed with cancer is examined in Chapter 3 (Study 1), a published systematic review of 24 independent studies mostly conducted in North America. This study also looked into how broadly the "cancer survivor" identity was accepted by individuals diagnosed with cancer, and reviewed the current findings about the factors that played a role in identifying with this cancer identity and the outcomes of these choices.

Chapter 4 explores lay understandings of cancer identities and survivorship (Study 2 – under review). An online survey was completed by 263 crowdsourced adult residents of United States of America (USA) who self-reported not having been diagnosed with cancer. This study asked the participants to choose a suitable cancer identity to describe an individual at different stages of the cancer trajectory, and to describe their understanding of the terms "cancer survivor" and "cancer survivorship".

The findings of Studies 1 and 2 highlighted the different understanding of cancer identities within these different populations (individuals with cancer and lay people), supporting the need for better communication between stakeholders within the cancer care sector and the community. Being considered trustworthy sources of information, the mass media is influential in shaping public opinion and their outputs could explain the differing opinions (between experts and lay people)

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regarding cancer identities and survivorship. Although past research has looked into the coverage of cancer in the media, the usage of terms associated with cancer identity has not been explored.

Chapter 5 reports Study 3, in which this issue was addressed by examining the coverage of cancer, the dominant imagery of an individual diagnosed with cancer, and the usage of terms associated with cancer identity in a sample of Australian print newspapers in 2015. In Study 4, which is reported in Chapter 6, the Australian study was replicated using a selection of Singaporean newspapers also in 2015, providing the opportunity for cross-national and cultural comparisons.

The findings of Studies 3 and 4 provided an indication of current public perceptions of cancer and individuals diagnosed with cancer, in two nations outside the USA. By highlighting mismatches between print media depictions of cancer, and the actual statistics, these studies highlighted the need for accurate dissemination of information from researchers and health professionals to the public with the assistance of the media. Print (and other) media are a source of potential misunderstandings with regard to cancer and cancer identities. However, they also provide a platform for health professionals and policymakers to develop and deliver programs to correct inaccurate public perceptions and explain terminology.

The findings and implications of all four studies are summarised and discussed in Chapter 7. Taken together, the above findings contribute to a better understanding of (a) how cancer identities can arise, change or be maintained after a cancer diagnosis and, (b) current print media depictions of cancer and cancer identities in Australia and Singapore – potentially impacting identity, treatment and even survival.

The references for all chapters can be found in the section "References". Supplementary material used for this research project are provided at the end of this thesis.

CHAPTER 2: INTRODUCTION

2.1 Preamble

As mentioned in the previous chapter, cancer is a leading cause of morbidity and mortality worldwide (International Agency for Research on Cancer [IARC], 2014) . However, due to improvements in cancer detection and more effective treatments, patients' survival rates have greatly increased over the years (Rowland, 2008; Saracci & Wild, 2015). This results in a shift towards viewing cancer, not as a death sentence, but instead as a chronic illness (Bellizzi & Blank, 2007). Hence, in the last two decades, researchers have started to focus on the other concerns which people have after a cancer diagnosis, including: their quality of life; the long term side effects of treatments; and, changes to an individual's identity at and beyond the period when their cancer is diagnosed and treated.

The current chapter is a literature review of the field, commencing with a discussion of the epidemiology of cancer. The healthcare systems of the two countries examined in the media studies (Australia and Singapore) are then briefly outlined. The several models of cancer survivorship are also presented, followed by a brief introduction to the impacts of cancer on physical, cognitive, financial and psychosocial functioning. Next, identity issues faced by individuals diagnosed with cancer are examined in greater detail. The influence of the mass media on the understanding of a particular disease and the people diagnosed with it is then discussed, alongside communication theories. Previous cancer-related media research is presented before the chapter concludes with a summary, explaining the importance in studying identity in the context of this chronic condition and presenting the specific aims of this research project.

2.2 Epidemiology

In 2013, there were 14.9 million new cancer cases and 8.2 million cancer deaths reported worldwide (Global Burden of Disease Cancer Collaboration, 2015). Although changes in lifestyle may lead to the prevention of at least one third of all cancer cases (Whiteman et al., 2015), the number

of new cases is still expected to increase by 75% to 25 million over the next two decades (IARC, 2014) . In Australia, it is estimated that 1 in 2 males and 1 in 3 females will be diagnosed with cancer by the age of 85, with an estimated number of 130,466 new cancer cases being diagnosed in 2016 (Cancer Australia, n.d.-a). An estimated number of 1,685,210 new cancer cases is expected to be diagnosed in 2016 in United States of America (USA; American Cancer Society [ACS], 2016) and the estimated figure for Singapore in 2012 was 15,693 (IARC, n.d.) . The 5-year relative survival rate for all cancers combined was 68% in Australia (from 2009 to 2013; Australian Institute of Health and Welfare [AIHW], 2017) , 69% in America (for cancers diagnosed during 2005-2011; ACS, 2016) , and 48.5% for males and 57.1% for females in Singapore (from 2008-2012; Singapore Cancer Registry, 2015b).

2.3 Healthcare systems

Most developed countries have some form of specialised healthcare systems in place for the treatment of cancer. For the purpose of this research project, the healthcare systems of Australia and Singapore are briefly introduced in this section.

2.3.1   Australia

Australia has a national health insurance scheme, Medicare, which provides basic medical care for all Australians and permanent residents, including public hospital admissions and visits to local doctors (i.e. general practitioners, or GPs; AIHW, 2016a) . Medicare assists with other health expenses incurred through out-of-hospital services (e.g. blood tests, scans, allied health services). Management and delivery of the health care system is divided between the three levels of Australian government: federal, state and territory, and local. The first two levels fund public hospitals, which are managed by the state and territory governments. Together, federal and state governments also fund and deliver a range of other health services, such as health and medical research and population health programmes (e.g. cancer screening programs). The local governments provide

community-based health and home care services. Non-government organisations (NGO) and charitable foundations also contribute significantly to cancer research and treatment, and the support of individuals diagnosed with cancer.

Primary healthcare services are delivered through a variety of settings, for example, government-funded community health centres, Aboriginal Community Controlled Health Services and GPs in the private sector. In 2013-14, there were 1359 hospitals (747 public hospitals; 612 private hospitals; AIHW, 2016a) . Specialised treatment centres for cancer exist within a number of hospitals, and Peter MacCallum Cancer Centre is the only Australian hospital dedicated solely to care for people with a cancer diagnosis. Publicly-funded screening programs include the following screening programs: (a) BreastScreen Australia with women aged 50-74 being offered a free mammogram every two years; (b) National Bowel Cancer Screening Program, in which a free bowel cancer screening kit is sent to Australians at regular intervals between ages 50 to 74; and (c) National Cervical Screening program that promotes routine screening with Pap smears for all women aged between 18 (or two years after their first sexual intercourse, whichever is later) and 69. Awareness programs are also held throughout the year, for example, the Ovarian Cancer Awareness Month in February and the Pancreatic Cancer Awareness Month in November.

The federal government subsidises the cost to patients of certain drugs used in cancer treatment (e.g. trametinib, trastuzumab) under the Pharmaceutical Benefits Scheme (PBS; Australian Government The Department of Health, 2015). The Medicare Safety Net and PBS Safety Net are in place to provide further subsidies for out-of-hospital costs and prescription medicine respectively once an individual has spent over a certain amount. Australians can also sign up for private health insurance, which is subsidised by the taxpayer; the amount that the insurance company would pay depends on the policy bought.

Cancer support organisations across Australia also provide support to individuals diagnosed with cancer. The Cancer Council of Australia is the peak national cancer control NGO, providing advice on practices and policies regarding cancer control and advocating for people affected by cancer. Cancer Councils in each state and territory organise programs and campaign for cancer control, provide information and support for people affected by cancer, and fund and carry out cancer research. There are other NGOs, such as Cancer Voices Australia (a consumer advocacy organisation, representing people who have been diagnosed by cancer and ensuring that they are heard at the national level), CanTeen (a support organisation for young people between the ages of 12 to 25 set up to meet the unique needs of youths diagnosed with cancer), and other not-for-profit organisations dedicated to caring for the people affected by a particular type of cancer (e.g. Myeloma Foundation Australia, Breast Cancer Network Australia).

2.3.2   Singapore

Singapore offers universal health coverage to all citizens and permanent residents through government subsidies and a multi-tiered financing scheme. The government subsidies up to 80% of the cost of treatment at public healthcare institutions. Primary healthcare services are predominantly provided by general practitioners (GPs) in 18 government polyclinics and about 1500 private medical clinics (Ministry of Health Singapore, 2015). These GPs are often the first point of contact and provide referrals to specialists and hospitals for more specialised treatment. There are a total of 26 hospitals and speciality centres. Within the public sector, the National Cancer Centre Singapore offers specialised services, focussing on the various types of cancer whereas the Children's Cancer Centre at the KK Women's and Children's Hospital provides paediatric cancer-related services. It should be noted that although Western medicine dominates the medical field in Singapore, traditional medicine practitioners are also consulted by the population. Publicly-funded screening programs include the following screening programs: (a) colorectal cancer, with Singaporeans and permanent residents who are 50 years and above being recommended to collect a

free faecal immunochemical test (FIT) kit anytime during the year; (b) breast cancer, with Singaporeans and permanent residents who are 50 years and above and have not had a mammogram done in the last 24 months being eligible for a $25 funding assistance anytime during the year; (c) gynaecological cancers, with free Pap smears being offered from May to August to Singaporeans and permanent residents between the ages of 25 and 69 who have not had a Pap smear for the last 3 years. Awareness programs are also held throughout the year, for example, colorectal cancer in March and gastric cancer in August.

For individuals diagnosed with cancer, certain cancer drugs (e.g. doxorubicin, cyclophosphamide) are government-subsidised. They can also draw upon (a) Medisave, a national medical savings scheme with each individual contributing a percentage of the income to meet their future personal or immediate family's medical expenses; (b) Medishield Life, a basic catastrophic health insurance plan provided by the government to pay for medical expenses for major or prolonged illnesses; and/or (c) private health insurance, to pay for cancer-related healthcare services such as cancer screening tests, diagnostics, chemotherapy, radiotherapy and surgeries. If a patient still faces financial difficulties after receiving subsidies and from using Medisave and Medishield, the government provides an endowment fund through Medifund.

Support is also provided through a number of cancer charities, one of which is the Singapore Cancer Society (SCS), a voluntary welfare organisation that organises programmes to raise public awareness and assists people who have been diagnosed with cancer during and after their treatment. Examples of support provided by SCS are counselling services, tuition programmes to help children and youth with academic difficulties and various financial assistance schemes to help with medical bills and out-of-pocket expenditure (e.g. diapers, medical dressings). SCS is also a co-organiser of several fund-raising events, such as Relay for Life and Race Against Cancer. Recently, Singapore's first community-based cancer rehabilitation centre, the Singapore Cancer Society

Rehabilitation Centre, was opened in November 2015 to provide specialised programmes to address the needs of both the individual diagnosed and the caregiver, such as fatigue management, cancer support groups, caregivers training and Return-To-Work programme (Grosse, 2016) .

2.4   Cancer survivorship

2.4.1   Cancer and its sequelae

Even when an individual is declared cancer free by his or her doctor, he or she is still not free from the consequential effects of cancer and its treatments. A full review of these effects is beyond the scope of this chapter and has been previously discussed elsewhere (Alfano & Rowland, 2006; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Stein, Syrjala, & Andrykowski, 2008). In the section immediately below, the more common effects are briefly described, with the specific psychological impact of cancer on identity and self-concept being discussed in greater detail in the following section.

Cognitive and physical impact of cancer and cancer treatments

A range of cognitive impairments, including impaired memory and poorer executive function, have been reported as a result of chemotherapy (Anderson-Hanley, Sherman, Riggs, Agocha, & Compas, 2003; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005) with recent evidence indicating that chemotherapy has affected the integrity of cerebral white matter (Deprez et al., 2012). These impairments particularly affect individuals who return to work after cancer treatment and can result in being passed over for promotion or taking early retirement (Boykoff, Moieni, & Subramanian, 2009).

Physical effects of cancer and its treatment sometimes influence an individual's body image and self-concept, thus potentially impacting on identity (as discussed in Section 2.3.2). Although

some physical side-effects such as hair loss or weight changes may be of short duration, research has shown that resolving these physical issues do not always result in the return of a normal body image (Munstedt, Manthey, Sachsse, & Vahrson, 1997). On the other hand, a prospective one-year follow-up study (Wilkins et al., 2000) revealed that successful corrective actions such as breast reconstruction could improve body image. Longer-term impacts include sexual dysfunction (e.g. erectile dysfunction in men, pain experienced during sexual activity in women) and infertility, which may contribute to problems associated with relationships and changes in one's perception of gender identity (Cecil, McCaughan, & Parahoo, 2010; Schover, 2005).

Examples of other physical effects include cancer-related fatigue (Barnes & Bruera, 2002; Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007) and sleep disturbances (Davidson, MacLean, Brundage, & Schulze, 2002; Mercadante, Girelli, & Casuccio, 2004). The above-mentioned effects are debilitating and distressing and can lead to poorer mental health which can also in turn limit daily functioning and the performance of daily activities (Fobair et al., 2006; Hofman et al., 2007).

Economic impact

Findings have generally not been consistent in relation to the reported financial burden of cancer and this is possibly due to differences in annual household income among the American participants and the different sampling strategies used within the two quantitative studies identified in our search. Fenn and colleagues (2014) reported that 8.6% thought they had many financial problems resulting from a cancer diagnosis whereas in the study conducted by Zafar and colleagues (2013), 42% of participants reported a significant or catastrophic financial burden. Participants who reported cancer to have caused them many financial problems were less likely to consider themselves having a good quality of life (Fenn et al., 2014). It was concerning that in the Zafar et al. study (2013), some individuals spent less money on food and clothing, used their savings for out-of-

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pocket health care costs, took less than the prescribed amount of medication, or avoided

procedures in order to reduce costs – which could potentially reduce their chances of survival and

quality of life. In addition, as mentioned earlier, some individuals might not be able to perform their

jobs the same way as before cancer, resulting in reduced earning power and shorter careers (Boykoff

et al., 2009; P. Kim, 2007).

Psychosocial impact

Cancer-related worries, such as fear of recurrence (Fardell et al., 2016), have been shown to

persist beyond five years in remission and are associated with poorer quality of life, poorer

psychological well-being and psychological disorders (e.g. depression, anxiety) (Deimling, Bowman,

Sterns, Wagner, & Kahana, 2006; Koch, Jansen, Brenner, & Arndt, 2013). Moreover, previous

research has indicated that almost 40% of individuals diagnosed with cancer will experience

significant psychological symptoms, with its prevalence varying depending on the cancer site

(Carlson et al., 2004; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Amongst

these people, a substantial number would require clinical attention, but because of differences in

methodology, prevalence rates for psychological disorders vary across studies (Akechi et al., 2001;

Derogatis et al., 1983; Harter et al., 2001; Mitchell et al., 2011; Singer, Das-Munshi, & Brahler, 2010).

At the same time, it is demonstrated and acknowledged in the literature that cancer can

sometimes have positive impacts on an individual (Bellizzi et al., 2012; Casellas-Grau, Vives, Font, &

Ochoa, 2016), especially in the area of post-traumatic growth and benefit finding (Mols, Vingerhoets,

Coebergh, & van de Poll-Franse, 2009; Schulz & Mohamed, 2004). Some individuals diagnosed with

cancer have reported positive phenomena including increased appreciation of life (Lelorain,

Bonnaud-Antignac, & Florin, 2010), discovery of inner strength (Lelorain et al., 2010), improved

relationships with their partners or families (Dorval et al., 2005), and spiritual growth (Denney, Aten,

& Leavell, 2011).

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2.4.2 Cancer and identity

According to Weinreich (2003, p. 80), identity is defined as "the totality of one's self-construal, in which how one construes oneself in the present expresses the continuity between how one construes oneself as one was in the past and how one construes oneself as one aspires to be in the future". A similar broad and inclusive logic is implicit in Brown's Identity Disruption Model which proposes that identity although central is not stable; certain life events have the capacity to disrupt an individual's identity whereby the individual will (a) discard the current identity, (b) adopt a new identity, 3) have other identities becoming more prominent, or (c) re-evaluate pre-existing identities , and these disruptions can cause or exacerbate health impairment (Brown & McGill, 1989). In a similar vein, Burke (1991, 1996) presented a model, Identity Interruption Theory, that is based on Mandler's (1982) overload concept. It describes how distress results from an interruption of the feedback loop that maintains identity and in turn causes changes in the identity of an individual.

An example of an interruption or life event that can cause changes in a person's identity is a cancer diagnosis. As mentioned in the previous section, cancer is a life-changing event, potentially affecting all aspects of an individual's life and functioning, such that the effects of cancer and its treatments often persist until the end of the person's life. An individual will, therefore, have to negotiate through the "same" world but perhaps as a different person, to the extent that they have been changed by their cancer experiences. Often, these individuals will experience an identity crisis because their "valued attributes, physical functions, social roles, and personal pursuits" have now been affected by cancer (Charmaz, 1994, p. 269). This may lead to the development of a new identity or the reformulation of a current identity (Zebrack, 2000), a coping strategy that may, in turn, affect the trajectory of the illness. According to Little and colleagues (2002), an individual's

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existing identity can be either: reconstructed (an old identity changing to accommodate the cancer experience and its sequelae); incorporated (an old identity being developed and expanded by the cancer experience and its sequelae); imbued with meaning (addition of new components to an old identity due to cancer experience and its sequelae); or alienated (loss of an old identity due to the cancer experience and its sequelae). Due to the different challenges faced during different phases of the cancer trajectory, it should be noted that an illness identity is dynamic, constantly changing as an individual encounters new cancer-related experiences (Little, Paul, Jordens, & Sayers, 2002).

In recent years, researchers have tried to quantify the extent that cancer becomes integrated into an individual's identity by measuring cancer centrality (Helgeson, 2011). In a quantitative study of 240 women diagnosed with breast cancer (M [years since diagnosis] = 10.58), they were found to have a moderate level of cancer centrality (Helgeson, 2011). Those who scored higher on cancer centrality were more likely to think that they had benefited from cancer, and also more likely to consider breast cancer as the most stressful event in their lives so far. When these women viewed cancer negatively, they were also more likely to report negative affect, poorer mental functioning and greater distress. A similar study conducted by Park and colleagues (2011) among young to middle-aged adults who had finished their cancer treatment two years earlier, found that overall, illness centrality was low. A higher level of cancer centrality was associated with poorer psychological well-being similar to the previous study, but it was not associated with post-traumatic growth. The results from these studies may have differed due to the different populations sampled and the different type of measures used to access cancer centrality. Accordingly, there is a need for a standardised measure of cancer centrality before more studies can be conducted in this area. However, this is beyond the scope of this research project so future studies should look into developing a standardised measure of cancer centrality.

Specific Identity Types

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Both qualitative and quantitative research conducted in the field of cancer and identity has revealed that different aspects of one's identity can be affected by cancer. In this section, the impact on social identity and gender identity is discussed.

Social identity

Group identification is demonstrated when an individual considers group membership to be an important aspect of the self, is proud of membership, and engages in actions or activities that are in line with this group membership (Harwood & Sparks, 2003). It is important to examine group memberships for two reasons. Firstly, positive and negative consequences may result from identifying with a group; for example, one might be more willing to pay attention to health behaviours and comply with treatment plans, but also feel a sense of loss of control. Secondly, stereotypes held by members of a certain group may influence their cancer-related outcomes.

Deimling and colleagues (1997) proposed four social identities that individuals with cancer could identify with, namely: survivor, victim, patient, and, ex-patient. In this section, these cancer identities, together with more recently popular identities (conqueror, someone who has/has had cancer), are discussed.

The word "survivor" is derived from the Anglo-French word "survivre" that meant to outlive and the Latin word "supervivre" that meant to live more (Merriam Webster, n.d.). Historically, this term has often been associated with living through extreme circumstances, for example, natural disasters or the Holocaust (K.D. Miller, 2010). As mentioned in an earlier section, it was first proposed in the cancer context by Mullan (1985) who felt that the words "cure" and "sickness" were inadequate to describe the cancer experience. Together with other people diagnosed with cancer, Mullan founded the first survivor-led advocacy organisation, the National Coalition for Cancer Survivorship (NCCS), which embraced the term from its inception to describe affected individuals

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and, because cancer is a relational illness, the organisation further extended the definition to include

caregivers, family members and friends (Kayser, Watson, & Andrade, 2007; NCCS, 2014) . However,

much controversy surrounds the usage of the term "survivor". Although this supposedly more

empowering term has been embraced worldwide, not everyone who has been diagnosed with

cancer has identified with it, and whether they choose to embrace this term or not may depend on

how they interpret it (Bellizzi & Blank, 2007; Kelly, Shah, Shedlosky-Shoemaker, Porter, & Agnese,

2011; Khan, Harrison, et al., 2012). As reported in these studies, some individuals diagnosed with

cancer felt that "survivor" was an accurate representation of their cancer experience; others

rejected being identified as a cancer survivor because it obscured their other achievements, or

because the term denied respect to those who had died from cancer. Moreover, these studies

revealed that some individuals had actively rejected this label and adopted alternative terminology,

such as "someone who has had cancer" and "conqueror".

In addition, due to inherent tensions in finding a definition that will fit all purposes from

service development to self-identification, policymakers and researchers in the field have variously

defined the term "survivor" based on their own professional interests. Medical and other health

practitioners have been more reluctant to use the term, however, because it may be taken to imply

that an individual can be or has been cured, when there is always a possibility of cancer recurrence

and the need for future tests or treatment (Bell & Ristovski-Slijepcevic, 2013; Deimling, Kahana, &

Schumacher, 1997; Sulik, 2013). Surbone and Tralongo (2016) highlighted the need for an

operational definition due to a heterogeneous group of individuals being grouped together under

the umbrella of cancer survivors when they have different medical needs and concerns. They argued

for awareness of the previously mentioned implications of this label, and against utilising it only

because it is convenient for the purposes of communication, cancer management and survivorship

care delivery (Surbone & Tralongo, 2016). They also suggested that the lack of proper distinction

within this huge group of "cancer survivors" would lead to poor communication, lowered patient

adherence and decreased effectiveness of survivorship care. Moreover, due to the positive notions of strength and hope being associated with "survivor", some people with cancer might be hesitate to express negative emotions, such as sadness and fear, as suggested by Sulik (2013) and this might affect their care.

In line with the dominant medical model, the term "cancer patient" was for many years accepted as suitable identification for people having treatment, and it has been suggested that this term is reinforced by medical professionals (Deimling et al., 1997). According to Harwood and Sparks (2003), identifying as a cancer patient may elicit one to look for more information to understand their condition, be more willing to pay attention to their health behaviours and comply with their treatment plan. However, it may also result in these individuals identifying with being sick or passive, leading to less desirable consequences such as feeling a loss of control and always deferring to physicians, especially when the treatment phase has concluded (Deimling et al., 1997; Harwood & Sparks, 2003).

The term "cancer victim" was more often used in the past when cancer was usually a fatal disease, and to replace it, NCCS promoted the usage of an alternative term, "cancer survivor" (NCCS, n.d.). An individual adopting the "cancer victim" identity has been indicated to feel vulnerable, have a fatalistic attitude regarding the illness and be sceptical about the efficacy of the treatments (Deimling et al., 1997). It should be noted that certain individuals in society, even healthcare professionals at times, still hold this fatalistic view of cancer and use this expression (Corner, 1988; Robb, Simon, Miles, & Wardle, 2014).

The term "cancer conqueror" has been suggested as an alternative to the term "cancer survivor" which is also positively connoted, possibly more empowering and implies that the individual has won against cancer (D. Cho & Park, 2015). Unlike "cancer survivor" , it does not imply

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that cancer is a battle in which one makes a choice concerning survival, making it potentially more acceptable to certain individuals.

The more neutral term "someone who has (has had) cancer" was first proposed by Bellizzi and Blank (2007) as a type of cancer identity because some people view their cancer as existing in the past and feel that it has made little impact on their present lives. A similar concept was suggested by Deimling and colleagues (1997) who proposed that an individual identifying as a "cancer ex-patient" is one who is now cancer-free and recognises that cancer is no longer central to their self. These terms have been shown to be popular among individuals diagnosed with prostate cancer (Bellizzi & Blank, 2007; Chambers et al., 2012; Deimling et al., 1997; Jeong et al., 2015).

Gender identity

In modern society, the terms "sex" and "gender" are often used interchangeably in day to day conversation, but they are related, yet distinct concepts (M. Diamond, 2002). The term "sex" refers to "the biological and physiological characteristics that define men and women" whereas the term "gender" refers to the "socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women" (World Health Organization, n.d.). Hence, gender is a fluid concept as demonstrated in previous studies (L. M. Diamond, 2005; L. M. Diamond & Butterworth, 2008) and gender identity refers to "a person's deeply felt, inherent sense of being a girl, woman, or female; a boy, a man, or male; a blend of male or female; or an alternative gender" (American Psychological Association, 2015, p. 834).

As mentioned in Section 1.3.2, a diagnosis of cancer brings about changes in the physical body and research has consistently shown that these changes may affect how one perceive him- or herself. For example, removal of the breast through mastectomy has been associated with a loss of desire and subsequently, a loss of femininity, for some women: "It takes your femininity away.

People say: The important thing is you overcome the disease, but I said to the doctor 'please, do not remove my breast'" (Arroyo & López, 2011, Section 3.2, para. 4; Fallbjork, Salander, & Rasmussen, 2012) . These women might also pay extra attention to themselves so that they would feel desirable. Moreover, they would feel that breast reconstruction was necessary to restoring their identity as a woman (Fallbjork et al., 2012). Similarly, for some males with testicular cancer, the loss of a testicle has been associated with feeling incomplete and less masculine: "It's just the part about being a man and the man having that ability to, and also losing part of that is like losing a part of yourself" (Carpentier, Fortenberry, Ott, Brames, & Einhorn, 2011, p. 743). Other issues that have been shown to threaten the sense of femininity and masculinity include fertility problems and infertility, lowered sex drive and compromised sexual functioning (Gardino, Rodriguez, & Campo-Engelstein, 2011; Molassiotis, Chan, Yam, Chan, & Lam, 2002).

2.5   Cancer within the mass media

People's understanding of health and illness is formed, in part, by how health and illness are portrayed in the world they live in (Lyons, 2000). Over the years, the media has been increasingly used and promoted as a source of information about health and health-related behaviours (World Cancer Research Fund & American Institute for Cancer Research, 2009). According to Lyons (2000), media representations can (a) influence an individual's understanding about health and illness, potentially affecting health-related issues, such as health behaviours and risk perception; (b) create and perpetuate certain attitudes towards people with an illness through imagery, words and discourses; and (c) act as reference points for which individuals with the illness can compare to and hence, influence the way they perceive themselves.

2.5.1 Models of cancer survivorship

Cancer and survivorship were once contradictory terms. However, with advances in the medical field, survival rates have improved and cancer has begun to be considered one of the many chronic medical conditions people may develop over their lifespans. As shown in Figure 1, receiving a cancer diagnosis no longer equates to a linear trajectory to death, because after successful treatment, some individuals may live cancer-free for the rest of their lives, and others have a period of remission before developing secondary or second cancers later in life.
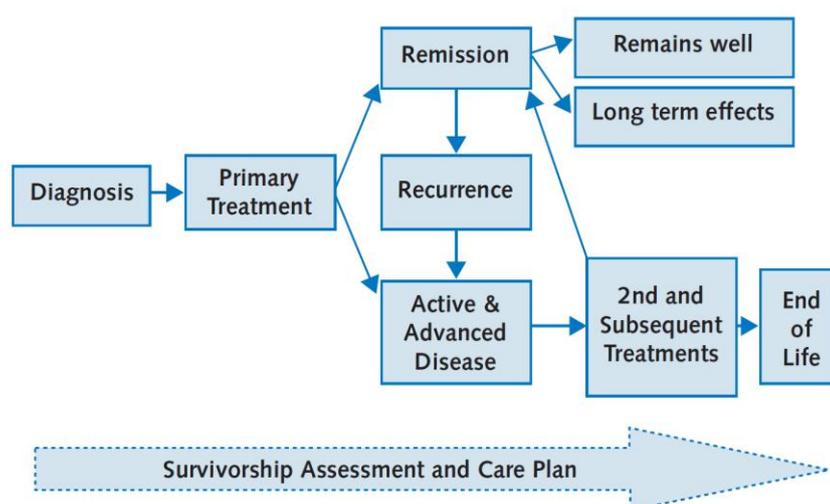
Figure 1. Survivorship Care Pathway. Reprinted from *The National Cancer Survivorship Initiative Vision* (p. 23), by Department of Health, Macmillan Cancer Support, & NHS Improvement, 2010. Copyright 2010 by Crown. Reprinted with permission.

Cancer survivorship is commonly defined in one of two different ways: (a) the experience after the completion of cancer treatment (Cancer Australia, n.d.-b; National Cancer Institute [NCI], n.d.) , and (b) the experience of the entire cancer care continuum, i.e. "living with, through, and beyond a cancer diagnosis" (Macmillan Cancer Support, n.d.; NCCS, 2014) . For the purpose of this research project, the latter definition of cancer survivorship has been adopted.

The initial survivorship model, "seasons of survival", proposed in 1985 by Mullan (a physician and also a cancer survivor) comprised three stages: *acute survival* that begins with receiving a cancer diagnosis and then primary treatment; *extended survival* that involves ongoing surveillance for cancer recurrence; and finally, *permanent survival* when there is a low risk of cancer recurrence and the individual is dealing with the sequelae of cancer and its treatments. Since then, this model has been revised by Miller and colleagues on various occasions, incorporating changes within the field of cancer survivorship over the last 30 years (K. D. Miller, Merry, & Miller, 2008; K.D. Miller, Pandey, Jain, & Mehta, 2015). This revised model, "Seasons of Survivorship" (see Figure 2) comprises: a) acute survivorship that begins with receiving a cancer diagnosis and end with the completion of primary treatment; b) transitional survivorship that is the stage when individuals finishing primary treatment try to return to life before cancer; c) extended cancer survivorship that encompasses the 5-year period of observation and ongoing surveillance after the initial diagnosis; d) chronic survivorship that refers to the stage when individuals are taking certain medication to maintain complete or partial remission, or receiving those medication for constant recurrences; and e) permanent survivorship that is used to describe the phase that individuals who have been cancer free for more than five years after their original diagnosis. During permanent survivorship, some individuals may develop a second cancer or secondary cancers and re-enter the stage of acute survivorship.
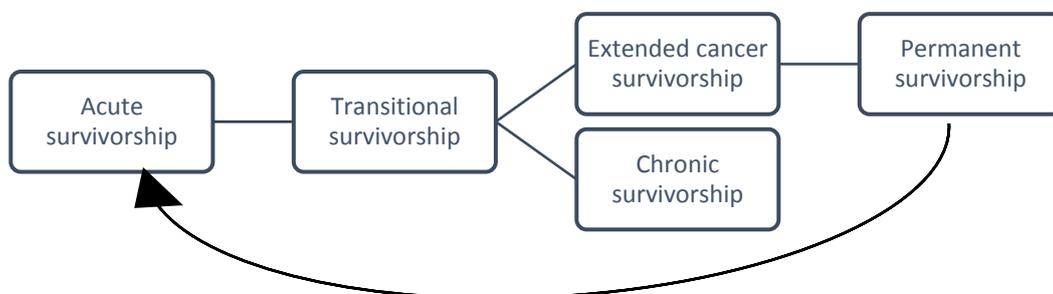
Figure 2. Seasons of Survivorship. Figure devised for this thesis based on the research by Miller and colleagues (K. D. Miller et al., 2008; K.D. Miller et al., 2015).

An alternative model is the Corbin and Strauss Chronic Illness Trajectory model (Corbin, 1998), which was adapted by Klimmek and Wenzel (2012) to describe the different tasks involved in managing one or more aspects of life during transitional cancer survivorship, a period they defined as starting from the completion of primary treatment and continuing throughout the first year of survival. As shown in Figure 3, the model includes three interactive types of work, namely: illness-related work, biographical work, and everyday life work. Illness-related work refers to the tasks needed to manage or treat cancer and its sequelae and includes not only symptom management, for example, but also ongoing surveillance to monitor any potential recurrence of cancer. Biographical work involves the tasks needed to maintain or reconstruct one's identity depending on the impact of the cancer experience, and an example is adapting one's self concept due to a cancer diagnosis. Everyday life work is about the tasks that might have been part of an individual's life before cancer which the cancer experience now needs to be integrated into, for example, adjusting duties at work due to self-effects of treatment. Although Klimmek and Wenzel intended this adapted model to be applied only during transitional cancer survivorship, various aspects of it are representative of those faced by an individuals throughout the entire cancer care continuum (Taplin et al., 2012).

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Illness-related Work

tasks needed to manage or treat cancer and its sequalae, e.g. symptom management and managing late effects; diagnostics; crisis prevention and handling; care-planning and maintaining continuum of care

Illness Trajectory Framework

Everyday Life Work

tasks that might have been part of an individual's life before cancer, of which the cancer experience has to be integrated into, e.g. occupational work, bill-paying, emotion work, health maintenance and health promotion

Biographical Work

tasks needed to maintain or reconstruct one's identity, e.g. contextualizing; coming to terms; reconstituing identity; recasting biography

Figure 3. Klimmek and Wenzel's (2012) adaptation of the Corbin and Strauss Chronic Illness Trajectory model to address the issues during transitional cancer survivorship. Figure devised for this thesis based on the research by Klimmek and Wenzel.

2.5.2   Media theories

Within media research, numerous theories have been proposed to help explain the influence of mass media on its audience. The section below briefly introduces some of the relevant theories. For a more in-depth review of these theories, see Bryant and Miron (2004).

Gatekeeping theory

A term initially coined by Lewin in 1947 to describe the process of making widespread social changes in a community using persons in key positions of influence, "gatekeeping" has become an important concept in media communication studies since the pioneering study by White (1950), which investigated the selection decisions concerning wired news items made by a wire editor. Media gatekeeping is, therefore, the process by which certain news items are selected or discarded. Research since that time has shown that this selection process is based on a combination of several factors, namely organizational factors, news norms and audience interests (Soroka, 2012). As a result, news items that are chosen for publication tend to be more sensational, unusual, conflictual, and/or local (Soroka, 2012).

Agenda-setting theory

The agenda-setting theory was formally developed by McCombs and Shaw (1972) in the seminal Chapel Hill study that demonstrated the relationship between patterns of news coverage for various election issues and the public's perception of the most important one. According to this view, the more *salient* (i.e. prominent) a news item is, the more importance the public would perceive for this new item. Apart from being examined in the context of political settings, agenda-setting has been increasingly examined in other contexts, such as health communication. A 2006 study by Jones and colleagues, for example, revealed that women who were directly or indirectly exposed to news articles about breast cancer were more likely to undertake screening for the disease. Similarly, Dixon and colleagues (2014) found that sun-related news coverage over 12 years

from 1994 to 2007 also indicated that more prominent new items can influence public opinion; for example, greater exposure to pro-sun protection stories about solaria was associated with fewer younger adults wanting a deep tan.

Framing theory

Framing theory has been considered by some researchers as an extension of the agenda-setting theory. Whereas agenda-setting theory focuses on the salience of news items, the framing theory describes how a news items can be presented in a range of ways presented with certain aspects being emphasized to influence news consumers' perceptions (de Vreese, 2005). As observed in the study conducted by Detweiler and colleagues (1999), beach-goers exposed to gain-framed messages (messages that emphasizes the benefits of adopting a particular health behaviour) were more likely to request sunscreen, to intend to use sunscreen with a SPF level of 15 or higher, and to repeatedly apply sunscreen while at the beach – compared to those exposed to loss-framed messages (messages that emphasizes the costs of not adopting a particular health behaviour; Salovey, 2002). An example of a gain-framed message included in the study was "Protect yourself from the sun and you will help yourself stay healthy" whereas an example of a loss-framed message was "Not using sunscreen increases your risk for skin cancer and prematurely aged skin".

The rule of rescue

The "rule of rescue" concept, first proposed by Jonsen in 1986, is defined as the imperative to rescue identifiable individuals from death because the "moral response to the imminence of death demands that we rescue the doomed" (p. 174). Similarly, the "identifiable victim effect" states that people are more willing to help identifiable individuals than unidentifiable or statistical individuals (Jenni & Loewenstein, 1997; Kogut & Ritov, 2005). Research has shown that this concept is observed in various medical settings, such as the allocation of the last intensive care unit bed to a gravely ill patient with little chance of living, rather than to a deceased or dying patient whose

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organs will be donated (Kohn, Rubenfeld, Levy, Ubel, & Halpern, 2011). This effect is also observed in relation to decision-making by Australia's Pharmaceutical Benefits Advisory Committee (PBAC) concerning the recommendation of medication for subsidy through the PBS where there is no other treatment available and the medical condition is severe progressive, and expected to lead to premature death (Harvey & Boer, 2015). An example of its application within the mass media is the news coverage of Herceptin, a cancer drug, which portrayed desperate and unfortunate women being unable to access it due to government incompetence and high costs (MacKenzie, Chapman, Salkeld, & Holding 2008). The media campaign lasted for 11 months and subsequently led to the drug being subsidised by the Federal Government.

2.5.3 Cancer and the media

A few decades ago, cancer was almost an unspoken topic. However, presently, it has become very topical in the mass media with much prominence given to celebrities who have received a cancer diagnosis (e.g Kylie Minogue) or those who like Angelina Jolie have taken action to reduce their cancer risk (Ristovski-Slijepcevic & Bell, 2014).

Influencing an individual's understanding about health and illness

Previous research has consistently shown that the degree of media coverage of the various types of cancer rarely reflects actual patterns of incidence or mortality of the cancer – whether in the USA (Slater, Long, Bettinghaus, & Reineke, 2008; Williamson et al., 2011), Australia (Jones, 2004; MacKenzie, Chapman, Johnson, et al., 2008; MacKenzie, Chapman, McGeechan, & Holding, 2010) or Asia (Cai, Yang, Liu, Ma, & Liu, 2009; Miyawaki, Shibata, Ishii, & Oka, 2016). Jensen and colleagues (2014) demonstrated in an American sample that the public's perceptions of the incidence of a cancer was related to its coverage, with higher news consumption associated with more distorted perceptions of incidence rates. Federal funding for research for different types of cancer was also

related to public perceptions and news coverage, with breast cancer receiving twice as much funding as it should, objectively, be allocated. This is indicative of the fact that policymakers may be influenced by the amount of news different cancers get and as a result, certain forms of cancer will be associated with more research development than others. This may have implications for the health outcomes for individuals diagnosed with cancers that were allocated low amounts of funding.

Creating and perpetuating attitudes towards people with cancer diagnoses

Due to the emergence of inspirational narratives of personal transformation in the media, it has been suggested that the cancer experience is increasingly construed as a potential opportunity for personal growth and cancer survival is perceived as a "badge of honour" (Sulik, 2013). The dominant narrative in the media is that of a triumphant breast cancer survivor who has beaten all odds and is filled with joy, excluding the uglier side of the disease, such as depression and mastectomy scars (Jagielski, Hawley, Corbin, Weiss, & Griggs, 2012). Words such as "normality" and "heroism" have become associated with the behaviour expected of a cancer survivor (Little et al., 2002). Accordingly, Little (2002) suggested, people who do express anger towards cancer, and act differently from those who have been positively transformed by the cancer experience, might therefore be negatively evaluated within society.

However, it should be noted that negative attitudes towards cancer and individuals diagnosed with the disease still prevail (Chen et al., 2006; J. Cho et al., 2013; Robb et al., 2014). For example, 23.5% of adults surveyed in South Korea would avoid working with individuals diagnosed with cancer (J. Cho et al., 2013), and more than 80% of those surveyed in Singapore revealed they would not employ anyone with a history of cancer if they were given a choice (Chen et al., 2006).

Acting as reference points against which individuals compare their own experiences

Media portrayals of individuals diagnosed with cancer and their experience of cancer do not capture the heterogeneous nature of people's experiences. Cancer treatments and survivorship care vary between individuals so media portrayals of a treatment and recovery in a particular way can potentially affect how people respond to, or interpret, their own experiences. For example, people who have experiences different from the dominant representation may tend to under-report symptoms and treatment side-effects, and be hesitant to express negative emotions, such as sadness and fear (Sulik, 2013). In addition, they may feel alienated (Deimling et al., 2007; Jagielski et al., 2012; Pieters & Heilemann, 2011), and become disheartened and less engaged in their treatment program.

Although the breast cancer movement has been very successful, increasingly, the "pinkification" of cancer is being condemned (Kaiser, 2008). Many women (e.g. Barbara Ehrenreich, 2001; Susan Gubar, 2012; Janice Malett, 2004) have stepped forward with opinion pieces published in major newspapers to show the other side of the story, and to promote the acceptance of scarred bodies and the acknowledgement of other emotions - often the negative ones - that are associated with treatment (Kaiser, 2008). This can potentially provide a more balanced media representation of people diagnosed with cancer.

2.5.4   Cancer-related media research

Although social responsibility theory states that the media is supposed to serve only the society by providing truthful and comprehensive news reports that are not influenced by pressures from external sources, such as the government and businesses (The Commission on Freedom of the Press, 1947), this is rarely the case. A significant and often, neglected, issue is that the media does provide misleading information (Goldacre, 2009). Hence, there is a need to scrutinize the content that people obtain regularly from the mass media because certain news outlets may have a private

agenda that affects the way news are reported and individuals are represented. To better

understand cancer, the trajectory and the people affected by it, it is important to examine cancer

discourses that discussed about identity to understand the changes occurring to an individual's

identity (Little et al., 2002). For the purposes of this thesis, which focussed on Australian and

Singaporean media coverage of cancer, research on media coverage in Australia and East Asia is

reviewed below. The findings are tabulated, and followed by a critical commentary.

Australia

A systematic search of PubMed, PsycINFO, Embase, and CINAHL was conducted to review

the current research findings of media coverage on cancer in Australia using search strategies

customized for each database: standardized subject terms and a wide range of free-text terms for

"mass media", "coverage", "cancer" and "Australia" (see Appendix A). Articles published in English

were reviewed and reference lists of identified articles were checked for additional relevant studies.

As seen in Table 1, of the 20 published studies analysing media coverage of cancer in

Australia, the majority of them (n=15) focused on a specific type of cancer, such as breast cancer

(n=6), skin cancer (n=4), and prostate cancer (n=3) in television broadcasts. A total of nine studies

were conducted by the same research team, The Australian Health News Research Collaboration

(AHNRC). Newspapers (n=11) and television (n=9) were the most common media source that was

investigated. These studies mainly focus on coverage about prevention or risk factors/cancer causes

(n=5), and detection and screening (n=5) (see Table 1).

Table 1

Description of articles examining media coverage of cancer in Australia

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
Lupton (1994)	Breast	960 print news items from August 1987 to February 1990	Print news items from major metropolitan newspapers in all states, capital city suburban newspapers, business and news magazines, and women's magazines obtained through a commercial clippings services	• To examine the dominant discourses evident in the Australian print media's reporting of breast cancer during a period in which the introduction of national mass mammographic screening programs was debated and ratified.	Dominant discourses: • Femininity (reproductive choices) • Medical and technological dominance in health matters • Usage of war metaphors (e.g. "fight", "weapon" • Lifestyle and responsibility to maintain good health
Jones (2004)	Breast	73 articles from magazines (*n* = 10) and weekend newspapers (*n* = 3); Dec 2000 to May 2001	All issues of 10 top-selling Australian women's magazines and 3 weekend newspapers Magazines: Australian Women's Weekly, Woman's Day, Readers Digest, That's Life, New Idea, Take 5, Cleo, Who Weekly, Dolly, Girlfriend Newspapers: The Australia, The Saturday West Australian, The Sunday Times	• To conduct an analysis of breast cancer detection (screening) messages currently presented to women by the Australian media. • To update the 1995 study and broaden the coverage of magazines. • To assess the accuracy of these messages against the major ongoing national social marketing advertising campaign conducted by BreastScreen Australia.	Current coverage conveys messages that are unlikely to encourage appropriate screening. • Age representation of women was below the recommended screening age – contradicting with BreastScreen's message. • Majority did not mention about mammographic screening. • Inconsistency and inaccuracy in material presented.
McKay and Bonner (2004)	Breast	January 1999 to December 2001.	Three highest circulation Australian women's magazines: New Idea,	• To look at coverage of breast cancer in Australian women's magazines over the last 3 years to	• Avocation of early detection through breast self-examination and mammograms

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
			Woman's Day and Australian Women's Weekly	see how this role in public health awareness operates	• Prevention of disease: diet and exercise • Publication of contact details for research foundations, charitable organizations and support groups • Illness narratives more often feature celebrities with sensational aspects that would evoke strong reader response • Over-representation of younger women being at risk
Chapman, McLeod, Wakefield, & Holding (2005)[b]	Breast	80 news items from television news and current affairs programs broadcast from Sydney on five free-to-air channels from 3-27 May 2005 Mammogram booking data from 4 state BreastScreen units (Queensland, Victoria, Tasmania, Western Australia) for the 19 weeks before the story broke (1 Jan – 13 May 2005), the 2 weeks during which the story broke and received its most intensive coverage (16-26	TV recordings Mammography data from BreastScreen units	• To describe the main media narratives in the reportage of singer Kylie Minogue's illness with breast cancer. • To assess the impact of this coverage on bookings for screening for breast cancer by mammography in four Australian states.	• 20-fold increase in average daily TV attention to breast cancer in the 7 days after the announcement. • Overall screening bookings rose 40% in the 2 weeks, with a 100.7% increase in non-screened women in the eligible age group 40-69 years • 39.3% higher for bookings in non-screened women even 6 weeks after the publicity • remaining the same for previously screened women

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
		May 2005), and the 6 weeks after the publicity period (27 May – 9 Jul 2005)			
Crabb & Lecouteur (2006)	Breast	"Fiona farewells her breasts" published in the popular Australian women's Magazine, *New Idea* (30 March 2002) selected due to its publication in one of the major, widely read women's magazines in Australia	The article was published in one of the major, widely read women's magazines in Australia	To examine a popular media account of prophylactic mastectomy – the surgical removal of 'healthy' breasts for preventive purposes – focusing on the ways in which the account works to normalize what might alternatively be considered extreme preventive health behaviour.	Such media accounts promote general acceptance of the procedure, and risk management more generally, as enterprising actions that reasonable, morally responsible, 'at-risk' women should undertake to maintain their own health and to care for their families. - As a mother (explicit references and descriptions of her relationship with her children being central both in her life and in her decision to have surgery) - As a patient without symptoms (not entirely healthy due to carrying the gene mutation but fine at the moment, and having the surgery will allow her to live)
MacKenzie, Chapman, Barratt, & Holding (2007)[b]	Prostate	42 items from news broadcast on Sydney free-to-air TV stations (2 May 2005 – 18 Dec 2006)	TV recordings Newspaper database: Factiva database (search strategy unknown)	To list and critically review recent inaccurate statements made by advocates of prostate cancer screening in Australian news media.	Inaccurate information which ignores scientific evidence and the general lack of expert agency support – 10% of statements false or misleading; 90% being rhetorical Increased prevalence and severity of prostate cancer

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
		388 items from print media in Australian capital cities (6 Feb 2003 – 31 Dec 2006) 436 statements in total			• recommendation for screening • accuracy of the PSA test increased • efficacy and importance of early detection and treatment – not supported by evidence • adverse effects downplayed
MacKenzie, Chapman, Holding, & McGeechan (2007)[b]	Prostate	42 items from news broadcast on 5 Sydney free-to-air TV stations (2 May 2005 – 18 Dec 2006) 388 items from print media in Australian capital cities (6 Feb 2003 – 18 Dec 2006) Transcripts from speeches on prostate screening made in the federal parliament in June 2003 436 statements in total	TV recordings Newspaper database : Factiva database (search strategy unknown)	• To examine media coverage of prostate cancer screening in Australia.	Unbalanced and often non-evidence-based appeals to go for screening • 86% of all quotes being positive and highly supportive of screening • 14% raising concerns about its reliability, associated side-effects and lack of evidence about screening • Pro-screening: urologists, politicians, survivors • Critics: Cancer Council Australia, cancer organisations, academics • recommendation for screening • adverse effects downplayed • comparison with breast cancer – about need for more advocacy for prostate cancer
MacKenzie, Chapman, Johnson, McGeechan, & Holding (2008)[b]	All	All news, current affairs and infotainment reports on cancer broadcast on 5 free-to-air TV channels in Sydney from 06:00-09:00 and 17:00-	TV recordings	• To test the hypothesis that television news coverage of different cancers reflects their incidence and burden.	Predominance of reports on breast and cervical cancer and on young women may be distorting public and political perceptions on the burden of cancer

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
		24:00 between 2 May 2005 – 6 Jan 2008		• To examine the journalistic approaches used in reporting cancer.	• Cancer was the 5th most reported health issue: 1319 items; 25 different cancers (breast 42.5%, melanoma 11.9%, cervical cancer 11.6%). • Over-reported DALY: cervical • Under-reported DALY: oesophageal, multiple myeloma • Story leads: treatment 32%, celebrities 21%, causes/risks 18% • Over-reported: breast, cervical • Under-reported: colorectal, brain
MacKenzie, Chapman, Salkeld (2008)[b]	HER2 breast cancer	239 statements in 43 TV news reports from 5 free-to-air TV channels in Sydney from 17 May 2005 – 31 Oct 2006	TV recordings	• To investigate how the campaign to have Herceptin (breast cancer drug) subsidized was framed in Australian TV news. • To reflect on the broader issue of media influence on the public health policy process.	News coverage of Herceptin subsidization underscores the profound influence the rule of rescue has on public discourse and possibly on policymakers' decisions • Dominant discourse 54%: Herceptin was a 'wonder drug' made unaffordable to the majority of women by government indifference, labyrinthine bureaucracy and unacceptable, cruel financial parsimony
MacKenzie, Imison, Chapman, & Holding (2008)[b]	Melanoma	279 statements in 26 TV (five free-to-air Sydney TV stations) and 83 print media reports (Australian capital	TV recordings Newspaper database: Factiva database using date-limited keyword searches	• To review TV and print media coverage of the campaign to regulate solaria that was initiated	Inaccurate reports of usage of the solaria Failure to ban solaria has been a disappointment in a high-profile window of opportunity to change public health law.

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Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
		city newspapers) from 21 Aug 2007 – 20 Feb 2008.	(Clare Oliver; melanoma; skin cancer; solaria)	by Clare Oliver before her death from melanoma in late 2007. • To investigate how the media constructed the aetiology of her disease.	
Scully, Wakefield, & Dixon (2008)	Skin cancer	547 articles published in the Age and the Herald Sun (1993 – 2006)	Database: • Age: via their annual CD-ROM archives • Herald Sun: via their news archive service Search strategy provided: ('skin cancer' and [tan or tanning or tanned or 'sun protection' or 'skin protection' or sunsmart or melanoma or sunburn or 'slip slop slap' or solarium or solaria]) or ('vitamin D' and [sun or skin])	• To provide a comprehensive overview of trends in news coverage about sun protection issues in an Australian setting over a 14-year period.	The mix of sun protection issues covered and views of sun protection have changed over time, resulting in greater coverage of controversies and issues not necessarily positive for sun protection objectives. • 25%: health effects of UV; 14% education/prevention; 12% product issues • More prominent themes overtime: vitamin D, solaria issues, fake tans • Less prominent: sun protection product issues, school policies/issues • 71%: news articles; 11% commentary • 60%: include a pro-sun protection spokesperson; 12%: anti-sun (increase overtime) • 50% positive view for sun protection objectives; 18% negative (increase overtime)
Lawrentschuk, Daljeet, Trottier,	Prostate cancer	48 articles from major newspapers in North America, UK and Australia	To establish most commonly accessed news sources from the top 20 ranked newspapers in USA, UK, Canada, Australia	• To characterize the world online media response to two large screening studies of prostate	World newsprint media in general portrayed screening in a negative light after publication of both studies.

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Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings

Crawley, & Fleshner (2011)		reporting online and Internet-only news organizations for a period of 6 months post-release
		
		4 from Australia/New Zealand
			and New Zealand: Google, Yahoo and Wikipedia
			
			Top 10 worldwide Internet-only news sources: determined by volume of visits to websites
			
			Online information gathering using search terms : 'newspaper', 'news', 'media', 'prostate', 'cancer', 'screening', 'prostate-specific antigen', 'European', 'American', 'ERSPC', 'PLCO', 'study', 'USA', 'United States', 'Australia', 'New Zealand', 'Canada', 'Scotland', 'Wales' and 'Northern Ireland'.
				cancer (the Prostate Lung Colorectal Ovarian Cancer and the European Randomized Study of Screening for Prostate Cancer) by assessing reports for quality and messages, as well as noting geographical differences	• Generally negative: 22/48
					  Positive: 10/48
					  Neutral: 16/48
					• PSA screening being excessive: 26/48
					  Insufficient: 12/48
					  7/48 quoting urologists
					• Median of 3 'experts' in prostate cancer quoted per article
					• UK more in favour of screening USA and Canada – screening deemed excessive Australia & NZ – more balanced reporting

MacKenzie, Chapman, Holding, & Stiven (2010)[b]	Breast	421 statements in 341 breast cancer broadcasts from 5 free-to-air TV channels in Sydney from 3 May 2005 – 28 Feb 2007	TV recordings	• To examine coverage of breast cancer on TV.	Overrepresentation of young women with breast cancer in TV news coverage does not reflect the epidemiology of the disease. • 29.9% celebrity; 26.4% screening policy; 25.7% treatment/scientific progress • Screening policy – focus: age specific screening policy is bad and critical of "younger: women not having free access to mammograms • 67% of women featured were below 40 with only 25% above 40

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
MacKenzie, Chapman, McGeechan, & Holding (2010)[b]	Colorectal	190 statements in 39 TV reports from 5 free-to-air TV channels in Sydney from 3 May 2005 – 30 May 2008	TV recordings	• To examine key issues surrounding colorectal cancer, including prevalence, screening and treatment that are presented on Australian TV news over 3-year period.	Media neglect of colorectal cancer may be an important factor in explaining low participation in the Australian colorectal screening programme. • Colorectal: 4.1% of all cancer reports (lower than expected if proportion of cancer reports reflected incidence or mortality) • 38% treatment; 26% screening; 19% prevention; 15% prevalence; 2% celebrity • Inaccurate info around prevalence
Wilson, Bonevski, Jones, & Henry (2010)	All	272 stories reviewed by Media Doctor Australia from Jun 2004 – Jun 2009 Search terms included, for example, "cancer", "leukaemia", "melanoma" and "tumour"	Data collected by the media-monitoring website Media Doctor Australia (http://www.mediadoctor.com.au)	• To describe an in-depth analysis of the content and quality of stories about new cancer interventions in Australian media.	Reporting of cancer in the general media is of low quality and many of the poorer aspects of content are directly attributable to the researchers. • 40.7% diagnostic test; 20.5% pharmaceutical; 7.9% surgical • 31% breast cancer (over-represented); 13% prostate • Broadsheet newspapers were of a significantly higher quality than online news services, tabloid newspapers or TV

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
					• 72% cited researcher/doctor who tested/administered the intervention; 32% independent expert; 11% industry sources
					• 39% featured estimates of the disease burden of a particular type of cancer but they were at times confusing and sometimes meaningless (variation in info given)
					• Highly emotive language and use of adjectives and literary devices with extensive use of personal narrative
					• 15%: use of patient testimonials
					• 41%: contained overtly emotive language in a direct quote from a source – 54% of them attributable to researchers talking about their work.
MacKenzie, Chapman, & Holding (2011)[b]	Lung cancer	157 statements in 45 reports from 5 free-to-air TV channels in Sydney from 2 May 2005 – 31 Aug 2009	TV recordings	• To analyse news portrayals of lung cancer associated inferences about responsibility in Australian TV news	Non-smokers were portrayed with considerable sympathy whereas smokers were depicted as responsible for their disease. • Lung cancer: 45 (2%) of all cancer-related reports – underreported despite being the leading cause of cancer death and the most widely recognised health consequence of smoking

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
					• 63% noted that the person with lung cancer wasn't a smoker
					• Incidence 27%; celebrity cases 21%; treatment 21%; prevention 11%
Mercurio & Eliott (2011)	All	119 articles between 1 Jan 1998 to 31 Dec 2007 in Australian national and capital city newspapers.	Database: Dow Jones Factiva database Search terms: (rst=AUSTR and (((cancer near10 alternative) or (cancer near10 complementary)) and (therap* OR medic* OR treat*))) 21 specific forms of CAM most commonly discussed in this search were then also included as criteria and the search rerun.	• To describe Australian newspaper coverage of CAM use for cancer between 1998 and 2007 • To describe the trends in reporting frequency and characteristics • To describe how the Australian press framed stories on CAM use for cancer	The media presented a story that could both benefit and hinder patient care. • Biological based CAMs were most frequently described and breast cancer most mentioned. • 2/3 described CAM use in the context of a cure with approximately half of these opposing this reason for use. • Potential benefits were discussed more frequently than potential risks. • Dominant frame: CAM as legitimate tools to assist biomedicine • Negative frames: CAM being questionable and risky and industry/practitioners as possessing malevolent intent
Dixon, Warne, Scully, Dobbinson, and Wakefield (2014)	Skin cancer	516 articles from 1994 to 2007	Two major daily newspapers in Melbourne: The Age and Herald Sun Adults' attitudes and beliefs about tanning and skin cancer assessed with cross-sectional telephone surveys	• To examine the agenda-setting effects of news stories relevant to skin cancer prevention on public attitudes and beliefs about tanning and skin cancer	• More articles on sun protection during summer period • Most commonly endorsed pro-tan belief: "a suntanned person looks more healthy" • Pro-sun protection stories were associated with older adults not

Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
					thinking a tan is healthy and with less preference for a deep tan among younger adults who like to tan
					• Public opinion on tanning and sun protection reflects salience and framing of new stories
Scully, Makin, Maloney, & Wakefield (2014)	Skin cancer	522 articles from 2 metropolitan daily and Sunday newspapers in Melbourne (The Age/Sunday Age and the Herald Sun/Sunday Herald) between Jan 2001 to Dec 2012	Database: Dow Jones Factiva database • Additional electronic data sources, including the news archive services for the Herald Sun (www.newstext.com.au) and The Age (http://newstore.fairfax.com.au/apps/newsSearch.ac), The Age's annual CD-ROM archives (2001-2006) and Fairfax Media Library Edition (2006-2012; http://www.libraryedition.com.au Search terms: ['skin cancer' and (tan or tanning or tanned or 'sun protection' or 'skin protection' or SunSmart or melanoma or sunburn or 'slip slop slap' or solarium or solaria)] or ['vitamin D' and (sun or skin)]	• To determine whether there have been shifts in recent and established coverage of sun protection issues over a 12-year period in the context of an evolving skin cancer prevention agenda	Potentially competing sun protection issues that emerge over time need not pose a threat to existing skin cancer prevention programmes but instead can provide opportunities to further spread programme messages while increasing credibility. • News coverage of vitamin D and sunbed issues were the most prevalent themes over the 12 years. • No decrease in traditional skin cancer prevention programme messaging • A need for improving consistency and accuracy of messaging the public receive about vitamin D – uncertainty within health professionals (vitamin D deficiency vs cancer risk) • Clare Oliver's death from melanoma effectively raised public awareness of health messages and advanced policy agenda in media – increased reports of cancer risk associated with sunbeds

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Article	Cancer type	Sample	Selection of sample	Objective(s)[a]	Findings
Li, Morway, Velasquez, Weingart, & Stuver (2015)	All	13 US articles and 51 non-US newspaper articles from major news outlets over a 11-year period from Jan 1 2010 – Dec 31 2010 8 from Australia/New Zealand	Database: LexisNexis Academic Search topics: medical error or mistake in combination with cancer or oncology and medication, chemotherapy, or drugs or surgical or radiation or diagnosis	• To analyse the print news media's coverage of sentinel events involving cancer patients (medical errors in cancer care)	News media regularly blame individual clinicians for mistakes and fail to present a systems-based understanding of these events. • 24% medication error; 25% diagnostic error; 22% radiation error • 48% severe harm; 25% fatal; 11% potential harm • 30% patient pov; 30% legal pov; 20% hospital pov • Blame: 41% clinician; 28% hospital systems/polices; 11% human error; 11% none • Perspective: 39% negatively slanted; 39% neutral; 11% positive; 11% mixed • Australia/New Zealand: 63% negative; 0 positive; 13% mixed; 25% neutral

[a] the statements under "objective(s)" are taken directly from the article; [b] studies conducted by the same research team, The Australian Health News Research Collaboration (AHNRC).

Table 2

Focus of the journal articles examining media coverage of cancer in Australia

Focus of the article	Studies
Prevention/risk factors/cancer causes	1. MacKenzie, Chapman, & Holding (2011) 2. MacKenzie, Imison, Chapman, & Holding (2008) 3. Mercurio & Eliott (2011) 4. Scully, Makin, Maloney, & Wakefield (2014) 5. Scully, Wakefield, & Dixon (2008)
Detection/screening	1. Chapman, McLeod, Wakefield, & Holding (2005) 2. Jones (2004) 3. Lawrentschuk, Daljeet, Trottier, Crawley, & Fleshner (2011) 4. MacKenzie, Chapman, Barratt, & Holding (2007) 5. MacKenzie, Chapman, Holding, & McGeechan (2007)
Interventions	
• Herceptin	1. MacKenzie, Chapman, Salkeld, et al. (2008)
• Complementary and alternative medicine	1. Mercurio & Eliott (2011)
• General	1. Wilson, Bonevski, Jones, & Henry (2010)

Medical errors	1. Li, Morway, Velasquez, Weingart, & Stuver (2015)
Incidence and burden	1. MacKenzie, Chapman, Johnson, McGeechan, & Holding (2008)
General	1. Lupton (1994)
	2. MacKenzie, Chapman, Holding, & Stiven (2010)
	3. MacKenzie, Chapman, McGeechan, & Holding (2010)

Certain cancers, such as breast cancer, were shown to be over-reported in Australian television news whereas others, such as colorectal cancer, were under-reported (MacKenzie, Chapman, Johnson, et al., 2008; MacKenzie, Chapman, McGeechan, et al., 2010). Inaccurate or misleading information (e.g. screening tests, incidence rates) were presented (Jones, 2004; MacKenzie, Chapman, Barratt, et al., 2007; MacKenzie, Chapman, Holding, et al., 2007; MacKenzie, Imison, et al., 2008). There were also misrepresentations of individuals diagnosed with cancer, for example, the preferable depiction of younger women who were below the recommended screening age for breast cancer (Jones, 2004; MacKenzie, Chapman, Holding, et al., 2010; MacKenzie, Chapman, Johnson, et al., 2008). This inaccurate representation of cancer has been shown to lead to more women attending breast cancer screening despite being outside the high risk age range (S. Chapman et al., 2005). The media's influence on public policies is also observed in a series of media publications lasting 11 months about desperate and unfortunate women who were unable to access one of the required drugs, Herceptin, due to government incompetence and high costs, ultimately leading to subsequent government subsidization (MacKenzie, Chapman, Salkeld, et al., 2008).

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Singapore

A similar systematic search of the research literature was conducted to review the current findings of media coverage on cancer in Singapore but no such studies were identified (see Appendix A). The search was then expanded to include the rest of East Asia (i.e. China, Hong Kong, Japan, Macau, Mongolia, Korea, Taiwan, Indonesia, Malaysia, Philippines, Brunei, Cambodia, Laos, Myanmar, Thailand, Vietnam, and Timor). Eight articles were retrieved (Japan: n=3; China: n=2; Korea: n=2; Malaysia: n=1). As seen in Table 3, the majority of them (n=6) did not focus on any particular type of cancer, and all eight of them examined cancer coverage in newspapers. Five of these studies examined cancer coverage with a general focus, and four of these either examined the changing trend of cancer reporting over time, or compared the cancer coverage at two time points.

Similar to observations within the Australian context, certain cancers, such as breast cancer, were shown to be over-reported (Cai et al., 2009; Kye et al., 2015), whereas others, such as stomach cancer, were under-reported (Kye et al., 2015; Miyawaki et al., 2016). The findings of the study by Higashi and colleagues (2013) demonstrated that misleading information can potentially be transmitted through the media.

Table 3

Description of articles examining media coverage of cancer in Singapore

Article	Cancer type	Sample/Country	Selection of sample	Objective(s)[a]	Findings
Kishi et al. (2008)	General	Five major newspapers (1992-2007) Japan	Database: Nikkei Telecom 21, the largest newspaper database in Japan Search terms: "cancer," "malignant tumor," and "malignant neoplasm" in hiragana, katakana and Chinese characters	• To investigate trends in public interest in health care	• The annual number of articles started to increase in the early 1990s and remained stable from 1992 to 2007, with the Nihon Keizai newspaper (specialising in economy, commerce and business) publishing an increasing number of cancer articles. • Most frequently mentioned cancer (in order): lung, breast, stomach • Most frequent keyword (in order): therapy, obituary, diagnosis • Cancer is a major topic in newspapers and information on cancer is affected by contemporary politics and incidents
Cai et al. (2009)	General	7643 articles retrieved from a database with more than 500 famous newspapers, 152 national newspapers and 362 local newspapers	Database: Database of Important Chinese Newspapers (http://www.cnki.net/login/ autonavi.aspx?id = 3)	• To investigate the number and content of published news stories focused on cancers from 2000 to 2007 in China main newspapers	• Increasing number of published articles each year • Most frequently mentioned cancer: breast, lung, liver (not in line with mortality rate)

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			Search terms: "cancer" or leukemia (癌或白血病) in the title	• To access the changes of cancer reporting in this time period	• Chinese Health Ministry's 8 key cancers – increasing coverage but oesophageal, colorectal and nasopharyngeal cancers are on a slow incline • More coverage for women's cancers (e.g. breast cancer and cervical cancer) • Significant increase for articles about cancer treatment but not prevention and diagnosis
Liu, Liu, Xiao, Cai, and Xu (2010)	Skin	134 articles China	Database: a database of the most commonly read Chinese newspapers Search terms: "skin cancer" (皮肤癌), "melanoma" (黑色素瘤), "squamous cell carcinoma" (鳞状细胞癌) , and "basal cell carcinoma" (基底细胞癌) in the title	• To analyse the skin cancer issues in the newspaper media over an eight-year period from 2000 through 2007	• Skin cancer articles representing 1.7% of all articles that were cancer related • Number of articles about skin cancer increased over the years • Most frequently mentioned cancer: melanoma (38.1%) • Most frequent topic: treatment (41.8%), followed by prevention and detection (~20%)
Al-Naggar and Al-Jashamy (2011)	Breast	18 articles for 1997 79 articles for 2007 Malaysia	Database: electronic archive of the Star newspaper Search term: breast cancer	• To determine whether the content of articles on breast cancer in women published in the Star newspaper in 1997 differed from that of those published in 2007 • To determine which factors may have caused any differences	• Most articles focused mainly on Chinese women with few addressing Malay and Indian women • Different content in terms of high risk factors, themes and preventive measures

					• Medical journals were more likely to be mentioned as a source for articles from 2007
Higashi et al. (2013)	General	13 articles from 5 national newspapers 10 key points that The Japanese Association for Clinical Cancer Centres (JACCCs) wanted the public to know about through an interview with the leader of the public reporting program Japanese	Database: electronic newspaper database	• To access coverage of the public reporting program's key points which were identified through interviews with the leader of the program	• 4.5 of the 10 key points were superficially covered, with the number of points covered highly correlated with space assigned to article • articles provided potentially misleading descriptions regarding the use of relative survival • Several articles ranked the facilities even though they mentioned the incomparability of the unadjusted survival data
Kye et al. (2015)	General	1138 articles from 16 general newspapers, 3 major television news stations, 3 medical newspapers and one news agency (1 Jan 2008-31 Dec 2012) Korea	Database: Eyesurfer (version 3.0.), an online database news scrap service system in Korea Search terms: combination of the primary keyword, "cancer," with sub-keywords, "cause," "incidence," "carcinogenesis," and "engenderment." They were selected based on a series of interviews with health journalists	• To examine how the news media encompasses a wide array of content regarding cancer risk factors and related cancer sites • To investigate whether news coverage of cancer risk factors is congruent with the actual prevalence of the disease	• Coverage of risk factor and cancer differed depending on type of media • Most frequently mentioned risk factors: occupational and environmental exposures • More than half of the news articles covered risk factors for cancer in general • Most mentioned cancer site: breast, followed by colorectal, cervical and prostate

| | | | | | • Over-representation compared to incidence and mortality rates: Breast, cervical, prostate and skin cancer |
| | | | | | • Under-representation compared to incidence and mortality rates: lung, thyroid, liver, and stomach cancer |

Miyawaki et al. (2016)	General	5314 articles from five daily national Japanese newspapers with the highest circulation (Jan – Dec 2011) Japan	Database: News archive services for each newspaper Search terms: 52 search terms in Japanese (developed based on previous studies, but not provided)	• To investigate how often different cancer types are mentioned • To investigate how often the cancer continuum is described • To investigate the topics of the articles mentioning cancer	• Most frequently mentioned cancer was lung cancer, followed by leukaemia (not a common cancer) • Stomach and colon cancers were underrepresented when compared with incidence and mortality • Most frequently mentioned area of the cancer continuum was treatment, followed by survivorship and finally screening/early detection • Mostly frequent topic was social issues (e.g. lawsuits, medical accidents), followed by information (e.g. books, films, events, groups related to cancer) and Great East Japan Earthquake (that caused a nuclear accident).

Shim, Kim, Kye, and Park (2016)	General	1138 articles from 16 general newspapers, 3 major television news stations, 3 medical newspapers and one news agency (1 Jan 2008-31 Dec 2012) Korea	Database: Eyesurfer (version 3.0.), an online database news scrap service system in Korea Search terms: combination of the primary keyword, "cancer," with sub-keywords, "cause," "incidence," "carcinogenesis," and "engenderment." They were selected based on a series of interviews with health journalists	• To examine news portrayal of specific cancer types with respect to threat (i.e. severity of the harm expected from getting cancer) and efficacy (i.e. ways of lowering cancer risk) • To investigate whether news portrayal corresponds to actual cancer statistics	• Threat was most prominent in news stories on pancreatic cancer, followed by liver, and lung cancers and least in stomach • Threat of pancreatic and liver cancers was over-reported and that of stomach and prostate cancers was under-reported • Most efficacy information conveyed in articles on colorectal cancer, followed by skin and liver cancers and least in thyroid cancer • Efficacy information regarding cervical and colorectal cancers was over-reported and that of lung and thyroid cancers was under-reported

[a] the statements under "objective(s)" are taken directly from the article.

Comments about current research in these two countries

There is a need for more research conducted in the field of cancer-related media coverage. Although past research has consistently shown that certain cancers are over- or under-represented in the media, with misleading information thus being transmitted to the public, there is also a need to examine the content of the messages that the public are receiving about individuals who have been diagnosed with cancer, an area that has been greatly neglected by the field. As mentioned earlier, the dominant imagery of a cancer survivor does not necessarily represent everyone who has been diagnosed with the disease, and has the potential to affect the health outcomes of these indiviudals. Therefore, it is important to investigate the representations of people diagnosed with cancer within the media, and in particular, examine the portrayal of identity.

2.6 Conclusion

In this chapter, the literature review of the field was presented. The epidemiollogy of cancer was briefly discussed with the healthcare systems of the two countries examined in this research project (Australia and Singapore) being outlined. Various models of cancer survivorship were also presented, followed by an examination of the impacts of cancer and its treatments with a focus on identity issues faced by individuals diagnosed with cancer. The influence of the mass media on the understanding of cancer was then deliberated before cancer-related media research was presented.

Although there is an increasing amount of research examining the psychosocial impacts of cancer, there is a lack of research examining the lay understanding of cancer identities and how the media might have influenced the way individuals with cancer perceive themselves and are perceived by others. Therefore, the aims of the research project presented in this thesis were (1) to examine the understandings of individuals with cancer and the community for cancer identities (and in particular the "survivor" identity); and (2) to investigate media representations of individuals

diagnosed with cancer that may not only affect the formation of cancer identities in these

individuals, but also influenced public perceptions and policies.

CHAPTER 3: STUDY 1

Preamble

The preceding chapter has shown that there is a lack of consensus around the definition of the term "cancer survivor" and the need to understand this term from the perspectives of those diagnosed with cancer. Although researchers have examined the endorsement of various cancer identities by individuals with cancer, no review, which specifically looked into responses from individuals explicitly identifying or refusing to identify as a cancer survivor, has yet been conducted to consolidate the existing literature. Therefore, the first paper addresses this gap through a systematic review. The specific aims were to: (1) examine how broadly the term "cancer survivor" is accepted by individuals diagnosed with cancer, (2) review the current findings about the factors that play a role in the choice of cancer identity, and (3) review the outcomes of these choices.

Statement of authorship

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Principal Author

Name of Principal Author (Candidate)	Sze Yan Cheung		
Contribution to the Paper	Performed analysis on all articles, interpreted data, wrote manuscript, and acted as corresponding author.		
Overall percentage (%)	80%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	21/04/2017

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i.   the candidate's stated contribution to the publication is accurate (as detailed above);

ii.   permission is granted for the candidate in include the publication in the thesis; and

iii.   the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Paul Delfabbro		
Contribution to the Paper	Supervised development of work and manuscript evaluation.		
Signature		Date	21/04/2017

Abstract

Purpose

Individuals diagnosed with cancer have been shown to interpret the term "cancer survivor" differently and this may have implications for how they cope with their illness. This article reviews the empirical research conducted in the field and aims to formulate recommendations for future research.

Methods

A literature search was conducted on PubMed, PsycInfo, Embase and CINAHL using search strategies customised for each database: standardized subject terms and a wide range of free-text terms for "cancer", "survivor", and "identity". Data from 23 eligible papers were extracted and summarized.

Results

Analysis of the studies revealed that individuals diagnosed with cancer could be categorised into five groups based on their attitudes towards being a cancer survivor: Embracing, Constructive, Ambiguous, Resisting and Non-salient. Identification as "cancer survivor" was found to be highly prevalent within the breast cancer community (77.9%), and least among individuals diagnosed with prostate cancer (30.6%). Self-identifying as a cancer survivor was related to better quality of life and mental wellbeing, with those having a childhood diagnosis more likely to transition successfully into adult care.

Conclusions

The findings show that, for a substantial group of individuals, "cancer survivor" is not a title earned upon receiving a cancer diagnosis or completion of treatment, but an identity that may be embraced in time after deliberation. Future studies should examine the endorsement rate in less common cancers and whether choice of cancer identity varies over time.

Implications for cancer survivors

Researchers and healthcare professionals should use caution when using the term "cancer survivor"

so as not to alienate anyone who has been diagnosed with cancer but does not identify with it.

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Introduction

Cancer is a leading cause of morbidity and mortality worldwide (International Agency for Research on Cancer [IARC], 2014) . IARC, a specialized cancer agency of the World Health Organization, reported an estimated total of 14.1 million new cancer cases worldwide and an estimated 8.2 million cancer deaths in 2012. Despite the high incidence and mortality rates, prevalence estimates indicated that there were 32.6 million people over the age of 15 who were alive and had received a cancer diagnosis within the previous 5 years.

Early detection, improved screening technologies, more effective treatments and better psychosocial care during and after cancer treatment have brought about great benefits, resulting in a better prognosis with an increased chance of long-term survivorship for individuals diagnosed with cancer (Rowland, 2008; Saracci & Wild, 2015). The improvement in survival rates in the last 30 years has led to a shift in the understanding of cancer from a once fatal disease to a long-term chronic disease, and a change of terminology for individuals diagnosed with the once deadly disease from the negatively-connoted term "victim" or "patient" to the arguably more empowering term, "survivor" (Bellizzi & Blank, 2007).

New terminology

Once a descriptive term generally for someone who have lived in remission for five or more years (Feuerstein, 2007), use of the term "survivor" began when Mullan suggested for it to be a replacement for the terms "sickness" and "cure" in 1985. He considered these traditional terms to be unrealistic and insufficient for describing the course of illness for an individual who has been diagnosed with cancer and proposed that a person becomes a survivor at the point of diagnosis when he or she has to rethink their life and make adjustments to it. Since then, the term has been greatly embraced by the media and advocacy groups with the surge in "success stories", especially of "celebrity" survivors and, in recent years, by researchers and policymakers.

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Despite the recognised importance and popularity of the term "cancer survivor", there is generally a lack of consensus about how it should be defined. Inspection of the literature shows that there is presently a variety of definitions, each one formulated differently to define the user's area of interest (Twombly, 2004). For example, there are those who have expanded on Mullan's definition to include family, friends and caregivers as they are also affected by the cancer diagnosis (Institute of Medicine and National Research Council of the National Academies, 2005; National Cancer Institute, 2014). Definitions also differ by geographic location. In Australia and Europe, generally, "cancer survivor" is a term used to identify those who have completed primary treatment, or who have lived beyond 3-5 years from diagnosis (Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013; The Peter MacCallum Cancer Centre. (n.d.)). On the other hand, a recent concept analysis on the term revealed that a cancer survivor is an individual who is living with a history of malignancy, who has lived through a difficult experience and been impacted in positive and negative ways by it, and is in the follow-up phase of their cancer treatment (Hebdon, Foli, & McComb, 2015). Thus, over the past decade, there has been considerable debate over as to when an individual with a cancer diagnosis becomes known (or seen) as a cancer survivor.

Cancer survivor as an identity

Another concern is the extent individuals diagnosed with cancer identify themselves as a "cancer survivor". As McGrath and Holewa (2012) have pointed out, evidence-based practice for cancer survivorship care should begin with finding out what the term means to these individuals and their thoughts on its significance.

It appears that not all who may be considered a cancer survivor by others will necessarily identify with it (Kaiser, 2008). Dominant images of a triumphant cancer survivor can sometimes co-exist with views that embrace the dark side of cancer: lack of cure and death (Kaiser, 2008). Even

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with breast cancer, the cancer given the most news coverage whether it be survivorship or other aspects of the cancer illness (Jensen, Moriarty, Hurley, & Stryker, 2010; Larson, Long, Slater, Bettinghaus, & Read, 2009), this dominant image fails to appreciate first-hand accounts of the continuing existential tensions and psychological difficulties that can persist beyond the point of remission (Hozman, 2005; Kaiser, 2008; Little et al., 2002).

Accordingly, to understand the ways in which people perceive survivorship, increasing attention has been directed towards research that involves asking the very individuals to which the term is applied. For example, Deimling and colleagues (2007) investigated the adoption of a "cancer survivor" identity in two separate studies. This work showed that the majority of respondents self-identify as a cancer survivor and that most also agreed or strongly agreed with the statement, "Being a cancer survivor is an important part of who I am." Other studies have, however, obtained differing results. A study involving individuals diagnosed with prostate cancer by Bellizzi and Blank (2007) indicated otherwise: 56.8% of their respondents indicated that they would identify as being "someone who has had prostate cancer" as compared to 25.9% who self-identified as a cancer survivor. A reason for this discrepancy is that the first study did not offer a neutral identity as a choice and allowed its respondents to endorse more than one identity. This might have resulted in the differences reported for identity adoption, although it also shows that there are individuals who prefer to be known as something other than a cancer survivor.

Investigation into the adoption of various cancer identities is important in that it may influence an individual's physical and mental well-being. Studies have shown that cancer experiences, not only give rise to changes in the self-identity of individuals, but also affect how they view themselves after the diagnosis and during long-term survivorship (Little et al., 2002; Zebrack, 2000). There is now a growing field of research showing that cancer identities are not only related to the appraisal of a cancer experience, but also associated with mental and physical well-being (Bellizzi

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& Blank, 2007; Deimling et al., 2007). Individuals self-identifying with more positive terms ("survivor", "conqueror") had significantly higher levels of positive affect than those who endorsed negatively connoted terms ("patient") (Bellizzi & Blank, 2007). Significantly higher levels of hostility and depression were also reported in those endorsing negatively connoted identities.

The present study

Understanding why certain individuals will choose to identify with a particular cancer identity and the psychological conditions associated with the identification may provide useful insights into providing better psychosocial care for the individual (Deimling et al., 2007; Jagielski et al., 2012; Pieters & Heilemann, 2011). It will also allow health professionals and policymakers to have a better communication with, and understanding of individuals diagnosed with cancer, and may assist in better formulation of programmes or policies. Although there have been studies looking into the adoption of the various cancer identities, no review has so far been conducted to examine the findings from these studies. Accordingly, this review aims to:

1. Examine how broadly the term "cancer survivor" is accepted by individuals diagnosed with cancer,
2. Review the current findings about the factors that play a role in the choice of cancer identity, and
3. Review the outcomes of these choices.

Methods

Literature search

Electronic searches of PubMed, PsycInfo, Embase and CINAHL were conducted using search strategies customised for each database: standardized subject terms and a wide range of free-text terms for "cancer", "survivor", and "identity" (see Appendix A). Articles published in English were reviewed. In addition, references lists of identified articles were checked for additional, relevant studies. Data from 23 eligible papers were extracted and summarized.

Inclusion and exclusion criteria

To be included in the review, studies had to (a) be published in a peer-reviewed journal, (b) be published in English, and (c) report either qualitative or quantitative data regarding one's identity as a "cancer survivor". Studies were excluded if (a) they did not address the "cancer survivor" identity, (b) they did not ask if their respondents identified with being a "cancer survivor" and/or (c) they were secondary works (e.g. review articles, book chapters, commentaries, editorials, poster abstracts, case reports or dissertations/theses).

Data extraction

Figure 4 presents a flow diagram adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, & The, 2009). It provides a pictorial representation of the process used to select studies to include in the systematic review. Only the first author was involved in determining the eligibility of studies for inclusion in this review.
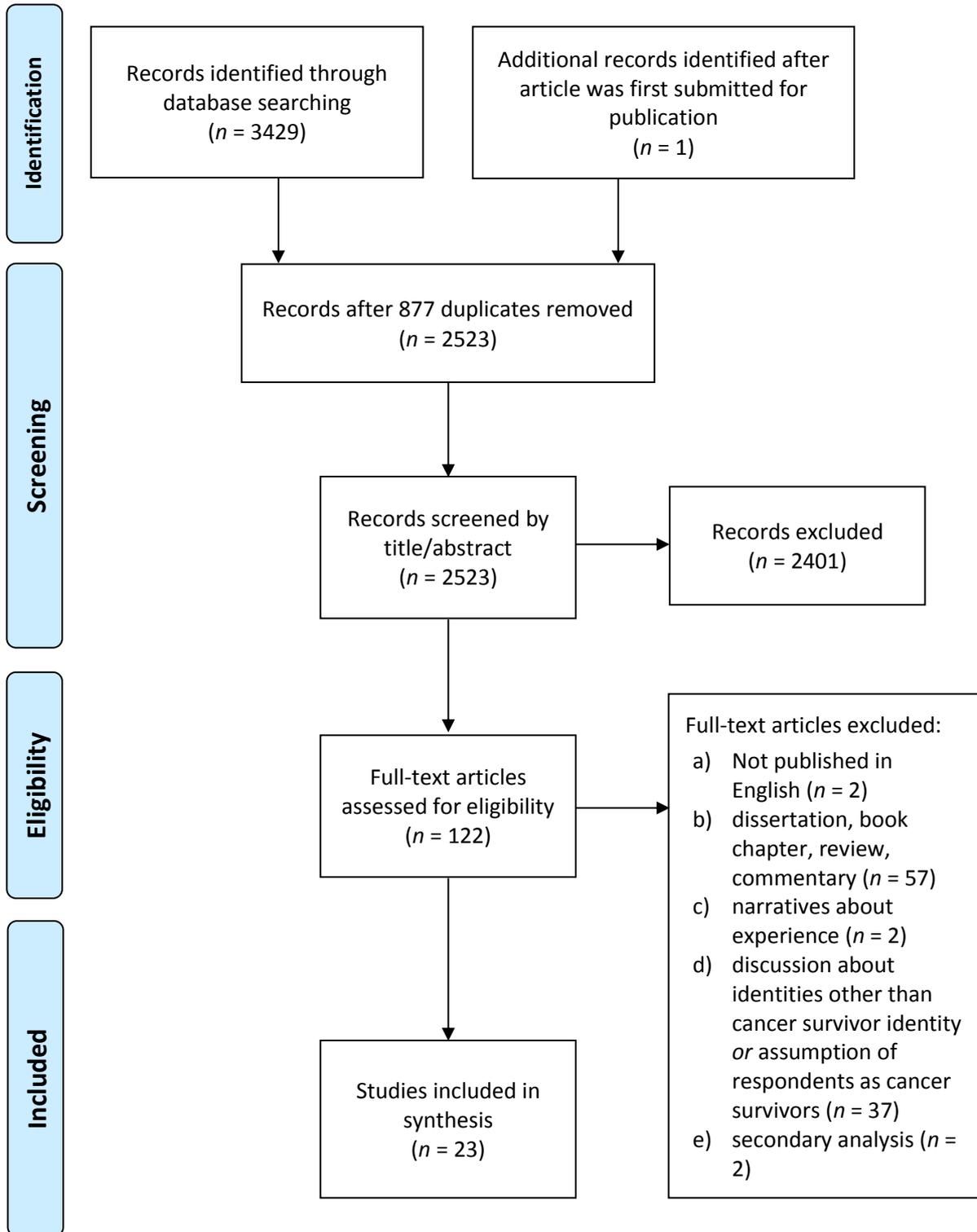
Figure 4. Flow Diagram depicting data screening.

Results

Studies' characteristics

Of the 23 articles selected for review (Table 5), there were 25 studies; one of the studies was a duplicate report of the same study (Deimling et al., 2007; Deimling et al., 1997), two of them reported findings from two separate studies (Deimling et al., 2007; Kelly et al., 2011), and another one did not fit in the inclusion criteria and was excluded (Morris et al., 2014).

There were 7 quantitative studies, 9 qualitative studies, and 8 mixed studies. 2 of them had a longitudinal design. A number of studies (n = 11) did not restrict the participants to a specific cancer; one study reported results separately for individuals diagnosed with prostate or breast cancer; the remaining studies examined individuals diagnosed with prostate (n = 2), breast (n = 7), colorectal (n = 1), haematological (n = 1), gynaecological (n = 1) cancers exclusively. Only one paper examined individuals diagnosed with childhood cancers exclusively.

The majority (n =17) were conducted in the United States of America, with 4 based in Australia, 2 in Canada and 1 in United Kingdom. There was only one paper examining a non-Western population (Dyer, 2015).

Table 4

Description of included studies

Study	Study Design	Methods	Study sample	Recruitment (year if available)	Type of cancer	Years since diagnosis	Age range (years)	Country
Deber, et al. (2005) [1]	Quantitative Cross-sectional	Questionnaire	*N* = 404 Breast cancer: 202♀ Prostate cancer: 202♂	Outpatient clinics of a Canadian teaching hospital (1997)	Breast and prostate cancer	Nil	*M* (breast) = 55.7 *M* (prostate) = 66.1	Canada
Bellizzi & Blank (2007)	Quantitative Cross-sectional	Questionnaire	*N* = 490♂	Metropolitan tertiary care hospital	Prostate cancer	1-8 (*M* = 46.7 months)	49-88 (M = 69.7; *SD* = 7.85)	United States of America
Deimling, et al. (Deimling et al., 2007; Deimling et al., 1997)	Study 1: Quantitative Cross-sectional Study 2: Mixed Cross-sectional	Interview	Study 1: *N* = 50 (43♀, 7♂) Study 2: *N* = 321 (190♀, 131♂)	Study 1: selection from the Golden Age Centre of Greater Cleveland and the Geauga County Unit of the American Cancer Society (1994) Study 2: Random selection from tumor registry at Ireland Cancer Center (ICC) at University Hospitals Health System (UHHS) in Cleveland, Ohio (1998-2008)	A range of cancers	Study 1: Survived for a period of 1-40 years at time of interview and at least one year post-treatment Study 2: 5 years minimum	Study 1: 50-80 Study 2: 98.4% being 60 and above	United States of America
Beatty, et al. (2008)	Qualitative Cross-sectional	Focus group	*N* = 19♀	1) Advertisements placed around the oncology ward of a South Australian public hospital	Breast cancer	*M* = 6.63months *SD* = 2.75 months	*M* = 53.50 *SD* = 12.47	Canada

				2) Information packs distributed by medical oncologist and breast care nurses				
Kaiser (2008)	Qualitative Cross-sectional	Interview	*N* = 39♀	Referral by cancer support centre and through personal referrals (2003-2006)	Breast cancer	Completed breast cancer treatment 3-18 months prior to the interview	28-87 (*M* = 52)	United States of America
Park, et al. (2009)	Quantitative Cross-sectional	Questionnaire	*N* = 167 (108♀, 59♂)	Cancer registry at Hartford Hospital	A range of cancers	1-3 (M=3.5; SD=1.7)	18-55 (*M* = 46.34; SD = 6.29)	United States of America
Kelly, et al. (2011)	Mixed Cross-sectional	Questionnaire	Study 1: *N* = 201 (162♀, 39♂) Study 2: *N* = 113♀	Study 1: Breast cancer-focused community events focussed on breast cancer held in Midwest Study 2: University-affiliated breast oncology clinic	Study 1: With (30.3%) and without (74.3%) prior cancer diagnosis Study 2: Breast cancer	Study 1: Not provided Study 2: Either within a year of diagnosis or 2-5 years post-diagnosis	Study 1: M= 47.8; SD=14.5 Study 2: M=58.9; SD=10.4	United States of America
Pieters & Heilemann (2011)	Qualitative Cross-sectional	Interview	*N* = 18♀	Flyers in waiting rooms or offices of healthcare professionals, churches, support agencies, retirement centres and senior community centres; Breast Center of Loma Lina University Medical Center;	Breast cancer	3-30 months since diagnosis (M=12.5 months) 3-15 months since completion of primary treatment (M=8.5 months)	70-94 (M = 76.1)	United States of America

				snowballing; newspaper advertisements				
Chambers, et al. (2012)	Quantitative Longitudinal	Questionnaire and interview	N = 786	Invitation letters sent through doctors treating individuals diagnosed with colorectal cancer (2003-2005)	Colorectal cancer (479 colon; 263 rectum)		20-80	Australia
Documet, et al. (2012)	Mixed Cross-sectional	Interview	N = 112 ♀	Invitation sent to those who previously participated in events organized by the Pittsburgh chapter of Susan G. Komen for the Cure or the University of Pittsburgh Cancer Institute's Celebration of Life annual luncheon (2003)	Breast cancer	1.53-29.36 years since diagnosis	34-81	United States of America
Granek, et al. (2012)	Qualitative Cross-sectional	Interview	N = 39 (15 ♀, 23 ♂)	Identified through clinic database of two major paediatric cancer hospitals (Hospital for Sick Children, McMaster Children's Hospital) (2010 –2011)	A range of cancers diagnosed at childhood (0-18 years)	Nil	15-26 (M = 21)	Canada
Jagielski, et al. (2012)	Quantitative Cross-sectional	Questionnaire	N = 629 ♀	Online questionnaire posted on the website of the organization "Breastcancer.org"	Breast cancer	84% < 5 years; 15%: 5 years and more	Nil	Worldwide (81.7% United

							States of America)
Khan, et al. (2012)	Qualitative Cross-sectional	Interview	$N = 40$ (22♀, 18♂)	Regional cancer registries: Oxford Cancer Intelligence Unit and the Northern and Yorkshire Cancer Registry and Information Service) (2009 –2010)	15 Breast, 13 colorectal and 12 prostate cancer	5-22 years post-diagnosis	46-92 (median = 71)	United Kingdom
McGrath & Holewa (2012)	Qualitative Cross-sectional	Interview and focus group	$N = 50$ (24♀, 26♂)	Patient database maintained by the Leukaemia Foundation of Queensland	Haematological malignancy	1-year post-diagnosis	Nil	Australia
Beehler, et al. (2013)	Qualitative Cross-sectional	Interview	$N = 35$ (33♀, 2♂)	1) Through informational study flyers posted in the VA Western New York Healthcare System Comprehensive Cancer Center 2) Referral by the oncology staff 3) Invitation letters sent to eligible individuals identified by the chief of oncology	A range of cancers	Less than 1 year – 17 years (median = 4)	$M = 64$ ($SD = 10$)	United States of America
Allen & Roberto (2014)	Qualitative Cross-sectional	Interview	$N = 20$♀	Identified through cancer centres by program directors and physicians (2011–2012)	Gynaecological cancer	5-76 months ($M = 37.65$ months; Median = 29 months)	51-82 ($M = 67.1$; Median = 66.5)	United States of America

Cho & Park (2015)	Quantitative Longitudinal	Questionnaire	N (T1) = 120 (88♀,25♂; 7 unknown)	Identified through a regional hospital cancer registry	A range of cancers	T1: 0-24 years since diagnosis (M = 3.83; SD = 3.03)	T1: 16-47 (M = 32.59; SD=7.43)	United States of America
			N (T2) = 88 (67♀, 15♂; 2 unknown)			1-270 months since completion of primary treatment (M = 38.97; SD = 34.67)	T2: 17-47 (M = 33.63; SD = 7.20)	
						T2: 0-24 years since diagnosis (M = 4.71; SD = 3.24)		
						1-9 months since completion of primary treatment (M = 4.15; SD = 2.56)		
Davis, et al. (2014)	Mixed Cross-sectional	Questionnaire	N = 155♀	Convenience sample from AABCS groups within southern and northern California, word-of-mouth, flyers in key community locations	Breast cancer	Post-active treatment for at least 1 year Years of survivorship: 1-27 (mean=9.17)	31-77 years at diagnosis (M = 51.7; SD = 10.03)	United States of America
Morris, et al. (2014) [2]	Mixed Cross-sectional	Questionnaire	N = 514♂	Identified using Brisbane Prostate Support Network	Prostate cancer	M = 7.5 years (SD = 4.66)	44-94 (M = 70; SD = 8.36)	Australia

Dyer (2015)	Qualitative Cross-sectional	Interview	N = 23 (20♀, 3♂)	Snowball sampling, presentations at cancer support group meetings and clinic-based recruitment at a cancer hospital in San Juan (June 2010 to March 2012)	A range of cancers	13-45 (*M* = 33.61)	27-73 (*M* = 43.43)	United States of America
Miller (2015) [1]	Qualitative Cross-sectional	Interview	N = 35 (22♀, 3♂)	Part of a larger study not referenced; purposive sampling in a variety of Midwestern cities	A range of cancers	4months-5 years since completion of primary treatment (*M* =21 months)	22-86 (*M* = 51)	United States of America
Smith, et al. (2015)	Mixed Cross-sectional	Questionnaire and interview	N = 53	Multiple care settings (e.g. follow-up oncology visits, physician mailings, waiting room flyers, support groups, and cancer-related organizations)	25 breast cancer , 20 prostate cancer, 8 non-Hodgkin's lymphoma	3 years or more with completion of acute treatment (*M* = 6)	47-74 (*M* = 61)	United States of America

♀*: female*; ♂: male; Nil: Not provided.

[1] Only information regarding individuals diagnosed with cancer was included in the review.

[2] Morris and colleagues reported on 2 studies in their paper but only the first one fitted the inclusion criteria and was included in the review.

Acceptability of "cancer survivor" as an identity

The question regarding whether a respondent would identify as a "cancer survivor" was asked in varying forms in the studies: 1) a forced-choice endorsement of one identity out of a provided list (Bellizzi & Blank, 2007; Chambers et al., 2012; Morris et al., 2014), 2) possible endorsement of one, many or none of the identities from a provided list (Deimling et al., 2007; Kelly et al., 2011), 3) a dichotomous question whether they identified as a cancer survivor or not (Documet et al., 2012; Granek et al., 2012; Jagielski et al., 2012; Kaiser, 2008; Kelly et al., 2011), 4) a Likert-scale question asking about degree of endorsement of various identities (D. Cho & Park, 2015; Deber et al., 2005; Park et al., 2009), 5) open-ended question about a "cancer survivor" (Beatty et al., 2008; Beehler et al., 2013; Davis et al., 2014; Khan, Harrison, et al., 2012; McGrath & Holewa, 2012; Pieters & Heilemann, 2011), and 6) not provided (Allen & Roberto, 2014; Dyer, 2015).

There were some studies that did not specify how many identified with the term but reported that most, such as individuals diagnosed with ovarian cancer, did not embrace such an identity (Bell, 2014; Khan, Harrison, et al., 2012; L. E. Miller, 2015; Pieters & Heilemann, 2011) or the need to maintain a sense of identity separate from being a "cancer survivor" (Beatty et al., 2008). On the other hand, Davis and colleagues (2014) found that most identified with the term. 13 of the 23 studies reported numerical figures with respect to endorsement of a specific cancer identity and the results are presented as percentages in Table 5.

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Table 5

Endorsement of different cancer identities (percentage)

Study	Customer	Consumer	Partner	Client	Cancer patient	Ex-cancer patient	Cancer victim	Cancer survivor	Someone who has (has had) cancer	Cancer conqueror	Member	Others[a]
Deber, et al. (2005)[e]	✓	✓	✓	✓	✓			✓				
	0.0B	4.0B	15.9B	14.4B	79.2B			21.8B				
	1.0P	1.0P	5.0P	3.5P	90.5P			0.5P				
Bellizzi & Blank (2007)[b]					✓		✓	✓	✓	✓		✓
					8.8		0.6	25.9	56.8	6.2		1.7[f]
Deimling, et al. (2007)[c]					✓	✓	✓	✓				✓
Study 1					22.0	60.0	30.0	90.0				-
Study 2					13	42	13	86				Nil
Kaiser (2008)[d]								✓				✓
								51.3				48.7
Park, et al. (2009)[e]					✓		✓	✓	✓			
					58		18	83	81			
Kelly, et al. (2011)[d]					✓			✓				
Study 1					25.0			75.0				
Study 2					31.6			68.4				

Study						
Chambers, et al. (2012)[b]	✓	✓	✓	✓		✓
	1.4	1.2	55.0	39.4		3.0[f]
Documet, et al. (2012)[d]			✓			✓
			95.5			4.5
Jagielski, et al. (2012)[d]			✓			✓
			78			22
Allen & Roberto (2014)[d]			✓			✓
			55.0			45.0
Cho & Park (2015)[e]	✓	✓	✓	✓	✓	✓
Time 1	50.8	6.7	55.0	75.0	35.0	59.2
Time 2	44.0	3.6	61.9	77.4	34.9	56.6
Morris, et al., (2014)[b]	✓	✓	✓	✓		✓
	6.2	1.9	35.0	53.1		3.8
Dyer (2015)[d]			✓			✓
			69.6			30.4

✓ : Identity was provided as an option for endorsement; Nil: Results were not provided.

[a] Participants who did not identity as a cancer survivor (in dichotomous questions) or who did not identify with any of the available options (in forced-choice questions); [b] Participants were allowed to endorse only one identity (forced-choice); [c] Participants were allowed to endorse more than one identity; [d] Participants were asked whether they identified as a cancer survivor or not (dichotomous); [e] Participants were asked to assess the extent to which each

identity described them; [f] Participants were asked an open-ended question about whether they considered themselves cancer survivors; [B] Breast cancer; [P] Prostate cancer

Results from studies that allowed respondents to endorse multiple identities (Deimling et al., 2007) or to assess the extent to which each identity describes them (D. Cho & Park, 2015; Park et al., 2009) revealed that there were some participants who would endorse multiple identities, suggesting that different identities might be endorsed simultaneously for the individual to make sense of different aspects of their cancer experience.

In a longitudinal study, Cho and Park (2015) found a significant decrease in the endorsement of the patient and victim identities after a follow-up with the same respondents a year later, showing that cancer identities can change overtime.

Pooling the results from studies that asked dichotomous or forced-choice questions about cancer identity endorsement, it was found that there was an almost even distribution for endorsement of a cancer survivor identity (Table 6). When examining specific cancers, 77.9% of individuals diagnosed with breast cancer agreed that they were cancer survivors, as opposed to 30.6% of individuals with a prostate cancer diagnosis. The difference was also reported by Deimling and colleagues (2007) in that respondents who were diagnosed with prostate cancer were less likely to identify as survivors as compared to those who had breast or colorectal cancer (r = -.22, p<.01).

Table 6

Identification as a cancer survivor (Data from forced-choice or dichotomous questions)

Studies	*N*	Age range	Identify with being a cancer survivor	
			Yes (%)	No[a] (%)
Breast cancer				
Kaiser (2008)	39	28-87	20	19
		M = 52	(51.3)	(48.7)
Kelly, et al. (2011)	114	*M* = 59.9; *SD* = 10.4	78	36
			(68.4)	(31.6)
Documet, et al. (2012)	112	34-81	107	5
			(95.5)	(4.5)
Jagielski, et al. (2012)	629	Nil	491	138
			(78)	(22)
Total	894		696	198
			(77.9)	(22.1)
Prostate cancer				
Bellizzi & Blank (2007)	490	49-88	127	363
		M = 69.7; *SD* = 7.85	(25.9)	(74.1)
Morris, et al., (2014)	514	44-94	180	334
		M = 70; *SD* = 8.36	(35.0)	(65.0)
Total	1004		307	697
			(30.6)	(69.4)
Colorectal				
Chambers, et al. (2012)	786	20-80	432	354
			(55.0)	(45.0)
Gynaecological				
Allen & Roberto (2014)	20	51-82	11	9
		M = 67.1;	(55.0)	(45.0)
		Median = 66.5		

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A range of cancers				
Dyer (2015)	23	27-73	16	7
		M = 43.43	(69.6)	(30.4)
Total	2727		1462	1265
			(53.6)	(46.4)

Nil: not provided

[a] includes respondents who chose another identity (forced-choice) or refused to be identified as a cancer survivor in a dichotomous setting

Thematic analysis of the qualitative studies revealed that individuals diagnosed with cancer could possibly be categorised into five groups when their attitudes towards being a cancer survivor were examined.

1. Embracing: identifies as a survivor and accepts the dominant image of a survivor (Kaiser, 2008; Pieters & Heilemann, 2011; Smith et al., 2015)
    a. They often feel that they have won the battle and/or beaten the cancer. They are visually embodying the identity (e.g. pink ribbons, fundraising events).
2. Constructive: identifies as a survivor but is selective about what they identify with and/or alters the meaning (Kaiser, 2008; Pieters & Heilemann, 2011)
    a. For example, they will identify as being a survivor who has to live with ongoing fears of recurrence.
3. Ambiguous: unsure about it (Allen & Roberto, 2014; Khan, Harrison, et al., 2012; McGrath & Holewa, 2012; L. E. Miller, 2015; Pieters & Heilemann, 2011; Smith et al., 2015)
    a. They may like the term, but are not sure if their experience qualify them to be part of the community, or that their fear of recurrence prevented them from accepting the term completely
4. Resisting: dislike the term or do not want to be labelled even when they acknowledge about fitting the criteria to be one (Beatty et al., 2008; L. E. Miller, 2015; Pieters & Heilemann, 2011; Smith et al., 2015)
    a. They often find the term inappropriate or feel that it is not a suitable term to describe them. Some may feel uncomfortable with the term while others find it offensive.

5. Non-salient: have never heard of the term or considered the matter about being a "survivor" (Kaiser, 2008; Pieters & Heilemann, 2011).

   a. This was more prominent among elderly women who might have other more defining circumstances in life, and that they did not find their lives after cancer any different from their lives before the cancer diagnosis.

Alternative terms

Alternative terms have been proposed by respondents during the collection of qualitative data. Certain terms like "cancer free for now" and "cancer warrior" were proposed as these phrases were thought to be able to capture broader attitudes, including a recognition of the tentative nature of health and the ongoing struggle with cancer (Kaiser, 2008). The need for certainty and truth can also be observed through the suggestion of factual descriptions, such as "was treated for cancer" or "has had cancer" (Kaiser, 2008; Khan, Harrison, et al., 2012). In general, more positive terms are preferred as survivor, to some, seemed like a harsh term. Other suggestions include "cancer recovered", "survived cancer", "fighter" and "cheerleader" (Dyer, 2015; Kaiser, 2008; Khan, Harrison, et al., 2012; Smith et al., 2015).

Possible reasons for identification as a "cancer survivor"

There are three factors that may lead to the identification as a survivor: 1) a fitting description of the cancer experience; 2) positive thoughts, and 3) lack of symptoms (Table 7). First, for some, the term 'cancer survivor" is an appropriate, if not factual, description of their experience. This experience has become an important part of their life, a part of their sense of self. Second, studies have indicated that certain trait-like characteristics, such as optimism, play a role in cancer identity (Allen & Roberto, 2014; Deimling et al., 2007). Religious faith has also been associated with optimism whereby they feel that their faith in God has brought them through the experience and helped them in dealing with cancer (Allen & Roberto, 2014; Deimling et al., 2007). Third, adoption of a survivor identity can be dependent on the success in treatment(s) and/or getting desirable results

from medical tests (Deimling et al., 2007; Jagielski et al., 2012; Pieters & Heilemann, 2011). Cancer symptoms might go away with successful treatment, leading to remission, and treatment effects might dissipate after a period of time. Some have commented that they feel like a survivor when they do not feel sick any longer, and individuals who were still experiencing cancer-related symptoms had been found to be less likely identify as survivors, and more likely as patients. Moreover, as would be expected, a choice to identify as a cancer survivor has been shown to increase if they perceived themselves as having a "very good" prognosis compared to others or recalled being told that they were cured (Jagielski et al., 2012). It should be noted that though the respondents might see themselves as a cancer survivor, they were reported to rarely refer to themselves as such spontaneously (Kaiser, 2008; Pieters & Heilemann, 2011; Smith et al., 2015).

Table 7

Possible reasons for identification as a "cancer survivor" and example quotes

Factor	Example quote
An fitting description of the cancer experience	"Yes, we've had cancer but it hasn't killed us. I mean, you've only got to look at the dictionary. That is the word, cancer survivor. Yes, how could anybody object to that" (Khan, Harrison, et al., 2012, p. 179)
Positive thoughts	"I think I am proud that I survived it. I didn't fall apart. I found an inner strength. There is part of me that is gone, but there is something else that came in. (The surgeon) might have taken a boob, but he gave me a different personality … something has happened to quiet little Kim." (Kaiser, 2008, p. 83)
Lack of symptoms	"when I didn't have the symptoms anymore" (Deimling et al., 2007, p. 762)

Possible reasons against identification as a "cancer survivor"

Four factors have been repeatedly brought up by different respondents as their reasons for not wanting to identify as a cancer survivor (Table 8).

a. Inappropriate terminology

The practicality of the term "cancer survivor" was questioned. Some respondents commented that they dislike the term as it gives the implication of survival being a choice instead of luck or good care, and this would be disrespectful towards those who have died from cancer (Khan, Harrison, et al., 2012). Others find the term inappropriate due to the fear of recurrence (Kaiser, 2008; Khan, Harrison, et al., 2012; McGrath & Holewa, 2012). To them, to call themselves "cancer survivors" is considered to be "tempting fate" and that the term does not recognise the possibility of death from future recurrences (Khan, Harrison, et al., 2012). It was felt that a survivor of cancer should be someone who will pass away because of old age and/or a reason unrelated to cancer, and this would hold true even for those with high survival rates such as individuals who have completed breast cancer treatment. Moreover, with cultural differences across the globe, the community in Puerto Rico has an alternative term "viviente" because they feel that merely to survive is not enough. They want to thrive and thriving, in their opinion, which is a step removed from surviving (Dyer, 2015).

b. Not comparable to other "survivors"

There are individuals who decline to be known as cancer survivors because they feel that they were not sick or close enough to death and that the phrase was more suitable for those who had struggled more or had survived through a poor prognosis (Beehler et al., 2013; Kaiser, 2008; Khan, Harrison, et al., 2012; McGrath & Holewa, 2012; L. E. Miller, 2015; Pieters & Heilemann, 2011). Although a weak association, some evidence has shown that individuals who identify as a survivor are more likely to have received a wider range of treatments, whereas individuals experiencing a greater number of symptoms during treatment were more likely to identify as being a patient (Deimling et al., 2007). People also compared themselves to others who have a cancer diagnosis, other life-threatening/debilitating diseases or even a war veteran, and consider their cancer experience to fall short of the experiences that the others have or are going through, even if they have had a few cancer diagnoses (Khan, Harrison, et al., 2012; McGrath & Holewa, 2012). On the other side, there are others who feel that the phrase is unsuitable as it resounds more with breast cancer survivors (Beehler et al., 2013). They feel that it is easier

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to have moved on back to their before-cancer life after the breast cancer has gone into remission, whereas experiences with other forms of cancer were considered more complicated.

c.   Not wanting a label or to join a club

Some do not wish to "join a club", a membership they consider to be undesirable due to the ripple of effects from a diagnosis of cancer (Allen & Roberto, 2014; Kaiser, 2008; Khan, Harrison, et al., 2012; Smith et al., 2015). Others simply wish to move on and a label is considered to result in an unnecessary focus on their disease, especially for childhood cancer survivors who was diagnosed at a young age and considered cancer as something of the past that has not created much, if any, impact in their lives (Allen & Roberto, 2014; Granek et al., 2012; L. E. Miller, 2015). The term "cancer survivor" makes them feel as though they are still dwelling on the disease instead of re-focusing on life and on living well (Dyer, 2015; McGrath & Holewa, 2012). They do not want to be associated with cancer symbols, such as pink ribbons for breast cancer, which will be a reminder of the disease and of what they have been through (Kaiser, 2008).

d.   Presence of more defining life experiences

The term "cancer survivor" is considered too restrictive and not a true illustration of their lives (Allen & Roberto, 2014; Khan, Harrison, et al., 2012). To certain individuals, cancer was just a short episode of their life and some have gone further to liken it to an episode of flu (Dyer, 2015). This is especially true for older respondents because they may have more experiences in life that they find to define them better and were of much greater importance to their identities (Pieters & Heilemann, 2011). Surviving does have a different meaning for them especially when there are other potentially debilitating medical conditions which they could be concerned with (Khan, Harrison, et al., 2012; Pieters & Heilemann, 2011). As one person argued, the nature of the game at old age has become one of surviving anything and everything.

Table 8

Possible reasons against identification as a "cancer survivor" and example quotes

Factor	Example quote
Inappropriate terminology	"I don't like that term because I don't know if I have beaten it… I guess I don't think of it that way because … if you're in a plane crash and you survive, you survived the plane crash. You're not gonna get back in the plane and crash again. But, I had cancer, I made it through treatment, it is gone for now. But that doesn't mean it's not gonna come back." (Kaiser, 2008, p. 84)
Not comparable to other "survivors"	"I know somebody else who's had really serious cancer, chemotherapy, and was diagnosed with 6 months and is now alive a year later. Now that to me is a cancer survivor I think mine was breast cancer, it was a lump they took away, and there is a part of me that thinks I was very unlikely to die of it, so I don't really see myself as a cancer survivor. I'm somebody who was touched by cancer that then went away. I haven't done enough to call myself that really." (Khan, Harrison, et al., 2012, p. 180)
Not wanting a label or to be part of a club	"Going to a gym and exercising with a bunch of women who have cancer wasn't my identity. I didn't want to stand around and talk with cancer. I didn't want to be around people that I might not, in ordinary life, want to be around, period. I didn't want to be put in a group where the only thing that was drawing us together was that we had cancer." (Allen & Roberto, 2014, p. 1031)
Presence of more defining life experiences	"I think of myself as a family person and for close friends. I'm proud that I worked 31 years for the same company and that was I was married 34 years before my husband died. That's who I am really. The breast cancer was something that happened to me, but it does not define me for the rest of my life." (Pieters & Heilemann, 2011, p. 128)

Outcomes associated with the choice of identity

Mental wellbeing

A number of studies found individuals identifying as a survivor (Bellizzi & Blank, 2007; Chambers et al., 2012; Jagielski et al., 2012; Park et al., 2009) or conqueror (Bellizzi & Blank, 2007) report better psychological well-being. The former also had greater post-traumatic growth

(Chambers et al., 2012; Morris et al., 2014; Park et al., 2009), lower threat appraisal (Morris et al., 2014), higher deliberate rumination (Morris et al., 2014), life satisfaction (Chambers et al., 2012) and were more likely to have a positive outlook on life (Pieters & Heilemann, 2011).

Individuals who preferred negatively-connoted labels were found to fare poorly compared to those who chose more positive identities. Self-identifying as a victim was associated with having higher levels of negative affect, more intrusive thoughts and lower life satisfaction (Park et al., 2009). Similar to those who identified as "patients", they reported higher levels of hostility (Deimling et al., 2007). Adoption of the "patient" identity was also related to higher levels of depression (Deimling et al., 2007). Cho and Park (2015) found a lower level of quality of life was reported for those who identified as a "patient" a year ago and identifying as a "victim" was related to higher levels of self-blame and worry a year later.

Although the amount of time since diagnosis was not associated with adoption of the "survivor" identity (Jagielski et al., 2012), the timing of adoption has been linked with several aspects of mental well-being. Early adoption of the "survivor" identity was significantly associated with higher levels of self-esteem and these adoptees had significantly lower levels of anxiety and depression (Deimling et al., 2007). Those who took longer to take on the "survivor" identity were more likely to view themselves as "not a whole person" (Deimling et al., 2007).

Coping

Individuals identifying as a survivor were more likely to deal with it actively using instrumental strategies (Deimling et al., 2007).

Risk of recurrence

A "victim" identity was shown to be associated with fears of recurrence, and surprisingly, so was the "survivor" identity (Park et al., 2009). They also showed that those who identified with being a "patient" were more likely to perceive a higher risk of recurrence.

Follow-up care

Granek and colleagues (2012) reported that individuals diagnosed with childhood cancers who identified themselves as a "survivor" would be more likely to make a successful transition into adult care, but those who refrained from identifying with the term would be less likely to do so.

Engagement in cancer-related activities

Individuals who identified as a cancer survivor felt that they were able to help others and participate in support groups to share and discuss about their experiences (Dyer, 2015; Khan, Harrison, et al., 2012; Pieters & Heilemann, 2011). Such actions were not restricted to just those individuals who identified as cancer survivors (Pieters & Heilemann, 2011).

Park and colleagues (2009) reported significant differences in the engagement in cancer-related activities among the various cancer identities. Cancer or ex-cancer patients were not shown to be significantly engaging in any cancer-related activities. Cancer victims were more likely to belong to cancer-related organisations and to participate in cancer-related advocacy to public officials. Individuals who identify as a survivor or as someone who has had cancer would follow media stories related to treatment or survivorship, wear cancer –related items, and were more willing to share their experience and cancer-related information with people around them. Survivors were also found to be more likely to contribute money to cancer-related causes and participate in cancer-related events. Individuals diagnosed with childhood cancers who identified themselves as a

"survivor" would be more likely to be involved with cancer organizations, such as camps for children with cancer (Granek et al., 2012).

Discussion

Although the phrase "cancer survivor" is widely accepted, past research has shown that not all who have been diagnosed with cancer may identify with it. The available literature was reviewed to obtain a better understanding of the acceptability of this term; the factors that play a role in the choice of identification; and, the apparent outcomes of these choices. It was found that endorsement of a "cancer survivor" identity was dependent on cancer type and was typically more likely to be adopted within the breast cancer community as compared to those affected by other cancers. The principal advantages associated with self-identifying as a "cancer survivor" appeared to be a better quality of life and mental wellbeing and it also appeared to have a positive influence on engagement in cancer-related activities such as being involved with events run by cancer organizations (Park et al., 2009).

A number of factors have been shown to affect the adoption of identities, and for a substantial group of individuals, "cancer survivor" is not simply a title earned upon receiving a cancer diagnosis or completion of treatment. Instead, as indicated by the studies reviewed in this paper, it appears to be an identity that people may choose to adopt and at a time of their own choosing after deliberation. A participant in Pieters and Heilemann's (2011) study best describes it in the following statement: "Deciding whether you are a cancer survivor is something that your mind decides until you feel like the battle is done, for you." (p. 129). It has been shown that this deliberation often includes social comparison because these individuals are likely to judge whether they are fitting of the "cancer survivor" identity by comparing their situations with those who have had similar forms of cancer and such comparisons have previously been shown to have both positive and negative consequences (Bellizzi, Blank, & Oakes, 2006).

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Identifying as a "cancer survivor" was seen to have a positive effect on both physical and mental wellbeing with some evidence that the timing of the endorsement of this identity also plays a role in affecting wellbeing. These findings suggest the potential value of further longitudinal studies to examine how the timing of adoption of different cancer identities can affect longer-term physical and mental health. As cancer identity or psychological variables were only assessed once in either of the longitudinal studies reviewed in this paper, future studies should assess both cancer identity and psychological variables at all time points to obtain a better understanding.

Despite these potential benefits, there still remain some concerns surrounding the use of the term. At present, there are several variations in how this term is being defined and this may influence the type of samples which are included in research studies. This means that different conclusions may be drawn even if the variables examined or the intervention administered is the same. Future studies should allow its respondents to define the term or choose an identity so as to determine whether the choice of endorsement of a particular cancer identity may influence outcome measures. It is also important to acknowledge the views of a number of researchers who have cautioned about the risk of alienation created by the usage of the term "cancer survivor" (Deimling et al., 2007; Jagielski et al., 2012; Pieters & Heilemann, 2011). Moreover, research has shown that dominant images of a triumphant survivor may hinder some individuals from acknowledging or recognising health issues (Pertl, Quigley, & Hevey, 2014). It may be that both researchers and healthcare professionals need to rethink when using terms such as "cancer survivor" and "cancer survivorship" because not only do these terms perpetuate an image of happiness and success, not all of those who may seek treatment for cancer may necessarily wish to embrace the term and benefit from it.

Most of the studies were conducted within the United States of America, and only one study (Dyer, 2015) had involved a non-Western population. Accordingly, some caution needs to be applied when considering the generalizability of these findings, since high acceptance of the term "cancer survivor" in USA might be a result of the survivorship movement, especially within the breast cancer community as well as the positive image portrayed by both the media and advocacy groups (Deimling et al., 2007). Another issue that the strong focus on breast cancer means that the generalizability of the results may be limited. Research has shown, for example, that while the majority of those with a breast cancer diagnosis identified as a "cancer survivor", the majority with a prostate cancer diagnosis do not endorse the term and only approximately half of those with other cancer diagnoses would consider themselves as cancer survivors. This suggests that the adoption of the term may be influenced by gender, the type of cancer and the likely prognosis. Future studies should look into the adoption of a "cancer survivor" identity in other cancer populations, such as individuals diagnosed with less common cancers, having poorer prognoses, or from different racial backgrounds. Providing the more neutral option of "someone who has had cancer" would also help to identify those who do not feel that the cancer experience is central to their identity.

It should not be taken for granted that just because "cancer survivor" is a widely accepted term, individuals diagnosed with cancer would readily identify with it. The concept of cancer survivor identification is multifaceted and it is a term not uniformly endorsed by everyone who has received a cancer diagnosis. With more research, the relationship between various cancer identities and health will be better understood, and subsequently, assists with the planning of better suited programmes and policies.

CHAPTER 4: STUDY 2

Preamble

Analysis of the 24 independent studies in Study 1 (Chapter 3) indicated that not everyone who has been diagnosed with cancer would identify as a cancer survivor and highlights the need to understand non-professional understandings of cancer identities. Understanding the lay person's perceptions is also important because the increasing numbers of people living longer with cancer mean that more and more community members are coming into contact with them – and differences in understandings may impact on communication and relationships.

Accordingly, the second paper explores the lay understanding of cancer identities by investigating: (1) how individuals without a diagnosis label those with a diagnosis; (2) what they understand by the terms "cancer survivor" and "cancer survivorship"; and (3) whether their understanding may be influenced by relevant experiences such as a personal cancer scare, or by having a close friend or family member being diagnosed with cancer. To address the above aims, an online survey was conducted using Crowdflower, an online crowd-sourcing platform.

Statement of authorship

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Name of Principal Author (Candidate)	Sze Yan Cheung		
Contribution to the Paper	Performed analysis on all articles, interpreted data, wrote manuscript, and acted as corresponding author.		
Overall percentage (%)	80%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	21/04/2017

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

   i.   the candidate's stated contribution to the publication is accurate (as detailed above);

   ii.   permission is granted for the candidate in include the publication in the thesis; and

   iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

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Abstract

Use of the term "cancer survivor" by health agencies and professionals is broad and can extend to include people newly diagnosed with cancer and also significant others. We examined lay understandings of the term and the impact of cancer-related experiences. An anonymous online survey was completed by 263 crowdsourced adult USA residents without personal cancer diagnoses. Participants indicated which cancer identity best described individuals at three cancer stages; whether they considered significant others to be cancer survivors; their understanding of the terms "cancer survivor" and "cancer survivorship"; and finally, whether they had certain cancer-related experiences. To describe someone newly-diagnosed, someone who had finished primary treatment and someone in remission for 5 years or more, respondents most commonly selected "someone who has cancer" (39.9%), "a cancer patient" (39.2%), and "cancer survivor" (57.4%) respectively. "Cancer survivor" as an identity for relatives or friends was endorsed by 65.4%. Life experiences did not appear to be related to opinions about cancer identities. Lay definitions of a cancer survivor and survivorship most commonly depicted someone who has beaten cancer, is cancer-free and/or is in remission. In general, community members understand the term "cancer survivor" differently from health professionals or agencies, leading to potential miscommunications.

Introduction

In 1995, Ong and colleagues proposed a theoretical framework to explain how health

outcomes can be affected by the quality of communication between a patient and a doctor. Since

then, effective communication has been related to better adherence to treatment plans and better

health outcomes (Makoul & Curry, 2007). Effective communication includes the usage of the same

language by the individual with the diagnosis and multidisciplinary team who is treating this

individual, but within the field of cancer survivorship, there have been debates around the term

"cancer survivor".

Increasingly, individuals who have received a cancer diagnosis are described by others as

"cancer survivors", a term that is not uniformly endorsed or interpreted in the same way by these

individuals (Bellizzi & Blank, 2007; Dyer, 2015; Khan, Harrison, et al., 2012; Park et al., 2009). This

phrase, first contributed to the cancer discourse by Dr Fitzhugh Mullan in 1985, was initially applied

to an individual "from the time of diagnosis and for the balance of life" (National Coalition of Cancer

Survivorship [NCCS], n.d., para. 1). It is now sometimes extended to encompass significant others

affected by the cancer, such as caregivers, relatives or friends (NCCS, n.d.). Although the dominant

imagery of a cancer survivor portrayed by the media is of an inspiring individual who has fought a

hard, almost heroic, battle with cancer, it does not necessarily represent everyone who has been

diagnosed with cancer (Gubar, 2012). Hence, there are a substantial number who prefer other

identities, such as "cancer conqueror" or "someone who has/has had cancer" (Bellizzi & Blank, 2007;

Dyer, 2015; Khan, Harrison, et al., 2012; Park et al., 2009).

Using a term that people with cancer do not identify with may heightened a risk of

alienation (Deimling et al., 2007; Jagielski et al., 2012; Pieters & Heilemann, 2011) and possibly,

hinder these individuals from acknowledging or recognizing certain health problems (Pertl, Quigley,

& Hevey, 2014). They may become less engaged in their treatment programme or choose not to

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attend certain beneficial health programmes, due to the usage of the term "cancer survivor" in promotional materials or by the multidisciplinary team of health professionals caring for them.

A cancer diagnosis is life-changing, not only for the individual receiving the diagnosis but also for the people around them, influencing their understanding and perceptions of cancer (Balmer, Griffiths, & Dunn, 2014). Therefore, there is a need to communicate, not only with the individuals having the cancer diagnosis, but also members of the public who may have friends or relatives with cancer. Kelly and colleagues (2011) examined the understanding of the phrase "cancer survivor" in a sample including both cancer patients and individuals without cancer, recruited at breast cancer community events. Having a "cancer survivor" identity was only endorsed by participants with a cancer diagnosis and, of the 139 participants without prior cancer diagnoses, only 3 would describe family and friends as cancer survivors. However, not all presented results were reported separately for participants with and without cancer diagnoses, making them difficult to interpret. Moreover, all participants likely had prior knowledge and experience of cancer and its treatments, so these findings would not truly represent broader lay understandings.

Accordingly, this study expanded on Kelly et al. (2011) by exploring lay understandings of cancer survivorship. Specifically, our research questions were: (1) how individuals without a diagnosis label those with a diagnosis; (2) what they understand by the terms "cancer survivor" and "cancer survivorship"; and (3) whether their understanding may be influenced by relevant experiences such as a personal cancer scare, or by having a close friend or family member being diagnosed with cancer.

To obtain a representative community sample, crowdsourcing, defined as "soliciting over the Internet from a group of unselected people, services and data that could not normally be provided solely by automated sensors or computation lacking human input" (Ranard et al., 2014, p. 188), was

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used. Crowdsourcing is increasingly utilised in online health research, from solving complex protein structure prediction problems through games (Cooper et al., 2010) to replicating classic laboratory experiments online such as prisoner's dilemma game (Horton, Rand, & Zeckhauser, 2011). Compared with traditional data collection, crowdsourcing has been shown to be an equally, if not more, reliable recruitment method, providing access to people with diverse backgrounds who better represent the general population (Behrend, Sharek, Meade, & Wiebe, 2011; Germine et al., 2012; Weinberg, Freese, & McElhattan, 2014).

Methods

The study was approved by the School of Psychology Human Research Ethics Subcommittee of the University of Adelaide: Protocol #15/79.

Participants

Survey participation was open to all individuals (a) aged over 18 years and (b) currently residing in the United States of America (USA). Crowdflower, an online crowd-sourcing platform, was used to obtain survey responses over a period of 2 days. For this exploratory study, an initial sample of 300 people was expected to provide sufficient diversity of responses and statistical power, while satisfying the assumptions of statistical tests. Of the 300 people completing the online questionnaire, 263 participants met eligibility criteria, were included in the study, and received US$0.50 as compensation for their time. This sample size exceeded the requirement ($N = 133$) previously identified through a power analysis for achieving significance ($p < .05$) with a medium effect size and 80% power (Faul, Erdfelder, Lang, & Buchner, 2007).

Measures

Each participant completed an anonymous questionnaire (see Appendix B) that included demographic questions (e.g. age, marital status, and ethnicity). Dichotomous (Yes/No) questions

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were asked: whether the respondent had ever been diagnosed with cancer themselves, had ever had a personal cancer scare, or had ever had someone close (such as a family member or friend) with a cancer diagnosis. They were also asked to consider which of the following cancer identities – a cancer conqueror, a cancer patient, a cancer survivor, a cancer victim and someone who has (or has had) cancer – best described individuals (a) at cancer diagnosis, (b) upon completion of primary treatment, and (c) in remission for 5 years or more. Another dichotomous question asked whether they considered someone close to an individual diagnosed with cancer to also be a "cancer survivor". Finally, participants were asked to provide their own definitions of the terms "cancer survivor" and "cancer survivorship".

Quality control

To ensure that all participants were from USA, the survey was made available only to participants with USA internet provider addresses. Participants were also asked for their current country of residence, in case they were using a proxy. To exclude participants who were completing the survey solely for remuneration and would compromise data quality, a time period of 60 seconds was chosen as the minimum time for survey completion, and the amount of remuneration was that recommended for a 15 minute study (University of Waterloo [Office of Research Ethics], 2013).

Data analysis

The data were screened for meaningless responses e.g. ghjgj and hgr5ed ($n = 9$), incorrect country ($n = 11$), age below 18 ($n = 1$), and non-consent ($n = 1$). Because only people without a cancer diagnosis were eligible for the study, respondents reporting previous cancer diagnoses were excluded ($n = 15$). Descriptive statistics were conducted on the remaining data ($N = 263$) to examine participants' opinions concerning which cancer identities best described individuals diagnosed with cancer at different stages of the cancer journey. SPSS 21 was used for all statistical testing (Chi-square, Cochran's Q, and McNemar tests) of relationships between preferred identities at different

cancer stages and (a) a personal history of cancer scare(s); (b) having a significant other who has had a cancer diagnosis; or (c) considering someone close to be a cancer survivor.

To identify prominent themes within the qualitative data (participants' definitions of cancer survivor and survivorship), word frequency queries were conducted using NVivo. Each response was then reviewed to check its context, and recategorised if necessary by the first author. Ambiguous responses were discussed with the other authors before being recategorised.

Results

The study sample in this study was demographically representative of the population of the USA. As indicated in Table 9, 129 men (49.0%) and 134 women (51.0%) participated. Percentages in the 2010 United States Census were 49.2% male and 50.8% female (Howden & Meyer, 2011). Mean age was 35.6 years (SD = 12.8; range = 18-70), comparable with the 2010 census mean of 37.2 years, and 73.0% of our sample indicated that they were white, similar to the census figure of 72.4% (U.S. Census Bureau, 2011). Forty-six participants had had at least one previous cancer scare and 172 had had someone close being diagnosed with cancer. The answers to our research questions are presented below.

Table 9

Participants' characteristics

	Gender	
	Male *n* (%)	Female *n* (%)
N	129 (49.0)	134 (51.0)
Age (*M* (*SD*))	33.2 (12.0)	37.9 (13.2)
Marital status		
Single, never married	70 (54.3)	57 (42.5)
Married or domestic partnership	53 (41.1)	66 (49.3)
Widowed	0 (0.0)	3 (2.2)
Divorced	5 (3.9)	7 (5.2)
Separated	1 (0.8)	1 (0.7)
Ethnicity		
Caucasian European/White	87 (67.4)	105 (78.4)
Hispanic or Latino	18 (14.0)	7 (5.2)
Black/African American	8 (6.2)	5 (3.7)
Native American or American Indian	4 (3.1)	1 (0.7)
Asian	10 (7.8)	12 (9.0)
Pacific Islander	0 (0.0)	1 (0.7)
Other	2 (1.6)	3 (2.2)
Education		
No formal schooling	6 (4.7)	5 (3.7)
Primary/elementary school	1 (0.8)	0 (0.0)
Some secondary/high school	6 (4.7)	3 (2.2)
Completed secondary/high school	42 (32.6)	41 (30.6)
Technical/trade/vocational training	8 (6.2)	18 (13.4)
Associate degree	1729 (7.0)	17 (12.7)
Bachelor's degree	32 (24.8)	35 (26.1)
Master's degree	12 (9.3)	12 (9.0)
Professional degree	7 (5.4)	2 (1.5)
Doctorate degree	6 (4.7)	1 (0.7)
Prior cancer scare		
Yes	23 (17.8)	23 (17.2)
No	106 (82.2)	111 (82.8)

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Someone close with a cancer diagnosis		
Yes	76 (58.9)	96 (71.6)
No	53 (41.1)	38 (28.4)

Cancer identities: how individuals without a diagnosis label those with a diagnosis

As depicted in Figure 5, most participants selected either "someone who has cancer" (n = 105; 39.9%) or "a cancer patient" (n= 95; 36.1%) to describe someone newly diagnosed with cancer, with only 3.8% (n=10) endorsing "cancer survivor". Someone who had finished primary treatment was most often termed "a cancer patient" (n = 103; 39.2%) or "a cancer survivor" (n = 77; 29.3%). The term "cancer survivor" was selected by 57.4% (n =151) of the respondents to describe individuals in remission for 5 years or more.
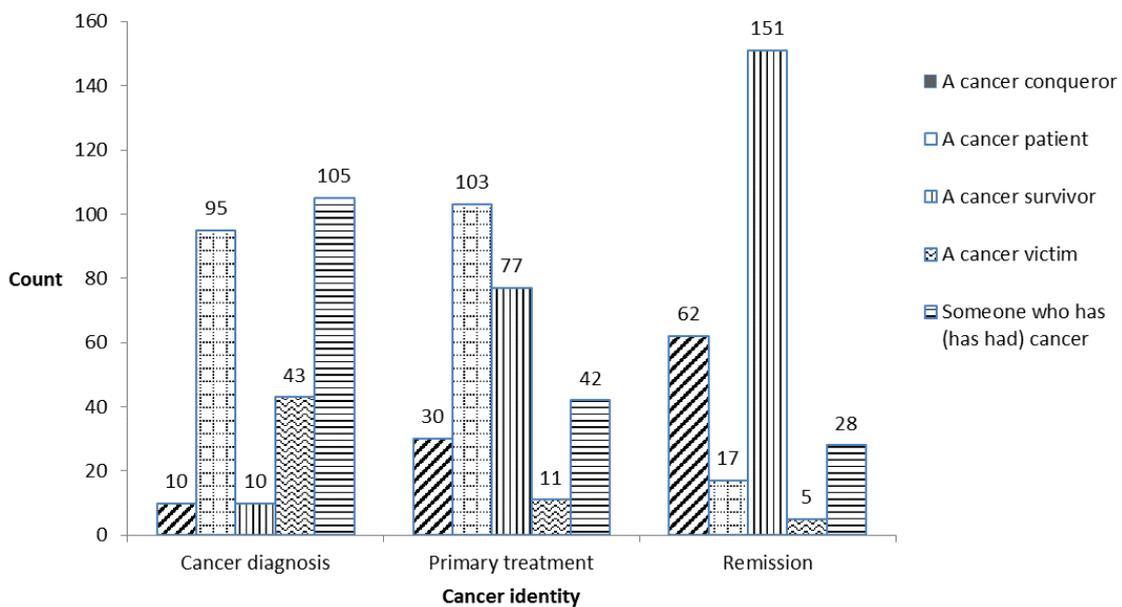

Figure 5. Choice of cancer identity at different stages of cancer survivorship.

Further analyses using Cochran's Q for repeated categorical samples were then conducted to compare the probability of endorsing different identities at different cancer stages. As indicated in

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Table 10, there were significant differences in the proportion of participants choosing the various identities at different stages of cancer survivorship, except for the choice of "cancer patient" between diagnosis and treatment and the choice of "cancer victim" between treatment and remission. Significantly more participants chose "cancer conqueror" and "cancer survivor" to describe an individual in remission than for someone at diagnosis or after primary treatment. Significantly fewer participants chose "cancer patient" to describe an individual at remission, but there was no significant difference between the number of participants choosing this term to describe an individual at diagnosis or after primary treatment. A smaller proportion of participants described an individual as a "cancer victim" after primary treatment and in remission, compared to the diagnosis stage. There were significantly fewer participants choosing "someone who has (has had) cancer" to describe an individual after primary treatment or in remission than at diagnosis.

Table 10

Choice of cancer identity at different stages of cancer survivorship

	Cochran's Q (Cramer's *v*)	McNemar test (φ)		
		Diagnosis VS Treatment	Treatment VS Remission	Diagnosis VS Remission
Cancer conqueror	49.74***	12.03***	12.32***	44.85***
	(0.31)	(0.21)	(0.22)	(0.41)
Cancer patient	79.21***	0.37	64.51***	60.50***
	(0.39)	(0.04)	(0.50)	(0.48)
Cancer survivor	153.85***	56.57***	33.73***	128.11***
	(0.54)	(0.46)	(0.36)	(0.70)
Cancer victim	52.17***	22.80***	.146 [a]	32.60***
	(0.31)	(0.30)		(0.35)
Someone who has (has had) cancer	103.00***	45.22***	6.04*	69.59***
	(0.44)	(0.41)	(0.15)	(0.50)

* $p < .05$, ** $p < .01$, *** $p < .001$

[a] The exact significance value is provided here instead because a binomial distribution was used by SPSS during data analysis and no chi-square value was reported.

What do "cancer survivor" and "cancer survivorship" mean to lay people?

Of the 259 participants who provided definitions, most considered a "cancer survivor" to be someone who has beaten cancer, is cancer free and/or is in remission (n = 121; 46.7%). Thirty-four participants (13.1%) indicated that the phrase referred to someone who has survived cancer or its treatment(s). Only 10 participants (3.9%) said that a "cancer survivor" is someone who has or had cancer treatments and only 9 (3.5%) considered that a cancer diagnosis was sufficient for someone to be considered a "cancer survivor".

The three most frequently recurring themes (see Table 11) were of someone being cancer-free or in remission (n = 92; 35.5%), beating cancer (n = 70; 27.0%), or having had treatment (n = 66; 25.5%). Although 17 (6.6%) included caregivers in their responses, three other participants (1.2%) specified that the term only applied to individuals who has been diagnosed with cancer.

Table 11

Frequency of common themes for the terms "cancer survivor" and "cancer survivorship"

Themes	Cancer survivor (n = 259)	Cancer survivorship (n = 248)
Returning to normal	4 (1.5%)	-
Cancer recurrence	10 (3.9%)	2 (0.8%)
Strength	11 (4.2%)	-
Being cured	18 (6.9%)	8 (3.2%)
Being alive	20 (7.7%)	8 (3.2%)
Fighting spirit	25 (9.7%)	16 (6.5%)
Survival	55 (21.2%)	63 (25.4%)
Having had treatment	66 (25.5%)	24 (9.7%)
Beating cancer	70 (27.0%)	44 (17.7%)
Being in remission or cancer-free	92 (35.5%)	50 (20.2%)

There were 248 responses to the question concerning the perceived meaning of "cancer survivorship". Of these, 36 participants (14.5%) reported that they thought "cancer survivorship" meant the same as "cancer survivor", and 31 (12.5%) commented that they had never heard of it. It was a less familiar phrase than "cancer survivor", with another 29 participants (11.7%) expressing uncertainty about its meaning.

Most thought that the phrase referred to a person ($n = 90$; 36.3%) or a group of people ($n = 23$; 9.3%). The phrase was also considered to be a type of abstract noun – a concept of time ($n = 17$; 6.9%) with 5 years being the most frequent time period specified ($n = 5$; 29.4%), ability ($n = 10$; 4%), or cancer experience ($n = 44$; 17.7%). Common themes resembled those for "cancer survivor" (see Table 11): surviving cancer and/or treatment ($n = 63$; 25.4%), being cancer-free or in remission ($n = 50$; 20.2%), and beating cancer ($n = 44$; 17.7%).

Personal opinions concerning these two phrases were diverse. "Cancer survivor" was mostly seen as a positive and empowering phrase. However, three participants expressed dislike for this phrase or any term relating an individual to cancer: "… people are not defined by cancer. They are not the cancer, no one with the flu would be described as a flu survivor or flu patient so why are people being defined when they have cancer." Only two liked the phrase "cancer survivorship" – the overwhelming response was negative. It was described as a meaningless phrase that "stigmatises people with cancer more than it helps", and some respondents questioned the need to use it.

The impact of cancer-related personal experiences

Having someone close with a cancer diagnosis was significantly related to choice of cancer identity for an individual who has been in remission for 5 years or more, X^2 (4, N = 263) = 10.40, p < .05, ϕ = 1.99. Interpretation of standardised residuals revealed that participants without someone close having cancer diagnoses more often considered an individual in remission to be "someone who

has/has had cancer", compared with other identities. However, having someone close with a cancer diagnosis was not significantly related to choices of cancer identity for individuals either newly diagnosed with cancer or having recently completed primary treatment (see Table 12).

Table 12

Comparing respondents with and without relevant life experiences: Chi-square statistics

	Cancer scare	Having someone close with a cancer diagnosis
Cancer identity for cancer diagnosis	8.50	8.85
Cancer identity for primary treatment	2.07	3.29
Cancer identity for remission	1.65	10.40*
Considering someone close to an individual diagnosed with cancer to be cancer survivors	0.42	0.00

* $p < .05$

A personal history of cancer scare(s) did not affect participants' selection of cancer identities. A close friend or family member of a person diagnosed with cancer was considered to be a "cancer survivor" by 65.4% of participants (n = 172): this was not influenced by having had a cancer scare or someone close being diagnosed with cancer.

Discussion

This study expanded on Kelly and colleagues' (2011) study by utilising a large and diverse sample of community adults to examine: (1) how individuals without a diagnosis label those with a diagnosis; (2) what they understand by the terms "cancer survivor" and "cancer survivorship"; and (3) whether their understanding may be influenced by relevant experiences such as a personal cancer scare, or by having a close friend or family member being diagnosed with cancer. Most participants chose "someone who has cancer", "a cancer patient", and "a cancer survivor" to describe someone who has just received a cancer diagnosis, who has completed primary treatment,

and who has been in remission for 5 years or more respectively. Comparing descriptions at remission versus initial diagnosis, significantly more participants chose "cancer conqueror" and "cancer survivor", and fewer chose "cancer victim", "cancer patient" or "someone who has (has had) cancer". Choice of cancer identities was not related to cancer scare history. Participants who had not had someone close diagnosed with cancer were significantly more likely to consider an individual in remission to be "someone who has/has had cancer", compared with other identities.

The finding that lay individuals without a cancer diagnosis would identify an individual with a cancer diagnosis with different terminology at different stages of cancer survivorship is congruent with a previous study reporting that cancer identities endorsed by individuals diagnosed with cancer may also change over time (D. Cho & Park, 2015). For the remission stage, there was an increase in the endorsement of identities with more positive connotations over identities with more negative or neutral connotations, possibly symbolising the triumphant imagery of an individual winning the battle against cancer.

Similar to previous research investigating lay understanding of cancer terminology used during consultations (K. Chapman, Abraham, Jenkins, & Fallowfield, 2003; Pieterse, Jager, Smets, & Henselmans, 2013) and other studies reporting the understanding of cancer survivorship among individuals diagnosed with cancer (Bellizzi & Blank, 2007; Dyer, 2015; Khan, Harrison, et al., 2012; Park et al., 2009), a substantial number did not interpret the phrases "cancer survivor" or "cancer survivorship" in the same way as health organisations or health professionals may. Instead, they perceived a "cancer survivor" as an individual in remission.

This study identified that although "cancer survivor" was mostly seen as a positive term, some community members considered it inappropriate. This is congruent with previous research with individuals diagnosed with cancer. A recent review of those studies revealed that some

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individuals considered the term to be offensive to people who died from cancer (Cheung & Delfabbro, 2016). The more abstract phrase "cancer survivorship" was not readily recognised in this community sample, possibly due to a lack of usage outside the oncology setting.

In this study, life experiences such as having had a cancer scare or having a friend or relative with a cancer diagnosis did not generally appear to influence the allocation of cancer identities to stages. However, people who had not had someone close diagnosed with cancer were more likely than others to describe an individual in remission to be "someone who has/has had cancer" rather than as a cancer survivor. This may reflect a lay assumption that cancer no longer plays a significant role in life or identity after the individual has gone into remission, similar to observations concerning individuals diagnosed with prostate cancer (Bellizzi & Blank, 2007).

This study has limitations that must be acknowledged. We utilised an online self-report method that can lead to biases both in sampling and in the nature of the responses received. For example, people may not respond in a way that is entirely congruent with their actual beliefs, or they may respond in certain ways influenced by what they infer to be the purpose of the study. Moreover, the study can only generalise from the population that is amenable to taking part in this type of research: literate in English, with online access, and an interest in undertaking surveys. Although the age-range for participants was wide, their mean age was in the thirties. Given that cancer and cancer survivorship are largely phenomena of middle and late life, older people's understandings are also important.

Nevertheless, these results confirm that crowdsourcing is a quick and efficient method for obtaining data from a large and diverse community sample. Furthermore, the study had a more representative sample in terms of the participants' gender than Kelly and colleagues' (2011) that had a mainly female sample. Future studies should compare these results with responses from other

samples, including health professionals, people with cancer diagnoses, and older community members, perhaps incorporating interviews and focus groups for richer information from specific populations.

Despite its limitations, the study has, however, provided a greater understanding of how people without a cancer diagnosis understand certain cancer terminology and illuminated the extent to which this lay understanding differs from definitions published by cancer professionals and advocacy organisations such as NCSS. These results demonstrate the need for stakeholders within the cancer care sector to communicate with the community more effectively so that the outcomes of individuals diagnosed with cancer can be improved.

CHAPTER 5: STUDY 3

Preamble

Together, the findings of Studies 1 and 2 (Chapters 3 and 4) revealed that people diagnosed with cancer and lay people had a different understanding of the term "cancer survivor", compared with professional understandings and definitions. These perceptions may have been influenced by the media (Lyons, 2000). Although there has been research examining cancer coverage within the mass media in various countries as previously mentioned in Chapter 2's literature review, no study has looked into the media's usage of terms associated with cancer identities.

Study 3 was subsequently designed to investigate: (1) the coverage of cancer in Australian printed news and whether specific cancers were over- or under-reported, in terms of their actual impact on Australians' lives; (2) the dominant imagery used to describe individuals diagnosed with cancer; (3) the context in which the terms "survivor", "conqueror", and "victim" were used; and 4) the media portrayal of the impact of cancer on an individual's identity. Unlike the previous study, Australia was selected as the setting for the present study on the basis of the researchers' cultural context and understanding. To address the aims for this study, a content analysis of all cancer-related news items from 4 Australian newspapers published in 2015 was carried out.

Statement of authorship

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Principal Author

Name of Principal Author (Candidate)	Sze Yan Cheung		
Contribution to the Paper	Performed analysis on all articles, interpreted data, wrote manuscript, and acted as corresponding author.		
Overall percentage (%)	80%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	21/04/2017

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

  i.   the candidate's stated contribution to the publication is accurate (as detailed above);

  ii. permission is granted for the candidate in include the publication in the thesis; and

  iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Paul Delfabbro		
Contribution to the Paper	Supervised development of work and manuscript evaluation.		
Signature		Date	21/04/2017

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Contribution to the Paper	Supervised development of work and manuscript evaluation.		
Signature		Date	21/04/2017

Abstract

Objectives

To investigate the coverage of cancer in Australian printed news and the media portrayal of individuals diagnosed with cancer.

Design and setting

Content analysis of all cancer-related news items published in 2015 from two national newspapers (*The Australian* and *Australian Financial Review*) and two randomly selected state newspapers (*The Age* and *The Daily Telegraph*).

Main outcome measures

Coverage of cancer: focus for each news items, number of news items on specific cancers, and relationship with disability-adjusted life-years for that cancer.

Media portrayal of individuals diagnosed with cancer: dominant imagery of someone diagnosed with cancer; impact of cancer on identity; and the usage of "survivor", "conqueror", and "victim" as descriptors.

Results

The top focus for the news items were human interest stories (20.3%). The most commonly reported cancer was breast cancer (24.8% of all items on specific cancers). Some cancers were over-reported (e.g. Hodgkin lymphoma), whereas others like larynx cancer were under-reported. The dominant imagery of an individual diagnosed with cancer was that of a woman aged under 50 years with breast cancer. Issues around cancer identity were rarely mentioned (n = 9): some individuals preferred not to be defined by cancer, whereas others felt that cancer had not affected them much. The term "survivor" appeared in 59 news items and was mostly used to describe someone who had

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beaten cancer or was in remission; "victim"(n = 16) was mostly used to depict someone who was dying or had died of cancer; and "conqueror" did not appear in any news items.

Conclusions

The findings indicate Australian printed news can potentially mislead news consumers to form inaccurate perceptions of cancer and of individuals diagnosed with the disease. Journalists should provide more balanced coverage and refrain from using terminology that people with the diagnosis do not identify with.

Background

The mass media is influential in shaping public opinion and ultimately, public policies
(McCombs, 2002; Soroka et al., 2012). Not only can the media's health representation of a particular
disease affect the understanding of this disease, it can also influence how people diagnosed with the
disease are viewed (Lyons, 2000) and their usage of health services (Grilli, Ramsay, & Minozzi, 2002).
Hence, it is important to examine media representations because they are indicative of current
public perceptions and can thus inform the development of public education programs, correcting
inaccurate perceptions for existing and future patients and their families.

Previous studies into media coverage of cancer in Australia have mostly focused on specific
types of cancer, such as breast cancer (S. Chapman et al., 2005; Crabb & LeCouteur, 2006; Jones,
2004; MacKenzie, Chapman, Holding, et al., 2010; MacKenzie, Chapman, Salkeld, et al., 2008),
prostate cancer (Lawrentschuk et al., 2011; MacKenzie, Chapman, Barratt, et al., 2007; MacKenzie,
Chapman, Holding, et al., 2007), and skin cancer (MacKenzie, Imison, et al., 2008; Scully et al., 2014;
Scully et al., 2008) in television broadcasts. Most of these studies were conducted by the same
research team, The Australian Health News Research Collaboration (AHNRC). They have found that
certain cancers, such as breast cancer, were over-reported in Australian television news whereas
others, such as colorectal cancer, were under-reported (MacKenzie, Chapman, Johnson, et al., 2008),
similar to findings from the United States of America (USA; Williamson et al., 2011). Not only were
inaccurate or misleading information about screening tests and incidence rates presented
(MacKenzie, Chapman, Barratt, et al., 2007; MacKenzie, Chapman, Holding, et al., 2007), there were
also misrepresentations of individuals diagnosed with cancer (Jones, 2004; MacKenzie, Chapman,
Holding, et al., 2010). This inaccurate representation of cancer has been shown to lead to more
women outside high risk age-brackets attending breast cancer screening (S. Chapman et al., 2005).
Another high-profile example of media influence on Australian public health policy was the depiction
in media stories of desperate and unfortunate women who were unable to access an effective but

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costly cancer drug, Herceptin, with the government being portrayed as cruel and/or incompetent for

refusing to approve the national Pharmaceutical Benefits Scheme (PBS) subsidy (MacKenzie,

Chapman, Salkeld, et al., 2008). This 11-months publicity eventuated in PBS approval for Herceptin.

In Australia between 2009 and 2013, people diagnosed with cancer had an overall 68%

probability of 5-year survival, an increase from 48% for 1984-1988 (Australian Institute of Health and

Welfare [AIHW], 2017). This improvement in survival rates highlights the need to extend media

research beyond screening, treatment and prevention measures, and to examine media depictions

of individuals living in the aftermath of cancer diagnoses, because such depictions may impact on

policy, and on the experience and psychological identity development of people in the community

living with cancer diagnoses. Research suggests that in the USA media, survivorship is generally

portrayed in a positive light, with little coverage of specific challenges of life after treatment such as

treatment effects or financial issues (Kromm, Smith, & Singer, 2007; Larson et al., 2009), but those

studies have not explored the usage of terms associated with cancer identities. Similarly, our

systematic search revealed no study examining cancer identities in an Australian context.

Cancer is a life-changing event, affecting all aspects of an individual's life, and often the

effects of cancer and its treatments will persist until the end of life. People with cancer will, hence,

develop a new identity, discard an old one, or reformulate a current identity to incorporate the

experience of cancer (Little et al., 2002; Zebrack, 2000). The replacement of the term "cancer victim"

with "cancer survivor" has been embraced by the media and policymakers. However, not everyone

who has been diagnosed with cancer identifies as a "survivor", and whether people with cancer

embrace the term has been shown to be dependent on their interpretation of it (Bellizzi & Blank,

2007; Deimling et al., 2007; Khan, Harrison, et al., 2012). Australian studies examining the

acceptability of this term have shown there are individuals who would actively reject this term,

preferring alternative terminology, for example "someone who has had cancer" or "conqueror" (Chambers et al., 2012; McGrath & Holewa, 2012; Morris et al., 2014).

This study aimed to extend on a study of Australian television reporting (MacKenzie, Chapman, Johnson, et al., 2008) by utilising an Australian print newspaper sample to investigate: (1) the coverage of cancer in Australian printed news and whether specific cancers were over- or under-reported, in terms of their actual impact on Australians' lives; (2) the dominant imagery used to describe individuals diagnosed with cancer; (3) the context in which the terms "survivor", "conqueror" and, "victim" were used; and (4) the media portrayal of the impact of cancer on an individual's identity. Printed newspapers were chosen for analysis because this is still the preferred medium for news consumption within the Australian population having 13.8 million readers: two-thirds of adults picked up a metropolitan or national newspaper within the last month, despite the increasing popularity of digital news media (The Newspaper Works, 2016). Moreover, newspapers have been acknowledged within Australia as the agenda-setters for other forms of media in the daily news cycle (S. Chapman, 2004; Pearson, Brand, Archbold, & Rane, 2001).

Methods

Search strategy

Both national Australian newspapers (*The Australian* and *Australian Financial Review*) were selected for review, along with two randomly selected state newspapers, one from each of the major mass media corporations (*The Age* from Melbourne, Victoria and *The Daily Telegraph* from Sydney, New South Wales). The LexisNexis database was searched for all printed cancer coverage in the four newspapers between 1 January and 31 December 2015, using a published search strategy (see Appendix A; Stryker, Wray, Hornik, & Yanovitzky, 2006). 1485 articles were retrieved and a

content analysis was subsequently performed on all relevant articles. Given the public nature of the

data, ethical approval was not required.

Articles were excluded if they were (a) duplicates of another article; (b) not about cancer,

not cancer-focused, or only incidentally mentioned cancer; (c) about cancer risk factors but not

related to cancer itself; (d) about "tumour" but with insufficient information to confirm that the

topic was a malignant tumour (i.e. cancer); or (e) alerting readers to a more extensive article

elsewhere in the same issue. To be included for analysis, the main focus of the article had to be

cancer-related, or the article contained a cancer-related human interest story (i.e. included a story

about a person diagnosed with cancer). This strategy resulted in a final sample of 845 articles

included for review (see Figure 6).
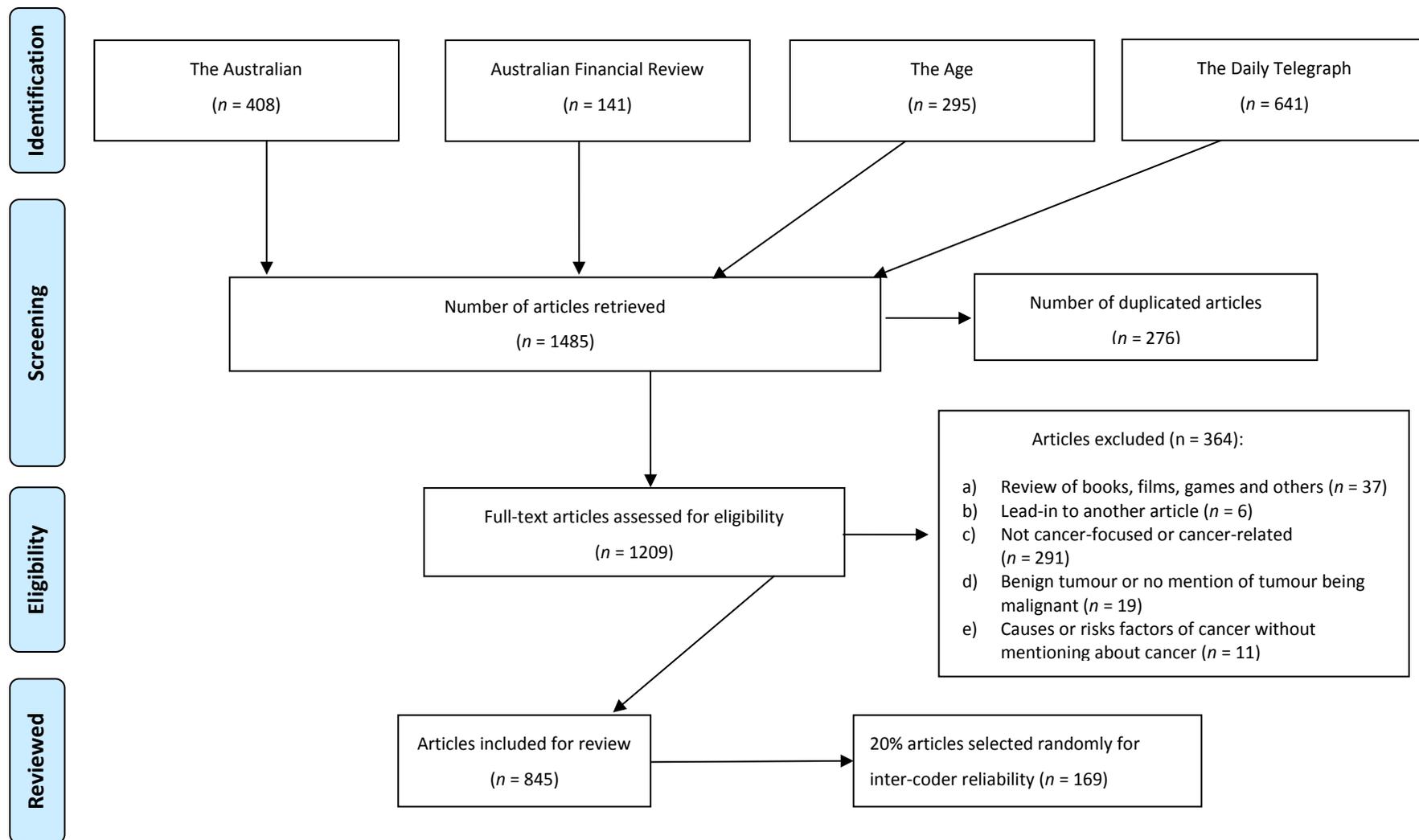
Figure 6. Flow diagram showing selection for eligible newspaper articles for review.

Measures

Based on published research in the field (Kromm et al., 2007; Larson et al., 2009; MacKenzie, Chapman, Johnson, et al., 2008), a coding template was developed, piloted with a separate sample (newspaper articles published in November and December 2014) and revised. The final version (see Appendices B-D) recorded the newspaper in which the article appeared, its publication date, headline, and the cancer site(s) to which it referred. If the article had two or more sections reporting different news, each section (i.e. news item) was recorded separately. The focus of the news item was then determined, and if more than one cancer-related issue was raised, the dominant focus was recorded.

Each news item was also coded for whether it featured one or more human interest stories (i.e. included a story about a person diagnosed with cancer). For each human interest story, information about the individual's gender, age at diagnosis and cancer type was recorded, along with Information about how the impact of cancer was depicted.

Analysis

Following Lombard and colleague's (2002) approach to intercoder reliability for content analysis, the first author and an independent coder pilot-tested the template with a random sample of 30 articles published between November and December 2014 before examining a random subset of 170 articles published in 2015. Coding discrepancies were subsequently resolved through discussion.

For the variables discussed in this article, intercoder reliability was examined using Krippendorff's Alpha (Hayes & Krippendorff, 2007) that was calculated using SPSS 21 and it ranged from 0.67 to 0.99 (see Table 17 in Appendix E). The low value of 0.67 was considered to be acceptable because there was only one disagreement for that variable.

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An over- or under-reporting factor was calculated for each cancer (observed/predicted number of articles). In order to predict what an accurate reporting level would be, we obtained Australian data on prevalence, incidence, mortality and disability-adjusted life-years (DALYs) from the Global Burden of Disease (GBS) Cancer Collaboration (2016) and ranked this information in order of DALYs lost (see Table 13). Spearman's rank correlation was subsequently calculated using SPSS 21 to compare those ranks with the ranked volume of news coverage given to each specific cancer.

Qualitative information about (a) the usage of the terms "survivor", "conqueror", and "victim", and (b) the portrayal of cancer's impact on life (i.e. physical, psychological, cognitive and economic impacts) was categorised into themes by the first author. Discrepancies and ambiguities were resolved through discussion with the other authors.

Results

Cancer coverage

On average, 70.1 relevant articles (SD = 16.5; range: 46-97) were published each month in 2015. Most articles were published in The Daily Telegraph (*n* = 369), followed by The Australian (*n* = 192), The Age (*n* = 187), and the Australian Financial Review (*n* = 97).

Of the 845 articles included for analysis, there were 854 unique news items (one article contained 3 news items; seven had 2 news items each). The most common focus of articles was *human interest stories* (20.3%), followed by *treatment* (17.0%) and *awareness* (14.3%) (see Figure 7). Of the news items whose main focus was on *human interest stories*, 121 reported the cancer experiences of public figures, including the deaths of former Victorian premier Joan Kirner and cricket icon Richie Benaud. More than a third of the *miscellaneous* articles featured Belle Gibson, a

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celebrity alternative health advocate exposed for fraudulent claims about having had cancer and having cured it with controversial therapies (*n* = 33).
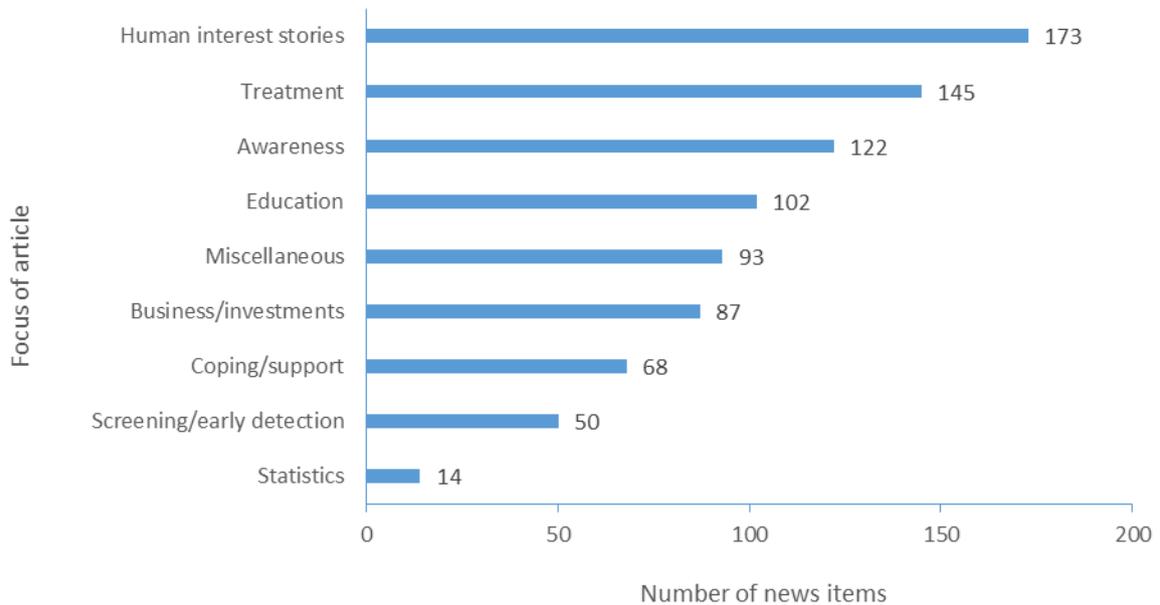
Figure 7. Number of news items by focus of the article (*N* = 854).

There were 403 news items (47.2%) that either did not mention a particular cancer site, or focussed on multiple cancer sites. As shown in Figure 8, of the remaining 451 news items, breast cancer was the most frequently mentioned cancer site (*n* = 112; 27.8%), followed by brain and nervous system cancer (*n* = 47; 11.7%), and prostate cancer (*n* = 43; 10.7%). Cancers of the larynx or nasopharynx were not mentioned in any news items.
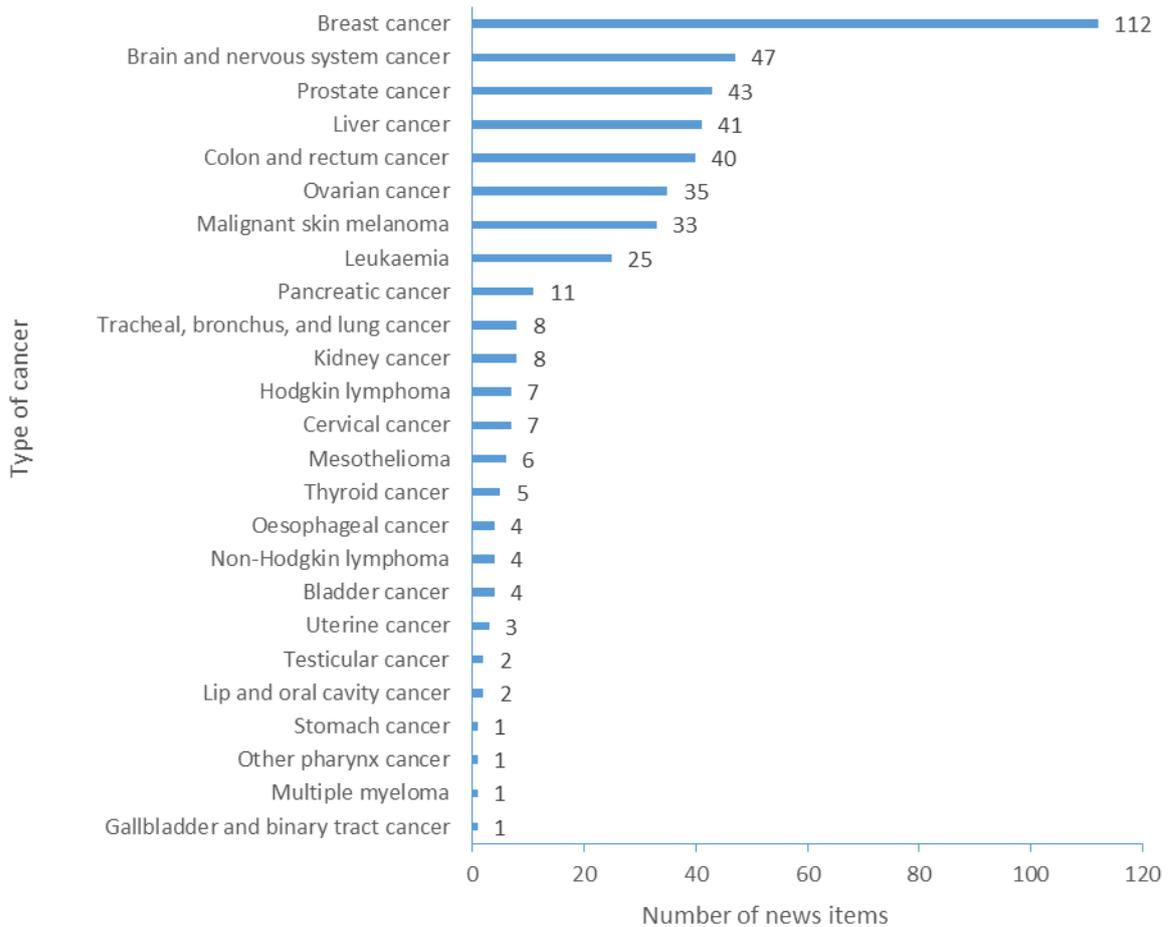
Figure 8. Number of news items by type of cancer (*N* = 854).

There were significant correlations between the rank orders of each cancer for number of articles and for DALYs (ρ = .69, *p* = .000), incidence (ρ = .61, *p* = .001) and mortality (ρ = .63, *p* = .000). Hodgkin lymphoma was the most over-reported cancer site, being mentioned 5.53 times more than it should have been, possibly reflecting news items on Tessa James, an Australian actress, returning to the public scene. The second and third most over-reported cancer sites were liver cancer (reporting factor = 3.21) and ovarian cancer (reporting factor = 3.20) respectively. Larynx cancer and nasopharynx cancers were the most under-reported cancer sites (reporting factor = 0), followed by stomach cancer (reporting factor = 0.07) and tracheal, bronchus, and lung cancer (reporting factor = 0.10).

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Table 13

Ranking of cancers by burden, incidence, mortality and news items

	DALYs		Incidence		Mortality		News items			Reporting factor (%)
	ASR[a]	Ranking	ASR[a]	Ranking	ASR[a]	Ranking	n	Ranking	Predicted[b]	
Tracheal, bronchus, and lung cancer	495.1	1	39.5	5	26.5	1	8	10	79.26	0.10
Colon and rectum cancer	333.9	2	77.4	2	17.3	2	40	5	53.46	0.75
Breast cancer	280.8	3	64.1	3	10.1	4	112	1	44.95	2.49
Prostate cancer	211.2	4	125.1	1	10.7	3	43	3	33.81	1.27
Malignant skin melanoma	149.0	5	54.1	4	5.5	8	33	7	23.85	1.38
Pancreatic cancer	139.7	6	10.4	10	7.9	5	11	9	22.37	0.49
Leukemia	137.9	7	10.4	10	6.2	6	25	8	22.08	1.13
Brain and nervous system cancer	132.8	8	8.1	14	4.5	10	47	2	21.26	2.21
Non-Hodgkin lymphoma	115.1	9	22.5	6	5.7	7	4	16	18.43	0.22
Stomach cancer	91.3	10	11.5	8	5.2	9	1	22	14.62	0.07
Liver cancer	79.9	11	6.3	15	3.9	12	41	4	12.79	3.21
Oesophageal cancer	79.9	11	5.5	18	4.3	11	4	16	12.79	0.31
Kidney cancer	69.8	13	12.6	7	3.3	13	8	10	11.17	0.72
Ovarian cancer	68.3	14	5.6	17	3.2	15	35	6	10.93	3.20
Multiple myeloma	51.1	15	6.3	15	2.8	16	1	22	8.18	0.12
Bladder cancer	49.1	16	10.0	12	3.3	13	4	16	7.86	0.51
Mesothelioma	42.0	17	2.9	21	2.3	17	6	14	6.72	0.89
Cervical cancer	31.0	18	2.8	22	1.3	19	7	12	4.96	1.41
Lip and oral cavity cancer	28.0	19	2.6	23	1.3	19	2	20	4.48	0.45
Gallbladder and biliary tract cancer	26.7	20	3.0	20	1.7	18	1	22	4.27	0.23
Uterine cancer	23.5	21	11.5	8	1.0	21	3	19	3.76	0.80
Other pharynx cancer	23.2	22	3.9	19	1.0	21	1	22	3.71	0.27
Larynx cancer	16.2	23	2.4	25	0.8	23	0	26	2.59	0.00
Nasopharynx cancer	15.4	24	1.3	27	0.7	24	0	26	2.47	0.00

Thyroid cancer	11.5	25	8.7	13	0.3	25	5	15	1.84	2.72
Hodgkin lymphoma	7.9	26	1.4	26	0.2	26	7	12	1.26	5.53
Testicular cancer	4.4	27	2.5	24	0.1	27	2	20	0.70	2.84

[a] Age-standardized rate per 100,000. Values were obtained from Global Burden of Disease Cancer Collaboration (2016); [b] Predicted number of news items based on proportion of DALYs,

calculated as $\frac{DALY\ of\ a\ particular\ cancer}{DALYs\ for\ all\ cancers} \times total\ number\ of\ news\ items$; [c] Over/under-reporting factor, calculated as $\frac{number\ of\ news\ items}{predicted\ number\ of\ news\ items}$.

This table format is from MacKenzie and colleagues (2008).

Dominant imagery of an individual diagnosed with cancer

There were 459 human interest stories. The dominant imagery of an individual diagnosed with cancer was that of a woman aged under 50 years with breast cancer. For men, skin cancer, in particular melanoma, was the most frequently mentioned cancer type, followed by brain cancer. Children were most commonly portrayed with brain cancer or acute lymphoblastic leukaemia.

Impact of cancer and its sequelae

Although three individuals reported that they had had a quick recovery and that cancer had no impact on their lives, many others were reported as saying that they had been changed by the experience, or that cancer had paused their lives or caused them to lose a future they had envisaged. The most frequently mentioned impact was the physical impact (n = 98), followed by the psychosocial (n = 71), and economic impacts (n = 50), and the most rarely mentioned impact was cognitive (n = 9; see Table 14 for the top 3 sequelae of each category).

Table 14

Various impacts of cancer and the top 3 sequelae of each category

Cognitive impact	Economic impact	Physical impact	Psychosocial impact
Cognitive difficulties (e.g. compromised memory, lowered concentration)	• Time away from work/school • Expensive treatments • Re-evaluation of career plans	• Compromised sexual functioning • Hair loss • Fatigue	• Negative emotions (e.g. distress, worry, feeling overwhelmed) • New perspectives/ outlook • Gender identity affected

Cancer was reported in some instances to have affected gender identity (*n* = 6). Women with breast cancer were quoted as not feeling comfortable with the changes in their bodies after surgery (because parts that are considered female had been removed or altered), and conversely, reporting that breast reconstruction or scar-covering tattoos allowed them to feel more feminine. Similarly, some men indicated that their masculinity had been affected by compromised sexual functioning. Some news items (*n* = 9) specifically raised the issue of cancer identity in the negative, reporting instances of individuals rejecting cancer identity altogether, preferring not to be defined by cancer, or not wanting to be known as the "cancer girl" or the "cancer guy". In some instances those individuals also commented that their life had not been impacted much by cancer.

Usage of the terms "conqueror", "survivor", "victim"

The term "conqueror" did not appear in any news items. The term "survivor" appeared in 59 news items and was used in various stages of the care continuum: treatment phase (*n* = 1); completion of primary treatment (*n* = 6); beat the odds/survived cancer/remission (*n* = 14). It was used once to describe a family member. Of these 59 mentions of the term "survivor", 29 of them referred to individuals with cancer helping out with cancer-related activities, such as fund-raising, lobbying for new drugs to be approved and subsidized (e.g. Ron Walker) and fighting against breast cancer genes being patented (e.g. Yvonne D'Arcy).

The term "victim" appeared in 16 news items, most often used to describe an individual who was dying or had died of cancer (*n* = 8). It was also used when describing individuals who were suffering from cancer and its sequelae, such as hair loss or an unhealthy-looking complexion (*n* = 3)

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Discussion

This study aimed to extend on a study of Australian television reporting (MacKenzie, Chapman, Johnson, et al., 2008) by utilising an Australian print newspaper sample to investigate: (1) the coverage of cancer in Australian printed news and whether specific cancers were over- or under-reported, in terms of their actual impact on Australians' lives; (2) the dominant imagery used to describe individuals diagnosed with cancer; (3) the context in which the terms "survivor", "conqueror", and "victim" were used; and (4) the media portrayal of the impact of cancer on an individual's identity.

The most common focus of the articles was *human interest stories*, of which the majority reported the cancer experiences of public figures. Similar to the findings from previous studies that examined other types of media in Australia (MacKenzie, Chapman, Johnson, et al., 2008; Wilson et al., 2010), the most frequently mentioned cancer site was breast cancer. Certain cancers were over-reported with Hodgkin lymphoma being the most over-reported cancer site whereas other cancers, such as uterine cancer and pancreatic cancer, were under-reported. Although it is not possible to directly compare the findings from this study with those of MacKenzie and colleagues (2008) because the timeframe for the media analysis was different, the findings of this study are consistent with past research that media often over- or under-reports certain types of cancer (MacKenzie, Chapman, Barratt, et al., 2007; MacKenzie, Chapman, Holding, et al., 2010; MacKenzie, Chapman, Johnson, et al., 2008; MacKenzie, Chapman, McGeechan, et al., 2010).

The dominant imagery of an individual with cancer was that of a female adult under the age of 50 diagnosed with cancer, which is consistent with other research (MacKenzie, Chapman, Holding, et al., 2010; MacKenzie, Chapman, Johnson, et al., 2008). A previous study by Chapman and colleagues (2005) showed that inaccurate representation of breast cancer led to more women

attending breast cancer screening even if they did not fall into the at risk-age bracket. This highlights

the importance of accurate coverage within the media so that news consumers will not obtain

misleading or inaccurate information from the media, which may negatively impact on healthcare

services and usage.

Although a few people indicated that cancer had had no impact on their lives, most were

reported as describing one or more impacts and of those, overall, physical impact was the most

frequently mentioned. Cognitive impact was the least frequently mentioned and was reported in

only 9 news items despite documented effects of chemotherapy being associated with cognitive

impairment (Deprez et al., 2012; Schagen, Muller, Boogerd, Mellenbergh, & van Dam, 2006; van

Dam et al., 1998). There is a need for an increased coverage of cognitive impacts because people

with cancer become less willing to report side-effects or negative emotions when their experiences

are not congruent with those reported in the media (Sulik, 2013). This can result in certain issues not

being addressed in survivorship care and hence, lower quality of life.

This study found that changes to one's gender identity and the reluctance to adopt a cancer

identity were reported in the news, which is consistent with previous studies that examined identity

changes in individuals diagnosed with cancer (Bellizzi & Blank, 2007; Cecil et al., 2010). The term

"conqueror" was not mentioned in any news item. The term "victim" had negative connotations and

was used to describe those who were dying or had died from cancer. The term "survivor" was the

most frequently mentioned term and was used to describe those who had completed primary

treatment, had survived cancer or were in remission, and, in some news items, used to describe

people who were carrying out cancer-related activities. Past Australian research has shown that

some people with cancer do not identify as a "survivor" but as a "conqueror" or "someone who

has/has had cancer" (Chambers et al., 2012; McGrath & Holewa, 2012; Morris et al., 2014). Hence,

these labels used in the media, together with the portrayal of cancer experiences, may result in

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miscommunication because they can influence the public's perception of people with cancer and how an individual with a cancer diagnosis will perceive himself or herself (Lyons, 2000). Therefore, the media should look into the usage of more appropriate and sensitive terms (e.g. "people with cancer", "people living with cancer") to replace the terms "survivor" and "victim" as suggested by the Cancer Institute of New South Wales (2017).

A limitation of this study is that the news articles were sourced from an online database that may not have had every article uploaded. This study examined a single year's coverage of cancer and findings could potentially be influenced by a spike in reporting from certain events such as Belle Gibson being exposed as making fraudulent claims about having cancer, or the World Health Organisation report about the risk of developing colorectal cancer from eating red or processed meats. Hence, more research should be conducted with news articles over a longer timeframe to obtain a better understanding of the representation of cancer and the people diagnosed with cancer.

The findings of this study add to the understanding of media discourse within the area of cancer. They are not only important to other researchers in the field but also to policymakers, the media and healthcare professionals. With the understanding of the amount of coverage of various cancers, and the dominant portrayal of cancer and people diagnosed with cancer, policymakers can develop certain programmes to assist in correcting misconceptions and inaccuracies - and encourage journalists and media outlets to portray the full range of cancers, and their impacts, in more factual and meaningful ways. Meanwhile, healthcare professionals involved in oncological care can see which topics may need more clarification when communicating with people with cancer and their families. Only with proper communication can there be a well-considered and individualised survivorship care plan that a person with cancer will more likely adhere to, potentially increasing their length of survival and quality of life.

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CHAPTER 6: STUDY 4

Preamble

The previous chapter (Study 3) showed that cancer identities of individuals were rarely mentioned in Australian printed news. It was found that individuals featured in the news items would not want to be identified as a "cancer survivor", which is consistent with findings from past research examining endorsement of this identity within Australians diagnosed with cancer (Chambers et al., 2012; McGrath & Holewa, 2012; Morris et al., 2014). However, of the three cancer identities examined in our study, it was the most commonly mentioned one and was most frequently used to describe those who had beaten cancer or were in remission.

Previous research has suggested that cultural differences affect the way news was delivered (Kanayama & Cooper-Chen, 2005; Y. S. Kim & Kelly, 2008) so the portrayal of cancer and individuals diagnosed with cancer in Australia could be different from that in other countries. Chapter 2's literature review showed that no study has yet examined cancer coverage within the Singaporean context or the portrayal of cancer identity in Asian media. Study 4 was, therefore, conducted with the aims to replicate the Australian study and to extend on it by comparing the Singaporean findings with the Australian ones. Similar to the Australian study, a content analysis of all cancer-related news items published in 2015 from the Singaporean English-language dailies was carried out.

Singapore was selected as the setting for this study on the basis of the researchers' cultural context and understanding, and also because Singapore is one of the few Asian countries where English is an official and primary language. Its rapid growth from a poverty-stricken country to one with a high income economy has made other nations view it as a story of economic success (Birdsall, et al., 1993), but also raised concerns within the local government about the need to maintain Asian values rather than adopting "a more Westernised, individualistic, and self-centred" way of life

(Singapore Parliament, 1991, p.1). Singapore's resident population is predominantly Chinese in ethnic composition (74.3%) (Singapore Department of Statistics, 2016) whereas the most commonly reported ancestries in Australia are English (33.7%) and Australian (33.0%) (Department of Immigration and Border Protection, 2014). Hence, Study 4 offered the opportunity for direct cross-country and cross-cultural comparisons between Australian and Singaporean newspapers, and its findings could potentially highlight different forms of media representation of cancer and of individuals diagnosed with cancer.

Statement of authorship

Title of Paper	A tale of two countries: A comparison of cancer coverage in Australian and Singaporean printed news.
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Publication Details	N.A.

Principal Author

Name of Principal Author (Candidate)	Sze Yan Cheung		
Contribution to the Paper	Performed analysis on all articles, interpreted data, wrote manuscript, and acted as corresponding author.		
Overall percentage (%)	80%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	21/04/2017

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

    i.   the candidate's stated contribution to the publication is accurate (as detailed above);

    ii.   permission is granted for the candidate in include the publication in the thesis; and

    iii.   the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Paul Delfabbro		
Contribution to the Paper	Supervised development of work and manuscript evaluation.		
Signature		Date	21/04/2017

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Contribution to the Paper	Supervised development of work and manuscript evaluation.		
Signature		Date	21/04/2017

Abstract

Aim

To investigate the coverage of cancer in Singaporean printed news, in particular the media portrayal of individuals diagnosed with cancer, and to compare the findings with those from Australian printed news.

Methods

A content analysis of all cancer-related news items published in 2015 (n=421) from all English-language dailies was carried out.

Results

The top focus for the news items was human interest stories (21.9%). The most commonly reported cancer was breast cancer (22.4% of all items on specific cancers). Some cancers were over-reported (e.g. testicular cancer), whereas others like larynx cancer were under-reported. The dominant imagery of an individual diagnosed with cancer was that of a woman aged under 50 years with breast cancer. Issues around cancer identity were rarely mentioned (n = 2). The term "survivor" appeared in 43 news items and was mostly used to describe someone who had survived cancer or was in remission; "victim" (n = 4) was mostly used to depict someone who was dying or had died of cancer; and "conqueror" did not appear in any news items. Cancer coverage in Singaporean printed news was very similar to that in Australian printed news, but Singapore had significantly more human interest stories than Australia.

Conclusion

This study shows that the current representation of cancer and individuals diagnosed with the disease may cause news consumers to form inaccurate perceptions. There is a need for more

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accurate coverage within the media and future research should explore whether culture could

potentially affect the way messages are delivered through the media.

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Background

In Singapore, cancer survival rates have increased in recent years due to advancements in technology and improvements in medical care, with a 48.5% and 57.1% chance of 5-year survival, and 43.3% and 51.6% chance of 10-year survival for males and females respectively (Singapore Cancer Registry, 2015b). However, negative attitudes towards cancer and individuals diagnosed with the disease still prevail, not only within the nation, but worldwide (Chen et al., 2006; J. Cho et al., 2013; Robb et al., 2014). For example, 23.5% of adults surveyed in South Korea would avoid working with individuals diagnosed with cancer (J. Cho et al., 2013), and more than 80% surveyed in Singapore revealed they would not employ anyone with a history of cancer if they were given a choice (Chen et al., 2006).

Past research has indicated that the understanding of a particular disease can be influenced by its representation in the mass media, including how individuals with the disease perceive themselves and are perceived by others (Lyons, 2000). Being a life-changing event, cancer affects one's concept of self and people with cancer have been shown to develop new identities or incorporate the experience of cancer into a pre-existing identity (Little et al., 2002; Zebrack, 2000). Our previous study examining identity within Australian printed news has revealed that although identity changes within individuals diagnosed with cancer were rarely reported in Australian printed news (n = 9), the term "cancer survivor" was the most commonly used term to describe them, being mentioned in 59 news items. This was despite Australian research indicating that a substantial amount of individuals diagnosed with cancer would not like to identify as such (Chambers et al., 2012; Morris et al., 2014) and the Cancer Institute of New South Wales (2017) recommending usage of sensitive and neutral terms like "people diagnosed with cancer" in the mass media. Although there has been media coverage of cancer within Asia, no study has yet examined cancer coverage in Singapore or the portrayal of identity in Asian media. Understanding media representations of

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cancer within Singapore is important because it is indicative of the current public perception and can inform the development of educational programs targeting inaccurate perceptions.

This study aimed to replicate and extend the Australian study by investigating: (1) the coverage of cancer in Singaporean printed news and whether specific cancers were over- or under-reported, in terms of their actual impact on Singaporean's lives; (2) the dominant imagery used to describe individuals diagnosed with cancer; (3) the context in which the terms "survivor", "conqueror" and "victim" were used; and, (4) the media portrayal of the impact of cancer on an individual's identity. This study also aimed to extend on our previous study by comparing the above findings with that of the Australian study to examine whether there were differences between the two nations in the form of coverage and the dominant representations of an individual diagnosed with cancer.

Because Singapore is a collectivist society where decisions are made based on the interest of collectivities (whereas Australia is an individualist society where decisions are more based on self-interest (Hofstede, 1991)), Singaporean newspaper reporters might be more likely to include stories about identifiable individuals diagnosed with cancer in order to evoke certain emotions in the community. Under Jonsen's "Rule of Rescue" (1986), readers would then be more likely to act upon the main message delivered by the article. Thus, in terms of specific comparisons, it was hypothesized that (1) Singaporean newspapers would include more human interest stories in their articles than Australian newspapers.

Cancers in Singapore are generally detected later stages than in other developed countries (Singapore Cancer Registry, 2015b; Tan, Lim, Czene, Hall, & Chia, 2009). Hence, it was hypothesized that there would be significantly more articles in the areas of (2) awareness and (3) detection and early screening amongst Singaporean newspapers than Australian newspapers.

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Methods

Search strategy

With the exception of *Today* which is published by MediaCorp Press, all other newspapers in Singapore are published by Singapore Press Holdings. For this study, all English-language dailies (*The Straits Times*, *The Business Times*, *The New Paper*, *Today*) were included for analysis. The 2015 Nielsen Media Index report found that *The Straits Times* and *Today* were the most-read and second most-read daily newspapers respectively (TODAY second-most-read newspaper, 2015). Ethical approval was not required for this study.

With the exception of *Today* whose articles were only available through the Factiva database, all cancer-related articles in the above-mentioned newspapers were retrieved from The LexisNexis database using a published search strategy (see Appendix A; Stryker et al., 2006). The timeframe was restricted: 1 January 2015 to 31 December 2015 – the same time-period sampled in the Australian study. A content analysis was subsequently performed on all relevant articles.

Articles were included for review if they had cancer-related foci, or they contained at least one cancer-related human interest story (i.e. included a story about a person diagnosed with cancer). They were excluded if they were (a) duplicates of another article; (b) not about cancer, not cancer-focused, or only incidentally mentioned cancer; (c) about cancer risk factors but did not relate these factors back to cancer; (d) about "tumour" but having insufficient information to verify that the tumour in question was malignant (i.e. cancer); or (e) alerting readers to a more extensive article elsewhere in the same issue. A final sample of 417 articles was included for review (see Figure 9).
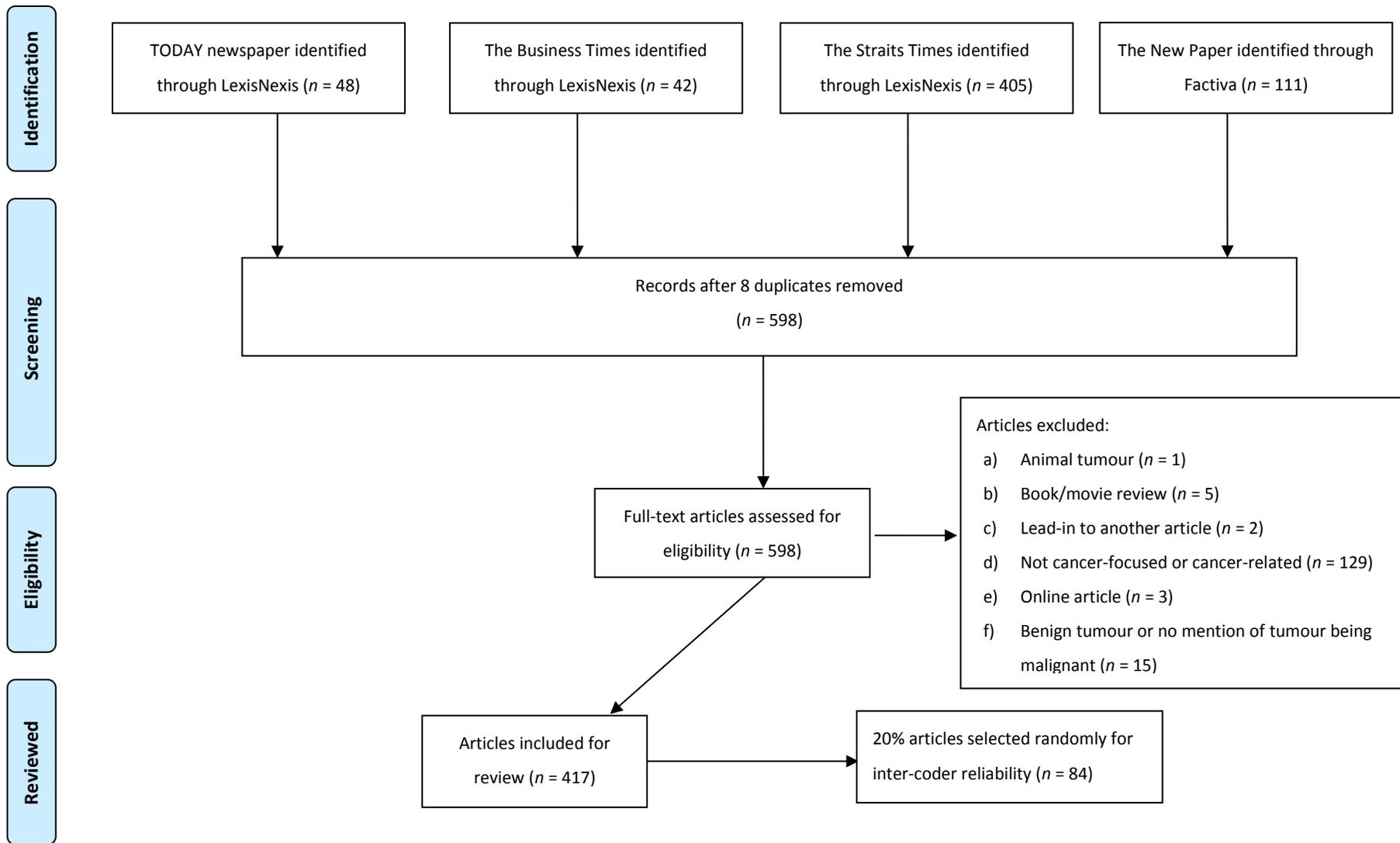
Figure 9. Flow diagram showing selection for eligible newspaper articles for review.

Measures

Using the coding template from our previous study (see Appendices B-D), the newspaper in which the article appeared, its publication date, headline, and the cancer site(s) to which it referred to were recorded. If the article had two or more sections reporting different news, each section (i.e. news item) was recorded separately. The focus of the news item was then determined, and if more than one cancer-related issue was raised, the dominant focus was recorded.

Each news item was also coded for whether it featured one or more human interest stories. For each human interest story, information about the individual's gender, age at diagnosis and cancer type was recorded, along with information about how the impact of cancer was depicted.

Analysis

In accordance with Lombard and colleague's (2002) approach to intercoder reliability for content analysis, an independent coder examined a random subset of 84 articles, and coding discrepancies were resolved through discussion. Intercoder reliability was calculated using SPSS 21 and Krippendorff's Alpha ranged from 0.71 to 1.0 (see Table 18 in Appendix E; Hayes & Krippendorff, 2007). .

An over- or under-reporting factor was calculated for each cancer (observed/predicted number of articles). Singaporean data on prevalence, incidence, mortality and disability-adjusted life-years (DALYs) from the Global Burden of Disease (GBS) Cancer Collaboration (2016) was obtained to predict an accurate reporting level and this information was ranked in order of DALYs lost (see Table 15). Those ranks were subsequently compared with the ranked volume of news coverage given to each specific cancers using Spearman's rank correlation. To calculate whether the differences for news articles between Singapore and Australia with regard to human interest stories,

awareness, and detection and early screening were significant, proportions were first calculated before being tested.

Qualitative information about the usage of the terms "survivor", "conqueror" and "victim", and the portrayal of cancer's impact on life (i.e. physical, psychological, cognitive and economic impacts) was categorised into themes by the first author. Discrepancies and ambiguities were resolved through discussion with the other authors.

Results

Cancer coverage

An average of 34.7 articles were published per day (SD = 10.6; range: 16-55). Majority of the articles were published in The Straits Times (n = 277), followed by The New Paper (n = 84), TODAY (n = 36), and The Business Times published the fewest articles (n = 19).

There were 421 unique news items (5 articles having 2 news items each). The most common focus of the articles was *human interest stories* (21.9%), followed by *treatment* (19.0%) and *education* (17.8%) (see Figure 10). For the news items whose main focus was on *human interest stories*, 46 of them reported about the cancer experience of various public figures. Of these 46 items news, 15 were about the cancer diagnoses of Singapore's Prime Minister Lee Hsien Loong, who was revealed to have received a prostate cancer diagnosis in February. Singapore did not have significantly more new items on awareness (p = .807) or screening/early detection (p = .051) than Australia but had the same top two foci.
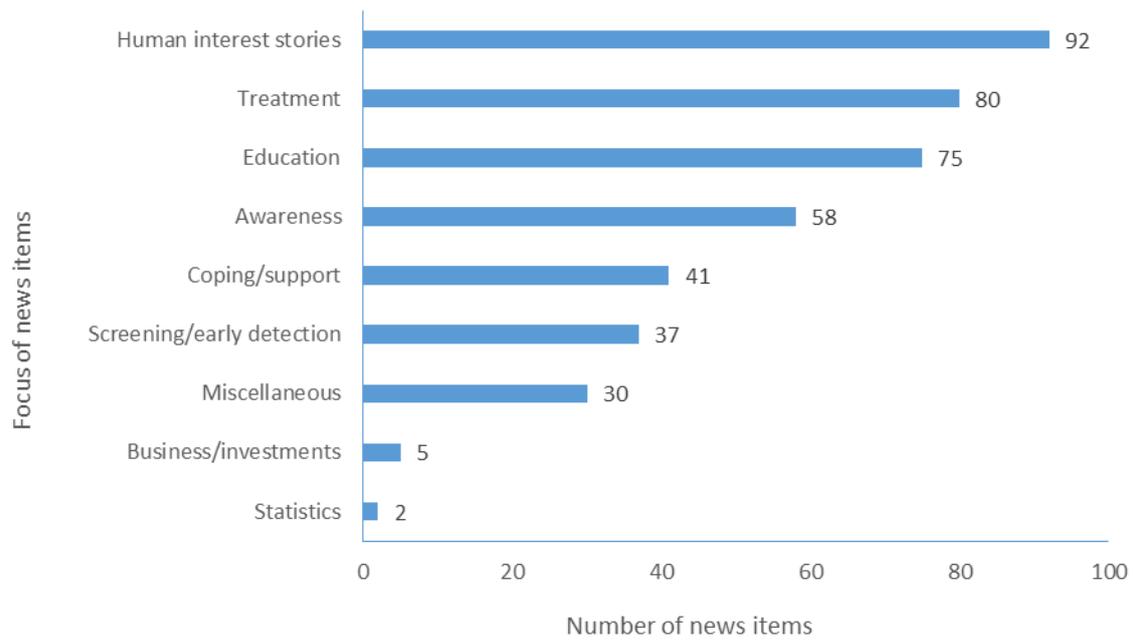
Figure 10. Number of news items by focus of the article (*N* = 421).

205 news items reported on multiple cancer sites or did not focus on any particular cancer site (48.7%). As seen in Figure 11, breast cancer was the most frequently mentioned cancer site of the remaining news items (*n* = 46; 10.9%), which is similar to Australia, followed by colon and rectum cancer (*n* = 39; 9.3%), and prostate cancer (*n* = 35; 8.3%). Larynx cancer, other pharynx cancer and mesothelioma were not mentioned in any of the news items. The former was also not mentioned in any of the news items in Australia.
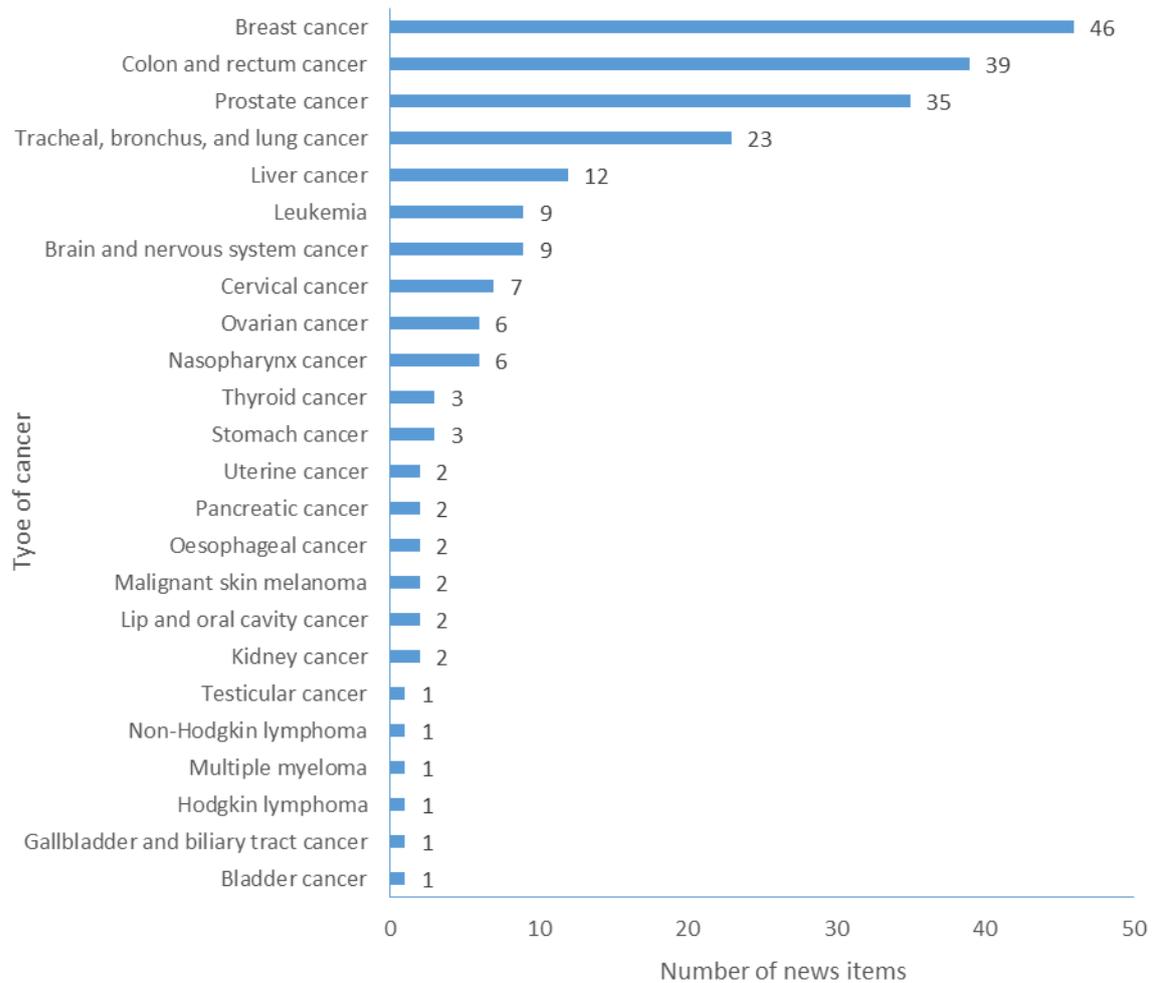
Figure 11. Number of news items by type of cancer (*N* = 421).

Similar to the findings in the Australian study, there were significant correlations between the rank orders of each cancer by number of articles and by DALYs (ρ = .76, *p* = .000), incidence (ρ = .73, *p* = .000) and mortality (ρ = .70, *p* = .000). Testicular cancer was the most over-reported cancer site, being mentioned 6.93 times more than it should have been, followed by prostate cancer (reporting factor = 6.61) and Hodgkin lymphoma (reporting factor = 3.01) (see Table 15). Larynx cancer, other pharynx cancer and mesothelioma were the most under-reported cancer site (reporting factor = 0), followed by non-Hodgkin lymphoma (reporting factor = 0.14) and pancreatic cancer (reporting factor = 0.19). Although the over-reported cancers were different, larynx cancer was similarly under-reported in Singapore and Australia.

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Table 15

Ranking of cancers by burden, incidence, mortality and news items

	DALYs		Incidence		Mortality		News items			Reporting factor (%)
	ASRa	Ranking	ASRa	Ranking	ASRa	Ranking	n	Ranking	Predictedb	
Tracheal, bronchus, and lung cancer	489.9	1	34.0	3	28.4	1	23	4	41.61	0.55
Colon and rectum cancer	355.9	2	52.8	1	19.4	2	39	2	30.23	1.29
Breast cancer	248.0	3	45.2	2	8.6	5	46	1	21.06	2.18
Liver cancer	231.0	4	16.6	5	12.3	3	12	5	19.62	0.61
Stomach cancer	157.7	5	15.2	6	9.3	4	3	11	13.39	0.22
Pancreatic cancer	122.7	6	7.7	11	6.8	6	2	13	10.42	0.19
Leukemia	121.9	7	9.2	9	4.2	7	9	6	10.35	0.87
Nasopharynx cancer	91.7	8	5.1	15	3.2	10	6	9	7.79	0.77
Non-Hodgkin lymphoma	82.1	9	11.8	8	3.6	8	1	19	6.97	0.14
Ovarian cancer	66.5	10	6.6	11	2.7	11	6	9	5.65	1.06
Brain and nervous system cancer	59.1	11	3.6	17	1.7	16	9	6	5.02	1.79
Prostate cancer	62.3	11	26.5	4	3.3	9	35	3	5.29	6.61
Kidney cancer	50.6	13	8.5	10	2.4	13	2	13	4.30	0.47
Cervical cancer	46.4	14	3.4	19	2.1	14	7	8	3.94	1.78
Esophageal cancer	46.3	15	3.5	18	2.6	11	2	13	3.93	0.51
Gallbladder and biliary tract cancer	34.2	16	4.4	16	2.0	15	1	19	2.90	0.34
Uterine cancer	30.5	17	12.2	7	1.2	18	2	13	2.59	0.77
Lip and oral cavity cancer	26.2	18	3.3	20	1.2	18	2	13	2.23	0.90
Bladder cancer	25.6	19	5.4	14	1.7	16	1	19	2.17	0.46
Multiple myeloma	22.8	20	3.1	21	1.1	20	1	19	1.94	0.52
Larynx cancer	13.9	21	1.7	22	0.8	21	0	25	1.18	0.00
Other pharynx cancer	13.0	22	1.5	23	0.6	22	0	25	1.10	0.00

Thyroid cancer	12.4	23	5.7	13	0.5	23	3	11	1.05	2.85
Malignant skin melanoma	8.4	24	0	24	0.3	25	2	13	0.71	2.80
Mesothelioma	8.2	25	0.4	27	0.4	24	0	25	0.70	0.00
Hodgkin lymphoma	3.9	26	0.8	24	0.1	26	1	19	0.33	3.02
Testicular cancer	1.7	27	0.8	24	0.0	27	1	19	0.14	6.93

[a] Age-standardized rate per 100,000. Values were obtained from Global Burden of Disease Cancer Collaboration (2016); [b] Predicted number of news items based on proportion of DALYs, calculated as $\frac{DALY\ of\ a\ particular\ cancer}{DALYs\ for\ all\ cancers} \times total\ number\ of\ news\ items$; [c] Over/under-reporting factor, calculated as $\frac{number\ of\ news\ items}{predicted\ number\ of\ news\ items}$.
This table format is from MacKenzie and colleagues (2008).

Dominant imagery of an individual diagnosed with cancer

There were 263 human interest stories and as hypothesized, Singapore had significantly more human interest stories than Australia (p = .003). Similar to the portrayal in Australian printed news, the dominant imagery of an individual diagnosed with cancer was that of a female adult under 50 years of age with breast cancer. While skin cancer was the most frequently mentioned cancer type among males in Australia, the most frequently mentioned cancer type in Singapore was prostate cancer, which might be a result of the prostate cancer diagnosis of Singapore's Prime Minister, Lee Hsien Loong. The most common portrayal of a child was one whd has been diagnosed with brain cancer.

Impact of cancer and its sequelae

The most frequently mentioned impact was the physical impact (n = 92), followed by the psychosocial impact (n = 39), and the economic impact (n = 21), and the least frequently mentioned impact was the cognitive impact (n = 3; see Table 16 for the top 3 sequelae of each category), which was the same as the ranked order for impacts mentioned in Australian newspapers.

Table 16

Various impacts of cancer and the top 3 sequelae of each category

Cognitive impact	Economic impact	Physical impact	Psychosocial impact
Cognitive difficulties (e.g. compromised memory, difficulty in decision making)	• Time away from work/school • Expensive treatments • High usage of savings or insurance	• Pain • Hair loss • Impaired motor skills	• Negative emotions (e.g. distress, worry, feeling overwhelmed) • New perspectives/ outlook • Relationships with family and friends affected

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Although one neurosurgeon was reported in a news item as commenting that cancer could rob someone of their identity, another news item mentioned a lack of cancer identity: the person concerned felt as though he never had cancer because he could continue with daily activities. There were only two news items mentioning gender identity and how cancer would affect one's sense of femininity or masculinity when sexual organs (e.g. breasts, testicles) were removed or altered.

Usage of the terms "conqueror", "survivor", or "victim"

The usage of these terms were similar to the findings from the Australian study. The term "conqueror" did not appear in any of the news items.

The term "survivor" appeared in 43 news items and was used in two different stages of the care continuum: completion of primary treatment (n = 5), and recovered from cancer/survived cancer/remission (n = 16). There were 13 news items about individuals with cancer helping out with cancer-related activities, such as fund-raising and sharing their experiences on social media to inspire other individuals with cancer.

The term "victim" appeared only in The Straits Times and in 4 news items, most frequently used to describe an individual who was dying or had died of cancer (n = 3).

Discussion

This study aimed to replicate and extend the Australian study by investigating: (1) the coverage of cancer in Singaporean printed news and whether specific cancers were over- or under-reported, in terms of their actual impact on Singaporean's lives; (2) the dominant imagery used to describe individuals diagnosed with cancer; (3) the context in which the terms "survivor", "conqueror" and "victim", were used; and, (4) the media portrayal of the impact of cancer on an

individual's identity. This study had also aimed to extend on our previous study by comparing the above findings with that of the Australian study to examine whether there were differences between the two nations in the form of coverage and the dominant representations of an individual diagnosed with cancer. In particular, it was hypothesized that Singaporean newspapers would include more human interest stories in their articles and have more articles in the areas of awareness and detection and early screening than Australian newspapers.

Similar to the Australian study, the most common focus of the news items was *human interest stories*. A total of 263 human interest stories were found in all the news items and Singapore had significantly more human interest stories than Australia as hypothesized, providing some evidence that Singaporean newspapers included more human interest stories in their news items due to the collectivist culture. However, Singapore did not have significantly more awareness or detection and early screening news items than Australia, even though cancers have been found to be detected at a later stage compared to other developed countries, possibly due to its treatment being on par with those countries (Singapore Cancer Registry, 2015b) so it was not viewed as being as much of an issue. Breast cancer was found to be the most frequently mentioned cancer site, which is in line with the findings of other studies in the region (Cai et al., 2009; Kishi et al., 2008; Kye et al., 2015).

As studies have shown in the news coverage of cancer in other countries like Australia (MacKenzie, Chapman, Holding, et al., 2010; MacKenzie, Chapman, Johnson, et al., 2008; MacKenzie, Chapman, McGeechan, et al., 2010), Japan (Kye et al., 2015) and USA (Williamson et al., 2011), certain cancers were over-reported (e.g. testicular cancer, prostate cancer) whereas others were under-reported (e.g. oesophageal, mesothelioma). It should be noted that certain head- or neck-related cancers were reported as "head and neck cancers" in the news items but they could only be categorised under "not specified cancers" because they do not fit under any category specified by

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The GBS Cancer Collaboration. Therefore, the various categories related to head and neck cancers (e.g. larynx cancer, nasopharynx cancer, other pharynx cancer) might have been shown to be under-reported in this article for this reason.

The dominant imagery of an individual with cancer was that of a female adult under the age of 50 diagnosed with cancer, which is in line with the findings from our Australian study and previous studies conducted by other researchers (Jones, 2004; MacKenzie, Chapman, Johnson, et al., 2008). Prostate cancer was found to the most commonly mentioned cancer among the male population and this high number of news items being published may have been a result of the prostate cancer diagnosis of Singapore's Prime Minister, Lee Hsien Loong, in February. Among children aged 0 to 14 years, those with brain and nervous system cancer were featured the most in Singaporean printed news, possibly due to it being the childhood cancer with the highest mortality rate (Singapore Cancer Registry, 2015a).

Just like the findings from the Australian study, physical impact was the most frequently mentioned impact with cognitive impact being the least frequently mentioned one. People with cancer have been shown to be less willing to report certain side-effects or negative emotions if their experiences are not similar to those reported in the media (Sulik, 2013) so there is a need to accurately represent all aspects of the cancer care continuum. Although there were fewer mentions about identity issues within Singaporean printed news, the usage of the terms "conqueror", "survivor" and "victim" were similar to the usage in Australian printed news. The term "conqueror" was not mentioned in any news item; the term "survivor" was used for those who have completed primary treatment, have recovered from cancer or are in remission, and sometimes used in conjunction to describe those who are carrying out cancer-related activities; the term "victim" was used to describe those who are dying or have passed away from cancer. Such labels used by the media can influence how the public perceive people with cancer and how people with cancer will

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perceive themselves (Lyons, 2000). Research looking into cancer identities has shown that some

people, especially those diagnosed with prostate cancer, do not like the term "survivor" and prefer

other terms like "conqueror" and "someone who has/has had cancer" (Bellizzi & Blank, 2007; D. Cho

& Park, 2015; Morris et al., 2014). Our recent systematic review indicated that 46.4% of 2727

respondents from 9 independent studies chose not to identify as a cancer survivor (Cheung &

Delfabbro, 2016) so there is a need to look into the usage of alternative terms for "survivor" within

the media in order not to alienate any individual diagnosed with cancer.

A limitation of this study is that the findings about usage of terms related to cancer identities

had no Singaporean data to compare with, unlike the Australian study. Hence, there is a need to

investigate the acceptability of the various cancer identities among Singaporeans and to find out

whether the increased usage of the term "cancer survivor" would reflect a greater endorsement of

the identity as compared to other types of identities. In addition, to obtain a better understanding of

the representation of cancer and the people diagnosed with cancer, future studies should also

examine the portrayal of identity over a longer timeframe because certain events (e.g. recent

diagnosis of Singapore's Prime Minister, Lee Hsien Loong) can affect the reporting of cancer. Other

forms of media should also be examined so that the findings can be made generalizable.

This study has added to the understanding of media discourse within the area of cancer and

the findings are important, not only to researchers in the field, but also policymakers and healthcare

professionals. Knowing the media's portrayal of cancer and the individuals diagnosed with the

disease will allow them to know which areas need clarification when communicating with the

individuals diagnosed with cancer and the various parties involved in cancer care. This study has also

provided evidence that culture may affect representation of cancer and the individuals diagnosed

with the disease, and its findings will assist in future research, especially those focused on the

perceptions on cancer and individuals with cancer in a non-Western context.

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CHAPTER 7: GENERAL DISCUSSION

The aims of the research project presented in this thesis were (1) to examine the understandings of individuals with cancer and the community for cancer identities (and in particular the "survivor" identity); and (2) to investigate media representations of individuals diagnosed with cancer that may not only affect the formation of cancer identities in these individuals, but also influence public perceptions and policies. This final chapter reviews the aims and findings of each study, and addresses the relevance of these findings to current literature. The implications of this research project for theory and practice, the limitations of the studies conducted, and future research directions are discussed.

7.1 Main research findings

As highlighted in the literature review in Chapter 2, there is no consensus on the definition of the term "cancer survivor" and often, the term is defined for the purpose of the activity (e.g. research study, new policy to be implemented) being carried out. Past research has suggested that one's identification as a cancer survivor may affect one's prognosis (Deimling et al., 2007), and hence, Study 1 (Chapter 3) took the form of a systematic review to examine the understanding of the "cancer survivor" identity in individuals diagnosed with cancer and the extent to which this identity was accepted by these individuals. This chapter also examined the factors that may play a role in the choice of identification and the outcomes of these choices. Analysis of the 24 included studies revealed that although "cancer survivor" is a widely accepted term, not everyone with a cancer diagnosis, especially those diagnosed with prostate cancer, would use this term. Moreover, this decision of non-identification was associated with poorer mental health and perception of a higher risk of recurrence. This study has therefore indicated that it is important to examine other understandings of cancer identities apart from that of health professionals and policymakers; for example, the lay understanding of various cancer identities should be examined because the

increasing numbers of people living longer with cancer mean that more and more community members are coming into contact with them – and differences in understandings may impact on communication and relationships.

The exploration into the lay understanding of the various cancer identities and survivorship was, therefore, the main focus of the next study (i.e. Study 2). A total of 263 crowdsourced adult USA residents who self-reported not having been diagnosed with cancer completed an online survey, which asked them to choose a suitable cancer identity to describe an individual at different stages of the cancer trajectory, and to describe their understanding of the terms "cancer survivor" and "cancer survivorship". Only 57.4% of the respondents considered someone who is 5 years in remission to be a "cancer survivor" and some felt that the term was unnecessary or unhelpful. Lay definitions of both terms most commonly depicted someone who has beaten cancer, is cancer-free and/or is in remission. This understanding (by lay people) resembled that of individuals diagnosed with cancer, rather than reflecting the views of health professionals.

These findings from Studies 1 and 2 were consistent with those of Hebdon and colleagues (2015), who carried out a concept analysis into the term "survivor" and revealed that it describes more than just an individual living with cancer. Critical attributes of a survivor were found to include (a) the individual receiving follow-up care after cancer treatment, and (b) having a personal cancer experience with both positive and negative consequences. A similar study to Study 1 was published in the same timeframe by Marzorati and colleagues (2016) who examined the definitions of "cancer survivor" in various published materials, and similarly, they pointed out the lack of consensus around its definition despite the extensive usage. In light of the findings from these studies (other published research and our own studies), it was deemed important to examine cancer and cancer identities in the context of the mass media because it is influential in shaping public opinions, which could explain the differing opinions between the experts and lay people.

Study 3, hence, addressed this issue by examining the coverage of cancer, the dominant imagery of an individual diagnosed with cancer, and the portrayal of the impact of cancer on an individual's identity in a sample of Australian newspapers covering 2015. The most frequently mentioned cancer site was breast cancer and it was over-reported relative to what might be expected based on the disability-adjusted life years (DALYs) of this disorder in Australia. Another cancer over-represented in the media was Hodgkin lymphoma whereas uterine cancer and pancreatic cancer were under-reported. The most common portrayal of an individual diagnosed with cancer was that of a female adult under the age of 50 and diagnosed with breast cancer. The above findings were consistent with previous Australian findings, which reported over-reporting or under-reporting of certain cancers and a preferable depiction of younger women who were below the recommended screening age for breast cancer (Jones, 2004; MacKenzie, Chapman, Holding, et al., 2010; MacKenzie, Chapman, McGeechan, et al., 2010). Identity issues was reported in the printed news with certain individuals being reluctant to adopt a cancer identity, in line with the findings of Study 1. The "cancer survivor" identity was the most frequently mentioned term and was mostly used to describe people who had finished treatment, had survived cancer, or were in remission. It was also sometimes used in the context of describing people who were carrying out cancer-related activities such as fundraising or advocating for better care of current cancer patients.

To examine the possibility of cultural differences, Study 4 involved a replication of the Australian study by investigating the same aims using a selection of Singaporean newspapers, also in 2015. Similar to Study 3, the most frequently mentioned cancer type was breast cancer and it was over-reported by 2.18 times. The most common portrayal of an individual diagnosed with cancer was that of a female adult under the age of 50 and diagnosed with breast cancer. Identity issues was rarely reported in Singapore, compared with Australia. In line with the findings from the Australian study, the "cancer survivor" identity was also the most frequently mentioned term; was used to

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describe people who had finished treatment, had survived cancer or were in remission; and was used at times to describe those who were carrying out cancer-related activities like fundraising or sharing their experiences on social media in the hope of inspiring others with cancer.

7.2 Research strengths

Study 1 is the first published systematic review that aimed to understand the term from the perspectives of people diagnosed with cancer – by compiling existing research specifically conducted with those individuals. Although Marzorati and colleagues (2016) conducted a similar study that was published around the same timeframe, they did not restrict the reviewed material to include only original papers that examined the perspectives of those who chose to or not to identify as a cancer survivor. Instead, they also included definitions drawn from online news sites and websites of advocacy organisations and cancer-related government departments. Moreover, they did not utilize search strategies customized for each database but used the same search terms (e.g. "cancer survivor definition", "cancer survivor label") for all databases. On the other hand, our study not only restricted the reviewed material to individuals who explicitly identified or refused to identify as a cancer survivor, but also utilised search strategies that were customised for each database – a methodological strength.

Unlike Kelly and colleagues' study (2011) on which Study 2 was based, our analyses were only conducted on data gathered from people without a cancer diagnosis and the participant pool was found to be demographically representative of the USA population. This provided a further insight to the understanding of the term "cancer survivor" and the usage of other cancer identities among lay people. Therefore, both Studies 1 and 2 add to the current field of literature about the understanding of various cancer identities from the perspectives of individuals diagnosed with cancer and the general public. Moreover, the first study also collated the possible reasons why an

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individual with cancer might choose to or not to endorse a "cancer survivor" identity, along with the related outcomes of these choices.

The findings of Studies 3 and 4 have contributed to the understanding of media discourse within the area of cancer. To our knowledge, they are the first studies to investigate the media's usage of terms associated with cancer identities to describe individuals diagnosed with cancer. Furthermore, Study 4 is the first study to examine media coverage of cancer in Singapore. The usage of a published search strategy to retrieve newspaper articles relevant for review was a methodological strength (Stryker et al., 2006). Moreover, by using the same study methodology, these studies allow for direct cross-country and cross-cultural comparisons between Australian and Singaporean newspapers and findings from these studies contribute towards the understanding of different representations in countries with different cultures.

7.3 Research limitations

A number of limitations can be identified, of which most issues have already been outlined in the preceding four chapters. In this section, limitations pertaining to the overall research project are also discussed. First, in Study 1, which reviewed the literature on how individuals with cancer would interpret the term "cancer survivor", not all journal articles were found to be published in English so some relevant articles could have been excluded due to the language. Second, it may be that there are cultural considerations that limit the generalizability of findings within this thesis: most eligible studies reviewed in Study 1 had been conducted in the USA and Study 2 was an online survey with American adults as the sample population. The term "cancer survivor" and survivorship research originated from USA so the samples in Studies 1 and 2 would presumably be exposed to cancer survivorship terminology at a higher frequency than people from other countries and may share a different understanding of cancer survivorship as compared to them. For example, Dyer (2015) showed that among Latino Americans in Puerto Rico, respondents considered the differences

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in cancer experiences to be a result of cultural differences. Hence, it is possible that residents of other countries understand the term "cancer survivor" and the other cancer identities differently and may have a different opinion with regard to the choice of a cancer identity.

Third, in relation to the findings from the media studies (Studies 3 and 4), it is important to acknowledge that the studies were restricted to the regions that were examined: selected on the basis of the researchers' cultural context and understanding. Asian countries are culturally diverse so the differences in media may reflect these cultural differences. Therefore, the differences between Australia and Singapore cannot be generalized to the differences between Australia and other Asian countries that (a) are not predominantly made up of Chinese people or (b) are more collectivistic than Singapore. Portrayal of cultural differences between the various races in Singapore within cancer-related media was also not explored so the representation in the media could be more reflective of the Chinese population and less so of the Malay or the Indian populations.

7.4 Practical implications

Overall, the findings of this research project raise the need for better communication between the sectors involved in cancer care and the community because the choice of words used can either help the individual with cancer to cope better or to increase their discomfort, and may even affect their survival if they choose not to adhere to their survivorship care plan. Although other researchers have pointed out that words can be inadequate to describe the reality that an individual with cancer is experiencing (Surbone & Tralongo, 2016), it is important not to disregard the current population who has chosen to endorse a particular type of cancer identity and for the people supporting them to understand their reasons for the choices made and how this choice is related to psychological well-being and participation in cancer-related activities (as discussed in Study 1). As recently recommended by the Cancer Institute of New South Wales, using neutral terms such as "people with cancer" and "people living with cancer" unless otherwise specified by the individual

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with the diagnosis would ensure that no one is alienated. Informational sessions could also be regularly conducted to ensure that the correct language is utilised in day-to-day communication with people with cancer or in cancer-related material such as media broadcasts or health program promotions. In this section, the implications for the various sectors involved in cancer care are discussed.

Healthcare professionals

The finding about identity issues, together with the cognitive effects of cancer and its sequelae, being rarely mentioned in the printed news highlights the need for the multi-disciplinary healthcare team treating the individual with cancer to find out what he or she understands about cancer and about survivorship and to let the person know about both the favourable outcomes and the long-term sequelae associated with cancer treatments and how to reduce them. Identity issues, various types of cancer identity and portrayal of these issues in the media should also be discussed with the person. This will ensure that they are aware of the debate around certain terminology like "cancer survivor" and the fact that media depictions of cancer are not necessarily normative and often downplay the more challenging aspects of people's experiences. Moreover, healthcare professionals need to carefully consider their use of terminology in order not to alienate any individual with cancer who may not necessarily embrace those terms and as a result, not attend or adhere to health programs, ultimately affecting their cancer care.

Researchers

Researchers should not passively rely on the media to monitor, interpret and disseminate their findings about cancer and its sequelae. Instead, they can make their findings more readily available by, for example, releasing plain language summaries that are targeted at a general audience to make their research findings more easily accessible and the resultant media reports more accurate. This will ensure that cancer-related matters are explained consistently and reduce

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the likelihood that misleading or inaccurate information may be disseminated. Researchers can also be proactive in publicising and publicly promoting awareness of research into lesser-known cancers and their risk factors and outcomes.

Mass media

Studies 3 and 4 demonstrated that the "cancer survivor" identity was more often used in the media to describe people who had moved beyond the treatment stage and in certain cases, used in in the context of cancer-related activities such as fund-raising and advocacy, which would have influenced how news consumers and other lay people would have perceived the term, and affected their understanding of who a cancer survivor is and how this individual would behave. This was not consistent with the recent recommendations of the Cancer Institute of NSW (2017). Terms such as "people with cancer" and "people living with cancer", are considered to be more appropriate for addressing or referring to individuals with the diagnosis whereas terms like "cancer victim", which was used in both countries, are considered less appropriate. Hence, it is an essential responsibility for journalists handling cancer-related material to carefully consider using alternative terms to replace the terms "survivor" and "victim" within their news materials. Similarly, the accurate evidence-based depiction of cancer and its diversity – of risk factors, symptoms, treatments, outcomes and impacts – is an important community service to which media outlets and professionals in every country need to commit themselves.

7.5 Theoretical implications

The findings from this research project provided evidence to support the applicability of Brown's Identity Disruption Model within individuals diagnosed with cancer. Specifically, Study 1 has shown that the diagnosis of cancer disrupts an individual's identity and that some individuals may adopt a new identity with its endorsement being related to health outcomes.

Although the contribution to theory is limited for this research project, its findings may inform further research into, and understanding of, the diversity and sensitivity of cancer identities and cancer experiences. In turn, demonstration of the extent to which cancer challenges and changes an individual's identity may assist in informing future development of a cancer identity theory, and inform identity theory more generally.

7.6 Future directions

As acknowledged in the literature review, although researchers have tried to quantify the extent that cancer becomes integrated into an individual's identity – that is, cancer centrality (Helgeson, 2011; Park et al., 2011) – the identified studies used different types of measures for assessment. Hence, future researchers could explore the development of a standardised measure of cancer centrality, enabling more systematic future studies of this topic.

The present research has generated some important findings. While the term "cancer survivor" is used in the media frequently, the first two studies have shown that it may not be the best term to describe an individual with cancer. Future research should focus on investigating the acceptability of other terms and explore possible ways for the multi-disciplinary team, which is looking after the individual with a cancer diagnosis, to formulate an individualised healthcare plan that addresses the issues around identity changes and consequences arising from these changes.

In this research project, data were collected in different countries. Study 1 (the systematic review) identified that most of the eligible studies of people diagnosed with cancer had been conducted in the USA, and Study 2 also relied on data from the USA: facilitating comparison of the findings of Studies 1 and 2. Studies 3 and 4 specifically examined media representations in Australia and Singapore, reflecting the local cultural knowledge and expertise of the student researcher and supervisors. In the future, when more empirical studies are available from outside the USA, future

researchers could aim to carry out all these investigations in the same countries (i.e. examine the understandings of cancer identities in people with cancer and other lay people, and the media coverage of cancer). It would be particularly useful to examine the aims of Studies 1 and 2 in other countries and/or cultures. Investigating the understanding of the various cancer identities and the overall cancer experience in other contexts would allow other types of understandings to emerge, especially if individuals interpret the cancer experience in locally appropriate ways. Survey research could also be complemented by one-to-one interviews or focus groups to obtain more detailed data that captures people's experiences in greater depth context. Similarly, to complement Studies 1 and 2, USA researchers could critically analyse the usage of terms associated with cancer identities in the USA media.

Within media studies, examining the media in other contexts (e.g. television, radio, digital, social) would allow for a more in-depth understanding of the various representations of cancer and the individuals diagnosed with it. For example, differences in how messages are framed in terms of individualism and collectivism could be explored. This would provide an understanding of the culture of a country because messages are usually framed in a way that will convince news consumers to behave in a particular manner. The language that is used to describe individuals with cancer within cancer-related news or broadcasts should also be accessed to see if appropriate language that is supportive and sensitive to them is being used. The Cancer Institute of NSW (2017) has provided some guidelines for writing about cancer on its website, for example, the usage of appropriate terms to address the individual with the diagnosis (e.g. people with cancer, people living with cancer), and to avoid language that has connotations of war and battle. Future research can examine the extent to which the media adheres to these guidelines.

Future studies should also be conducted with news reports over a longer timeframe to avoid the findings being influenced by a spike in reporting from certain events. This will allow for a better

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understanding of the representation of cancer and the people diagnosed with the disease.

Moreover, a society becomes more individualistic as it becomes more developed over time. Trends in how messages are framed over the years can also be investigated to see if the cultural changes are reflected in the way messages are being delivered through the media as countries, such as Singapore, transform from developing to developed nations.

7.6 Concluding statement

This thesis has shown that not everyone interprets the various cancer identities, especially the "cancer survivor" identity in the same way. The media's portrayal of a cancer survivor is generally similar to the understanding of individuals with cancer and lay people, but does not reflect either the reality of cancer (e.g. DALYs lost or experience), or the terminology used by health agencies. For example, the identity changes experienced by individuals after a cancer diagnosis were rarely mentioned in either the Australian or the Singaporean printed news. It is important for the media to report on these issues instead of only portraying the dominant imagery of a happy, triumphant person who has won the battle against cancer and is engaging in cancer-related activities such as fundraising. As highlighted by the World Cancer Research Fund International (2009), there is a need for all sectors of society, including the media, policymakers and the health professionals, to work together at the various levels (i.e. local, national and international). Only when the different sectors work together will there be a better healthcare system available to those with cancer and a media sector that provides a realistic and appropriate portrayal of the experiences of people affected by this disease.

APPENDIX A: SEARCH STRATEGIES

Systematic review of current cancer-related newspaper coverage in Australia

Pubmed

1. ("Mass Media"[Mesh] OR "radio"[tw] OR "television"[tw] OR newspaper[tw] OR magazine[tw] OR newspapers[tw] OR magazines[tw] OR media[tw] OR "Newspapers as Topic"[mesh])
2. (coverage[tw] OR analysis[tw] OR portrayal[tw] OR representation[tw] OR reporting[tw] OR framing[tw] OR frames[tw])
3. #1 AND #2
4. ("neoplasms"[mesh] OR cancer[tw] OR neoplasm[tw] OR neoplasms[tw] OR tumor[tw] OR tumour[tw] OR tumors[tw] OR tumours[tw])
5. (Australia[mh] OR Australia[tw])
6. #3 AND #4 AND #5

EMBASE

1. 'mass medium'/syn OR 'publication'/syn OR 'television'/de OR 'newspaper':ab,ti OR 'newspapers':ab,ti OR 'television':ab,ti OR 'radio':ab,ti OR 'magazine':ab,ti OR 'magazines':ab,ti OR 'media':ab,ti
2. 'coverage':ab,ti OR 'analysis':ab,ti OR 'portrayal':ab,ti OR 'representation':ab,ti OR 'representations':ab,ti OR 'reporting':ab,ti OR 'framing':ab,ti OR 'frames':ab,ti
3. #1 AND #2
4. 'neoplasm'/exp OR cancer:ab,ti OR cancers:ab,ti OR neoplasm:ab,ti OR neoplasms:ab,ti OR tumor:ab,ti OR tumour:ab,ti OR tumors:ab,ti OR tumours:ab,ti
5. 'Australia'/exp OR 'Australia':ab,ti
6. (#3 AND #4 AND #5) AND [embase]/lim

CINAHL

1. (MH "Communications Media") OR (MH "Newspapers") OR (MH "Radio") OR (MH "Television") OR AB media OR TI media OR TI television OR AB television OR TI radio OR AB radio OR TI newspaper OR AB newspaper OR TI newspapers OR AB newspapers OR TI magazine OR AB magazine OR TI magazines OR AB magazines

2. TI coverage OR TI analysis OR TI portrayal OR TI representation OR TI representations OR TI reporting OR TI framing OR TI frames OR AB coverage OR AB analysis OR AB portrayal OR AB representation OR AB representations OR AB reporting OR AB framing OR AB frames OR (MH "Content Analysis")

3. #1 AND #2

4. MH Neoplasms+ OR TI neoplasms OR AB neoplasms OR TI neoplasm OR AB neoplasm OR TI cancers OR AB cancers OR TI cancer OR AB cancer OR TI tumour OR AB tumour OR TI tumours OR AB tumours OR TI tumor OR AB tumor OR TI tumors OR AB tumors

5. (MH "Australia") OR TI Australia OR AB Australia

6. #3 AND #4 AND #5

PsycINFO

1. exp mass media/ OR newspapers.tw OR newspaper.tw OR television.tw OR radio.tw OR magazine.tw OR magazines.tw OR media.tw

2. exp content analysis/ OR coverage.tw OR analysis.tw OR portrayal.tw OR representation.tw OR representations.tw OR reporting.tw OR framing.tw OR frames.tw

3. #1 AND #2

4. exp Neoplasms/ or neoplasm.tw. or neoplasms.tw or cancer.tw or cancers.tw or tumour.tw or tumours.tw or tumor.tw or tumors.tw

5. Australia.tw

6. #3 AND #4 AND #5

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Systematic review of current cancer-related newspaper coverage in Singapore

Pubmed

1. ("Mass Media"[Mesh] OR "radio"[tw] OR "television"[tw] OR newspaper[tw] OR magazine[tw] OR newspapers[tw] OR magazines[tw] OR media[tw] OR "Newspapers as Topic"[mesh])
2. (coverage[tw] OR analysis[tw] OR portrayal[tw] OR representation[tw] OR reporting[tw] OR framing[tw] OR frames[tw])
3. #1 AND #2
4. ("neoplasms"[mesh] OR cancer[tw] OR neoplasm[tw] OR neoplasms[tw] OR tumor[tw] OR tumour[tw] OR tumors[tw] OR tumours[tw])
5. (Singapore[mh] OR Singapore[tw])
6. #3 AND #4 AND #5

EMBASE

1. 'mass medium'/syn OR 'publication'/syn OR 'television'/de OR 'newspaper':ab,ti OR 'newspapers':ab,ti OR 'television':ab,ti OR 'radio':ab,ti OR 'magazine':ab,ti OR 'magazines':ab,ti OR 'media':ab,ti
2. 'coverage':ab,ti OR 'analysis':ab,ti OR 'portrayal':ab,ti OR 'representation':ab,ti OR 'representations':ab,ti OR 'reporting':ab,ti OR 'framing':ab,ti OR 'frames':ab,ti
3. #1 AND #2
4. 'neoplasm'/exp OR cancer:ab,ti OR cancers:ab,ti OR neoplasm:ab,ti OR neoplasms:ab,ti OR tumor:ab,ti OR tumour:ab,ti OR tumors:ab,ti OR tumours:ab,ti
5. 'singapore'/exp OR 'singapore':ab,ti
6. (#3 AND #4 AND #5) AND [embase]/lim

CINAHL

1. (MH "Communications Media") OR (MH "Newspapers") OR (MH "Radio") OR (MH "Television") OR AB media OR TI media OR TI television OR AB television OR TI radio OR AB radio OR TI newspaper OR AB newspaper OR TI newspapers OR AB newspapers OR TI magazine OR AB magazine OR TI magazines OR AB magazines

2. TI coverage OR TI analysis OR TI portrayal OR TI representation OR TI representations OR TI reporting OR TI framing OR TI frames OR AB coverage OR AB analysis OR AB portrayal OR AB representation OR AB representations OR AB reporting OR AB framing OR AB frames OR (MH "Content Analysis")

3. #1 AND #2

4. MH Neoplasms+ OR TI neoplasms OR AB neoplasms OR TI neoplasm OR AB neoplasm OR TI cancers OR AB cancers OR TI cancer OR AB cancer OR TI tumour OR AB tumour OR TI tumours OR AB tumours OR TI tumor OR AB tumor OR TI tumors OR AB tumors

5. (MH "Singapore") OR TI Singapore OR AB Singapore

6. #3 AND #4 AND #5

PsycINFO

1. exp mass media/ OR newspapers.tw OR newspaper.tw OR television.tw OR radio.tw OR magazine.tw OR magazines.tw OR media.tw

2. exp content analysis/ OR coverage.tw OR analysis.tw OR portrayal.tw OR representation.tw OR representations.tw OR reporting.tw OR framing.tw OR frames.tw

3. #1 AND #2

4. exp Neoplasms/ or neoplasm.tw. or neoplasms.tw or cancer.tw or cancers.tw or tumour.tw or tumours.tw or tumor.tw or tumors.tw

5. Singapore.tw

6. #3 AND #4 AND #5

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Systematic review of current cancer-related newspaper coverage in East Asia

Pubmed

1. ("Mass Media"[Mesh] OR "radio"[tw] OR "television"[tw] OR newspaper[tw] OR magazine[tw] OR newspapers[tw] OR magazines[tw] OR media[tw] OR "Newspapers as Topic"[mesh])
2. (coverage[tw] OR analysis[tw] OR portrayal[tw] OR representation[tw] OR reporting[tw] OR framing[tw] OR frames[tw])
3. #1 AND #2
4. ("neoplasms"[mesh] OR cancer[tw] OR neoplasm[tw] OR neoplasms[tw] OR tumor[tw] OR tumour[tw] OR tumors[tw] OR tumours[tw])
5. ("Asia, Southeastern"[Mesh] OR "Far East"[Mesh] OR China[tw] OR "Hong Kong"[tw] OR Japan[tw] OR Macau[tw] OR Mongolia[tw] OR Korea[tw] OR Taiwan[tw] OR Indonesia[tw] OR Malaysia[tw] OR Singapore[tw] OR Philippines[tw] OR Brunei[tw] OR Cambodia[tw] OR Laos[tw] OR Myanmar[tw] OR Thailand[tw] OR Vietnam[tw] OR Borneo[tw] OR Timor[tw])
6. #3 AND #4 AND #5

EMBASE

1. 'mass medium'/syn OR 'publication'/syn OR 'television'/de OR 'newspaper':ab,ti OR 'newspapers':ab,ti OR 'television':ab,ti OR 'radio':ab,ti OR 'magazine':ab,ti OR 'magazines':ab,ti OR 'media':ab,ti
2. 'coverage':ab,ti OR 'analysis':ab,ti OR 'portrayal':ab,ti OR 'representation':ab,ti OR 'representations':ab,ti OR 'reporting':ab,ti OR 'framing':ab,ti OR 'frames':ab,ti
3. #1 AND #2
4. 'neoplasm'/exp OR cancer:ab,ti OR cancers:ab,ti OR neoplasm:ab,ti OR neoplasms:ab,ti OR tumor:ab,ti OR tumour:ab,ti OR tumors:ab,ti OR tumours:ab,ti
5. 'Far East'/exp OR 'Far East':ab,ti OR 'Southeast Asia':ab,ti OR 'Southeastern Asia':ab,ti OR 'China':ab,ti OR 'Hong Kong':ab,ti OR 'Japan':ab,ti OR 'Macau':ab,ti OR 'Mongolia':ab,ti OR 'Korea':ab,ti OR 'Taiwan':ab,ti OR 'Indonesia':ab,ti OR 'Malaysia':ab,ti OR 'Singapore':ab,ti OR 'Philippines':ab,ti OR 'Brunei':ab,ti OR 'Cambodia':ab,ti OR 'Laos':ab,ti OR 'Myanmar':ab,ti OR 'Thailand':ab,ti OR 'Vietnam':ab,ti OR 'Borneo':ab,ti OR 'Timor':ab,ti
6. (#3 AND #4 AND #5) AND [embase]/lim

CINAHL

1. (MH "Communications Media") OR (MH "Newspapers") OR (MH "Radio") OR (MH "Television") OR AB media OR TI media OR TI television OR AB television OR TI radio OR AB radio OR TI newspaper OR AB newspaper OR TI newspapers OR AB newspapers OR TI magazine OR AB magazine OR TI magazines OR AB magazines

2. TI coverage OR TI analysis OR TI portrayal OR TI representation OR TI representations OR TI reporting OR TI framing OR TI frames OR AB coverage OR AB analysis OR AB portrayal OR AB representation OR AB representations OR AB reporting OR AB framing OR AB frames OR (MH "Content Analysis")

3. #1 AND #2

4. MH Neoplasms+ OR TI neoplasms OR AB neoplasms OR TI neoplasm OR AB neoplasm OR TI cancers OR AB cancers OR TI cancer OR AB cancer OR TI tumour OR AB tumour OR TI tumours OR AB tumours OR TI tumor OR AB tumor OR TI tumors OR AB tumors

5. (MH "Far East+") OR (MH "Asia, Southeastern+") OR TI 'Far East' OR AB 'Far East' OR TI 'Southeast Asia' OR AB 'Southeast Asia' OR TI 'Southeastern Asia' OR AB 'Southeastern Asia' OR TI China OR TI 'Hong Kong' OR TI Japan OR TI Macau OR TI Mongolia OR TI Korea OR TI Taiwan OR TI Indonesia OR TI Malaysia OR TI Singapore OR TI Philippines OR TI Brunei OR TI Cambodia OR TI Laos OR TI Myanmar OR TI Thailand OR TI Vietnam OR TI Borneo OR TI Timor OR AB China OR AB 'Hong Kong' OR AB Japan OR AB Macau OR AB Mongolia OR AB Korea OR AB Taiwan OR AB Indonesia OR AB Malaysia OR AB Singapore OR AB Philippines OR AB Brunei OR AB Cambodia OR AB Laos OR AB Myanmar OR AB Thailand OR AB Vietnam OR AB Borneo OR AB Timor

6. #3 AND #4 AND #5

PsycINFO

1. exp mass media/ OR newspapers.tw OR newspaper.tw OR television.tw OR radio.tw OR magazine.tw OR magazines.tw OR media.tw

2. exp content analysis/ OR coverage.tw OR analysis.tw OR portrayal.tw OR representation.tw OR representations.tw OR reporting.tw OR framing.tw OR frames.tw

3. #1 AND #2

4. exp Neoplasms/ or neoplasm.tw. or neoplasms.tw or cancer.tw or cancers.tw or tumour.tw or tumours.tw or tumor.tw or tumors.tw

5. Southeast Asia.tw OR Southeastern Asia.tw OR Far East.tw OR China.tw OR Hong Kong.tw OR Japan.tw OR Macau.tw OR Mongolia.tw OR Korea.tw OR Taiwan.tw OR Indonesia.tw OR Malaysia.tw OR Singapore.tw OR Philippines.tw OR Brunei.tw OR Cambodia.tw OR Laos.tw OR Myanmar.tw OR Thailand.tw OR Vietnam.tw OR Borneo.tw OR Timor.tw

6. #3 AND #4 AND #5

Systematic review in Study 1

Pubmed

(((Neoplasms[mh] OR neoplasm[tw] OR neoplasms[tw] OR cancer[tw] OR cancers[tw])) AND

(identity[tw] OR social identification[mh] OR social identification[tw] OR definition[tw] OR

defining[tw] OR define[tw] OR Terminology as Topic[mh] OR self concept[mh] OR self concept[tw]

OR self-concept[tw])) AND (survivors[mh] OR survivors[tw] OR survivor[tw] OR survivorship[tw])

EMBASE

1. 'neoplasm'/exp OR cancer:ab,ti OR cancers:ab,ti OR neoplasm:ab,ti OR neoplasms:ab,ti
2. 'cancer survivor'/exp OR 'cancer survivors':ab,ti OR 'cancer survivor':ab,ti OR 'survivorship':ab,ti
3. 'identity'/syn OR 'self concept'/syn OR 'nomenclature'/syn OR 'defining':ab,ti OR 'define':ab,ti OR 'identity':ab,ti OR 'self concept':ab,ti OR 'nomenclature':ab,ti
4. (#1 AND #2 AND #3) AND [embase]/lim

CINAHL

1. MH Neoplasms+ OR TI neoplasms OR AB neoplasms OR TI neoplasm OR AB neoplasm OR TI cancers OR AB cancers OR TI cancer OR AB cancer
2. MH Nomenclature+ OR MH "Self Concept+" OR TI Nomenclature+ OR TI "Self Concept+" OR AB Nomenclature+ OR "Self Concept+" OR TI definition OR TI defining OR TI terminology OR TI define OR AB definition OR AB defining OR AB terminology OR AB define
3. MM "Cancer Survivors"+ OR TI "Cancer Survivors"+ OR AB "Cancer Survivors"+ OR TI "cancer survivorship" OR AB "cancer survivorship"
4. (#1 AND #2 AND #3

PsycINFO

1. (survivor or survivors or survivorship).tw. or survivors/
2. (identity or self concept or self-concept).tw. or self concept/ or social identity/ or social identification.tw. or definition.tw. or defining.tw. or define.tw. or Terminology/
3. exp Neoplasms/ or neoplasm.tw. or neoplasms.tw. or cancer.tw. or cancers.tw.
4. 1 and 2 and 3

Newspaper article retrieval in Studies 3 and 4

LexisNexis

BODY(atleast 2 (cancer! OR leukemia! OR lymphoma! OR melanoma! OR hodgkin! OR tumor! OR tumour! OR sarcoma! OR carcino! OR retinoblastoma! OR adenoma! OR astrocytoma! OR blastoma! OR glioma! OR macroglobulinemia! OR meningioma! OR mesothelioma! OR mycosis! OR myelo! OR neoplas! OR neuroblastoma! OR osteosarcoma! OR pheochromocytoma! OR rhabdomyosarcoma! OR anticancer! OR oncol!)) AND NOT body((feline pre/l leukemia) OR (capricorn))

Factivac

(Atleast2 cancer* OR Atleast2 leukemia* OR Atleast2 lymphoma* OR Atleast2 melanoma* OR Atleast2 hodgkin* OR Atleast2 tumor* OR Atleast2 tumour* OR Atleast2 sarcoma* OR Atleast2 carcino* OR Atleast2 retinoblastoma* OR Atleast2 adenoma* OR Atleast2 astrocytoma* OR Atleast2 blastoma* OR Atleast2 glioma* OR Atleast2 macroglobulinemia* OR Atleast2 meningioma* OR Atleast2 mesothelioma* OR Atleast2 mycosis* OR Atleast2 myelo* OR Atleast2 neoplas* OR Atleast2 neuroblastoma* OR Atleast2 osteosarcoma* OR Atleast2 pheochromocytoma* OR Atleast2 rhabdomyosarcoma* OR Atleast2 anticancer* OR Atleast2 oncol*) NOT ((feline leukemia) OR (capricorn))

APPENDIX B: ONLINE QUESTIONNAIRE FOR STUDY 2

Your Opinion On Cancer (A University Study)

Instructions ▲

Thank you for your interest in completing this job. This job forms part of a research study being undertaken by Sze Yan Cheung, a PhD candidate at the University of Adelaide, supervised by Professor Paul Delfabbro. The research study has been granted approval by the School of Psychology Human Research Ethics Subcommittee at the University of Adelaide (Ethics approval number: 15/79)

What is the project about?

Different people may have a different understanding of particular concepts. Terms used within the cancer discourse have been shown to be understood differently within the cancer community, with some being labelled as "misleading".

This research study aims to find out the lay understanding of terms commonly used within the cancer discourse.

What will I be asked to do?

You will be answering some questions about yourself and your opinion on certain phrases used within the cancer discourse. This short questionnaire should take around 10 minutes.

What are the risks associated with participating in this study?

There are no foreseeable risks. However, it is possible that you may experience transient discomfort when answering some of the questions.

Immediate support can be found through contacting the American Cancer Society 24/7 hotline at 1-800-227-2345 . Should you require any further support, please contact your family physician.

What are the benefits associated with participating in this study?

There are no immediate benefits to you from participating in this study. However, your responses will provide a greater understanding as to how people perceive certain cancer terminology and may assist in communications between different groups involved in the health sector (e.g. patients and their families, health professionals, and policy makers).

Can I withdraw from the project?

Participation in this project is completely voluntary. As this is an anonymous survey, you can withdraw at any time up to the point you submit this job.

What will happen to my responses?

The responses collected will be in a non-identifiable form and is not traceable to any individual. They will be analysed and its results will be written into a research report as part of the PhD dissertation, and may go on to be submitted for a journal article publication. The responses collected in this study will be stored at the University of Adelaide for 5 years before being destroyed.

Who do I contact if I have questions about the project?

Professor Paul Delfabbro (paul.delfabbro@adelaide.edu.au)

Sze Yan Cheung (szeyan.cheung@adelaide.edu.au)

What if I have a complaint or any concerns?

The study has been approved by the School of Psychology Human Research Ethics Subcommittee at the University of Adelaide (approval number 15/79). If you have questions or problems associated with the practical aspects of your participation in the study, or wish to raise a concern or complaint about the study, then you should consult the Principal Investigator, Professor Delfabbro.

If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Subcommittee's Deputy Chair, Dr Linley Denson, on phone +61 8 8313 5693 or by email to linley.denson@adelaide.edu.au. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

Thank You!

If you would like to receive information about the findings, please leave your email address when prompted at the end of this questionnaire. Your email address will be added to a separate file by the researcher, and will not be associated with your survey results.

Thank you for taking your time to complete this survey.

I have read the Instructions and agree to take part in this research project. I understand that I am free to withdraw from the project at any time.

Please select at least one of these.

○ Yes
○ No

What is your age (in years)?

This field is required.

[   ]

What is your gender?

Please select at least one of these.

○ Male
○ Female

Which country do you currently reside in?

This field is required.

[   ]

What is your race?

Please select at least one of these.

○ Caucasian European/White
○ Hispanic or Latino
○ Black/African American
○ Native Amercian or American Indian
○ Asian
○ Pacific Islander
○ Other

What is your marital status?

Please select at least one of these.

○ Single, never married
○ Married or domestic partnership
○ Widowed
○ Divorced
○ Separated

Which is the highest level of education obtained?

Please select at least one of these.

○ No formal schooling
○ Primary/Elementary school
○ Some secondary/high school
○ Completed secondary/high school
○ Technical/trade/vocational training
○ Associate degree
○ Bachelor's degree
○ Master's degree
○ Professional degree
○ Doctorate degree

How would you rate your fluency in English?

Please select at least one of these.

○ Poor
○ Fair
○ Good
○ Very good
○ Excellent

Which is the highest level of education obtained in English?

Please select at least one of these.

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- ○ No formal schooling
- ○ Primary/Elementary school
- ○ Some secondary/high school
- ○ Completed secondary/high school
- ○ Technical/trade/vocational training
- ○ Associate degree
- ○ Bachelor's degree
- ○ Master's degree
- ○ Professional degree
- ○ Doctorate degree

Have you ever been diagnosed with cancer?

Please select at least one of these.

- ○ Yes
- ○ No (please put "Not applicable" for the next two questions)

If you have been diagnosed with cancer before, what is the type of cancer?

This field is required.

[   ]

When you think about yourself in relation to your cancer, which of the following phrases best describes you?

Please select at least one of these.

- ○ A cancer conqueror
- ○ A cancer patient
- ○ A cancer survivor
- ○ A cancer victim
- ○ Someone who has/has had cancer
- ○ Not applicable (I do not have a cancer diagnosis)

Do you have someone who is close to you (e.g. family member, friend) who has received a cancer diagnosis?

Please select at least one of these.

- ○ Yes
- ○ No (please choose "Not applicable" for the next question)

When you think of your close one in relation to his/her cancer, which of the following phrases do you think best describes him/her?

Please select at least one of these.

- ○ A cancer conqueror
- ○ A cancer patient
- ○ A cancer survivor
- ○ A cancer victim
- ○ Someone who has/has had cancer
- ○ Not applicable (I do not have a close one who has a cancer diagnosis)

If you have never had a cancer diagnosis, have you had a cancer scare?

Please select at least one of these.

- ○ Yes
- ○ No
- ○ Not applicable (I have previously been diagnosed with cancer)

Which phrase would you consider the most appropriate to describe someone who has just received a cancer diagnosis?

Please select at least one of these.

- ○ A cancer conqueror
- ○ A cancer patient
- ○ A cancer survivor
- ○ A cancer victim
- ○ Someone who has cancer

Which phrase would you consider the most appropriate to describe someone who has finished primary treatment for cancer?

Please select at least one of these.

- ○ A cancer conqueror

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○ A cancer patient
○ A cancer survivor
○ A cancer victim
○ Someone who has/has had cancer

Which phrase would you consider the most appropriate to describe someone who has been in remission for cancer for 5 years or more?

Please select at least one of these.

○ A cancer conqueror
○ A cancer patient
○ A cancer survivor
○ A cancer victim
○ Someone who has/has had cancer

Do you consider someone who does not have a cancer diagnosis but has been affected by a cancer diagnosis (e.g. caregiver, close friend or family member of someone diagnosed with cancer) to be a cancer survivor?

Please select at least one of these.

○ Yes
○ No

The term "cancer survivor" means different things to different people. What is your opinion on this term? What do you think it means?

This field is required.

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The term "cancer survivorship" means different things to different people. What is your opinion on this term? What do you think it means?

This field is required.

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From whom/where do you receive information about cancer? Please check all that apply.

Please select at least one of these.

☐ Friends/Family members
☐ Health care professionals
☐ Support services (e.g. patient support groups, churches)
☐ Printed materials (e.g. books, newspapers, magazines)
☐ Media (e.g. internet, TV, radio)

Which do you consider the most reliable/trustworthy source for information about cancer and why?

This field is required.

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Please check all that apply. Have you been more actively obtaining information about cancer since:

Please select at least one of these.

☐ A cancer diagnosis
☐ A cancer scare
☐ Close ones being diagnosed with cancer

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☐ Reading about cancer in printed materials
☐ Hearing about cancer in the media
☐ No, I have not been actively obtaining information about cancer.

Thank you for completing this survey. If you would like to receive a copy of the findings from this study, please provide your email address in the blank below.

[   ]

APPENDIX C: CODEBOOK FOR NEWSPAPER COVERAGE OF CANCER

Basic information

Article ID: *Each article is assigned an identification number. First 3 letters refer to the name of the*

newspaper the article is from.

> AUS/AFR/AGE/SDT #

- AUS – The Australian
- AFR – Australian Financial Review
- AGE – The Age
- SDT – Daily Telegraph

Title of article:

Survivor: someone who is living with or

beyond their cancer

Survivorship: describes the broad experience

on the cancer continuum — living with,

through, and beyond a cancer diagnosis

Author: *provided in byline*

Profession of author: *sometimes provided at the end of the article or in the byline*

Date of publication: *DD/MM/YYYY*

Newspaper:

- AUS – The Australian
- AFR – Australian Financial Review
- AGE – The Age
- SDT – Daily Telegraph

Exclusion criteria

The article <u>will</u> only be included for analysis if

1. it contains a cancer-related human interest story (i.e. individual diagnosed with cancer as the protagonist), or
2. the main focus of the article is cancer-related.

It <u>will not</u> be analysed if it meets any one of the below exclusion reasons.

Exclusion reason

- A duplicate of another article
- Not about cancer, not cancer-focused, or cancer is a passing mention
- About cancer side-effects but with no mention about it relating to cancer in the article
- Mention of "tumour" without sufficient information to show that the article is referring to cancer (a malignant cancer)
- Article is a lead-in to another in later pages

Duplicate: # of duplicates

If article is to be excluded, stop here. No other information is required.

The Daily Telegraph (Australia) **-> Newspaper**

November 1, 2014 Saturday **-> Date of publication**
Telegraph Edition

7 Bridges walk may top record **-> Title of article**

BYLINE: JIM O'ROURKE **-> Author**

SECTION: NEWS; Pg. 25 **-> Section / Page #**

LENGTH: 111 words **-> Word count**

IN what is becoming an iconic Sydney event, the Seven -Bridges Walk looks set to break its **cancer** research -fundraising -record.

About 12,000 people, -including 900 children, took part in the walk to raise funds for the **Cancer** Council NSW.

Seven Bridges Walks -organiser Harold Scruby, the chairman of the Pedestrian Council of Australia, said -despite the hot conditions last Sunday about 80 per cent of the walkers managed to cross all seven bridges - the -Harbour, Pyrmont, Anzac, Iron Cove, Gladesville, Tarban Creek and Fig Tree bridges.

"We are -looking at reaching about $600,000 raised this year," Mr Scruby said.Walkers collected $579,742 in sponsorship last year.

LANGUAGE: ENGLISH

PUBLICATION-TYPE: Newspaper

JOURNAL-CODE: The Telegraph

SUBJECT: FUNDRAISING (90%); ONCOLOGY (88%); SPONSORSHIP (88%); MEDICAL RESEARCH (88%); CANCER (88%)

CITY: SYDNEY, AUSTRALIA (92%)

STATE: NEW SOUTH WALES, AUSTRALIA (91%)

COUNTRY: AUSTRALIA (91%)

LOAD-DATE: November 2, 2014

Other information

Type of article: news | editorial, feature article, column, opinion piece | letter | others

> *News:* Newly received or noteworthy information, especially about recent events
>
> *Editorial:* A newspaper article expressing the editor's opinion on a topical issue
>
> *Feature article:* A newspaper or magazine article that deals in depth with a particular topic
>
> *Column:* A regular section of a newspaper or magazine devoted to a particular subject or written by a particular person
>
> *Opinion piece:* An article in which the writer expresses their personal opinion, typically one which is controversial or provocative, about a particular issue or item of news

Section:

Page #: *provided in section*

Word count: *provided in length*

Several small parts: yes/no

> *Is the article broken up into smaller sections, each about a different topic (may include non-cancer topics)?*
>
> Put "yes x #" if more than one part is about cancer (e.g. "yes x2" for two parts)

Type of cancer: specify the type or put "general"

> *A list is available here: http://www.cancer.gov/types*
>
> *Include "(childhood)" if the individual has been diagnosed as a child (14 and below)*
> *Include "(adolescent)" if the individual has been diagnosed as an adolescent (15 to 19).*

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Focus of article

The message that the article is trying to convey: *For items that discussed more than one cancer-*

related issue, the dominant focus will be determined.

1. Treatment
   a. Drug trials
   b. Cancer care in hospitals and other facilities
   c. Research initiatives and associated funding announcements
   d. Development of vaccines
   e. Conventional treatment
   f. Alternative treatment
   g. Reports of 'scientific breakthroughs'
   h. New drug treatments
2. Human interest stories (experience/narrative/death)
   a. Everyday person
   b. Celebrity diagnoses
3. Education
   a. Causes/risk factors *(Refer to "Additional information" for examples)*
   b. Prevention *(Refer to "Additional information" for examples)*
4. Awareness
   a. Information/awareness campaigns
   b. Fundraising
5. Screening/early detection
   a. Screening (e.g. government screening policies)
   b. Genetic testing
   c. Scientific progress in identifying new testing methods
6. Coping/support *(Refer to "Additional information" for examples)*
   a. Sexuality
   b. Fertility
   c. Psychological issues – depression, anxiety
   d. Body image
   e. Role changes
7. Statistics
   a. Incidence, prevalence and mortality (reports from government agencies and NGOs)
8. Business/Investments - companies
9. Miscellaneous
   a. Fraud, award ceremony

Comment on focus: e.g. if it has a positive or negative slant in an opinion piece/feature/editorial

Human interest stories

(only for individuals diagnosed with cancer)

Human interest stories: yes/no

Identified? yes/no

>*Put "yes x #" if more than one person has been identified in the article (e.g. "yes x2" for two*
>
>*people)*

Specifics of the individual diagnosed with cancer:

- Gender
- Age of diagnosis
  Put "not specified" if the age is not given. Provide rough age whenever possible.

- Type of cancer: specify the type or put "general"
  Include "(childhood)" if the individual has been diagnosed as a child (14 and below)

  Include "(adolescent)" if the individual has been diagnosed as an adolescent (15 to 19).

- Survivorship status: recently diagnosed | primary treatment | post treatment/remission | discontinued treatment | alternative treatment | passed away

  > *Primary treatment:* The first treatment given for a disease. It is often part of a standard set of treatments, such as surgery followed by chemotherapy and radiation. If it doesn't cure the disease or it causes severe side effects, other treatment may be added or used instead. This does not include long-term treatment such as hormone medication, which may be taken for several years to maintain remission.

- Treatment: traditional | trad + complementary / integrative | alternative | none

  > *Complementary:* a non-mainstream practice used <u>together with</u> conventional medicine
  > *Alternative:* a non-mainstream practice used <u>in place of</u> conventional medicine
  > *Integrative:* bringing conventional and complementary approaches together in a coordinated way

- Type of treatment (specify) *(Refer to "Additional information" for examples)*
  Please specify drug name if provided in the article.

  Put "new technology" if the treatment is under trial or has been just approved.

Impact of cancer and its treatments *(Refer to "Additional information" for examples)*

  o Physical, cognitive, psychosocial, Economic effects

Quotes about identity (inclusive of quotes from family members, friends, clinicians)

Mentions of the terms "survivor", "conqueror", and "victim"

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Information provided in article

Statistics about cancer (incidence, prevalence, mortality, survival): yes/no

Put quotes in a separate document along with article ID

> *Example:*
>
> - More than 15,000 women are diagnosed with breast cancer every year in Australia
> - Of the roughly 600 childhood cancers diagnosed in Australia each year, 80 per cent can expect to survive
> - Prostate cancer remains the most common cancer in men with 4257 diagnoses last year
> - Last year, the five most common cancers for Victorians were prostate, breast, bowel, lung and melanoma

General survivor representation:

Who are they? How old are they?

> *Example:*
>
> - The disease, known as non-small-cell lung cancer with a change in the "ALK gene", tends to affect younger people with a median age of 50 who are non-smokers. This means half of sufferers are aged in their 20s, 30s and 40s.
> - While 90 per cent of women diagnosed with uterine cancers were aged over 50, the report says diagnoses are increasing 1 per cent per year, with steeper increases among younger women.

Mobilizing info (e.g. websites/hotlines/addresses)

Risk/causes info *(Refer to "Additional information" for examples)*

Prevention info *(Refer to "Additional information" for examples)*

Detection/screening info (including symptoms reported in article)

> - Colorectal/bowel:
>   - Colonoscopy
>   - Faecal occult blood test
> - Breast
>   - Self-examinations
>   - Mammogram
> - Cervical
>   - Pap smear
>   - Primary human papillomavirus test
> - Prostate
>   - Prostate-specific antigen test

Treatment (specify type): *(Refer to "Additional information" for examples)*

- o Physical, cognitive, psychosocial, socioeconomic effects

Copy and paste from the human interest stories' section if required and add more details if necessary

(e.g. other mentions of treatment not related to the human interest story)

Please specify drug name if provided in the article.

Put "new technology" if the treatment is under trial or has been just approved.

For psychological intervention and CAM only:

1. Purpose of the intervention
2. Mention of risks/benefits/costs
3. (non-)Recommendation to discuss use with their general practitioner
4. (non-)Recommendation on how to access the intervention
5. (non-)outright statement to use or not to use intervention
6. Provision of credible support (e.g. research, clinicians)?

Impact of cancer and its treatments *(Refer to "Additional information" for examples)*

Copy and paste from the human interest stories' section if required and add more details if necessary

(e.g. clinician's understanding of the impact)

- o Psychosocial
- o Economic
- o Physical
- o Cognitive

Additional information

A **cancer incidence rate** is the number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 population at risk.

A **cancer mortality rate** is the number of deaths, with cancer as the underlying cause of death, occurring in a specified population during a year. Cancer mortality is usually expressed as the number of deaths due to cancer per 100,000 population.

Prevalence is defined as the number or percent of people alive on a certain date in a population who previously had a diagnosis of the disease. It includes new (incidence) and pre-existing cases and is a function of both past incidence and survival.

Cancer survival statistics are typically expressed as the proportion of patients alive at some point subsequent to the diagnosis of their cancer.

- *Relative survival* is an estimate of the percentage of patients who would be expected to survive the effects of their cancer.
- *Observed survival* is the actual percentage of patients still alive at some specified time after diagnosis of cancer. It considers deaths from all causes, cancer or otherwise.
- *Five-Year Survival Rate* is the percentage of people in a study or treatment group who are alive five years after they were diagnosed with or treated for a disease, such as cancer. The disease may or may not have come back.

Examples of causes/risk factors

1. Age
2. Alcohol
3. Environmental carcinogens
   a. asbestos, consumption of processed meat, secondhand tobacco smoke
4. Chronic inflammation
5. Diet
   a. alcohol, antioxidants, calcium, charred meat, cruciferous vegetables, garlic, vitamin D
6. Hormones
   a. estrogens (female sex hormones)
7. Immunosuppression and infectious agents
   a. Immunosuppressive drugs taken by transplant recipients
   b. Hep B and Hep C, EBV, HIV/AIDS, HPV
8. Obesity
9. Radiation
   a. ionizing radiation (e.g. x-rays, gamma rays)
   b. sun, sunlamps, tanning booths
10. Tobacco (smoking)
11. Genetic susceptibility/family history
    a. inherited genetic mutations e.g. Li-Fraumeni syndrome, BRCA1 and BRCA2, cowden syndrome)

Preventive measures

1. Behavioural prevention
    a. Increasing physical activity
    b. Maintaining a healthy weight
    c. Smoking cessation and control
    d. Moderating alcohol intake
    e. Screening utilization and genetic counselling measures
2. Chemoprevention: the use of drugs, vitamins, or other agents to try to reduce the risk of, or delay the development or recurrence of, cancer
    a. E.g. aspirin, omega-3-fatty acids, pomegranate
3. Immunotherapy
    a. E.g. vaccines
4. Surgical prevention
    a. Prophylactic surgery (e.g. Angelina Jolie having a double mastectomy and the removal of ovaries and fallopian tubes)
    b. Screening and resection of premalignant lesions (e.g. Pap screening and cervical IEN removal)

Treatment

Examples of conventional treatment:

1. *Surgery*

   A procedure to remove or repair a part of the body or to find out whether disease is present. E.g. mastectomy (breast cancer), radical prostatectomy (prostate cancer)

2. *Chemotherapy*

   Treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.

3. *Radiotherapy*

   The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors.

4. *Immunotherapy*

5. A type of biological therapy that uses substances to stimulate or suppress the immune system to help the body fight cancer, infection, and other diseases.

6. *Targeted therapy*

   A type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells.

7. *Hormone therapy*

   Treatment that adds, blocks, or removes hormones.

8. *Stem cell transplant*

   A procedure that restore blood-forming stem cells in people who have had theirs destroyed by the very high doses of chemotherapy or radiation therapy that are used to treat certain cancers

9. *Personalized medicine*

   A form of medicine that uses specific information about a person's tumor to help diagnose, plan treatment, find out how well treatment is working, or make a prognosis.

Examples of complementary and alternative medicine:

Biological-based	Non-biological based
• Nutritional supplements (e.g. vitamins, minerals, enzymes, antioxidants) • Special diet and foods (e.g. macrobiotic, Gerson, Gawler, Pritikin, vegetarian, juicing) • Chinese herbal medicine • Western herbal medicines (e.g. garlic, St. John's Wort, Essiac) Other examples: https://nccih.nih.gov/health/herbsataglance.htm • Homeopathy • Shark cartilage • Colonic irrigation • Laetrile or amygdalin • Ozone therapy	• Meditation • Massage • Yoga • Acupuncture • Tai chi • Qigong • Relaxation techniques (e.g. progressive muscle relaxation, guided imagery, breathing exercises) • Movement therapies (e.g. Pilates, Alexander technique, Feldenkrais method) • Aromatherapy • Art therapy • Music therapy • Dance therapy • Chiropractic manipulation • Reflexology • Osteopathic manipulation • Hypnosis • Energy healing (e.g. reiki, Bowen therapy) • Prayer/spiritual practices • Homoeopathy

Examples of traditional indigenous medicine:

• Bush medicine
• Traditional healers
• Healing songs or ceremonies by the elders or women practitioners

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Examples of the impact of cancer

Treatment side-effects	Other impacts

• Anemia
• Appetite Loss
• Bleeding and Bruising
• Constipation
• Delirium
• Diarrhea
• Edema
• Fatigue
• Hair Loss
• Infection and Neutropenia
• Lymphedema
• Memory, attention or concentration Problems
• Mouth and Throat Problems
• Nausea and Vomiting
• Nerve Problems
• Pain
• Sexual health and functioning (e.g. decreased frequency of intercourse, erectile dysfunction)
• Infertility
• Skin and Nail Changes
• Sleep Problems
• Urinary and Bladder Problems
	• Financial impact
	• Relationships with family and friends (social support)
	• Body image
	• Role changes
	• Gender identity
	• Employment (e.g. early retirement)
	• Depression
	• Anxiety
	• Distress
	• Fear of recurrence
	• Spirituality
	
	• Post-traumatic growth (experience of positive change that occurs as a result of the struggle with highly challenging life crises)
	   o Change in life perspective
	   o Improved view of self
	   o Changes to health behaviours

APPENDIX D: INTER-RELIABILITY CODER'S CODEBOOK FOR

NEWSPAPER COVERAGE OF CANCER

Article ID

Each article is assigned an identification number. First 3 letters refer to the name of the newspaper

the article is from.

- AUS – The Australian
- AFR – Australian Financial Review
- AGE – The Age
- SDT – Daily Telegraph

Type of article

1. *News:* Newly received or noteworthy information, especially about recent events
2. *Editorial:* A newspaper article expressing the editor's opinion on a topical issue
3. *Feature article:* A newspaper or magazine article that deals in depth with a particular topic
4. *Column:* A regular section of a newspaper or magazine devoted to a particular subject or written by a particular person
5. *Opinion piece:* An article in which the writer expresses their personal opinion, typically one which is controversial or provocative, about a particular issue or item of news

Focus of article

The message that the article is trying to convey: *For items that discussed more than one cancer-*

related issue, the dominant focus should be determined.

1. Treatment
   a. Drug trials
   b. Cancer care in hospitals and other facilities
   c. Research initiatives and associated funding announcements
   d. Development of vaccines
   e. Conventional treatment
   f. Alternative treatment
   g. Reports of 'scientific breakthroughs'
   h. New drug treatments
2. Human interest stories (experience/narrative/death)

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        a. Everyday person

        b. Celebrity diagnoses

3. Education

        a. Causes/risk factors

        b. Prevention

4. Awareness

        a. Information/awareness campaigns

        b. Fundraising

5. Screening/early detection

        a. Screening (e.g. government screening policies)

        b. Genetic testing

        c. Scientific progress in identifying new testing methods

6. Coping/support

        a. Psychosocial (e.g. depression, relationships, gender roles, identity, changed life perspectives, new outlook)

        b. Economic (e.g. financial impact, early retirement, employment issues)

        c. Physical (e.g. pain, loss of hair, nausea, lymphedema, fertility)

        d. Cognitive (e.g. "chemobrain", concentration problems, slowed processing)

7. Statistics

        a. Incidence, prevalence and mortality (reports from government agencies and NGOs)

8. Business/Investments - companies

9. Personal Cost (for cancer survivors and families)

        a. Financial burden

        b. Cost of drugs

        c. Health insurance

        d. Government funding of drugs

10. Miscellaneous

        a. Fraud, awards

Human interest stories

Human interest stories: yes/no

Information provided in article

Impact of cancer and its treatments

        a. Psychosocial (e.g. depression, relationships, gender roles, identity)

        b. Economic (e.g. financial impact, early retirement, employment issues)

        c. Physical (e.g. pain, loss of hair, nausea, lymphedema, fertility)

        d. Cognitive (e.g. chemobrain, concentration problems, slowed processing)

Causes/risk factors	Prevention

1. Age
2. Alcohol
3. Environmental carcinogens
   a. asbestos, consumption of processed meat, secondhand tobacco smoke
4. Chronic inflammation
5. Diet
   a. Insufficient vegetables and fruits
6. Hormones
   a. estrogens (female sex hormones)
7. Immunosuppression and infectious agents
   a. Immunosuppressive drugs taken by transplant recipients
   b. Hep B and Hep C, EBV, HIV/AIDS, HPV
8. Obesity
9. Radiation
   a. ionizing radiation (e.g. x-rays, gamma rays)
   b. sun, sunlamps, tanning booths
10. Tobacco (smoking)
11. Genetic susceptibility/family history
   a. inherited genetic mutations e.g. Li-Fraumeni syndrome, BRCA1 and BRCA2, cowden syndrome)
	1. Behavioural prevention
	   a. Increasing physical activity
	   b. Maintaining a healthy weight
	   c. Smoking cessation and control
	   d. Moderating alcohol intake
	   e. Screening utilization and genetic counselling measures
	   f. Usage of sunscreen
	2. Chemoprevention: the use of drugs, vitamins, or other agents to try to reduce the risk of, or delay the development or recurrence of, cancer
	   a. E.g. aspirin, omega-3-fatty acids, pomegranate
	3. Immunotherapy
	   a. E.g. vaccines
	4. Surgical prevention
	   a. Prophylactic surgery (e.g. Angelina Jolie having a double mastectomy and the removal of ovaries and fallopian tubes)
	   b. Screening and resection of premalignant lesions (e.g. Pap screening and cervical IEN removal)

Psychosocial

- Depression
- Anxiety
- Relationships with family and friends
- Gender roles
- Identity
- Spirituality
- Change in life perspectives
- Improved view of self

Economic

- Financial impact (financial toxicity) – health expenditures
- Early retirement
- Passed for promotion
- Employment issues due to physical and cognitive effects of cancer

Physical

- Pain
- loss of hair
- nausea
- lymphedema
- fertility
- appetite loss
- sexual functioning
- nails dropping off
- insomnia
- fatigue

Cognitive

- "chemobrain"
- concentration problems
- slowed processing
- memory problems
- attention problems

APPENDIX E: INTER-RELIABILITY CODER'S CODESHEET FOR

NEWSPAPER COVERAGE OF CANCER

Article ID: AFR | AGE | AUS | SDT ☐ ☐ ☐ ☐

1. Article type

   ☐ Editorial, feature, column, opinion piece   ☐ Letter

   ☐ News   ☐ Others

2. Focus of article

   ☐ Treatment   ☐ Coping/support

   ☐ Human interest stories   ☐ Statistics

   ☐ Education   ☐ Business/Investments

   ☐ Awareness   ☐ Miscellaneous

   ☐ Screening/early detection

3. Human interest stories

   Does the article include a human interest story?

   Yes   No ☐

4. Impact of cancer

   ☐ Physical   ☐ Psychosocial

   ☐ Cognitive   ☐ Economic

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APPENDIX F: RESULTS FOR INTER-RELIABILITY

Table 17

Intercoder reliability for Australian newspapers using percent agreement and Krippendorff's Alpha

	Percent Agreement (%)	Krippendorff's Alpha (α)
Focus	84.6	0.820
Human interest stories	99.4	0.988
Physical impact	94.7	0.728
Cognitive impact	99.4	0.665
Psychosocial impact	99.4	0.972
Economic impact	99.4	0.962

Table 18

Intercoder reliability for Singaporean newspapers using percent agreement and Krippendorff's Alpha

	Percent Agreement (%)	Krippendorff's Alpha (α)
Focus	91.7	0.898
Human interest stories	96.4	0.929
Physical impact	95.2	0.887
Cognitive impact	100.0	1.000
Psychosocial impact	96.4	0.892
Economic impact	96.4	0.710

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