

THE PSYCHOSOCIAL NEEDS OF RURAL CANCER PATIENTS

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ABSTRACT

Psychosocial interventions are increasingly recommended as a standard part of care for cancer patients due to their proven utility and this patient groups' elevated risk of psychological distress. However, providing the third of Australian cancer patients who live in rural areas with psychosocial care is challenging.

Little is known about rural cancer patients' level of psychosocial service use or how suitable existing rurally-based services are to deal with cancer. Therefore, Study 1 identified key issues with the provision of psychosocial care from the perspective of rural South Australian cancer patients and explored ways these issues could be addressed. A thematic analysis of data from 17 semi-structured interviews revealed that, contrary to previous research, rural South Australian cancer patients do not consider lay support as an adequate substitute for professional services. However, a lack of relevant information, beliefs that such services are unnecessary and concerns about stigma and dual relationships hindered access to professional help. The study concluded that providing rurally relevant information on psychosocial services may improve knowledge about their availability and help to address rural cancer patients' attitudinal barriers to service use.

In light of the barriers identified in Study 1, the objectives of Study 2 were to develop a website that provided rural-specific information on psychosocial care for those affected by cancer in rural South Australia, (by engaging people with relevant life experience and reviewing the psychological literature), and to document the lessons learnt during this process. A Participatory Action Research (PAR) framework guided the website's development. To motivate users to access psychosocial care, behaviour change techniques were also incorporated. The resulting 84-page interactive website, entitled *Country Cancer Support*, garnered widespread interest and use. It includes practical written information, low-intensity Cognitive Behaviour Therapy (CBT) self-help material, videos and a distress screening tool that provides tailored feedback and is linked to a support services directory. This

method resulted in collaboration between several stakeholders, increased awareness of the value of rural-specific information and participants also reported a sense of empowerment associated with being involved. This study demonstrates the utility of PAR in addressing the psychosocial information needs of rural cancer patients and may inform the development other online, consumer-driven health-promotion interventions.

In Study 3, how acceptable this website is to its users was evaluated using an online survey and Google Analytics. There were 3957 visits to the website in the first 5 months. It was evaluated as easy to use, helpful and relevant, written by people who understood what they were going through and self-report measures suggested it was associated with increased motivation to access professional psychosocial support services and/ or travel for medical treatment (if relevant). Of relevant patients and supporters, 73% said using the website made them less isolated and 54% felt less distressed.

The results reiterate the importance of interventions being targeted, creative and flexible, attitudinal barriers being addressed and the value of consumer involvement, particularly when developing interventions for populations whose unique needs are often overlooked and/or can easily be misunderstood. These findings have implications for isolated rural cancer patients in many parts of the world.

DECLARATION

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution to Kate Gunn 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.

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The first paper contained in this thesis has been accepted for publication in Supportive Care in Cancer. The other two papers are currently under consideration for publication by the Australian Journal of Rural Health (Study 2) and the Journal of Medical Internet Research (Study 3).

Signed: Miss Kate Gunn

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DEDICATIONS

For Mum and Anny (from whom I have inherited a love of learning and helping others) and the rural South Australian cancer patients who inspired me to take on this task.

LIST OF ABBREVIATIONS

ACT	Acceptance and Commitment Therapy
ARIA	Accessibility and Remoteness Index of Australia
CBT	Cognitive Behaviour Therapy
CHERRIES	Checklist for Reporting Results of Internet E-Surveys
DT	Distress Thermometer
MBCT	Mindfulness-Based Cognitive Therapy
MBSR	Mindfulness-Based Stress Reduction
NGO	Non-Government Organisation
PAR	Participatory Action Research
PDF	Portable Document Format
QOL	Quality of Life
RCT	Randomised Control Trial

OVERVIEW

Outline of candidature

This dissertation was undertaken to fulfil the requirements of a combined Master of Psychology (Clinical) with Doctor of Philosophy at The University of Adelaide, South Australia. This program combines the coursework and 1000 hours of clinical placement from the Master of Psychology (Clinical), with a full research program for a Doctor of Philosophy. All placement and coursework requirements of the Master of Psychology have been completed successfully. This thesis is submitted to fulfil the remaining requirements of a Doctor of Philosophy.

Outline of thesis

This dissertation investigates the psychosocial needs of rural cancer patients and how they could be better addressed. Based on the current literature, Chapter I begins by explaining how rural cancer patients are different to their urban counterparts and why their psychosocial needs require special consideration. Chapter II provides background information on the aims of the research and the methodological and theoretical methods and assumptions employed throughout. Chapter III outlines the context of the research, in keeping with the epistemology outlined in Chapter II. Chapters IV-VI contain prefaces, the three studies in manuscript format and an accompanying statement about each author's contribution. Finally, Chapter VII summarises the findings from across the three studies and discusses their application to other settings as well as strengths, limitations and directions for future research.

CHAPTER I: LITERATURE REVIEW

The psychological consequences of cancer and the efficacy of interventions to address psychosocial issues have been thoroughly explored (Sullivan, Weinert & Fulton, 1993 cited in Holland, 2002). It is now widely acknowledged that being diagnosed with cancer may lead to social, emotional, psychological and spiritual issues that can disrupt work and family life, hinder recovery, weaken adherence to prescribed treatments (Alder & Page, 2008, p. 31) and contribute to the high rate of mental disorders in the cancer population (Pascoe, Neal, Allgar, Selby, & Wright, 2004; Razavi & Stiefel, 1994). The International Psycho-Oncology Society (IPOS) have endorsed distress as the ‘6th vital sign’ in need of monitoring in health care settings (Bultz & Johansen, 2011).

The most commonly quoted estimate of the prevalence of psychological disorders among people diagnosed with cancer is 30% (Ford, Lewis, & Fallowfield, 1995; Pascoe et al., 2004; Zabora et al., 1997). Although evidence of both higher (e.g. Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Kissane et al., 1998; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001) and lower prevalence (e.g. Osborne, Elsworth, & Hopper, 2003) exists, it is generally accepted that the rate of psychological disorders in this population is higher than that of both the general population (Pascoe et al., 2004; Razavi & Stiefel, 1994) and the general medical patient population (Razavi & Stiefel, 1994). More specifically, Razavi and Stiefel (1994) state that the incidence of psychiatric disorders in cancer patients is twice that of general medical patients and three times that of the general population.

Given this elevated rate of psychological morbidity, the expansive research on the utility of psychosocial interventions (Osborn, Demoncada, & Feuerstein, 2006; Rehse & Pukrop, 2003; Ross, Boesen, Dalton, & Johansen, 2002) and the resulting conclusion that they have a “consistent beneficial effect” on patients’ emotional, functional, treatment and disease-related adjustment (Meyer & Mark,

1995, p. 106), clinical practice guidelines now widely recommend psychosocial care for treatment of a range of cancers (Turner et al., 2005).

Psychosocial interventions and services are designed to “optimize biomedical health care and to manage the psychological/behavioural and social aspects of illness and its consequences” (Alder & Page, 2008, p. 9). Care of this type often includes the provision of information and assistance to cope with emotional, relationship, transport, work, school, family life and financial issues (Alder & Page, 2008). The emotional issues they tend to address include “distress, anxiety, depression, fear of death, adaptation and coping, social support, communication with the family, sexuality, self-esteem, body image, side effects of treatment, pain, psychovegetative symptoms, and sleep disturbance” (Mehnert & Koch, 2005, p. 583). Internationally, Psychologists are the health care professionals that most commonly provide specialised services in coping with these sorts of emotional issues, followed by Oncologists, Oncological Nurses, Social Workers and Psychiatrists (Mehnert & Koch, 2005). Psychosocial interventions are growing in acceptance and availability in many large treatment centres (Pascoe et al., 2004) and are increasingly recommended as a standard part of patient care (Fallowfield, 1995b; National Breast Cancer Centre & National Cancer Control Initiative, 2003). However, few cancer patients have been found to receive the evidence-based psychosocial care that the clinical practice guidelines recommend (Leykin et al., 2012) and providing these services to cancer patients from rural areas is a key challenge (Shepherd, Goldstein, Olver, & Parle, 2008).

Approximately one third of people affected by cancer in Australia live in rural and regional areas and previous research has shown that “for them the burden of cancer is disproportionately heavy” (National Rural Health Alliance, 2009, p. 1). While rural people who have cancer experience the issues associated with a diagnosis of cancer in any setting, they also face a number of additional stressors (Baldwin & Usher, 2008; Bettencourt, Talley, Molix, Schlegel, & Westgate, 2008), which are compounded by multiple barriers to psychosocial service use.

The following review examines the literature on the geographic, financial, practical, service-related and cultural factors that make coping with cancer in *rural* areas particularly difficult. It then examines the evidence that these and other factors translate into poorer outcomes for rural cancer patients. Conclusions highlight what is currently known about the barriers to psychosocial service provision and usage for this unique group. Suggestions of future research to build on these findings and facilitate more equitable cancer-care are also outlined.

Unique stressors rural cancer patients face

Travel for specialist treatment

Perhaps the most significant, unique stressor for rural cancer patients, is the burden of relocating to more populated centres to receive specialist cancer treatment. This is often for unspecified periods (Baldwin & Usher, 2008) and is a source of great financial, emotional, social and practical strain (Baldwin & Usher, 2008; CanNET South Australia, 2008; Hegney, Pearce, Rogers-Clark, Martin-Mcdonald, & Buikstra, 2005; McGrath, 1999, 2000a; K. J. White et al., 2011; Zucca, Boyes, Newling, Hall, & Girgis, 2011). Financial strain may be incurred due to accommodation costs, increased shopping and telephone costs, incidentals associated with relocation (e.g. airfares for family members, wear and tear on car), costs associated with maintaining a home in absentia and the inability to continue working during treatment, particularly for those who are self-employed (CanNET South Australia, 2008; McGrath, 2000a). Travel can be emotionally and socially straining, as it often disrupts family life and social roles (Bettencourt, Schlegel, Talley, & Molix, 2007; CanNET South Australia, 2008; McGrath et al., 1999a). It also can mean undergoing treatment in an unfamiliar city (McGrath, 1999; McGrath et al., 1999b), which may be confusing and alienating (McGrath, 1999), while being removed from the support of close friends, family (Hegney et al., 2005; McGrath, 1999) and local voluntary organisations (McGrath, 2000a). Travelling to another centre for treatment also requires preparation and organisation (Sabesan & Piliouras, 2009). As Sabesan and Piliouras (2009) point out,

“It is usual for specialist review clinic appointments to be cancelled and rescheduled multiple times, which may discourage rural patients from attending subsequent appointments due to difficulties in reorganising work and family commitments” (p. 3). Patients may encounter difficulties with unfamiliar accommodation (Hegney et al., 2005) and as a result of needing to be away from home, feel as though they are a burden on others (Hegney et al., 2005). In addition, having to leave a rural community for long periods of time can mean that more community members are aware of a person’s diagnosis than they would like (Baldwin & Usher, 2008).

Travel costs and distance can be a barrier to seeking and completing medical treatment (Rankin et al., 2001). Some rural cancer patients have suboptimal treatment to avoid travel (Craft et al., 2010). A small percentage refuse to have any cancer treatment at all, due to travel related concerns (Zucca et al., 2011).

Lack of local medical services

The lack of local medical services with knowledge about cancer can add to rural patients’ levels of uncertainty, fear, isolation and distress, particularly post-treatment, upon returning home (Bettencourt et al., 2007; CanNET South Australia, 2008). A study by McGrath (2000b) of rural people with haematological malignancies found that over 40% of participants felt that after returning home, local health and allied health professionals did not have sufficient knowledge about their illness and associated concerns, to provide adequate assistance. Similarly, Bettencourt et al. (2007) found rural breast cancer patients’ satisfaction with their medical care decreased after completion of their primary treatment due to restricted access to doctors in their local community, rural doctors’ limited knowledge about oncology related care (due to a lack of local professional development opportunities) and poor communication between local doctors and those cancer specialists who provided treatment in urban settings. This “lack of coordination or continuity of care between metropolitan and regional centres” has also been documented by a South Australian study (CanNET South Australia, 2008, p. 17).

Patients’ sense of isolation may be exacerbated by the shortage of doctors in rural areas and the need to

use expensive, long-distance phone calls to contact health professionals in larger treatment centres (McGrath et al., 1999a). This can be particularly troublesome post-treatment, as appropriately informed local medical assistance is necessary to help these patients feel supported (McGrath, 2000b).

For patients who face a terminal illness, poor access to specialised palliative care services is also often problematic. Rural patients are less likely to receive care from a hospice service than their urban counterparts (Evans, Stone, & Elwyn, 2003).

Poor access to psychosocial services

In addition, lack of access to psychosocial services for rural people affected by cancer is well documented (Aylward et al., 2012; Baldwin & Usher, 2008; Bettencourt et al., 2007; C. Davis, Williams, Redman, White, & King, 2003; Lawler, Spathonis, Masters, Adams, & Eakin, 2011; McGrath et al., 1999b; National Rural Health Alliance, 2009). This results in high levels of unmet needs (Beesley et al., 2008; Harrison, Young, Price, Butow, & Solomon, 2009).

In a sample of Australian rural breast cancer patients (Minstrell, Winzenberg, Rankin, Hughes, & Walker, 2008), it was found that at one month post-diagnosis, these patients' top seven unmet needs were in the psychological domain, and at three months post-diagnosis, four of their top ten needs were in the psychological domain. Similarly, McDowell, Occhipinti, Ferguson, Dunn and Chambers (2009) found that the "highest ranked unmet supportive care needs were in the physical/daily living and psychological needs domains" in a sample of patients from an Australian regional cancer treatment centre (p. 513). A South Australian study also documented a lack of support (in particular emotional and practical support) for cancer patients and their families (CanNET South Australia, 2008).

More specifically, the Clinical Oncological Society of Australia (2006) found that 61% of rural and remote Australian hospitals that were administering chemotherapy requested urgent access to psychological services and support. Only 39% of these centres had dedicated oncology counselling services; 50% had social workers, 30% had access to a psychologist and only 23% had specialist

cancer nurses (Clinical Oncological Society of Australia, 2006). Further, “Only a minority of [rural] women... report turning to a breast cancer or general cancer support group” (Koopman, Angell, Kreshka et al., 2001, p. 31). Davis et al. (2003) found that less than 10% of Australian rural breast cancer patients and 5% of their families access psychosocial help through a counsellor, psychologist, social worker or psychiatrist during their diagnosis and treatment. In a study of cancer patients recruited from an Australian regional cancer treatment centre, 14% were found to have used a psychosocial support service in the previous 6 months (McDowell, Occhipinti, Ferguson, & Chambers, 2011). This is remarkable, given the previously discussed high rate of psychological morbidity in this population; and because upon completion of treatment and on their return home, rural patients’ access to psychosocial services is likely to be even lower, which is particularly concerning given the important role it is thought to play for patients at this time (Bettencourt et al., 2007; McGrath, 2001b) in helping them to return to their ‘normal’ lives (Baldwin & Usher, 2008). Depending on the program and the patients, previous research has shown that between 25-67% of cancer patients in the general population participate in psychosocial interventions (Plass & Koch, 2001).

In addition to a lack of local psychosocial services, there is also evidence of a lack of locally relevant information for rural cancer patients (Bettencourt et al., 2007; Burman & Weinert, 1997b; CanNET South Australia, 2008; C. Davis et al., 2003; Duggleby et al., 2010; Lawler et al., 2011; Wilson, Andersen, & Meischke, 2000). For example, Davis et al. (2003) found that only 9% of the women with early breast cancer in their rural sample had been provided with resources specifically for rural people. Not having access to appropriate informational support is known to be a great cause of unnecessary stress for cancer patients (Dakof & Taylor, 1990) and there is evidence that rural cancer patients actually have a greater need for education than their urban counterparts (Silveira & Winstead-Fry, 1997).

For rural patients, not having access to information on accommodation options during outpatient cancer treatment (McGrath, 1999), along with financial assistance and emotional and practical support,

is both common and distressing (C. Davis et al., 2003). It is also important to provide information to help address misconceptions about cancer and make rural patients more aware of helpful coping strategies (Bettencourt et al., 2007), particularly for dealing with emotional concerns (McGrath, 2001b).

Cultural and social issues

In addition to a lack of access to formal services and information, cultural and social issues associated with living in rural communities can make coping with cancer particularly difficult in these settings. Cancer can be a difficult topic to discuss in rural communities (Burris & Andrykowski, 2010; McGrath et al., 1999a). The perception that ‘everyone knows everyone else’s business’ means many people affected by cancer are reluctant to speak with other local people about their diagnosis and treatment (Baldwin & Usher, 2008). The rural women interviewed in Baldwin and Usher’s study (2008) reported that by limiting the number of people they told of their experiences, they could maintain their original identity and prevent themselves from being thought of as “a cancer patient”. Different social norms also appear to operate in rural communities around what is appropriate to disclose to others (Burris & Andrykowski, 2010) .

When concerns about privacy and gossip (Baldwin & Usher, 2008; McGrath et al., 1999b; Rogers-Clark, 2002; Thorndyke, 2005) in close-knit rural communities result in non-disclosure, the opportunities to meet other cancer patients (which might otherwise help them normalise their experiences, minimise their fears and offer a ‘survivorship’ perspective) are limited (Bettencourt et al., 2007). Fear of disclosure may also stem from a desire to protect loved ones from suffering in rural communities (Rogers-Clark, 2002), as it also does in urban settings (Ussher, Kirsten, Butow, & Sandoval, 2006). Non-disclosure to lay support networks may be particularly problematic, if professional support services are not available. A sense of isolation may also develop when rural patients leave the supportive relationships built with health and allied health professionals (McGrath, 2000b) and possibly other patients in the treatment setting to return home to their rural communities.

Further, due to the importance of traditional gender roles in rural communities, rural cancer patients who can no longer perform these roles as a result of their diagnosis, may experience greater levels of stigmatisation and stress than their urban counterparts (Bettencourt et al., 2007).

Comparing cancer patient outcomes in rural and urban areas

Quality of life

Given these unique stressors alone, it is no surprise that rural cancer patients have a demonstrably poorer quality of life (QOL) than those who face a diagnosis of cancer and live in an urban location (Butow et al., 2012). An American study of breast cancer patients who had completed treatment found that increasing rurality was associated with lower overall QOL as well as lower functional well-being (Reid-Arndt & Cox, 2010). Momeni and Ghanbari (2011) also found QOL was poorer among colorectal cancer patients who resided in rural rather than urban locations in Iran. In Australia, rural breast cancer patients have been found to have more needs in the physical/daily living domain than their urban counterparts (Girgis, Boyes, Sanson-Fisher, & Burrows, 2000).

Treatment outcomes

Robust data from the New South Wales Cancer Registry demonstrate that the further a person lives away from a large treatment centre, the higher their risk of a poor treatment outcome (Jong et al., 2004). Poorer outcomes in rural areas have been explained by the tendency for rural patients to have their cancer diagnosed at a later stage possibly because of differences in access to, or utilisation of, screening services (Liff, Chow, & Greenberg, 1991). However, differences in survival outcomes of patients with rectal cancer in Queensland have been shown to exist even after the cancer stage is controlled for (Bydder & Spry, 2011). They are also likely to receive poorer treatment, possibly to minimise the amount of time they spend away from home (National Rural Health Alliance, 2009). Recent research by Craft et al. (2010) concluded that “There were differences in both the care provided and treatment outcomes between women treated in rural centres and women treated in metropolitan

centres” (p. 396). For example, in rural centres, women are less likely to have adjuvant radiotherapy (Craft et al., 2010). Across the world, research has shown that the further a person lives from a radiotherapy facility, the less likely they are to receive it (even when demographic, socioeconomic and pathologic factors are controlled for) (Bydder & Spry, 2011). There are also more disadvantaged groups living in these areas (e.g. Aboriginal and Torres Strait Islander people) (Jong et al., 2004), a higher incidence of some types of cancer due to lifestyle factors (National Rural Health Alliance, 2009) and as previously alluded to, a lack of GPs, nurses, allied health professionals, support services, clinical trials and specialist follow-up and knowledge, which all contribute to this (Sabesan & Piliouras, 2009).

These findings are implicated with rural patients’ psychosocial health for two reasons. Firstly, because poorer physical health has been linked with higher levels of distress (Spiegel & Giese-Davis, 2003) and secondly, because the “... emotional well-being of patients is known to have a significant impact on their attitudes to treatment and the final outcomes” (Baldwin & Usher, 2008, p. 327). That is, because of their poorer treatment outcomes alone, rural patients may be at a higher risk of distress. Therefore, it is possible that improved access to psychosocial care could translate into changed attitudes towards treatment and improved treatment outcomes.

Levels of psychological distress

Given the findings discussed thus far, it is unsurprising that a study conducted by Burris and Andrykowski (2010) in the United States found evidence that rural cancer survivors had significantly poorer mental health functioning, higher levels of anxiety and depression, were more distressed and experienced more emotional problems than their urban counterparts (even when education and physical functioning were controlled for). They also reported less life satisfaction than their urban counterparts (Burris & Andrykowski, 2010). While undoubtedly an important finding, a limitation of this study is that no control group was included and further local research of a similar nature is warranted.

In a related vein, Wilson, Andersen and Meischke (2000) found that breast cancer survivors living in rural areas required more education about cancer and after diagnosis, more emotional support than their urban counterparts. Beesley et al. (2008) found gynaecological cancer survivors were more likely to have unmet supportive care needs, if they lived in rural or remote locations. Similarly, an Australian study by Girgis, Boyes, Sanson-Fisher and Burrows (2000) found that “a significantly higher proportion of rural women expressed a moderate or high need for help with dealing with fears about the cancer spreading or returning than urban women” (p. 169). Lyons and Shelton (2004) found that “Rural residents travelled greater distances for appointments and felt more isolated. They were less likely to know what services were available to them and were less confident about taking the necessary steps to access those that they did know about” (p. 20). Koopman et al. (2001) also found high levels of depression, hopelessness and helplessness among rural American women living with breast cancer. Further, a study comparing health status among cancer survivors in the United States found that “Rural survivors reported worse health in all domains” including distress (18.8% rural survivors versus 12.8% urban survivors) (Weaver, Geiger, Lu, & Case, 2012, p. 1). These authors concluded that “Rural cancer survivors are at great risk for a variety of poor health outcomes, even many years after their cancer diagnosis, and should be a target for interventions to improve their health and well being” (Weaver et al., 2012, p. 1). In addition, a recent review of the literature by Butow et al. (2012) concluded that most controlled studies found rural patients had worse outcomes than their urban counterparts and had significant information, financial and support needs.

Therefore, one can conclude that the psychosocial needs of rural people affected by cancer are at least equivalent to, if not greater than, those of their urban counterparts, while the accessibility to psychosocial services in rural Australia (like many other rural areas of the world) is generally sub-standard.

This chapter will now turn to examine what is thought to explain rural cancer patients’ low uptake rates of services to support them (Corboy, McLaren, & McDonald, 2011).

Barriers to the provision of psychosocial services in rural areas

Lack of trained staff

Previous research suggests that the lack of staff trained in mental health care in rural areas is a major contributor to the shortage of psychosocial services for cancer patients in rural Australia and other rural areas around the world (Bettencourt et al., 2007; C. Davis et al., 2003; Jameson & Blank, 2007; Minstrell et al., 2008). Jameson and Blank (2007) explain that difficulties in recruiting and retaining mental health staff in rural areas is the result of lower levels of job satisfaction, stemming from burnout, cultural barriers and a lack of respect for their professional judgment. They go on to point out that “Psychologists in rural communities have the deck stacked against them: Barriers to quality care are numerous, and suspicion of “shrinks” is high. Psychologists may be seen as stuffy, overly intellectual elitists as well. This perception (right or wrong!) does little to instil a sense of partnership and trust with the community” (p. 292). As a result, rural General Practitioners (only a minority of whom have an interest in and training in mental health) are often left to deal with these issues (McGrath, 2001a; Taylor, Edwards, Kelly, & Fielke, 2009). In addition, a lack of funding has been highlighted as a barrier to good psychosocial care in rural areas (Sabesan & Piliouras, 2009; Shepherd et al., 2008).

Geographic isolation and small patient numbers

Geographic isolation (Aylward et al., 2012; Bettencourt et al., 2007; Jameson & Blank, 2007) and small patient numbers also hinder the provision of psychosocial services in many rural settings (Goldstein & Underhill, 2007). For example, inadequate numbers make support groups in some rural localities unfeasible (Sullivan, Weinert, & Cudney, 2003). Similarly, smaller populations can make it difficult to find or be connected with someone who has had a similar diagnosis (Baldwin & Usher, 2008). Distance, costs associated with travel and unpredictable road and weather conditions may also

prevent some patients from accessing psychosocial services in rural areas, particularly if they are not well (Sullivan et al., 2003).

Lack of integration between psychosocial services and primary health care

The lack of integration between psychosocial services and primary health care in rural areas is another factor that is thought to make access difficult for rural patients (Jameson & Blank, 2007; Lee, 2007). Lee (2007) describes the delivery of psychosocial services for rural cancer patients in Victoria as “haphazard” and goes on to explain, “There is a lack of clarity about the kinds of tasks undertaken by different professions and health workers themselves have diverse perceptions about their roles” (p. 97). He also highlights that comprehensive psychosocial assessments are rarely carried out and there is reluctance to share patients in many rural settings (Lee, 2007). Even if available, psychosocial services are often poorly promoted to patients, because health professionals view them as stigmatising, find them difficult to discuss and/or lack understanding about their role (Hutchison, Steginga, & Dunn, 2006). As a result, many patients are unaware of local services and ‘struggle on’ unless they present to a local hospital or are referred to services by a family member (Lee, 2007). A cross-sectional study of over 400 cancer patients at an Australian regional tertiary cancer centre found that of those that stated they were not aware of psychosocial services, 47% said they would have used them if they had known they existed (Steginga et al., 2008).

Stigma

Stigma associated with mental health (even in medically ill patients) is thought to be another major barrier to the development and use of psychosocial services. The negative effects of stigma on psychosocial service-use by rural patients has been widely documented (Bettencourt et al., 2007; Hewitt & Rowland, 2002; Jameson & Blank, 2007; Thorndyke, 2005) and means that even when services are geographically accessible and required, many patients will choose to not access them (Hewitt & Rowland, 2002). Stigma is thought to be particularly rife among rural men (Judd, Komiti, & Jackson, 2008) and previous research has shown that the more isolated a rural community is, the more

likely it is that its residents will hold stigmatised attitudes towards seeking mental health care (Hoyt, Conger, Valde, & Weihs, 1997).

Other cultural issues

In addition to stigma and practical and system-based issues, there are also unique sub-cultural values that affect help-seeking patterns in rural communities (Jackson et al., 2007; Jameson & Blank, 2007; Koopman, Angell, Turner-Cobb et al., 2001; Sullivan, Weinert, & Fulton, 1993; Thorndyke, 2005). Rural people have been found to be more conservative, religious, work-orientated, intolerant, fatalistic and familial than their urban counterparts (Melton, 1996). Closely associated with this is evidence that they are more self-reliant (Bushey, 1992 cited in Collins, Winefield, Ward, & Turnbull, 2009; Corboy, McLaren et al., 2011; Silveira & Winstead-Fry, 1997), independent (Burman & Weinert, 1997a) and less likely to ask for help (Cuss & Woodcock, 2003 cited in Eley, Rogers-Clark, & Murray, 2008; Thorndyke, 2005), or accept it (Lee, 2007), particularly if that help is being offered by someone with a higher level of education than them (Bushey, 1992 cited in Silveira & Winstead-Fry, 1997).

Rural cancer survivors have been found to have less favourable personal attitudes and social norms towards using mental health resources than their urban counterparts (Andrykowski & Burris, 2010). Many rural people are also sceptical of 'new comers', which many health providers are considered (Elliott-Schmidt & Strong, 1997) and see 'outsiders' as intruding. This is a difficult issue to address, as rural people have also been found to avoid seeking help from those with whom they may have dual relationships, and hence have concerns about privacy and gossip (C. Davis et al., 2003; Elliott-Schmidt & Strong, 1997; Rogers-Clark, 2002; Thorndyke, 2005). On the other hand, they are also more hesitant to expose their private lives to strangers and may be intimidated by travelling to use more distant services where they fear their cultural or behavioural differences may be misunderstood (Elliott-Schmidt & Strong, 1997).

As a result, they are far less likely to seek help for psychosocial issues than their urban counterparts (Corboy, McDonald, & McLaren, 2011). If rural patients do choose to seek help, they are likely to postpone this until it is economically and socially convenient to do so (Elliott-Schmidt & Strong, 1997). They are also thought to be more traditional, stoic, have more of a matter-of-fact approach and a fear of being perceived as a 'service over-user' (C. Davis et al., 2003).

Lower levels of mental health literacy (K. M. Griffiths, Christensen, & Jorm, 2009) may also explain a reluctance to use psychosocial/ mental health services and play a part in explaining negative attitudes towards seeking psychological help. Closely associated with this is the evidence that rural people often do not realise when they need psychological treatment and the denial of this necessity may be reinforced by their family and friends (Jameson & Blank, 2007). These factors, combined with limited exposure to professional psychosocial services - and hence limited awareness of their role or benefits (Collins et al., 2009) - may explain why some studies have concluded that rural cancer patients express a preference for informal, non-professional, sources of support (Burman & Weinert, 1997a; Jameson & Blank, 2007; McGrath, 2001b; McGrath et al., 1999b).

Facilitators of support-giving in rural communities

Despite the aforementioned well-documented barriers to psychosocial service utilisation in rural communities, it is important to note that there may be some advantages for cancer patients who live in rural communities in terms of the provision of support. Rogers-Clark (2002) found that an overwhelming majority of the rural breast cancer patients involved in her study "felt strongly that the positive aspects of rural living outweighed the difficulties" (p. 34) and some women reported finding emotional support and solace in their rural community even though it was away from specialist services and privacy. As a result, she highlights that "... it is vital that any interventions seek to build on the strengths of rural communities in relation to lifestyle and support, rather than assuming that rural communities are defined by their absence of specialized services" (p. 38).

Strong, informal support networks have also been highlighted by other studies (e.g. McGrath et al., 1999b). However, as McGrath et al. (1999b) point out, “Unfortunately, those who are new to the area, socially isolated or without established relationships can easily slip through this ‘rural net’ and experience a strong sense of aloneness” (p. 51).

It is also important to note that although some cancer patients are able to ‘get by’ with informal sources of support, if a patient’s level of distress places them within the aforementioned 30% of cancer patients who are considered to have a psychological disorder, their level of distress is likely to remain elevated if they do not seek professional help (Zabora et al., 1997).

Summary and rationale for this work

This literature review has highlighted three key points. Firstly, in addition to stressors that all cancer patients face, rural patients must travel to access specialist treatment. They lack access to local medical and psychosocial services, which may be particularly problematic following the completion of treatment and they may encounter a range of cultural and social stressors that are unique to or particularly prominent in, the rural environment. Secondly, rural cancer patients’ treatment outcomes are inferior to those of urban patients and there is emerging evidence that they may be at greater risk of experiencing psychological distress. Finally, despite some evidence of strong, localised lay support networks in rural communities, a range of barriers to the provision of formal psychosocial care to rural cancer patients are evident; these include a lack of trained staff, geographic isolation, small patient numbers, the lack of integration between psychosocial services and primary health care, stigma and other cultural issues.

It has been widely concluded that further research on the psychosocial needs and experiences of rural cancer patients would be beneficial (Bettencourt et al., 2007; Bettencourt et al., 2008; C. Davis et al., 2003; Kenny, Endacott, Botti, & Watts, 2007; McGrath et al., 1999b; Meneses et al., 2009; Palesh et al., 2006; Rogers-Clark, 2002). However, of even more clinical importance is to look beyond the

identification of unique stressors, to ways in which barriers to service use could be broken down. As Hauenstein et al. (2007) point out, "... effective treatment for many of these disorders is available so the failure to deliver these services results in unnecessary personal distress and cost to the economy" (p. 255).

Kenny, Endacott, Botti and Watts (2007) argue that "No consideration has been given to key issues that have an impact on the provision of psychosocial care to cancer patients in the rural setting" (p. 669), and similarly McGrath et al. (1999b) point out that "Key government reports on cancer control in Australia have concluded that relatively little is known about...the appropriateness of existing rural services to deal with cancer" (p. 44). Although some trials of innovative solutions to bridge these gaps have taken place (e.g. Angell et al., 2003b; Collie et al., 2007; Eley et al., 2008; Meneses et al., 2009; Shepherd et al., 2008; Solberg, Church, & Curran, 2003), further research into the unique preferences and perceptions of rural cancer patients will help to ensure that psychosocial interventions build on the existing strengths (Rogers-Clark, 2002), support and resourcefulness of rural communities (McGrath et al., 1999b) and are culturally appropriate, locally endorsed and likely to be used. Interventions will need to be targeted (Girgis et al., 2000; McGrath et al., 1999b), creative and flexible (Lee, 2007) to address these patients' needs because of the barriers identified in this review.

While conducting this type of research "requires patience, creativity, and a trusting relationship" (Angell et al., 2003b, p. 505) which can be challenging, the importance of involving clients in the planning of health care interventions is widely acknowledged (Sullivan et al., 2003) and as Green and Thorogood (2009) point out, "Without an empathetic understanding of why people behave as they do, we are unlikely to identify possibilities for change" (p. 29). As Jameson and Blank (2007) acknowledge, "Cultural competence and sensitivity are important considerations if linking the community members to the mental health service system is to be an achievable goal: this includes developing local knowledge, an understanding of belief systems and values" (p. 293).

Therefore, against the backdrop of these findings, the overall objective of this research is to improve understanding of the psychosocial needs of rural cancer patients and how they can be better addressed. With an enhanced understanding from consumers' perspectives, the aforementioned inequalities in the provision of evidence-based cancer care may be suitably addressed.

CHAPTER II: AIMS, RESEARCH METHOD AND THEORETICAL FRAMEWORK

This chapter details the aims of this research, methods employed to collect data and the underpinning assumptions and theory. The purpose is to explain why these particular methods were employed to do this research, aid in its evaluation and comparison with other work and to assist others to undertake similar projects in the future. While some of the questions this research investigates have been previously examined in other settings, what makes this a unique contribution, is the rural context in which it has been carried out.

Study 1

Given the evidence from the literature that rural cancer patients have unique attitudes and experience high levels of stress and poor levels of access to psychosocial services, the objective of Study 1 was to identify key issues in providing psychosocial care from the perspective of rural South Australian cancer patients, and culturally appropriate methods to reduce barriers to service use. A better understanding of this unique group's shared preferences for and perceptions of psychosocial care could help ensure future psychosocial interventions designed for them are likely to be used. The methods employed to do this, are outlined below.

Semi-structured interviews

In Study 1, a qualitative semi-structured interview design was employed as interviews are recommended when examining potentially sensitive issues (such as cancer), which may require clarification (Hinds, 2004) and when “researchers [wish] to learn about social life through the perspective, experience, and language of those living it” (Hesse-Biber & Leavy, 2006, p. 128). Interviews have also proven useful in identifying modifiable factors for improving health care (Tong, Sainsbury, & Craig, 2007), which was a focus of this research.

The interviewer asked open-ended questions and served as an active listener unless further prompting questions were required. This ensured that participants had the freedom to talk about issues that were important to them, that essential areas of enquiry were covered and that the responses of multiple participants could be contrasted and compared (Hesse-Biber & Leavy, 2006). Despite being more time-consuming, interviews were used rather than focus groups to minimise the chances that participants' responses would be influenced by their peers (Rice & Ezzy, 1999).

Thematic analysis

Thematic analysis is described as a “method for identifying, analysis and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79) and was employed in Study 1 as described by Braun and Clarke (2006). Thematic analysis was deemed appropriate, as the purpose of the analysis was to examine the ideas, issues and thoughts regarding psychosocial care, largely as raised by participants (although some guiding questions were used). Importantly, this approach allowed for the discovery of unintended insights.

Braun and Clarke's method of thematic analysis is commonly used to analyse qualitative data generated in similar research - for example, an Australian study into General Practitioners' perceptions of their role in cancer care (G. K. Mitchell, Burrige, Colquist, & Love, 2012) and in the United States in an examination of breast cancer patients' use of health information in decision making and coping (Radina, Ginter, Brandt, Swaney, & Longo, 2011).

Thematic analysis involves becoming familiar with the transcribed data, assigning grouping codes to each datum, identifying broader themes from the codes, considering the definitions and relationships between the resulting themes and reviewing contradicting themes until all data have been accounted for (Braun & Clarke, 2006). To enhance analytical rigor, special attention was paid to searching for negative cases for code and theme development. As outlined in Paper 1 (see Chapter IV), a datum was considered to be a segment of text that expressed one idea, grouping codes were labels used to roughly

but directly summarise the datum and a theme was “...something important about the data in relation to the research question, and represent[ed] some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p. 82). However in practice, determining what counts as a pattern or what size a theme needs to be can be difficult (Braun & Clarke, 2006). To add transparency to this process, the number of participants who articulated each theme is disclosed in Paper 1. Quoted extracts have also been included to add validity and aid interpretation in a similar fashion to that employed by Duggleby et al. (2011).

Participants’ descriptions of their experiences and realities were assessed as direct insights into these experiences and thematic meaning was generally situated at the semantic or surface level of the data (Braun & Clarke, 2006). Although an essentialist inductive or ‘bottom up’ approach was taken to the analysis (whereby what participants said was assumed to provide direct insights) and themes were derived from the data rather than pre-defined theory, it is acknowledged that “researchers cannot free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum” (Braun & Clarke, 2006, p. 84). That is, researchers are active in the research process - themes do not ‘emerge’ on their own (Braun & Clarke, 2006). A more detailed discussion on reflexivity (that is, how researchers’ positions impact upon the research process and findings) is presented later in this chapter.

Study 2

The purpose of Study 2 was two-fold:

A) to develop a website that provided rural-specific information on psychosocial care for South Australian rural cancer patients, their carers, families, friends and health professionals, by engaging people with relevant life experience (‘participants’) as well as knowledge from the psychological literature and,

B) to document the lessons learnt during this process.

As many of the rural cancer patients interviewed in Study 1 expressed a strong desire to help improve “the system” and had given permission to be re-contacted for follow-up research purposes, several of the same participants who identified the need for rural-specific information were able to help develop solution to this problem, through participation in Study 2. A Participatory Action Research Framework (PAR) was employed to engage participants in this process in hope that it would help aid the development of relevant and acceptable website content and simultaneously provide participants with a sense of empowerment.

Participatory Action Research

‘Action Research’, coined by Lewin (1947), is a research approach that aims to uncover and resolve problems (not just investigate them) (Whitehead, Taket, & Smith, 2003). *Participatory Action Research (PAR)* extends this by also incorporating a focus on the involvement of those who are being affected by a problem. Kidd and Kral (2005) explain that to ‘do’ PAR “you get the people affected by a problem together, figure out what is going on as a group, and then do something about it” (p. 187). Rapoport (1970) describes it as a collaborative research process that “contribute[s] both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework” (p. 499). PAR involves a process of reflecting, planning, acting, observing (Kidd & Kral, 2005) and views knowledge generation as the outcome of sharing, reflection and experience through dialogues with the community in question, as opposed to the process of experts remotely extracting information from them at a distance, which is the approach taken in more traditional methods (Green & Thorogood, 2009). Participants in PAR are considered ‘active subjects’ rather than ‘passive objects’ of research (Rice & Ezzy, 1999), and their local voices, culture and wisdom is typically privileged throughout the process.

PAR is better considered as an orientation or philosophical stand point, rather than a methodology (Khanlou & Peter, 2005). However, essential features of PAR are that it “is educative; deals with individuals as members of social groups; is problem-focused, context-specific and future-orientated; involves a change intervention; aims at improvement and involvement; involves a cyclic process in which research, action and evaluation are interlinked; is founded on a research relationship in which those involved are participants in the change process...” (Hart & Bond, 1995, p. 37).

This approach is considered useful in research that aims to produce knowledge and action that is directly relevant and helpful to a specific group (Rice & Ezzy, 1999). It is thought to be appropriate for dealing with “the complexities and subtleties of caring for human health and sickness” (Morrison & Lilford, 2001, p. 438) and can empower people by giving them the opportunity to use their own knowledge to improve lives (Rice & Ezzy, 1999).

PAR is also consistent with the politically mandated emphasis on involving consumers in the planning of health care (Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998; Rice & Ezzy, 1999) and away from the paternalistic assumption that ‘experts’ such as doctors are best positioned to determine the health research that need to be taken (Boote, Telford, & Cooper, 2002), which has led to rapid adoption of this approach (Rice & Ezzy, 1999). As White and Verhoef (2005) point out, “as a result of engaging people directly in the research process, we come closer to the reality of other people’s experience and, in the process, increase the potential for creating truly effective services and programs that will enhance the lives of the people we serve” (p. 24). Further, as Whitehead et al. (2003) suggest, “action research provides the best means by which to narrow the research-theory-practice divides” and according to DeKoning and Martin (1996), “helps to avoid mistakes and to develop programmes that take into account the specific situation and conditions which will influence the outcome of programmes” (p. 4 in Rice & Ezzy, 1999). Other advantages are that it can provide access to people, knowledge and contexts that might be inaccessible using traditional methods (Kidd & Kral, 2005), that it gives participants the opportunity to ensure researchers ‘keep it real’ (Smith, Bratini,

Chambers, Jensen, & Romero, 2010) and that it ‘feels good’ and can lead to genuine connections between people that are motivating and contribute to mutual personal growth (Kidd & Kral, 2005).

On the other hand, PAR is generally considered a more difficult method of research than more traditional forms of research, as it aims to generate not only knowledge, but also change (Dick, 1993). It is also time consuming (Dick, 1993) and requires interpersonal skills, self-awareness, self-reflexiveness and skills in managing data and politics (Rice & Ezzy, 1999).

PAR is sometimes criticised for producing results that are less generalisable than other research methods. However, Dick (1993) describes generalisability as a “trade-off” between local and global relevance. PAR researchers are not prepared to involve participants in projects that could produce something of global relevance (or could be generalised more easily) at the expense of creating local change and do not apologise for doing so. That is, local relevance is crucial to the PAR paradigm. Further, it is thought that some trade-off of traditional rigor is worth the additional face validity and practical implications that PAR allows. However, Morrison and Lilford (2001) point out that that action researchers should use “context-sensitive findings to draw generalizable lessons about human situations” (p. 448), which the present work also seeks to do. In this study, reliability was maximised by using a systematic approach, taking the time to carefully describe the method employed and, as recommended by Dick (1993), gathering information from multiple sources.

To enhance validity, interpretations were stringently examined for ambiguity and exceptions (Dick, 1993). Participants had the opportunity to comment on the conclusions drawn from discussions with them. This process is understood to reduce researcher bias by highlighting findings that they may not have otherwise considered (Knott, 2008). For this reason, it has been suggested that “Insiders as significant partners in a research team can enhance scientific validity” (Elden & Chrisholm, 1993, p. 128). Validity was also enhanced in the present work by carefully and reflexively explaining the context in which the work was carried out (see Chapter III) and the characteristics of those who

participated in each study. Using a cyclic process, later cycles challenged the information and interpretations established in earlier cycles. This refines understanding of the issue and adds methodological rigor thereby adding to the quality of data, interpretations (Dick, 1993) and in this case, the quality of the intervention. For these reasons, PAR is considered a valid and important research method (Whitehead et al., 2003).

Instead of keeping a diary as Hart and Bond (1995) recommend when using this method, memos were written so that they could be easily shared with participants and corrections made, should the participants think that their thoughts/ ideas had been misrepresented. These memos were used in conjunction with the website plan, which was a working document, updated when new suggestions came to light. This approach was employed based on Dick's (1993) advice that "you can improve the rigor of your study substantially by combining collection, interpretation, library research and perhaps reporting. Developing an interpretation right from the start gives you more time and more cycles to test it thoroughly... A further advantage in recording your interpretation as you proceed is that you spare yourself the mountain of data which qualitative research too often accumulates... because of the convergent nature of this process, the more detailed information collected in the later cycles supersedes the earlier data" (p. 28).

Reflexivity

As Green and Thorogood (2009) point out, in most quantitative traditions, "the assumptions of positivism imply a striving for 'objectivity', in which the researcher attempts to minimize the kinds of political values, subjective impressions and partial accounts that might bias their findings. However, in qualitative traditions... it is accepted that these values are inevitably part of the research process" (p. 23). The present research takes on the latter position because, as Green and Thorogood (2009) go on to argue, "It is impossible to have a field for study that is untainted by values and impossible for the researcher to stand outside those values and subjectivities" (p. 23). Researchers' values, backgrounds and positions affect what they choose to investigate and how they go about investigating it, as well as

how findings are framed and communicated (Malterud, 2001). It has been suggested that in qualitative research, objectivity should be redefined “to recognise that knowledge is partial and situated, and to account adequately for the effects of the positioned researcher” (Malterud, 2001, p. 484). A review by Evans et al. (2003) criticised some research that has examined the needs of rural cancer patients for omitting a discussion of the qualitative researchers’ backgrounds, viewpoints and relationships with subjects. By identifying preconceptions and beliefs prior to starting research studies and scrutinising data for competing conclusions, objectivity can be achieved according to Malterud (2001). Therefore, in accordance with best practice recommendations (Tong et al., 2007), before using a qualitative approach, it was necessary for the author to consider how her own social background and assumptions might intervene in the research process (i.e. engage in the process of reflexivity) (Hesse-Biber & Leavy, 2011). As Green and Thorogood (2009) point out, “this is not to assume that those data are merely subjective impressions that would have been different if generated by a different researcher, but to attempt to account explicitly for the fact that data are ‘produced’ rather than merely ‘collected’” (p. 28). This process examined the attributes that the author brought to the project, including gender, age, background, education, cancer status and similarities and differences to participants. See Chapter III for a summary of these. It is also important to consider the broader social and political field and why it is possible to attract funding and interest to carry out such tasks at a particular point in time (Green & Thorogood, 2009). This is also outlined in Chapter III. Reflexivity is of particular importance to the interpretation of the results of Study 1 and 2 as in both of these studies, the author interacted a lot with participants.

Study 3

The purpose of Study 3 was to objectively determine how acceptable providing rurally-relevant psychosocial cancer information via a carefully designed website is (*Country Cancer Support*), to rural

cancer patients, their “supporters” (i.e. family, friends, carers) and health professionals. It also provided the opportunity to check the validity of findings generated in Study 1 and 2, with a broader sample.

Online surveys

An online survey, modelled on questionnaires and scales previously used as research tools where possible, was used to do this. How this survey was developed is outlined in Paper 3.

Both quantitative and qualitative methods were used. Quantitative methods were viewed as a relatively simple way of measuring and comparing website user’s satisfaction with various aspects of the website. Qualitative questions were used to provide richer data and to avoid suggestive questioning by using pre-defined categories. The results were written up in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) by Eysenbach (2004). Web surveys have been successfully used in the past to evaluate similar websites, for example by Powell, Inglis and Large (2011) to evaluate the National Health Service Direct website in the United Kingdom.

Google Analytics

Google Analytics provided a direct measure of website usage. It is a free tracking system, external to the website being analysed and is often used by website administrators to improve website content and design (Plaza, 2011). This type of measurement is considered a useful addition to the evaluation of academic internet interventions (Bennett & Glasgow, 2009). Usage (including frequency of visits and participation in interactive website components) has been used previously as an outcome measure of the level of “success” in setting up a similar website (Winefield, Coventry, & Lambert, 2004).

Conventional qualitative content analysis

The method of conventional qualitative content analysis described by Hsieh and Shannon (2005) was chosen to analyse the qualitative data derived from the online survey. It is a systematic method (Elo & Kyngas, 2008) that “goes beyond merely counting words to examining language intensely for the purpose of classifying large amounts of texts into an efficient number of categories that represent

similar meanings” (Hsieh & Shannon, 2005, p. 1278). The inductive form of this method is often used to describe phenomena and when existing theory and relevant literature is limited (Elo & Kyngas, 2008; Hsieh & Shannon, 2005), as is the case in the present field of investigation.

Content analysis was used to analyse the written qualitative data collected in Study 3 instead of thematic analysis (used in Study 1 and described previously), as it is more appropriate when the unit of analysis is a word or phrase and the analysis needs to be conducted at a micro level (Braun & Clarke, 2006). In Study 3, the data analysed consisted of short answers in response to specific questions. However, many similarities exist between the two qualitative approaches (Braun & Clarke, 2006) and alternative views and definitions exist (Rice & Ezzy, 1999). For example, Rice and Ezzy (1999) argue that the difference between content analysis and thematic analysis is that “content analysis involves the identification of codes prior to searching for these in the data, and that thematic analysis involves the inductive identification of codes from the data” (p. 192). However, Hsieh and Shannon (2005) confirm that content analysis can also employ an inductive approach.

In the present study, categories were derived directly from the data (rather than the literature), but both explicit and inferred communication was considered, which is typical of this method (Hsieh & Shannon, 2005). Content analysis has grown in popularity over the last 30 years and has been used extensively in the fields of Psychology and public health (Elo & Kyngas, 2008). The number of participants whose responses fitted within a category is disclosed to add transparency. Quoted extracts have also been included to add validity and to aid interpretation in a similar fashion to that employed by Duggleby et al. (2011).

Multi-methods

From a broader perspective, a sequential multi- methods approach was employed throughout this work and each study was analysed separately. The results of one study informed the next.

Mixed or multi-methods are described as “the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language” (Johnson & Onwuegbuzie, 2004, p. 17). This eclectic approach, “the third research paradigm”, is one that recognises that both qualitative and quantitative forms of research are useful and provides a framework to allow researchers to capitalise on the strengths of both quantitative (e.g. relatively quickly provides easily analysable, precise, numerical data from a large number of subjects) and qualitative designs (e.g. can provide deep, rich insights into unexplored perceptions and opinions, and be responsive to stakeholders needs) (Johnson & Onwuegbuzie, 2004).

As previously outlined, quantitative elements were included in Studies 1 and 2 to describe the samples but the research questions were answered using a qualitative approach. Study 3 was predominantly quantitative involving data gathering from over 100 participants and a small written qualitative element was included to add detail.

Defining ‘rurality’

A criticism of existing research on the unique needs of rural cancer patients is that rurality is rarely defined, making it difficult to interpret and compare work (Butow et al., 2012). In their recent review, Butow et al. (2012) highlight the need for a definition and suggest that the Accessibility/Remoteness Index of Australia categories (ARIA) (Australian Institute of Health and Welfare, 2004) is a useful way of doing so. The ARIA a standard index of remoteness that is based on accessibility by road to services (Australian Institute of Health and Welfare, 2004) and is the method of defining the participants in this research. Classifications range from “Highly Accessible” (areas with scores between 0 - 1.84 where there is relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction, such as Gawler) to “Very Remote” (areas with scores >9.08 – 12 with very little accessibility to goods, services and/or social interaction such as Ceduna) (Australian Institute of

Health and Welfare, 2004). An example of an “Accessible” location in South Australia is Port Pirie, “Moderately Accessible” location is Maitland and a “Remote” location is Wudinna.

However, the term ‘rural’ is informally employed throughout this thesis to describe all those living outside of metropolitan Adelaide as South Australia’s population and services are heavily concentrated in Adelaide. See Chapter III for a more detailed discussion of this. It should also be noted that although Broken Hill is situated in New South Wales, it is included within the definition of South Australia in these studies (as it is for many other purposes). Broken Hill is very close to the South Australian border and a long distance from the capital of New South Wales (Sydney). Therefore many residents of Broken Hill and surrounding areas use South Australian-based health services.

Sampling/ data collection

A purposive sampling framework was adopted in Study 1, in which participants were selected from a pool of interested people, based on previously identified subgroups (Rice & Ezzy, 1999). Care was taken to ensure that all five of the most commonly diagnosed types of cancer in Australia were represented (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2008), as were each of the five ARIA categories (Australian Institute of Health and Welfare, 2004), and a similar number of male and female participants, with and without private health insurance. Purposeful sampling is widely employed in qualitative research (Malterud, 2001). Data collection ceased when data saturation occurred (i.e. little new information was being obtained). All of the participants in Study 1 had used some form of psychosocial service at the time of participation. This was due to the broad definition of ‘psychosocial service’ that was employed (see Chapter IV) and the fact that they were largely recruited as a consequence of their service use. Participants were asked to reflect on their experiences prior to accessing support services, to address this potential limitation. The duration of interviews ranged from 45 to 90 minutes.

As outlined in Chapter V, participants in Study 2 included participants from Study 1 who gave permission and could be contacted (only one person chose not to be involved in Study 2). An additional participant was recruited through personal networks and a rural health care professional, who had also cared for her own cancer-affected rurally-based relative, was recruited after expressing interest in the study. These two participants brought unique perspectives and were keen to assist. However, as per PAR methodology, it was important the majority of participants were those who had helped identify the problem (and therefore had participated in Study 1).

In Study 2, data were collected in a stepwise fashion. That is, further information was sought (or re-sought) from a particular participant if previous participants were unable to offer comment on that particular topic (or aspect of the intervention's design) (Malterud, 2001). This process is commonly employed in qualitative research (Malterud, 2001).

Participants were recruited to Study 3 via the *Country Cancer Support* website and by circulating a link to the online evaluation to clinical staff employed by Country Health SA (the state government rural health service).

To describe the sample (and to assess the generalisability of findings), demographic, medical and psychological (in Studies 1 and 3) information was gathered from all participants, predominantly in quantitative form, using validated measures. The measures employed are described in more detail where relevant in each paper; except for in Paper 1 at the reviewers' request. In summary, they were chosen because they had sound psychometric properties and there was evidence that they would be appropriate to use with participants in the present work.

CHAPTER III: RESEARCH CONTEXT

Introduction

This chapter outlines the context of this research beyond the academic literature and its methodological and theoretical framework, and answers the following questions:

- Why cancer?
- Why rural?
- Why South Australia?
- Why now?
- And why me?

In addition, in accordance with best practice recommendations on reflexivity in qualitative research (Tong et al., 2007), and consistent with the epistemology described in the previous chapter, brief descriptions of each member of the research team help to situate the researchers as social instruments in the collection, analysis, and interpretation of these data. The chapter concludes by reflectively and reflexively telling more of ‘the story’ about the circumstances in which this project unfolded.

Cancer in context

The number of people being diagnosed with chronic conditions such as cancer is growing rapidly around the world (Winters, Cudney, & Sullivan), due to aging populations (Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008) and improved screening practices (Cancer Council SA & SA Health, 2011). Cancer can affect a person of any age but the older the person, the more likely they are to develop the condition (Cancer Council SA & SA Health, 2011). Approximately 120,700 people are diagnosed with cancer each year in Australia (Australian Institute of Health and Welfare, 2012).

Exactly 8592 cases of invasive cancer were reported in South Australia in 2006 (Cancer Council SA & SA Health, 2011). Cancer is the second most common cause of death in Australia, accounting for 30% of fatalities and exceeded only by cardiovascular disease (32%). Australia has the highest rate of melanoma and prostate cancer in the world (Australian Institute of Health and Welfare, 2012). As the cancer survival rate continues to grow (Australian Institute of Health and Welfare, 2012), in the future there will be even more people living with cancer for long periods of time.

Chronic conditions like cancer take large physical and emotional tolls on patients and depressive symptoms are one of the most common complications of these illnesses, which in turn can intensify pain, fatigue, self-doubt and isolation (Winters et al.). These conditions, which come at a huge cost to health systems (Winters et al.), are gaining political and research attention around the world.

Further, the increasing proportion of patients who receive outpatient care for cancer (especially chemotherapy) (Guadagnoli & Mor, 1991) has created new challenges and responsibilities for families caring for them (Fallowfield, 1995a; Guadagnoli & Mor, 1991). There is increasing acceptance that psychological interventions “should no longer be seen as an optional extra but as an integral part of every patient’s management plan” (Fallowfield, 1995b, p. 1316) and with treatment and detection advances, the number of survivors and people who experience their condition for extended periods will continue to grow in the years ahead (Tuinman et al., 2008).

The state of health in rural Australia

Disparities in health outcomes have been found between people who live in rural compared to urban locations. According to statistics from the Institute of Health and Welfare, when compared to Australians living in major cities, people who live in inner regional, outer regional, remote and very remote areas have: “20 per cent higher reported rates of only fair or poor health; 10 percent higher levels of mortality; 24 per cent higher rates of smoking; 32 per cent higher rates of risky alcohol consumption; 20 per cent higher rates of injury and disability; 20-40 per cent higher reported levels of

sedentary behaviour (for males); 10-70 per cent higher rates of peri-natal deaths; and 15 percent higher rate of overweight and obesity” as well as 33 percent higher rates of injury (National Rural Health Alliance, 2010, p. 2). Education levels are also poorer; 32% of the Australian population lives in rural and remote areas but they only comprise 18 percent of tertiary students (National Rural Health Alliance, 2010). Reports show that the cost of accessing essential services such as health, education and aged care is between two and ten times that demanded of urban residents (National Rural Health Alliance, 2010). Further, life expectancy for those living in rural, regional and remote areas is up to four years shorter than it is in Australia’s major cities (National Rural Health Alliance, 2010). These statistics have placed rural and remote health on the agendas of governments and academics alike. A detailed discussion of rural residents’ cancer-related psychosocial and treatment outcomes is provided in Chapter I.

The South Australian context

South Australia’s population density

Approximately 77% of South Australia’s population live in greater metropolitan Adelaide (Australian Bureau of Statistics, 2011), which means that those living elsewhere in the state need to travel large distances for medical treatment. Figure I adapted from the Australian Bureau of Statistics (2011) demonstrates population density on both a South Australian and Australian scale, in particular the sparsity of some areas of South Australia and its relatively lower population density compared to states such as New South Wales and Victoria (Australian Bureau of Statistics, 2011). As a result, rural South Australians must travel greater distances to access medical care than many of their rural counterparts interstate. As previously outlined, travel of this type comes with significant social, physical, financial and emotional costs (Baldwin & Usher, 2008; CanNET South Australia, 2008; Hegney et al., 2005; McGrath, 1999, 2000a; K. J. White et al., 2011; Zucca et al., 2011). Travelling for one hour to access a local hospital is not uncommon in many parts of rural South Australia. These

hospitals are usually run by Nurses, provide emergency care and a limited number of other services and have a General Practitioner on-call. If patients' medical conditions are complicated, the Royal Flying Doctor Service transfers patients to larger regional hospitals such as Whyalla or, in most cases, Adelaide.

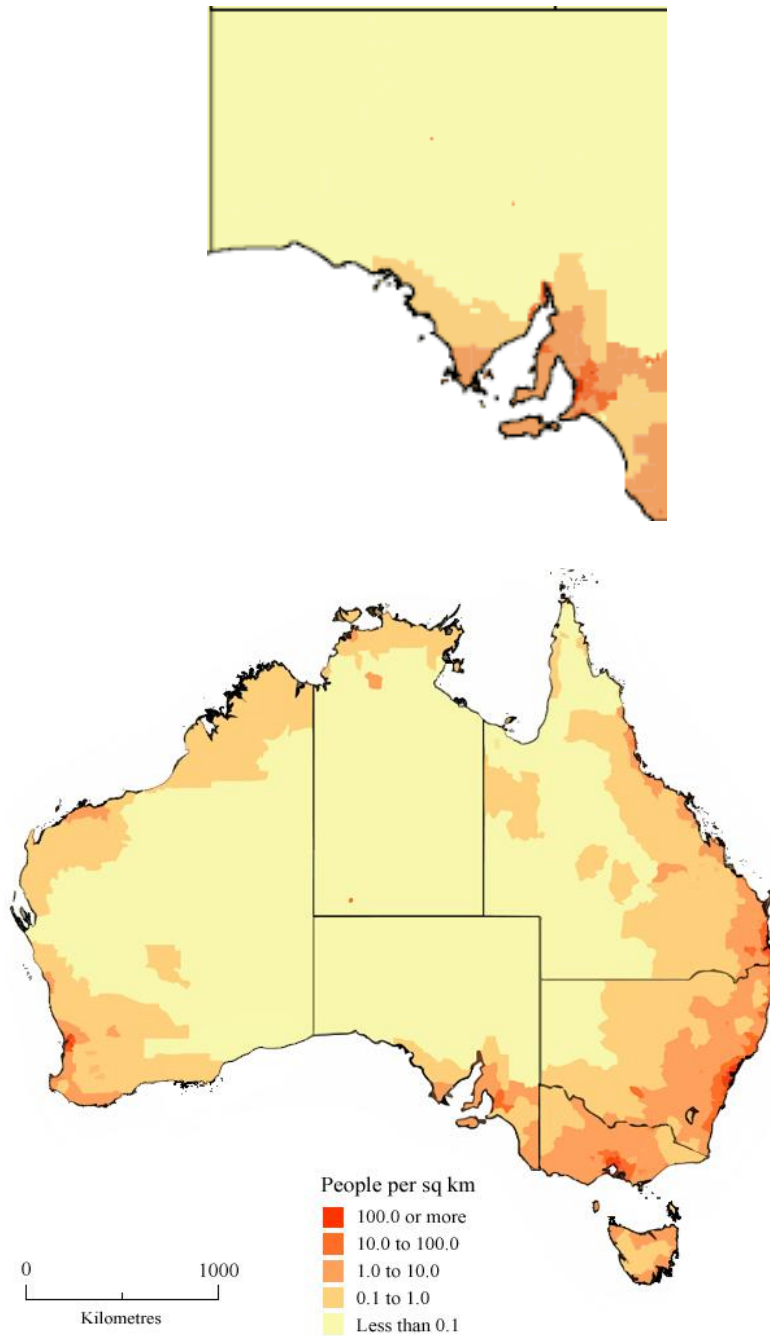


Figure 1. Population density of South Australia and Australia (ABS, 2011)

The provision of cancer care in South Australia

Most cancer care in South Australia is provided in Adelaide. However, according to a report by Deloitte Access Economics (2011), a limited amount of chemotherapy was administered in some rural areas of the state in 2011. Where this was administered is illustrated in Figure II.

NOTE:

This figure/table/image has been removed to comply with copyright regulations. It is included in the print copy of the thesis held by the University of Adelaide Library.

Figure II. Location of cancer services in South Australia (Deloitte Access Economics, 2011)

In 2010-2011, \$560 million was allocated by the Federal Government to upgrade regional cancer centres across Australia to improve access to treatment and support for rural and regional cancer patients (Department of Health and Aging, 2012a). According to the Department of Health and Aging (2012b), this funding will eventually result in the delivery of chemotherapy in several rural centres across South Australia. As detailed in Figure III, these are likely to be at the following locations:

- Mt Gambier Hospital (435km, 4 hours and 36 minutes drive from Adelaide)
- Pt Augusta Hospital (308km, 3 hours and 21 minutes drive from Adelaide)
- Mt Barker Hospital (33km, 32 minutes drive from Adelaide)
- South Coast District Hospital (Victor Harbor) (84km, 1 hour and 12 minutes drive from Adelaide)
- Pt Lincoln Hospital (650km, 7 hours and 12 minutes drive from Adelaide)
- Clare Hospital (141km, 1 hour and 51 minutes drive from Adelaide)
- Murray Bridge Hospital (76km, 57 minutes drive from Adelaide)
- Gawler Health Service (53km, 49 minutes drive from Adelaide)
- Northern Yorke Peninsula Regional Health Service (Wallaroo) (159km, 2 hours drive from Adelaide)
- Naracoorte Health Service (334km, 3.5 hours drive from Adelaide)

The distances and estimated travel times outlined above were calculated using www.travelmate.com.au (Unknown, 2013). In addition, according to the Department, Whyalla will become a 'Regional Cancer Centre', which will include a range of services including chemotherapy chairs, accommodation, counselling, patient education and palliative care (Department of Health and Aging, 2012b). The author has also become aware of the possibility of an additional two treatment centres being built; one at the Riverland Regional Health Service (Berri) (241km, 2 hours and 44 minutes drive from Adelaide) and one at the Ceduna Hospital (767km, 8 hours and 7 minutes drive from Adelaide), but this is yet to be confirmed.

The 'roll out' of many of these new services is currently underway and regarded by many as a very helpful in minimising the need for rural South Australians cancer patients to travel to Adelaide. However, some General Practitioners who have delivered chemotherapy in rural locations in the past will no longer be accredited to do this. Further, as Zucca et al. (2011) point out, the capacity of these new regional facilities is not expected to meet the rising cancer incidence requirements and there will still be patients with complex conditions that require specialist and allied health services that are only viable in metropolitan-based cancer centres. For example, the high set-up and delivery costs of radiotherapy (Clinical Oncological Society of Australia, Australian Cancer Society, & Commonwealth Department of Health and Aged Care, 2001), the large volume of patients required to justify the costs of establishing a new centre and South Australia's low population density (Australian Bureau of Statistics, 2011) prohibit the direct provision of radiotherapy in regional areas of South Australia. Therefore, despite the establishment of these new centres, many rural South Australian cancer patients will continue to face the challenges of travel to access cancer treatment in years to come.

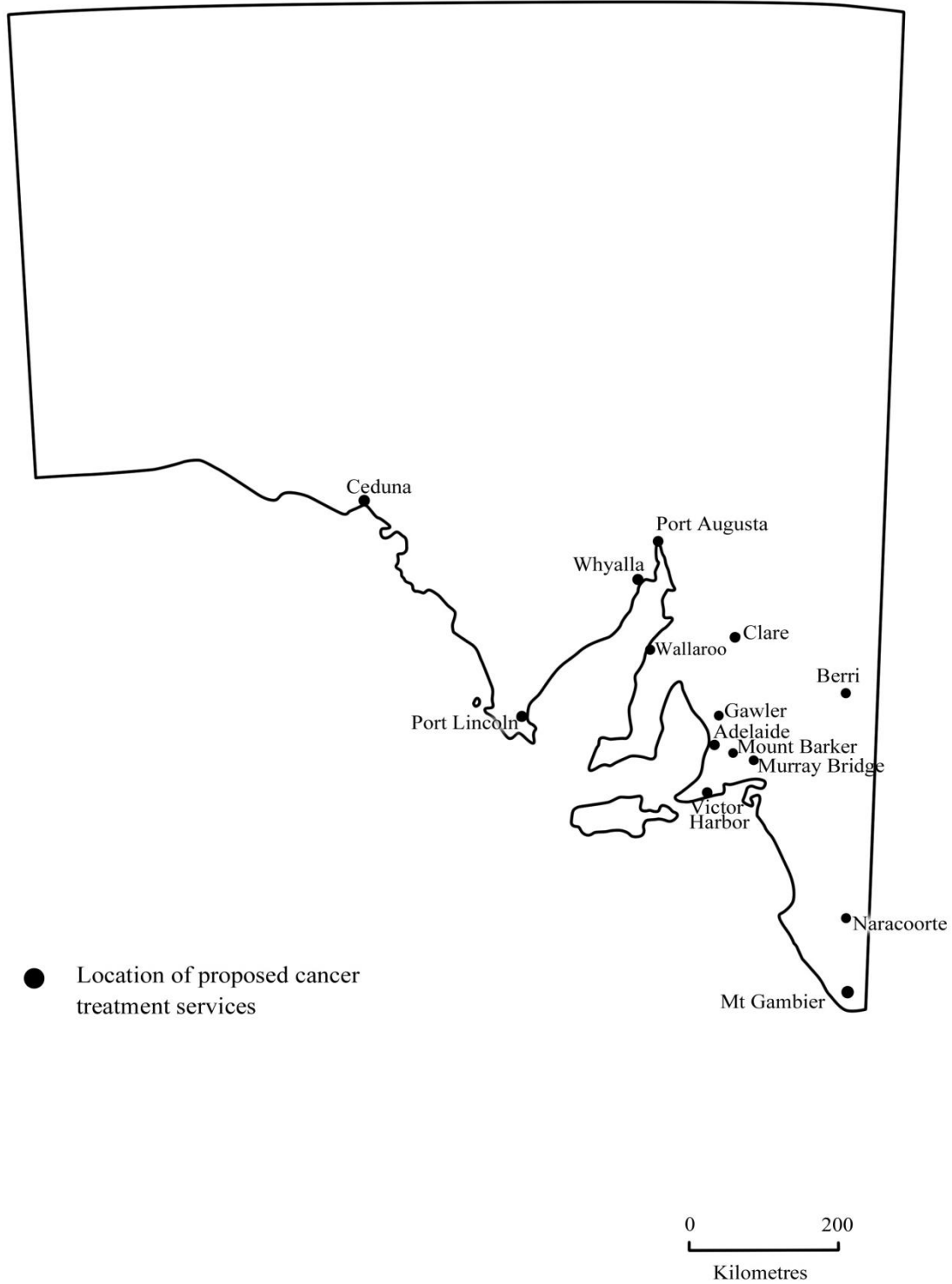


Figure III. Locations of proposed cancer treatment centres

Catalysts for the present research

As the previous sections have outlined, this research was undertaken at the present place and time because:

- The global burden of cancer is growing;
- The health disadvantages among rural populations are increasingly recognised;
- South Australia is a sparsely populated state at particular risk of rural disadvantage; and
- Funding to establish rural cancer centres in Australia has recently become available.

For these reasons, this topical research has garnered attention from both South Australian state government mental health and cancer bureaucracies, as well as Cancer Council SA, Cancer Council Australia and individuals looking for best practice solutions to the psychosocial care of rural cancer patients interstate and overseas.

However, these factors alone would not have facilitated this research. A set of fortuitous circumstances outlined in ‘the story’ below and a person interested in conducting research to improve the health and well-being of rural communities, who possessed the skills, opportunity and generous support from a group of experienced academics, were also necessary.

Academic supervisors’ backgrounds

Although my academic supervisors did not have any direct contact with the participants involved in this research, in the interests of transparency, I will outline their backgrounds as these are likely to have shaped the research methods and some of the conclusions drawn from the data.

Professor Deborah Turnbull *BA (Hons), M Psych (Clin), PhD, MAPS*, is the Chair of Psychology at the University of Adelaide. She has been researching the psychosocial aspects of cancer prevention and treatment since 1988. Her publications in this area examine issues such as the psychosocial aspects

of mammographic screening and methods to improve uptake of bowel cancer screening. Professor Turnbull is experienced in using a blend of qualitative and quantitative methods and teaches this approach to senior Psychology undergraduates. She grew up in Newcastle in NSW and has lived and worked overseas. Professor Turnbull currently resides in the Adelaide Hills and has a growing interest in rural mental health.

Professor Ian Olver AM MD, PhD, CMin, FRACP, FACHPM, MRACMA, is the Chief Executive Officer of Cancer Council of Australia. Prior to this, he was the Cancer Council Professor of Cancer Care at the University of Adelaide and the Clinical Director of the Royal Adelaide Hospital Cancer Centre. He has published approximately 220 papers, 23 book chapters, written 4 books (*Conquering Cancer, Your Guide to Treatment and Research, Is Death Ever Preferable to Life, Investigating Prayer: Impact on Health and Quality of Life*) and edited 3 (*When Cancer Crosses Disciplines - A Physician's Handbook, Perspectives on Complementary and Alternative Medicine, The MASCC Textbook of Cancer Supportive Care and Survivorship*). He has several publications on rural and remote cancer issues and practiced as an Oncologist in rural South Australia for many years. Professor Olver currently lives in Sydney and was recently appointed a Member of the Order of Australia (AM) for his service to Medical Oncology as a clinician, researcher, administrator and mentor, and to the community through leadership roles with cancer control organisations.

Ms Lindsay McWha MHS, DipCOT, is a Visiting Research Fellow at the University of Adelaide and an experienced Clinical Occupational Therapist who has combined practice with research into aspects of physical and mental health of older people. She completed a Masters of Health Science (Occupational Therapy) in 1999. She has 6 publications in peer reviewed journals. Ms McWha has lived and worked in many countries of the world, including with rural patients in New Zealand. She currently resides in Adelaide.

Dr Matthew Davies B. BSc (Hons), M. Psych (Clin), PhD, MAPS, is a Clinical Lecturer in the School of Psychology, University of Adelaide. He lives in Adelaide, but grew up in Whyalla in country

South Australia where some of his family still resides. Dr Davies has PhD and Masters qualifications in Clinical Psychology and broad interests in adult mental health research, including Cognitive-Behavioural assessment & intervention, behavioural activation for depression, Functional Analysis, third-wave clinical interventions and subjective well-being. He is a Clinical Psychologist in private practice and a member of The Australian Psychological Society College of Clinical Psychologists.

Associate Professor Niranjan Bidargaddi, *B. Eng (Hons), PhD*, is the Manager of Mental Health Research and Observatory Unit, Country Health SA, SA Health, a Clinical Senior Lecturer in the Discipline of Psychiatry, University of Adelaide and an academic in eHealth Systems Research in the School of Medicine at Flinders University. He brings experience in e-health and health services research. He has a PhD in Bioinformatics with Computer Science Engineering background and held a postdoctoral fellowship at the CSIRO in health related information technology where he worked on a technology enabled home-based cardiac rehabilitation programme at Queensland Health. In his current role, Associate Professor Bidargaddi led the establishment of a Country Mental Health Observatory Unit which measures outcomes associated with rural mental health services implementation and rural workforce models to guide future investments into evidence based programs. He has a special interest in the development of telehealth initiatives to overcome barriers in delivering care over vast geographic areas in Australia.

Personal perspective

My interest in rural health was borne from my upbringing on an isolated sheep, wheat and barley property at Mount Cooper, near Streaky Bay (7 hours drive from South Australia's capital city, Adelaide). In this location (which is classified as 'Remote' using the ARIA classification), the closest hospital is 45 minutes' drive away. Growing up, not only did I endure many long trips to hospital (sometimes meeting the ambulance on the road half-way), but I also watched family members travel via the Royal Flying Doctor Service to Adelaide for the treatment of various conditions. When my brother broke his leg and needed treatment in an Adelaide-based hospital for months, I had to relocate to Adelaide with my mother and attend a new school for a term, leaving my father to run the farm on his own. These experiences are not uncommon in rural Australia and gave me a firsthand understanding of the challenges of accessing health care from isolated locations. I have also had experience with several rural cancer patients (including close family friends) who faced significant challenges with cancer because of their rural location. These experiences have fuelled my passion for improving rural communities' health and well-being.

Although I no longer live in a rural area, my family still live on the property where I grew up, I have many rurally-based friends and I still feel connected to that rural community and country South Australia at large. As a result, I bring several assumptions and biases to the work of collecting and analysing data in this field. To minimise their effect, I attempted to identify these prior to conducting the research. They include the following:

- Living in a rural community is a disadvantage when it comes to healthcare.
- The people I interview who have had cancer will consider me an 'outsider' as I have not had cancer.

- My age (27 years) and education (*B. Psych (Hons)*, PhD/ Master of Psych (Clin) Candidate, School of Psychology, The University of Adelaide) will differentiate me from most of the people I interview.
- People are doing me a favour by participating in my research and it may be an inconvenience for many of them to do so.
- I will be better at engaging with rural cancer patients than someone without knowledge of the South Australian rural way of life (e.g. knowing when farmers do and do not want rain and asking appropriate questions accordingly!)
- People are likely to become distressed when talking about cancer so I should take a gentle approach.
- Many participants will be reluctant to discuss distress and psychosocial help-seeking with a 'stranger' like me.
- It will be depressing and sad to hear people's stories but worth it, if it helps improve 'the system'.
- I should appear professional but not intimidating.
- Psychologists are viewed with suspicion and as slightly strange by many rural people. Therefore it would be best to minimise this role and position myself as an inquisitive researcher who wants to find out about something with which they have firsthand experience.
- I sometimes struggle to empathise with people who believe they are disadvantaged as a result of their place of residence, but who live much closer to Adelaide than my family (e.g. Victor Harbor or Gawler).

Some of these assumptions proved incorrect during the course of the research. Contrary to my expectations, many participants did not want to position themselves as disadvantaged or in need of sympathy. Instead they thought there were many benefits of living in a rural community, and travelling for medical treatment was one of the costs which they had simply accepted as part of the rural way of life. My assumption that participants would see me as an ‘outsider’ because I have not had cancer was also challenged; they made it very clear that they saw me as ‘one of them’ because of my rural background. I do not think people were intimidated by my education, perhaps because I played it down. They appeared surprised, but genuinely appreciative that someone of my age was interested in their cause. I believe my experience in interacting with people older than myself minimised the impact of age difference on the interviews with the older participants. My assumption that it would be sad and depressing to hear these people’s stories was also challenged. I felt inspired by meeting these people, many of whom were very ill and faced great difficulties, but were willing to spare time to talk to me to improve ‘the system’ for those who followed in their path. Many of my participants shared my frustration with people who think they are severely disadvantaged by living about an hour away from the centre of Adelaide. Another surprise was that several participants expressed sincere gratitude for the opportunity to share their experiences and opinions and found it a therapeutic experience rather than an inconvenience. For example I received the following email from a participant in Study 1 shortly after conducting the interview with them.

“Hi Kate, Hope all is going well for you in your interview process. I thought I would give you some feedback about the interview because I reflected afterwards what an emotional time that was in my life. Talking about it again probably reminded me of how difficult diagnosis and everything that comes after that was especially at a young age when having a cancer diagnosis is the furthest thing from your mind. I wasn't upset by it but it did remind me of how strong you need to be and how much family and friends are important to you and how grateful I am now to see ... grow into a man. So thank you Kate you have lovely disposition and a beautiful manner and I wish you all the best for your future. Warm regards ...”

Another participant described her interview as a “cathartic experience”.

A similar result was reported in work by Wilson et al. (2000). Empowerment of participants was anticipated in the PAR component of the research (Study 2), but not in the interviews conducted in Study 1.

It should also be noted that before completing the interviews for Study 1, I had spent time observing the work of several Oncologists and had completed Masters level courses in interviewing and counselling as well as three Clinical Psychology placements. Before the interviews commenced, I spent time developing rapport with the participants and in all cases revealed my rural background which in almost every instance, appeared to put the interviewee at ease.

How the project unfolded - Beyond the data and literature

While the literature demonstrates not only that rural cancer patients differ to their urban cancer patients and therefore specific psychosocial needs, but also that little attention has been directed towards working out how these needs could be better addressed (C. Davis et al., 2003; Girgis et al., 2000; Oxlad, Wade, Hallsworth, & Koczwara, 2008), it was a combination of this and particular political and personal circumstances, that led me to conduct Study 1 (see Chapter IV).

Study 1

Study 1 was a qualitative investigation into how rural cancer patients perceive the existing provision of psychosocial services and how they this system could be improved. One of the key findings was the need to develop more rural-specific information on psychosocial care, to break down a major barrier (i.e. lack of knowledge) to use. This study highlighted (in contrast to findings from other work) that what stops many rural people from accessing services is not so much that services are unavailable in this state, but that patients and supporters have not known about them early enough.

Once I completed this study, I was moved by the generosity and openness of the participants and wanted to do more to help people like them. Although most refused to take a 'poor me' approach it was

obvious that they had endured great hardships unnecessarily as a result of not knowing about support services earlier. I became keen to test out whether or not simply providing rural cancer patients with more rurally-relevant information on psychosocial services could, as the participants suggested, make it much easier for them to access this sort of help. I felt well-positioned to help write this type of information resource given my recent contact with several rural cancer patients and the data I had collected on what these patients said they wish they had known earlier. As this insight was not part of the original set of research questions and as space was limited, these findings were not included in the paper for Study 1. However, they had obvious practical implications for the design of a rural-specific information resource that these participants had said they so desperately needed; I felt a degree of responsibility to use the information to its fullest benefit. My academic supervisors also believed it would be useful and were prepared to offer necessary support.

I expressed my desire to be involved in writing such a resource to a senior employee of Country Health SA (Associate Professor Niranjan Bidargaddi) who agreed that it would be a worthwhile piece of work, with interesting research implications. He was particularly interested in completing a survey of psychosocial services in rural areas and incorporating this into the resource. It was good timing, given Country Health SA's plans to establish chemotherapy treatment centres in rural areas of the state. This conversation led to the opportunity for collaboration with Country Health SA. The condition of the collaboration was that the resource be online, not paper-based. After examining the literature to determine whether or not this had the potential to work, the funding was accepted. Examining the extent to which an online intervention of this type would be acceptable to this client group then became the focal research question. Country Health SA granted me a scholarship to support me for two years and for a website designer to complete the technical aspects of the website's development. Cancer Council SA, Cancer Council Australia and the Spencer Gulf Rural Health School (now UniSA) also provided funding to develop and promote the website.

Although this was a more ambitious and complicated direction than I had originally envisioned the research would take, the immediate translation of research knowledge was appealing and it became evident that it would probably be of more benefit to the South Australian cancer community.

Study 2

As previously outlined, several of the rural cancer patients involved in Study 1 were keen to help the cause and, as already outlined, the benefits of consumer engagement are widely known, a PAR framework was employed to develop a possible web-based solution to this problem (Study 2). Using PAR was another risky move. As Dick (1993) points out, by using this approach, a student runs the risk of receiving “a lower grade for work of equivalent standard and greater effort” (p. 7) because the approach is less well understood than other forms of enquiry. However, my supervisors and I thought it was worth the risk and I was drawn to the opportunity of working collaboratively with a group of people to address a problem which they had helped to identify. Before starting Study 2, I was aware, as Kidd and Kral (2005) explain, that “PAR often entails a high level of personal connection and involvement, and it is precisely this involvement that exposes the researcher to risks and problems from which she or he is usually protected and, alternately, to remarkably positive experiences that are often not possible in traditional paradigms” (p. 190). While this stage of the research was undoubtedly the most time consuming, I also found that it was just as rewarding and interesting as I had hoped. In particular, giving people the opportunity to help their peers deal with cancer was a very moving experience, particularly in the case of one participant who was very ill and helped with the project until the very end of his life.

Study 3

The work concluded with a comprehensive evaluation of the website to determine the degree to which it is deemed acceptable and helpful by its users, increases psychosocial service help-seeking intentions and decreases self-perceived levels of distress and isolation. Usage levels, areas for

improvement, unexpected outcomes and how this resource is perceived in relation to other resources, were also investigated.

The overwhelmingly positive results have been met with great interest from Country Health SA and Cancer Council SA. Negotiations as to which body will adopt and maintain the website in the future are currently in progress. Clearly, this work has not only made a contribution to the academic literature and been a rewarding personal experience for those involved, but it has also helped to solve a problem and therefore has both immediate and long-term consequences for the rural people affected by cancer in this state. There are also opportunities for findings from this work to be applied in other settings. These are explored in detail in Chapter VII.

CHAPTER IV: STUDY ONE

Preface

The following study seeks to identify key issues associated with the provision of psychosocial care from the perspective of rural Australian cancer patients and determine culturally appropriate methods to reduce barriers to service use. As previously outlined, this topical issue is of interest to service providers and follows a path of enquiry well justified by the academic literature, which has consistently shown that rural cancer patients are exposed to a range of unique stressors, have poor treatment outcomes, high levels of psychological distress and limited access to psychosocial care.

Previous research has done a lot on describing these sorts of problems, but not enough on identifying barriers to treatment in this population, or on creating novel solutions (Burman & Weinert, 1997a; C. Davis et al., 2003; Girgis et al., 2000; Jameson & Blank, 2007; Oxlad et al., 2008). Understanding how rural cancer patients perceive psychosocial care, factors that they think affect their help-seeking and ways in which they believe barriers to access could be best overcome, is viewed as the best next step in efforts to increase service use and improve outcomes for this population.

Not accessing help to deal with distress often results in the seriousness of problems escalating, which has psychosocial and economic costs to both the individual and society (Tedstone Doherty & Kartalova-O'Doherty, 2010). When psychosocial distress prevents patients from seeking medical treatment, conditions often become worse, treatment becomes more complex and survival can even become less likely (Elliott-Schmidt & Strong, 1997). Therefore, ensuring rural cancer patients are appropriately supported, particularly in their efforts to seek medical treatment, is an important goal. This paper explores these issues from a novel perspective (that of the consumer) and sheds light on practical strategies that could be adopted to make accessing psychosocial cancer care easier for people of 'the bush'.

Statement of contributors

Miss Kate Gunn (candidate) was responsible for the literature review, conception of the study, data analysis, drafting and submitting the manuscript, as well as making revisions and responding to reviewers. The paper has been accepted for publication in *Supportive Care in Cancer*.

Signed: Miss Kate Gunn

Professor Deborah Turnbull, Ms Lindsay McWha, Dr Matthew Davies and Professor Ian Olver AM (co-authors) provided ongoing supervision throughout the research program that led to this publication. Their role included working with Miss Gunn to refine the direction of and methodology employed in the research, commenting on the material presented in drafts and providing editorial input. They hereby give their permission for this paper to be incorporated in Miss Gunn's submission for the degree of Masters of Psychology (Clinical) with Doctor of Philosophy from the University of Adelaide.

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Psychosocial service use: a qualitative exploration from the perspective of rural Australian cancer patients

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Abstract

Purpose: This study aims to identify key issues associated with the provision of psychosocial care from the perspective of rural Australian cancer patients and determine culturally appropriate methods that may reduce barriers to service use.

Method: Seventeen purposively sampled adult South Australians who lived outside metropolitan Adelaide, had a diagnosis of cancer and various demographic and medical histories, participated in semi-structured, face-to-face interviews. Participants also completed a demographic questionnaire. Qualitative data were analysed using thematic analysis.

Results: Five key themes were identified: (1) psychosocial support is highly valued by those who have accessed it, (2) having access to *both* lay and professional psychosocial support is vitally important, (3) accessing psychosocial services is made difficult by several barriers (lack of information about services, initial beliefs they are unnecessary, feeling overwhelmed and concerns about stigma and dual relationships), (4) medical staff located in metropolitan treatment centres are not sufficiently aware of the unique needs of rural patients and (5) patients require better access to psychosocial services post treatment. Methods through which rural patients believe access to psychosocial services could be improved include: (1) providing more rural specific information on psychosocial care, (2) improving communication between health care providers and

referral to psychosocial services and (3) making psychosocial services a standard part of care.

Conclusions: Rural cancer patients want their unique needs to be recognised and to be treated differently to their urban counterparts. There is a need for more targeted and rurally-relevant information for rural cancer patients, both to inform them of, and change their attitudes towards, psychosocial services. Other practical recommendations are also discussed.

Keywords: cancer, oncology, rural, psychosocial, support, barrier (6)

Introduction

Psychosocial care is increasingly recommended as a standard part of cancer patient treatment (Fallowfield, 1995b; National Breast Cancer Centre & National Cancer Control Initiative, 2003). However, providing psychosocial services to rural cancer patients is recognised internationally as a key challenge (Butow et al., 2012). Aside from the issues associated with a diagnosis of cancer in any setting, rural cancer patients experience a number of additional stressors (e.g. the travel required for treatment) (Baldwin & Usher, 2008; Bettencourt et al., 2008). There is preliminary evidence that this group may be more likely than their urban counterparts to experience poor mental health (Burriss & Andrykowski, 2010; Girgis et al., 2000; Lyons & Shelton, 2004; Wilson et al., 2000), low quality of life (Butow et al., 2012) and robust data show rural and remote cancer patients are at risk of poorer treatment outcomes (Jong et al., 2004). A high level of unmet psychosocial need in this population has also been well documented (Beesley et al., 2008; Butow et al., 2012; Harrison et al., 2009).

Further research to identify the specific psychosocial needs of rural cancer patients has been recommended (Bettencourt et al., 2007; Bettencourt et al., 2008; C. Davis et al., 2003; McGrath et al., 1999b, p. 44; Meneses et al., 2009; Rogers-Clark, 2002). However, a better understanding of exactly what prevents them from accessing psychosocial help is arguably of greater clinical importance. Unless access is improved, the impact of psychosocial interventions that research has shown are beneficial, will be minimal in clinical settings (Hutchison et al., 2006). Despite the recognised “sub-cultural values in rural communities that may affect help-seeking patterns” (Koopman, Angell, Turner-Cobb et al., 2001, p. 26) previous research has identified barriers to psychosocial service use in the general cancer population without identifying specific issues that affect psychosocial service provision in rural settings (Kenny et al., 2007). Further research into the unique preferences and perceptions of rural cancer patients would ensure future psychosocial interventions build on the existing strengths (Rogers-

Clark, 2002), sources of support and the resourcefulness of rural communities (McGrath et al., 1999b) and are culturally appropriate, locally endorsed and likely to be used.

This study aims to identify the key issues in psychosocial care provision and methods which might reduce barriers to service use, from the perspective of Australian rural cancer patients. Findings from this work may be used to inform larger scale quantitative investigations including the development and testing of new methods of increasing this patient groups' access to psychosocial care.

Method

Participants

Seven men and ten women with a diagnosis of cancer residing in rural areas of South Australia ranging from highly accessible to very remote, participated. Over half ($n=9$) had private health insurance and therefore access to treatment in private hospitals. Although not a participation requirement, the use of a broad definition of psychosocial care (including information and accommodation provision) meant that all participants had used psychosocial services, ranging from a telephone cancer helpline, supported accommodation facility¹ to a psychiatrist. Participants' demographic and medical characteristics are presented in Table 1 and Table 2 respectively. Their engagement with psychosocial services is outlined in Table 3.

Participants were recruited through Cancer Council SA's supported accommodation facilities, the rural media and personal contacts. Purposive sampling ensured representation of diverse demographic and medical histories.² All five of the most commonly diagnosed types of cancer in Australia were represented (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2008), as were each of the five Accessibility/Remoteness Index of Australia (ARIA)

¹ Supported accommodation facilities are available for cancer out-patients and their carers to stay in at a low cost, during their cancer treatment. Social Workers are on-site and interaction between guests (e.g. at morning teas) is encouraged. Buses are available to take patients to several of the main treatment facilities as many rural people are reluctant to drive in the city and car parking can be problematic.

² Personal contacts were used when a particular type of patient needed to be represented and other means of recruitment did not facilitate this.

categories (Australian Institute of Health and Welfare, 2004)³ and a relatively even number of men and women.

Procedures and materials

Confidentiality was explained, written consent obtained and information on sources of post-interview support was provided. The University of Adelaide Human Research Ethics Committee and Cancer Council SA's Human Research Ethics Committee granted ethical approval.

Qualitative data were collected by using semi-structured, face-to-face, hour-long interviews. Open-ended questions and probes were employed based on the relevant literature.⁴ The topics covered in the interviews are detailed in Table 4. Participants also completed a demographic survey. Qualitative data were collected until 'saturation' had been reached.⁵ Interviews were transcribed verbatim.

Analyses

Thematic analysis was used to determine the dominant *themes* that emerged from the data. Themes were considered to be ideas, relevant to the research questions that appeared in a pattern in the data set (2006).

An essentialist/realist methodology was adopted. Rather than using participants' accounts to examine how experiences or realities may be socially-constructed through language (Braun & Clarke, 2006), participants' descriptions of their experiences and realities were assessed as direct insights into these experiences (Braun & Clarke, 2006). Further, an inductive or 'bottom-up' approach to the analyses means the themes identified are closely linked with the data themselves. Thematic meaning is often situated at the semantic or surface level of the data (Braun & Clarke, 2006).

³ The Accessibility/Remoteness Index of Australia (ARIA) is a standard index of remoteness that is based on accessibility by road to services. Classifications range from "Highly Accessible" (areas with scores between 0 - 1.84 where there is relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction) to "Very Remote" (areas with scores >9.08 - 12 with very little accessibility to goods, services and/or social interaction) .

⁴ Where necessary, psychosocial care was explained to participants as help with dealing with stress management, adjustment to cancer/ coping, sleep, social support, decision making, communication skills, information, relaxation, pain management, interpersonal problems/ conflict resolution, anxiety (often about the future), depression/ low mood, thoughts about suicide, body image, sexuality/ fertility, spirituality, accommodation and financial issues. It was suggested that this type of care may be delivered by people such as social workers, specialist nurses, counsellors, peer support workers (i.e. someone who has also been affected by cancer), psychologists and/or psychiatrists.

⁵ That is, little new information was being obtained.

Using the method of Braun and Clarke (2006), grouping codes were assigned to each datum. A datum was defined as a segment of text that expressed one idea. Broader themes were then identified from the codes and the definitions, and relationships between the resulting themes were considered. Contradicting themes were reviewed until all data had been accounted for.

Results

The themes identified could be split into two broad categories – firstly, issues in the provision of psychosocial care (part A) and secondly, more specifically, how the provision of psychosocial care could be improved (part B).

Part A: key issues in the provision of psychosocial care

1. Perceived value of psychosocial services.

Almost all participants who had accessed psychosocial services (excluding accommodation facilities) felt they had been entirely beneficial (n=15/17).⁶ While the types of services varied, they were generally perceived as helpful for reducing uncertainty, fear and loneliness, normalising patients' experiences and in some cases encouraging a more positive outlook on their illness through downward social comparisons.

Every ache, pain, everything; you're always fearful...but I don't dwell on it anymore thanks to [my counsellor]...she helped me immensely... made me feel... as though a whole heap of things had been lifted off my shoulders...

Female, breast cancer, 61 years

Similarly, almost all participants (n=8/9) who stayed at the Cancer Council SA's city-based supported accommodation facilities reported very positive experiences. These facilities satisfied both the practical and emotional needs of the participants, primarily through easy access to peer support.

⁶ The two participants who criticised counselling services nonetheless reported positive experiences with cancer support groups. One of these participants did not elaborate on why he found counselling a "waste of bloody time" but the other said it was because the hospital counsellor kept encouraging her to "yell, scream, cry" after her surgery while she was thinking "let's fix it up and move on".

So often...real friendships come up...I'm not saying everybody's living in each other's rooms...but...certain times certain individuals go off to make their breakfasts, and you know. They have a wow of a time just sort of you know, "I've got someone to talk to," and just getting little bits of advice.

Male, lymphoma, 56 years

2. Need for both lay and professional support.

Many participants mentioned the strong lay support networks (n=8) as a great advantage of living in a rural community.

And then I came back here...the feeling generally was that of, of incredible support. Of like, invisible hands coming out and holding you up and I felt so loved and it was, it actually was a wonderful experience to go through.

Female, ovarian cancer, 48 years

However, while lay support is readily available in smaller, isolated, "earthy" rural communities, it is often less prevalent in larger rural centres (n=4).

Being in little country towns though, um, it doesn't really matter where you live... quick as a wink pink you would have a support group. These are, these are country towns where the whole town was set up because of the farming. They're the earthy people. I'm not talking your country towns like Gawler [a "highly accessible" large town near the state's capital, Adelaide]. See Gawler is a mini Adelaide....Um, I'm talking earthy.

Female, breast cancer, 54 years

In a different vein, some participants (n=4) identified the importance of accompanying lay support with access to professional support, because of the small and connected nature of the rural communities they live in.

Sometimes it's easier if that person's a little bit more removed from your situation...if it's with your family or your partner or your friends...it can sort of be thrown back somehow...in the rural setting everyone knows everyone, the smaller, the worse it is...well not worse but you know... you need to be able to go to someone and...say, "Yep, this is what I feel. The way I feel." And just yeah, talk straight about it... If you don't get both of those then you can still tip over into a low mental state quite easily, I think.

Male, testicular cancer, 41 years

Professional psychosocial services were valued as contexts where negative emotions can be safely expressed (n=3).

I didn't want to be seen to be falling into a heap...it was the Cancer Council I rang...they got the worst of it and the people around me got the best of me.

Female, ovarian cancer, 48 years

3. Multiple barriers to psychosocial service use.

i) Lack of information

Most participants (n=14) recognised a lack of information about relevant existing psychosocial services and how to access them as a significant barrier to service use.⁷

The biggest problem is we don't know about these...places and...what's available for us.

Male, lung, melanoma and prostate cancer, 69 years

ii) Belief that they do not need psychosocial help

Several participants (n=10) stated that initially, they did not access psychosocial help as they were not aware they needed it. All participants who had held this view acknowledged in hindsight that they could have benefited from such services at an earlier stage, or that they did benefit from them later (n=10/10).

...at the start, I think I needed a little bit more help than what I was getting and that wasn't anybody's fault but my own, because I didn't want it. But I think it should have been pushed upon me more. To get to talk and yeah...

Female, cervical cancer, 24 years

iii) Stigma

Several participants (n=8) raised the issue of stigma, but most (n=7/8) mentioned it when explaining why other people do not use psychosocial services, rather than as a personal barrier. For some, stigma related to cancer itself (n=3), while others described a fear of being perceived as not coping or as 'a failure' if they sought psychosocial help (n= 4).

And I think people are frightened to have counselling because they think it's a failure - even if they need it.

Female, breast cancer, 50 years

⁷ The three participants who did not mention that they lacked information on psychosocial services received treatment in private hospitals.

iv) Feeling overwhelmed

Some participants (n=5) described themselves as feeling overwhelmed by their diagnosis and situation and therefore unable to think about how to access services.

You've got enough running through your mind now. You know... "What are the kids going to do? How are the kids going to take it? I've got half my head shaved, and I've got to wear this scarf," and "I have bad days and good. I'm crying a lot, and what are the kids..." you know. "On top of this, I've got to try and... where am I going to stay? What accomo... I can't drive the bloody car around. The traffic's too much for me in Adelaide. How am I going to get around? I can't afford taxis."

Male, lung, melanoma and prostate cancer, 69 years

v) Dual relationships with service providers

Dual relationships with local psychosocial service providers (n=5) was also identified as a barrier.

I would have that feeling every time I looked at him... "Oh he thinks I'm nuts." You know... He's more like a person you know in the town and not the doctor... if I didn't know him so well through golf and things like that well then I probably would... I think it's because they live in the community.

Female, breast cancer, 61 years

vii) Others

Less frequently mentioned barriers included: confidentiality, lack of access to professional services, distance, insufficient numbers to sustain support groups and support group meetings being held during working hours.

4. Medical staff located in metropolitan treatment centres are not sufficiently aware of the unique needs of rural patients

Several participants (n= 8) attributed significant stress to metropolitan hospital staff's unawareness of the issues unique to rural patients.

I spent half my time trying to tell people where we live, you know. And how far it is here...the doctors think we live around the corner.

Male, prostate cancer, 61 years

5. Patients require better access to professional psychosocial support when they return home to rural communities after treatment

Several participants (n=5) highlighted the importance of being able to access professional psychosocial support in their rural community post-treatment.

...when the chemotherapy had finished...You would have thought that someone would have seen there that this guy is potentially going to have some mental problems at the end of that... looking back, I feel like I dropped off at the end...I just dropped into a mental hole.

Male, testicular cancer, 41 years

PART B: Ways in which the provision of psychosocial care could be improved

1. Provision of targeted, relevant information to rural patients

A number of participants (n=6) identified the need for the development and distribution of specialised information about psychosocial care for rural patients.

It should be recommended to you that this is what you can do...to help yourself- given the information, given the cards, the people that you can go in your district and how it's going to help you.

Female, breast cancer, 61 years

Participants stated that being informed about services could normalise their use, assist them in negotiating 'the system' and make them feel less isolated and distressed.

2. Improved communication between health care providers and clearer referral pathways to psychosocial care

Many participants believe more open communication between different health care providers and clearer referral to psychosocial care could have improved their experience (n=6).

If the doctors somehow could be trained to say "Look here's a letter. Take this to the person at 'X' Hospital and see the social worker there"...once the social worker has sorted out my petrol money to get there, I know I can get cheap accommodation and...I'm booked in...90% of the worry is gone.

Male, lung, melanoma and prostate cancer, 69 years

3. Provision of psychosocial services as a standard part of care

All participants who were questioned about this (n=15/15) agreed that making psychosocial services a standard part of care would help reduce barriers to service use⁸.

I think that for some people that it's probably a really, really good thing because they won't ever go and there's this stigma attached to being and going and seeing a psychologist...and that's why I kind of try and tell them, "Okay, well look I'm going to see a psychologist. I've been to a psychiatrist and I tell you it's really, really helped me a lot."

Female, breast, liver and bone cancer, 43 years

Participants believe this would ensure everyone is informed about services and, as the quote above illustrates, it may also help to overcome stigma and prevent people from refusing services without fully understanding what they offer.

4. Other suggestions

Participants also suggested that:

- Psychosocial support be provided via visiting counsellors (n=5), telephone (n=4) and videoconferencing (n=2); several others preferred face-to-face counselling (n=6).
- A rural peer support network be established (n=2).
- Psychosocial support be provided at local hospitals (n=2) or via home visits (n=2) to address confidentiality/stigma concerns.
- Case notes in metropolitan hospitals be marked "rural patient" (n=1).

Discussion

This study provides a unique insight into rural cancer patients' preferences and perceptions of psychosocial services. When compared with the most similar available research (often on broader cancer or rural populations), it yields both predictable and novel insights.

⁸ Not all participants were asked this question due to the unstructured nature of the interviews and interviewer error.

The dominant theme, that rural cancer patients who access psychosocial services value them highly, is consistent with the well-documented benefits of psychosocial care (Osborn et al., 2006; Rehse & Pukrop, 2003; Ross et al., 2002). The finding that rural cancer patients value the lay support networks in their communities (McGrath et al., 1999b; Rogers-Clark, 2002) is also unsurprising. However, previous research has not recognised that although lay support is readily available in many isolated, rural communities, it is often less accessible in larger rural centres. This finding emphasises the differences among rural communities and has implications for service provision. For example, cancer peer support groups may be most beneficial in larger regional centres where social cohesion and lay support networks are weaker.

The second most prevalent theme is also novel: despite valuing lay psychosocial support, rural cancer patients do not view it as a substitute for professional psychosocial help. Rural cancer patients need a safe place to express negative emotions away from the social pressures of their communities. The challenges of sharing cancer-related information in small communities (Baldwin & Usher, 2008) and patients' perceived need to retain a 'game face' to avoid criticism for being negative, have been previously noted (McGrath et al., 1999b). However, the idea that the closely connected nature of rural communities makes access to professional support *particularly* important, contradicts the literature that states rural cancer patients prefer non-professional psychosocial care (McGrath, 2001b; McGrath et al., 1999b). As many service providers hold beliefs consistent with this literature (McGrath et al., 1999b), educating health professionals about the value of both types of support could ensure that rural patients receive the help they want and need.

Given the low rates of cancer psychosocial service use in rural areas (Beesley et al., 2008; C. Davis et al., 2003; Harrison et al., 2009), the third theme, that multiple barriers impede psychosocial care, is unsurprising. Consistent with previous research (Butow et al., 2012; C. Davis et al., 2003; Neumann et al., 2010; Sullivan et al., 2003; Wilson et al., 2000), participants identified a lack of rurally-relevant information about existing psychosocial services as the most significant barrier. While urban-centric

resources may fail to adequately address rural-specific issues, it is noteworthy that rural patients want to be acknowledged and treated differently to urban patients. This complements Roger-Clark's (2002) finding that rural breast cancer patients have a strong desire to define themselves as rural. Clearly there is a need to design more rural-specific information for cancer patients. The present research suggests that providing such information is not only important to meet the unique informational needs of these cancer patients, but importantly, may also facilitate their desired differentiation from urban-based patients.

The next most common barrier was a belief among patients that they do not need psychosocial help, a belief found across all cancer populations (Carlson et al., 2004; Hewitt, Breen, & Devesa, 1999). However, it is possible that stronger stoicism, more traditional, matter-of-fact outlooks (C. Davis et al., 2003) and lower levels of mental health literacy (Jameson & Blank, 2007), mean it is particularly salient in the rural cancer population.

Other less dominant barriers included feeling overwhelmed and the stigma associated with cancer itself or with being viewed as "a failure" for needing psychosocial help. Despite the increasing acceptance of psychosocial and mental health interventions for people with cancer in the wider population (Hewitt & Rowland, 2002, p. 4588), these results echo previous findings (Bettencourt et al., 2007; Holland, 2002; Jameson & Blank, 2007) that stigma frequently prevents help-seeking in rural areas. The presence of dual relationships with service providers was also a notable barrier and has been documented elsewhere (Elliott-Schmidt & Strong, 1997). Conversely, cost (Hewitt & Rowland, 2002) and lack of service availability (Bettencourt et al., 2007; C. Davis et al., 2003; McGrath et al., 1999b), raised in other research on general and rural cancer populations, were not dominant themes in the present study.

With the exception of a lack of information, attitudinal barriers to accessing psychosocial care were endorsed more strongly by participants than structural barriers. Similar patterns have been noted among rural men with cancer accessing support (Corboy, McLaren et al., 2011) and among Canadian,

American and Dutch populations accessing mental health services (Sareen et al., 2007). Clearly attitudinal barriers must be considered when developing resources to encourage psychosocial service use among rural cancer patients.

Our findings also highlight that normalising psychosocial service use in rural areas may help overcome stigma. Resolving concerns about dual relationships with service providers is difficult given that some rural people prefer to avoid local service providers while others avoid services run by ‘newcomers’ or ‘outsiders’ (Elliott-Schmidt & Strong, 1997). Ideally, patients would have access to local, visiting and remotely offered psychosocial services.

A further dominant theme that distress stems from metropolitan hospital staff’s apparent unawareness of issues unique to rural patients, justifies calls for more widespread training of doctors and nurses in detecting and accommodating special psychosocial needs and expectations (Elliott-Schmidt & Strong, 1997). As highlighted previously, these results suggest that rural cancer patients want to be treated differently. When their place of rural residence is unacknowledged, they can feel misunderstood and frustrated, adding unnecessarily to their distress.

The final key issue, the importance of providing rural cancer patients with psychosocial care after completing treatment; is already widely recognised (Bettencourt et al., 2007; McGrath, 2001b; Meneses et al., 2009; Rogers-Clark, 2002).

The second part of this study explored rural cancer patients’ views on improving access to psychosocial care. Other studies have asserted the need to develop rurally-relevant resources for psychosocial care (Bettencourt et al., 2007; C. Davis et al., 2003) and our findings suggest that distributing such resources may normalise accessing psychosocial help. This may also address feelings of isolation, distress and being overwhelmed, making this a practical task and an area of research worthy of further investment.

The findings that rural cancer patients believe there is a need for more open communication between health care teams and clearer referral pathways to psychosocial care, are also consistent with

previous research (Bettencourt et al., 2007; Lawler et al., 2011; Lee, 2007; Neumann et al., 2010). More systematic screening of distress and triaging to appropriate services (Hutchison et al., 2006; Lee, 2007) and levels of care (Steginga, Hutchison, Turner, & Dunn, 2006), may help overcome these communication and referral issues. However, the implementation of screening must be accompanied by training for health professionals so they become comfortable with talking about emotional issues (Hughes, Sargeant, & Hawkes, 2011) and know where to refer patients for more help (Thewes, Butow, & Stuart-Harris, 2009).

While making psychosocial services a standard part of care is already widely recommended (Fallowfield, 1995b; National Breast Cancer Centre & National Cancer Control Initiative, 2003), this study, like others (Holland, 2002) highlights the gap between what we know is helpful for patients and what happens in clinical practice. Addressing this gap may also help normalise psychosocial service use, reduce information dissemination issues and help to overcome other attitudinal barriers.

Although the findings from this study are thought to be valid, self-selection bias may mean its participants are more open-minded, self-reflective and engaged than the wider rural cancer population. It should also be noted that individual differences predict interest in using psychosocial services (Steginga et al., 2008) and how likely people are to benefit from them (Helgeson, Cohen, Schulz, & Yasko, 2000). Furthermore, the identity of the interviewer may have affected the data generated as the interviewer's rural background was revealed during all interviews. The findings from this research (like most qualitative work) are not generalisable. However, the intention of this research is to provide a detailed insight into the experiences of rural South Australian cancer patients and thereby lay the foundations for larger scale, quantitative research (including evaluations of relevant interventions) that generate findings that can be generalised to other settings, to be carried out in the future.

Nonetheless, this study has highlighted the key issues surrounding psychosocial care for rural South Australian cancer patients and importantly and uniquely, how they think its provision could be improved. Rural cancer patients in this region who access professional psychosocial care value it

highly but most do not regard lay support, although important, as an effective substitute. Rurally-relevant information resources are necessary to direct rural patients to appropriate psychosocial services and overcome the attitudinal barriers that currently prevent or delay their use. Rural patients want to be treated differently to their urban counterparts and improving communication between health care providers, referral pathways to psychosocial care and urban staff's understanding of the unique stressors rural cancer patients face, could alleviate much distress in this patient group, as could making psychosocial care a standard part of care.

While solving the inequality in rural psychosocial cancer care is not simple, implementing the recommendations arising from this novel study and monitoring their effects on patients' help-seeking intentions and self-perceived, isolation and distress would be a useful area of investigation, likely to improve this patient groups' access to appropriate psychosocial care.

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Table 1

Demographic Characteristics of Participants

Age in years <i>M</i> (SD)	53.35 (12.01)	range 24-72	<i>n</i>
<i>Marital status</i>			
Single/ never married			2
Married/ living with a partner			13
Widowed			0
Separated/ divorced			2
<i>Education level</i>			
Finished primary school			2
Finished high school			6
Trade certificate, apprenticeship, diploma/certificate from a college or TAFE			5
Degree/ diploma from a university			3
Postgraduate degree			1
<i>Employment status</i>			
Full time			6
Part time			1
Casual			1
On leave			2
Not working- not looking for work			1
Not working- looking for work			0
Not working- retired			6
<i>Household income (per week)</i>			
< \$ 500			1
\$ 500-999			8
\$ 1000-1999			4
\$ 2000+			1
Do not wish to disclose			3
<i>Level of remoteness (ARIA)⁹</i>			
Highly accessible			1
Accessible			4
Moderately accessible			3
Remote			6
Very remote			3
<i>N</i> = 17			

⁹ The Accessibility/Remoteness Index of Australia (ARIA) is a standard index of remoteness that is based on accessibility by road to services. Classifications range from “Highly Accessible” (areas with scores between 0 - 1.84 where there is relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction) to “Very Remote” (areas with scores >9.08 – 12 with very little accessibility to goods, services and/or social interaction) (Australian Institute of Health and Welfare, 2004).

Table 2

Medical Characteristics of Participants

<i>Patient-reported site of disease</i>	
	<i>n</i>
Bones	1
Breast	5
Cervix	1
Colorectal/ bowel	3
Leukaemia	1
Liver	2
Lymphoma	2
Lung	3
Melanoma	1
Ovaries	1
Prostate	4
Testicles	1
Total= >17 as some participants reported multiple sites	
<i>Patient-reported time between diagnosis and interview</i>	
< 12 months	3
1-2 years	3
2 – 5 years	4
> 5 years	7
<i>Patient- reported state of disease</i>	
No activity	9
Recurrence	1
Metastases	5
Do not know	2
<i>Patient-reported cancer treatments received</i>	
Chemotherapy	10
Hormone therapy	5
Radiotherapy	13
Stem cell transplant	1
Surgery	14
Other	2

N= 17

Table 3

Participants' Self-reported Psychosocial Service Use

	<i>n</i>
Breast Care Nurse	2
Cancer Care Co-ordinator	2
Counsellor	6
Canteen	1
Education program	2
Helpline	5
Online forum/ support group	2
Palliative care services	1
Psychiatrist	2
Psychologist	3
Social Worker	4
Support group	6
Supported accommodation facility	8
Transport services (other than at accommodation facility)	2

Total= >17 as some participants reported using multiple services

Table 4

Interview Topic Guide

-
- General information about the participant's background and their experience with cancer
 - How living in a rural area has impacted upon their experience with cancer
 - Social, emotional, spiritual and/or psychological issues they have faced as a result of their cancer diagnosis
 - Knowledge and perceptions of existing support/psychosocial services
 - Unmet psychosocial needs
 - Reasons for using or not using existing support/psychosocial services
 - Preferred methods of receiving information on support/psychosocial services
 - How support/psychosocial services could be improved to overcome barriers to use and better address the needs of rural cancer patients
 - How psychosocial needs change over the cancer journey and services could be better designed to reflect this
 - Psychosocial services as a standard part of care?
 - Most accessible, acceptable and useful service/s offered to them since their diagnosis (other than medical treatment) and what made it/them so good
 - The people and/or groups that have been their greatest sources of support since their diagnosis and what made them so helpful
 - Advice for other rural cancer patients
 - Any other comments
-

CHAPTER V: STUDY TWO

Preface

This chapter details the process of developing a possible solution to the lack of rurally-relevant information on psychosocial services, identified in Study 1.

Traditional research findings alone will not promote change (Whitehead et al., 2003). As Jameson and Blank (2007) point out, “research efforts have done a better job describing problems than creating novel solutions... research on barriers to services alone does not, in the end, impact the people in need of services...[they] urge that the energies of rural psychologists, both in academic and in practice, be directed toward collaborative work to implement strategies for change” (p. 295). This is what Study 2 seeks to do.

Based on the results from Study 1 and the supporting literature outlined in Chapter 1 that shows high rates of distress, poor access to psychosocial care, a lack of rural-specific cancer related information and the presence of several attitudinal barriers to psychosocial help-seeking in rural areas, developing this intervention is aimed at:

- decreasing distress and isolation among rural cancer patients and their carers, families and supporters;
- increasing rural cancer patients’ (and their family, carer and supporters’) intentions to use psychosocial services and;
- educating health professionals about rural cancer patients’ unique psychosocial needs and providing them with information to assist in referring patients to relevant psychosocial services.

To determine how best to achieve this, the academic literature was rigorously consulted and a PAR methodology (described in Chapter II) was employed. The specific objectives of the PAR approach were to (1) develop relevant and acceptable website content and (2) create the opportunity for participants to be empowered by directly involving them in this process.

This preface to Paper 2 begins by outlining the literature that informed this intervention. The reasons for giving people affected by cancer information are outlined, then the development of the content on the *Country Cancer Support* website is detailed. This leads to the presentation of Paper 2 at the end of the chapter, which succinctly details how PAR was combined with the relevant literature to develop the intervention. The results of using this framework and lessons learnt from the process are also explored.

Internet use in Australia

In 2006, 66% of households in major cities had access to the internet, compared to only 42% in very remote areas (National Rural Health Alliance, 2010). By 2011, the difference in internet use between those living in capital and non-capital cities had reduced to 89.6% and 81.8% respectively (Ewing & Thomas, 2012). Internet use among older age groups is also growing rapidly as Figure I details below, adapted from the work of (Ewing & Thomas, 2012). In 2007 only 30% of people over the age of 65 used the internet, compared to 57% by 2011.

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Figure 1. Internet use in Australia by age group and year (Ewing & Thomas, 2012)

More recent figures show that overall use is growing by 10% per year (Australian Bureau of Statistics, 2012). At the end of June 2012, there were 12 million internet subscribers in Australia (Australian Bureau of Statistics, 2012).

Online interventions

What are online interventions?

An internet intervention, as described by Barak, Klein and Proudfoot (2009), is a primarily self-guided intervention program that “attempts to create positive change and or improve/ enhance knowledge, awareness, and understanding via the provision of sound health-related material and use of interactive web-based components” (p. 5). It is best viewed as self-help, like bibliotherapy (Leykin et al., 2012).

Why is interest in online interventions growing?

As Burman and Weinert (1997a) point out, “Given the large distances between rural communities..., alternative approaches to providing information and support must be considered.

Computer networking may be one approach. As the number of people who own and are comfortable with computers grows, the ability to network via computers in rural areas will be enhanced” (p. 1599). In the field of mental health, recent reviews have concluded that online self-help interventions can effectively target conditions such as anxiety and depression (K. M. Griffiths, Farrer, & Christensen, 2010). A recent meta-analysis concluded that online interventions focused on changing voluntary behaviour have moderate efficacy compared with wait lists and similar impacts when compared with print materials, but they cost less and have potential for far greater reach (Cugelman, Thelwall, & Dawes, 2011).

Automated evidence-based self-help interventions offer great promise in complementing existing services (Reynolds, Griffiths, & Christensen, 2011) and providing new ways to access health services, education, information (Liaw & Humphreys, 2006) and peer support (Winefield et al., 2004). This mode is particularly useful for rural patients (Munoz, 2010; Winters et al.). Such interventions would be particularly valuable when alternative services are not readily or immediately available. They are also useful when patients cannot travel to services because of physical, geographical, economic, time limitations, or fear of stigma and could “fill an important gap in quality cancer care by adding to limited available mental health services and offering valuable tools to help people better manage the emotional side of cancer treatment” (Leykin et al., 2012, p. 1017). They may also help improve follow-up care for cancer survivors (Lawler et al., 2011).

Major advantages include convenience, coverage and anonymity (Powell et al., 2011). The ease of updating information online (rather than in printed form) also makes them attractive for information providers and intervention developers.

Will online interventions work in rural areas?

Valid concerns exist about poor technological infrastructure in rural communities (Jameson & Blank, 2007; Liaw & Humphreys, 2006) and the lack of research on whether rural populations will adopt these sorts of interventions (Liaw & Humphreys, 2006). However, given the success of such

interventions in other populations (e.g. K. M. Griffiths et al., 2010) and evidence that levels of general internet use in rural areas is now reasonable (Ewing & Thomas, 2012), determining just how acceptable such interventions would be for rural communities would be an important contribution to knowledge. This became the aim of this work.

As self-help interventions offer opportunities to overcome barriers to accessing more traditional forms of services, designing these for cancer patients has recently provoked interest (Beatty, Oxlad, Koczwara, & Wade, 2010). While online tools and communication are demonstrably well received by patients, including cancer patients (Leykin et al., 2012), only a few studies specifically examined acceptability in rural populations. Corboy, McLaren, et al. (2011) found that the families of rural palliative oncology patients use the internet to seek information (Wilkes, White, & O'Riordan, 2000) and an online social support and health education (for rural women with chronic illness) website has been running successfully for several years (the Women to Women Project) in Western USA (Winters et al.). Another American study (by Angell et al., 2003a) found that a community-initiated but theoretically-based printed workbook/journal could reduce stress in women with breast cancer living in rural areas. Although not an online resource, it shows that relatively simple, self-administered psycho-education interventions can be beneficial to at least some rural populations.

A local example of an online health education and support intervention for rural women with breast cancer is that of Winefield et al. (2004). However, this website failed to attract further funding and/or permanency. Similarly, Beatty et al. (2010) designed a workbook for Australian breast cancer survivors, but did not find that their results provided endorsement for the workbook. Angell et al. (2003a) recognise these difficulties as inherent to the task: "Assessing the needs of underserved patients using traditional assessment instruments and procedures often misses key elements of the problem. Developing an intervention that is accepted, culturally appropriate, and locally endorsed is an enormous challenge" (p. 499). As some prior interventions of this type have been unsuccessful, the authors were keen to maximise consumer involvement to prevent similar results.

Why provide information to people affected by cancer?

Providing cancer patients with information can reduce fear and increase a sense of control and empowerment (Wilkes et al., 2000). Conversely, providing insufficient information has been found to increase anxiety, uncertainty, distress and dissatisfaction (Fallowfield, Ford, & Lewis, 1995), and previous research (including Study 1) has found that many cancer patients are unaware of the support services available to them (K. J. White et al., 2011). Fallowfield et al. (1995) found that 94% of the cancer patients they interviewed wanted as much information as possible to be given to them from their oncologist.

An Australian study of the support needs of rural families dealing with oncology patients in palliative care found that information was considered one of the most important needs to help them care for their relative (Wilkes et al., 2000). However, “Information in relation to services was problematic at all levels, including support services in metropolitan centres and financial assistance” (Wilkes et al., 2000, p. 45). A recent review Butow et al. (2012) highlighted the need for developing and evaluating web-based tools with locality-specific information for cancer patients. There is also a need for health professionals to take greater responsibility in informing patients and their families in an appropriate and timely fashion (Wilkes et al., 2000). However, health professionals obviously require the information themselves, before they can distribute it to patients.

Previously suggested solutions to this lack of information include providing patients with comprehensive lists of support services (Butow et al., 2012; McGrath et al., 1999b) including information on accommodation facilities and travel subsidies (Hegney et al., 2005) and/or developing rural information kits (C. Davis et al., 2003).

Why provide information for families/ friends/ carers/ supporters?

The impact of cancer not only affects patients, but also their relatives, friends and carers. This fact was frequently mentioned by PAR participants. In rural areas, a diagnosis of cancer can even affect the entire community (Burman & Weinert, 1997a). Fallowfield (1995a) points out that failing to address

the family's emotional needs can mean that patients do not get the support they need, through the course of their disease. Some studies have even found levels of anxiety and depression are higher among family members and supporters than the patients themselves (Fallowfield, 1995a). For these reasons, information to assist not only patients, but also their families and carers, was incorporated into the website.

Many rural people with a cancer diagnosis report feeling that other people in their community are uncomfortable talking to them or avoid them, which Burman and Weinert (1997a) suggest means that stigma around cancer still exists. An alternative interpretation is that they do not know how to approach the situation. This is why the *Country Cancer Support* website provides information for 'friends' on topics such as what they can do to help.

Why include information on different stages of treatment/ journey?

Providing information tailored to a patient's stage of treatment is important because the challenges and issues patients experience change over the cancer trajectory (Dunn, 2005; Wilson et al., 2000). Stress does not end with treatment either (Lavoie Smith et al., 2012); survivors may need informational and emotional support long into their survivorship period too (Foster, Wright, Hill, Hopkinson, & Roffe, 2009; Vivar & McQueen, 2005). Many need help adjusting to a new phase in life and dealing with the physical and psychosocial symptoms that can follow for months or even years after treatment has ceased (Lawler et al., 2011).

What information do rural cancer patients they need?

Very little research has been conducted to determine the information required by rural patients, or how this information should be communicated (Butow et al., 2012), which is why a PAR approach to the content development was viewed as important. However, some of the topics suggested by participants were similar to those identified in a paper written by Foran (2010), a rural health consumer from NSW who described her experience of travelling for medical treatment and the idea for a website

to help people deal with navigating ‘the system’. Headings shared between Foran’s and the present work included directions on how to get to treatment facilities, where to stay, and who was available to support patients in the city (Foran, 2010). This consistency added validity to the findings from Study 2 and suggests that the results may be applicable to other rural health settings (at least interstate, if not overseas). In addition, concerns of rural cancer patients highlighted in a paper by McGrath (1999a) were also considered. These included fear of recurrence of cancer, worries about the family, work-related concerns, emotional concerns (e.g. anxiety, how others perceive them, depression, anger, frustration), pain, financial concerns, loss of functional ability, relationship problems, loss of roles and uncertainty (McGrath et al., 1999a).

Development of the Country Cancer Support website

Design considerations

In designing the present website, Web Content Accessibility Guidelines (WCAG) 2.0 were consulted and where possible, adhered to. These guidelines aim to help website designers consider the needs of older adults with functional impairments (Vanderheiden, Reid, Caldwell, Henry, & Lemon, 2010). In accordance with these guidelines, the present website avoids flashing text and objects, headings organise content, abbreviations are avoided and navigation techniques are consistent across pages (Vanderheiden et al., 2010). Those who developed these guidelines (the Web Content Accessibility Guidelines Working Group) also advocate the involvement of users in the design of websites at an early stage to aid more efficient development and overcome issues of accessibility (Henry, Abou-Zahra, & Arch, 2010).

Tips from the National Institute on Aging and the National Library of Medicine on how to make websites “senior friendly” were also considered. Suggestions adopted from these guidelines included requiring single rather than double clicks, including a search engine that uses keywords (instead of special characters or Boolean terms), using sans serif typeface and dividing information into short

sections (National Institute on Aging, 2009). These issues were considered important as research suggests that websites are not helpful unless they are easy to use and accessible (Leykin et al., 2012).

An ‘open lesson plan flow’ allows users to view any topic in any order, to address the audiences’ broad range of needs and curb the high dropout rate of internet interventions (Leykin et al., 2012) (i.e. we wanted users to be able to view the topics most relevant to them first).

Great consideration was given to the website’s appearance as websites with higher aesthetic appeal are judged as being more credible (Robins & Holmes, 2008). Authors’ credentials and professional affiliations also enhance credibility (Liu, 2004 in Robins & Holmes, 2008) which, along with acknowledging their contribution, is the reason various organisations’ logos are displayed on the site.

Another interesting part of the content development process, beyond the scope of Paper 2, was how the website logo was formed. From the initial 20 designs, there were five obvious ‘stand outs’. Consistent with the consumer-focused approach for content development, potential website users were asked to select their favourite logo at weekly morning teas held in Cancer Council SA accommodation facilities for rural cancer patients and their carers. The present logo was the overwhelming winner.

The photos of rural landscapes displayed at the top of the web pages were also carefully considered. Landscapes from all regions of the state were represented, so that all South Australians could identify with the content. These pictures change each time a new page is loaded.

It was decided that interactive/discussion-board components of the website should be moderated. Like Winefield, Coventry & Lambert (2004), “we intended moderation to exclude any hostile or defamatory comments, medically or psychologically irresponsible advice or misinformation, and malicious insertions by hackers” (p. 177). The tailoring of content to users’ needs was also important as there is good “evidence for the utility of psychological tailoring as a health communication strategy” (Latimer, Katulak, Mowad, & Salovey, 2005, p. 137). Customisation can help patients feel more

understood and reduce the burden of irrelevant information (Leykin et al., 2012). This is discussed in further detail in the behaviour change literature section below.

Language considerations

The website avoids language that might create alarm or stigma and deter potential users from the website or services that it encourages users to use. As Cameron et al. (2005) pointed out, “Psychosocial support programs and informational materials promoting their use may attract more participants if they are tailored to focus on resolving cancer-related distress rather than on general anxiety or depression, appeal to those with high avoidance tendencies, address the role of immune function in cancer progression, and meet the needs of older participants” (p. 584). A conversational tone was adopted and the language chosen was as simple as practically possible.

Content generation

Various methods were used to draft the content in each section of the website. For example, the academic literature influenced the ‘Dealing with difficult emotions’ section more than the section on what to pack when going for treatment. Whatever the method or section, all content was approved by PAR participants before it was put online. The final plan of the *Country Cancer Support* website content is detailed in Figure II.

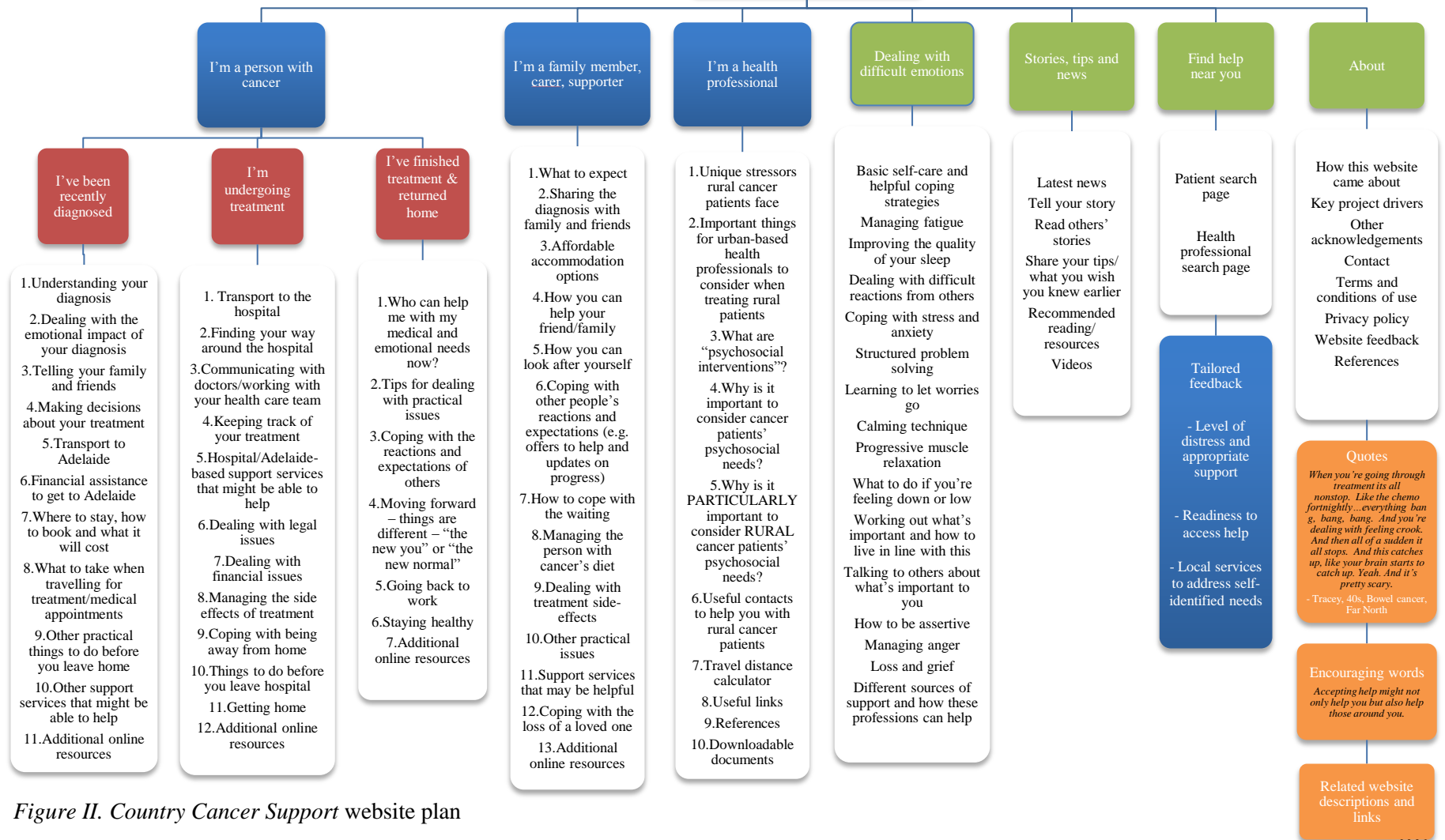


Figure II. Country Cancer Support website plan

General information

To produce the content, the first task was to generate headings. Memos were written on exactly what participants said they wished they knew earlier, in the interviews conducted for Paper 1. These were comments such as “book in early to Greenhill or Flinders Lodge”¹⁰ and “make sure you’ve got the support we’ve talked about, both on levels of family, friends and professionals and not necessarily in that order. The ones you start off with are the ones you feel more comfortable with and then build like a network of support.” From these memos, themes were identified and a rough content plan was drafted. Once this was done, the PAR process (as detailed in Paper 2) began.

To ‘bring this process to life’ in a way that is not possible within the constraints of a journal article, the comments one PAR participant made after seeing a draft of the website content plan are displayed below. This participant was named ‘John’. He was 69 years of age at the time. John lived in Broken Hill, had prostate cancer and malignant melanoma, gave permission for his story and details to be shared and took part in both Study 1 and Study 2. His suggestions included:

- Emphasising that there are many types of cancer, all have different prognoses. He said, “People think cancer is all the same, the same as they think kangaroos are all the same but in actual fact there are 48 different species of kangaroos and lots of different types of cancer”
- Including maps of hospitals so patients can orientate themselves before they go
- Highlighting the role that Cancer Care Co-ordinators can play
- Including information on what to take and what to expect at accommodation facilities
- Including details on how much accommodation will cost
- Including information on how to use public transport
- Including somewhere to share stories with other country people

¹⁰ Cancer Council SA’s supported accommodation facilities for rural outpatients

- Having an adjustable font size
- Keeping it simple
- Including video clips (which he ended up ‘starring’ in) that show potential patients and guests around Cancer Council Lodge Greenhill and Cancer Council Lodge Flinders, so they know what to expect

During the process of refining the content headings with participants, information under each heading was gradually filled in. It was then reviewed by the next participant. To do this, existing sources of written information were consulted (see Appendix 2). Several phone calls to and meetings with, service providers were also had.

Emotional health section

A key purpose of the *Country Cancer Support* website is to decrease users’ levels of distress. Although PAR participants clearly stated that they wanted practical information on dealing with emotional issues, and had some helpful strategies they could share, they were not able to articulate exactly what emotional self-help information should entail. Clinical practice guidelines, reviews and meta-analyses in the academic literature were deemed the best way to determine this and therefore were heavily consulted.

Devine and Westlake’s (1995) meta-analysis of 116 studies on psycho-educational care for adults with cancer concluded that psycho-education may assist this population with anxiety, depression, mood, nausea, vomiting and pain. Similarly, Barsevick, Sweeney, Haney & Chung’s (2002) systematic review found that psycho-educational interventions (information provision, discussion of concerns, coping skills training, problem solving, expression of emotion and social support) can alleviate depressive symptoms in cancer patients (Barsevick et al., 2002).

Rehse and Pukrop (2003) found evidence of the efficacy of psychosocial interventions for improving quality of life in adult cancer patients and that educational programs were more effective

than social support programs, coping skills training and psychotherapy in their meta-analysis. More recently, a review of meta-analyses by Söner and Keller (2007) found that “a variety of psycho-educational, cognitive-behavioural and psychodynamically orientated interventions, in an individual or a group setting was demonstrated to effectively reduce anxiety and depression in cancer patients of various tumour sites and stages of the disease” (p. 249). Relaxation, hypnosis and guided imagery were all also found to help with pain (Soner & Keller, 2007). Osborn et al. (2006) conclude from their meta-analyses that Cognitive Behaviour Therapy (CBT) has short term effects on depression and anxiety and both short and long term effects on quality of life. More generally, Carlson and Bultz (2003) conclude from their review that psychosocial interventions are helpful in reducing distress, possibly improving medical outcomes and reducing medical costs.

The difficulties of interpreting this research to determine the most appropriate therapeutic approach have been noted, as have problems with the methodological rigor of studies in this field (Newell, Sanson-Fisher, & Savolainen, 2002). The failure to provide clear definitions of particular interventions/treatment protocols, use of different outcome measures, poor study design, and poor reporting all contribute to this. Nonetheless, the positive impact of psychosocial interventions on psychological and functional adjustment (e.g. returning to work) and symptoms related to cancer treatment (e.g. anticipatory nausea) (Meyer & Mark, 1995) are widely accepted.¹¹ Fortunately, the *Clinical practice guidelines for the psychosocial care of adults with cancer* (National Breast Cancer Centre & National Cancer Control Initiative, 2003) provide a clear summary of psychosocial interventions, what they typically involve and a comprehensive analysis of the evidence supporting each intervention’s efficacy, as displayed in Table I.

¹¹ There is also an increasing amount of evidence to suggest that “psychosocial interventions are not only effective, but also economical” (Carlson & Bultz, 2004, p. 837) as in the long term they reduce health-care system usage. Evidence that psychosocial interventions improve survival (first suggested by Speigal, Bloo, Krawemer & Gottheil in 1989) is questionable (Edwards & Hulbert-Williams, 2009, Goodwin, 2005, Newell, Sanson-Fisher, Savolainen, 2002).

Table I

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Source: *Clinical practice guidelines for the psychosocial care of adults with cancer* (2003), reproduced with permission from Cancer Australia.

Clearly, this table highlights the value in providing CBT-based interventions to cancer patients (consistent with several of the aforementioned meta-analyses). As a result, most of the emotional self-help material on the *Country Cancer Support* website is CBT-based.

The internet is considered an appropriate medium for delivering psychological treatment, particularly CBT-based interventions (Shepherd et al., 2008). CBT is manualised and has strong empirical support for a variety of psychological disorders, making it adaptable for online administration for cancer patient and survivors (Leykin et al., 2012). There is a good amount of research on the usefulness of web-based CBT for mental health problems (but not with cancer patients) (Shepherd et al., 2008). It is acknowledged that self-help CBT does shift the focus from therapy to education/health promotion, but there is still evidence that it helps (Williams, Unknown). It also empowers people, allows people to work at their own pace and helps to avoid stigma/embarrassment (Williams, Unknown).

Since 2003, when the literature review that informed Table I was completed, there has been increasing evidence that three new therapies are also helpful for the cancer population; Acceptance and Commitment Therapy (ACT), Mindfulness-Based Cognitive Therapy (MBCT) and Mindfulness-Based Stress Reduction (MBSR). While CBT has been influential in the past, third wave therapies such as ACT and MBCT and MBSR offer new or complementary ways of treating distress associated with chronic disease (Prevedini, Presti, Rabitti, Miselli, & Moderato, 2011)

ACT is a type of psychological intervention that focuses on changing a person's relationship with their thoughts so they can have difficult thoughts and feelings without letting them 'get in the way' of doing what is important to them (Feros, Lane, Ciarrochi, & Blackledge, 2013). It usually involves values clarification, acceptance strategies, mindfulness techniques and behavioural activities (Feros et al., 2013). This approach is thought to be particularly appropriate for cancer patients given its focus on accepting issues one has no control over and living in accordance with personal values to get the most out of life (regardless of the situation at hand) (Karekla & Constantinou, 2010). Existing research has

been encouraging (e.g. Feros et al., 2013), but more research is required to examine the effectiveness and efficacy of this approach (Karekla & Constantinou, 2010).

Mindfulness meditation is incorporated into both MBSR and MBCT and is also increasingly popular and involves “moment-to-moment nonjudgmental awareness of internal and external experience, including thoughts, emotions, and body sensations” (Carlson, Labelle, Garland, Hutchins, & Birnie, 2009a, p. 385). Individuals are taught to focus on living fully in each moment (Shennan, Payne, & Fenlon, 2011) and to focus on their breath, bodily sensations and the objects that enter their awareness (Carlson et al., 2009a). This process can be undertaken informally while going about other tasks and helps people ‘live in the moment’ or in the present, rather than focusing on things in the past (which can be depressing) or things in the future (which can cause anxiety).

Recent reviews have concluded that mindfulness approaches are also promising for cancer care (Carlson, Labelle, Garland, Hutchins, & Birnie, 2009b; Shennan et al., 2011; Shigaki, Glass, & Schopp, 2006). There is evidence that they can assist in addressing anxiety, stress and mood disturbance (Shennan et al., 2011) and may also have positive effects on immune systems, but further research on this approach is required (Shennan et al., 2011).

Mindfulness techniques are often integrated into other therapeutic approaches (Shennan et al., 2011). The mindfulness techniques used most at follow up are less formal - that is, short, focused attention on the act of breathing and awareness of moment-by-moment, daily activity (Shigaki et al., 2006). Therefore these strategies have been incorporated into the self-help material for the *Country Cancer Support* website.

In addition to the literature described above, several texts and workbooks were consulted to develop these worksheets (see Appendix 2) and feedback was sought on each of the fact sheets from PAR participants (as detailed in Paper 2). From this comprehensive process, the following fact sheets were developed. To view them, refer to Appendix 3.

- Basic self-care and helpful coping strategies
- Managing fatigue
- Improving the quality of your sleep
- Dealing with difficult reactions from others
- Coping with stress and anxiety
- Structured problem solving
- Learning to let worries go
- Calming technique
- Progressive muscle relaxation
- What to do if you're feeling down or low
- Working out what's important and how to live in line with this
- Talking to others about what's important to you
- How to be assertive
- Managing anger
- Loss and grief

Service directory/ 'Find help near you'

Organisations that may provide services that could be of use to rural South Australian people affected by cancer were identified using Cancer Council SA's database and the Directory of Community Services written by Service SA (a government agency). Each service was entered into a spreadsheet and classified according to its local government area. All rural local councils were then emailed and asked if they could check the list of services identified in their local government area and help to identify missing services. Some councils highlighted the existence of directories of services they had developed for their regions. New services were then listed on the spreadsheet.

The organisations identified were then invited to complete an online questionnaire that contained questions on their contact details, services on offer and exactly how they may be able to assist people

affected by cancer. Several reminder phone calls were made and emails were sent before many of the services completed the survey. Some organisations opted to complete the survey over the phone rather than online. Support group leaders were sent pre-populated surveys via email or post to minimise the amount of time it would take them to complete our request. Collecting this information was a time consuming process. A very small proportion of services did not complete the survey despite being reminded several times, so the survey was completed on their behalf based on information available on their websites. Once surveying began, a snowball sampling recruitment strategy was utilised whereby those services surveyed were asked to identify other relevant services in their regions. See Appendix 4 to view the service provider survey.

Information was gathered on approximately 485 South Australia services (general practices, cancer support groups, transport services, Non-Government Organisation (NGOs), state government health services etc.). Most of these services are located rurally but several urban-based organisations were also found to cater for rural cancer patients and their supporters. Links to websites that provide information on other services (e.g. Yellow Pages for cleaning, gardening) were also identified.

The results of the online survey provided the basis for the “Find help near you” section of the website. It also added validity to the finding in Study 1 that rural access to support services is not hindered because these services do not exist, but rather because patients do not know about them. This survey and the resulting service directory, demonstrate that services do exist, but the difficulties encountered while collecting this information supported the notion that they can be difficult to find out about.

Behaviour change elements in the website

As a key goal of the *Country Cancer Support* website is to decrease barriers and increase help-seeking intentions among users, the literature on how to get people to change their behaviour was consulted to assist with its development; as Leykin et al. (2012) point out, “Just as a traditional psychotherapy is guided by its theoretical framework, an Internet intervention must be informed by an

appropriate, empirically supported theoretical system of behaviour change” (p. 1021). Increasing help-seeking in this population is vital because as Henshaw & Freedman-Doan (2009) recognise, “By attending to public perceptions of treatment and systematically developing approaches to reduce barrier-producing beliefs such as mental health stigma, progress can be made in closing the gap between those who would benefit from treatment and those who receive it” (pp 434-435).

In their recent review, Webb, Joseph, Yardley & Michie (2010) found that the three most commonly used behaviour change theories were social cognitive theory, the transtheoretical model and the theory of reasoned action/ planned behaviour. The most commonly used behaviour change techniques are providing information on the consequences of behaviour in general, promoting self-monitoring of behaviour and identifying barriers and problem solving, but the largest effects were observed for stress management or general communication skills training; the greater the number of influence components (i.e. behavioural change techniques and behavioural determinants) in interventions, the greater the effect (Cugelman et al., 2011; Webb et al., 2010). Like Webb et al. (2010), the present study employed the taxonomy of behaviour change techniques developed by Abraham and Michie (2008) to standardise descriptions of these methods. As Webb et al. (2010) state, “In order to identify techniques contributing to effectiveness across interventions and to ensure that effective interventions can be replicated, it is crucial that standardized definitions of the techniques included in the behaviour change interventions are used and linked to intervention effectiveness” (p. 2). The strategies selected from this taxonomy were those found to be effective online in Cugelman et al.’s (2011) recent meta-analysis.

Insights from an adapted version of Health Belief Model were also incorporated into the website’s design. According to this model, patients need information on the following to help them access mental health care (and similarly, psychosocial support), “(a) severity: when are my symptoms “bad enough” to seek professional help? (b) benefits: does professional help increase my chances of feeling better soon? (c) barriers: are the financial, emotional, or other costs of seeking professional help worth the

possible benefits? and (d) self-efficacy: am I capable of making the changes necessary to improve how I feel?” (Henshaw & Freedman-Doan, 2009, p. 434).

For further information on the behavioural change elements of the website, refer to Paper 2. However, this paper does not detail the online distress screen tool that is linked with service directory data, described in the following section.

Incorporation of distress thermometer and tiered model interventions

Online screening and diagnostic assessments are already available online and can be used by medical professionals or the general public for conditions such as anxiety and depression (Reynolds et al., 2011). Despite this and the acceptance of paper-based screening among cancer patients in Australia (Clover, Carter, MacKinnon, & Adams, 2009), accessing online distress screening is uncommon among cancer patients. Therefore, as Shepherd et al. point out, investigating the online provision of screening questionnaires for rural cancer patients would be useful (Shepherd et al., 2008). It is thought that “Future use of technology will help to bridge the gap between detection of problem-related distress and referrals for assessment or treatment, creating proactive approach to whole-person-centred care” (Clark, Bardwell, Arsenault, DeTeresa, & Loscalzo, 2009, pp. 28-29).

In America online screening to identify distress has been successfully carried out with a group of American cancer survivors, who reported that “the survey was easy to complete, and computer-naive users reported not being threatened by the technology” (Lavoie Smith et al., 2012, p. 79). Similarly, a study by Clark et al. (2009) in the United States, found that online screening for distress can be acceptable to patients and bridge the gap between identifying distress and accessing treatment for it. Even though over half of their participants considered themselves beginner or intermediate computer users, most found it easy to use (Clark et al., 2009). It is predicted that “the uniform application of screening and appropriate treatment for oncology patients would likely save the system money and scarce medical human resources over the long term” (Carlson & Bultz, 2003, p. 408).

For these reasons, it was thought that providing a facility for patients to self-screen and find out how they could help themselves by accessing services or more information, would be a useful experiment in the South Australian rural cancer population. The feedback provided by the resulting tool about what types of interventions might be useful is consistent with the National Comprehensive Cancer Network distress management guidelines and the tiered model of psychosocial care (Steginga et al., 2006), based on the results of a Distress Thermometer (DT) (National Comprehensive Cancer Network, 2011). This model is outlined in Figure III. It shows what sort of psychosocial services are required depending on a person's level of distress, thereby providing simple direction to patients and health professionals.

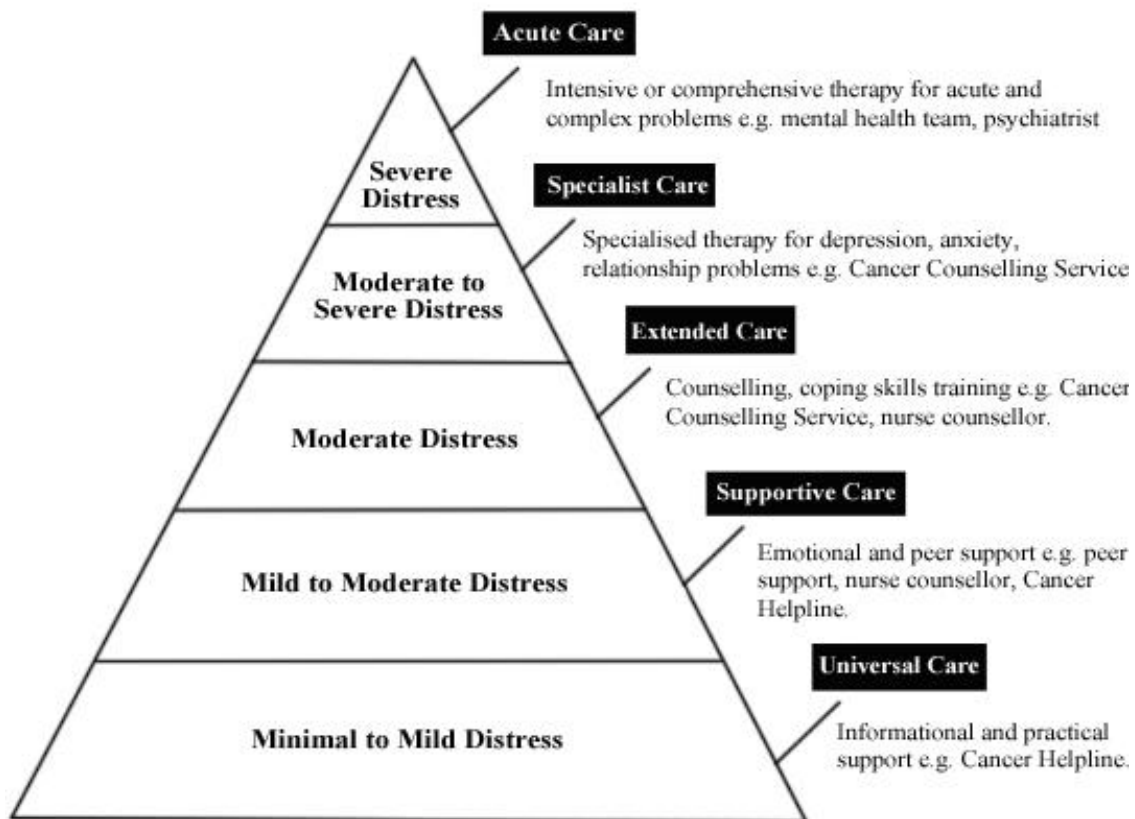


Figure III. The tiered model of psychosocial care (Hutchinson et al., 2006)

The DT is a single-item, self-report measure of distress that is non-invasive, valid and an acceptable alternative to longer instruments (Carlson & Bultz, 2003; Hughes et al., 2011). A recent meta-analysis supported the use of the DT - it was at least as successful as the HADs but more efficient and acceptable (A. J. Mitchell, 2010). Used in rural Australian samples, the DT has demonstrated acceptable sensitivity and specificity in detecting cases of psychological morbidity in rural adult cancer patients (Thewes et al., 2009). Using measures like the DT is considered useful, as it provides an “objective, structured and consistent means for distress screening and triage to supportive care services” (Hughes et al., 2011, p. 5), and as Tuinman et al. notes, “can result in the identification and consequent treatment of patients in need of professional psychosocial care who may not otherwise have had access to it” (2008, p. 871).

A ‘problem list’ is also often used to identify what is contributing to distress; however, there are concerns that this list does not cover all of the issues experienced by cancer patients (Hughes et al., 2011). Suggested additions include decision support, information, adjusting to illness, feeling alone, loss of independence/control, grief and bereavement (Hughes et al., 2011). To render it more relevant to the needs described by PAR participants, some items on the problem checklist were adapted for this work. These items are outlined in Appendix 5. The resulting user interface and example of a resulting page can be viewed in Figures IV and V below.

NOTE:
These figures/tables/images have been removed
to comply with copyright regulations.
They are included in the print copy of the thesis
held by the University of Adelaide Library.

Figure IV. Screen shot of the ‘Find help near you’ page for patients and supporters on *Country Cancer Support* website

Figure V. Screen shot of example ‘Results’ page on *Country Cancer Support* website

It is hoped that the distress thermometer feedback may act as a ‘cue to action’ and that, following (Henshaw & Freedman-Doan, 2009)’s model, when users understand how they can improve their daily functioning, they will be more likely to access services. Providing this feedback is considered useful as previous research shows that many rural people do not recognise when they need mental health assistance (Jameson & Blank, 2007).

Self-help/ empowerment

The aim of the distress screen tool and the self-help material is to empower people to take relatively simple actions to help overcome cancer related distress. As Mc Conigley et al. (2011) suggest, “strategies that promote self-management and self-advocacy... may help these patients to navigate the health care system and access care and support appropriate to their needs in a timely manner” (p. 6). Similarly, as Koopman, Angell, Turner- Cobb et al. (2001) state of breast cancer patients, “interventions need to focus on identifying ways to help the women feel empowered in coping with their breast cancer. This may entail helping women to identify available resources such as cancer or spiritual/church support groups” (p. 30). When access to healthcare services is limited, there is an increased need for self-care skills (Winters et al.). Similarly, Thewes et al. (2009) point out that if “psychosocial staff are limited, a focus on enhancing patient education about psychosocial issues coupled with avenues for self-referral is recommended” (p. 303).

Promotion of the County Cancer Support website

Once the website was developed, the first author did a promotional tour, visiting several regions of the state as outlined in Figure VI. This involved meeting with cancer support groups, providing promotional materials to GPs, community health services, chemists, hospitals and even bowling clubs and post offices (see Appendix 6 for promotional materials).

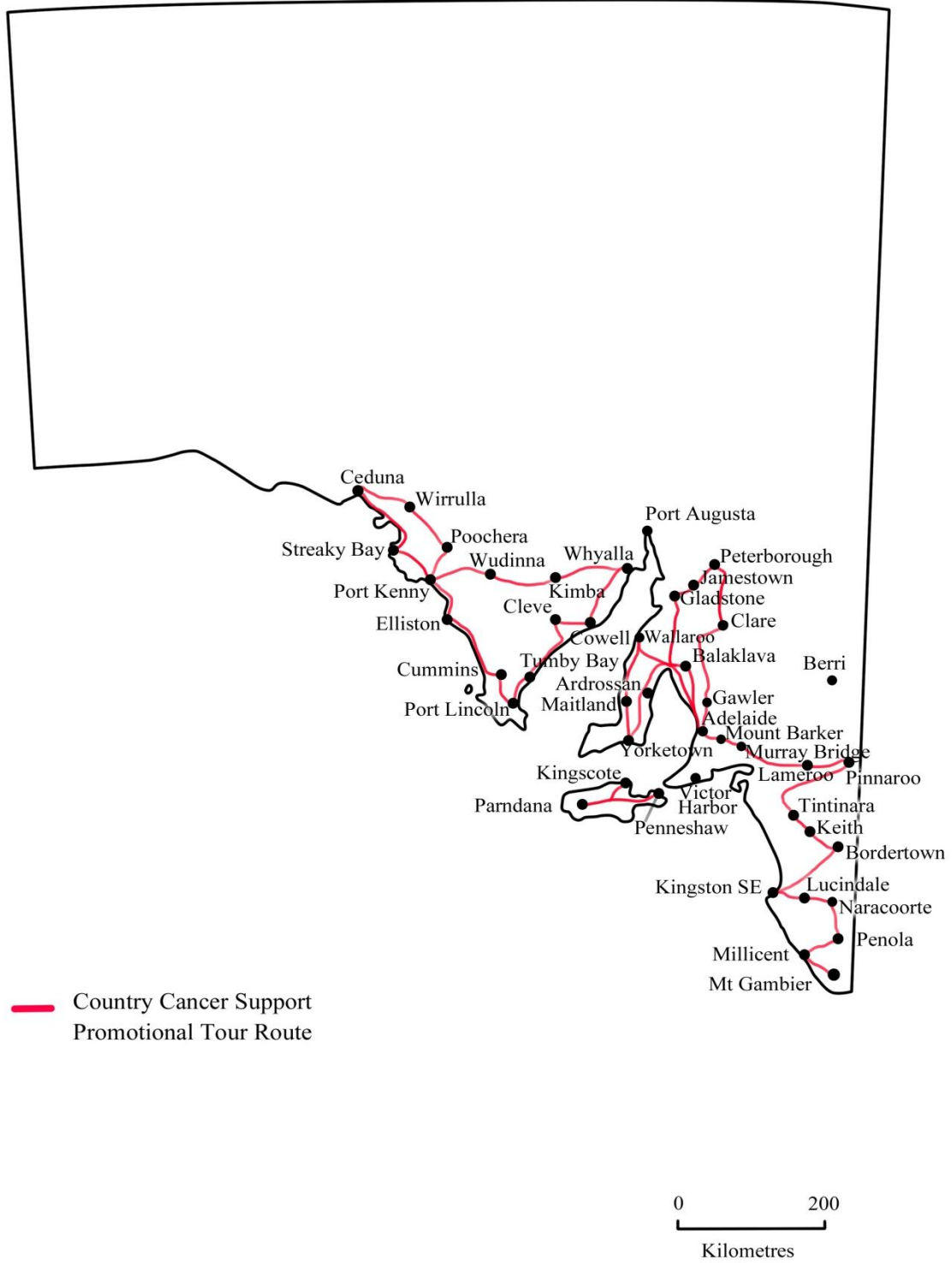


Figure VI. Country Cancer Support promotional tour route

The difficulties of introducing a new service to people in isolated areas, who do not expect outside help, have been noted elsewhere (Collie et al., 2007); however, the promotional materials and visits were welcomed across the state. Services and support groups appeared impressed that someone cared enough to visit their town and tell them about a new resource. A press release was issued and several newspaper articles and radio interviews resulted (see Appendix 7). One PAR participant was heavily involved in the promotion process, appearing in a newspaper and speaking on ABC radio about her experience with cancer and the *Country Cancer Support* project.

Rationale for Study 2

A recent review by Leykin et al. (2012) supports interventions of this type. It states that “Inadequate screening and referral, and barriers to psychosocial care for cancer patients highlight the need to develop and test new treatment models that can help fill these service gaps. Internet mental health interventions have the potential to help meet the needs described above and help reduce existing mental health disparities” (p. 1017). This assertion echoes Thorndyke (2005): “It is expected that greater access to health information will improve the overall health of rural women, but this hypothesis remains unproven... Future studies will need to evaluate the impact of greater use of technology on overall health status in rural women” (p. 202). A recent review by K. M. Griffiths et al. (2010) concluded that “Internet interventions for depression and anxiety disorders offer promise for use as self-help applications for consumers or as an adjunct to usual care” (p. S4). They also highlight the need to evaluate such interventions under different conditions and with different groups (i.e. they found no trials that involved rural residents) (K. M. Griffiths et al., 2010).

Butow et al. (2012) highlight that “Emerging priorities for intervention research include novel methods of overcoming distance barriers through use of internet- or phone-based modes of delivery” (p. 20) and White et al. (2011) recommend tailoring supportive interventions to the unique needs of rural patients. However, unsuccessful interventions developed in the past have shown that this must be

done with great care. As Shepherd et al. (2008) point out, if online psychological interventions are to be useful, there is no doubt that “consultation to ascertain the unique needs of the remote areas will enhance the probability of a program being successfully implemented” (p. 434). Similarly, Angell et al. (2003a) highlight that “It is vital to include underserved and understudied participants in health research; but it requires patience, creativity, and a trusting relationship ... Community-research partnerships are a way to build a bridge between community experience and academic knowledge, improving our ability to develop interventions that are more effective for more people.” (p. 505). It is statements such as these that justify Study 2.

In summary, this novel intervention was developed in an effort to decrease distress and increase psychosocial help-seeking among rural cancer patients, by helping them to overcome attitudinal barriers to service use and the lack of rurally- relevant information on psychosocial care identified in Study 1. While online interventions offer great promise in overcoming the health disparities experienced by rural populations, ensuring they are accepted by this under-researched, unique group can be challenging. Involving consumers in the development of interventions is considered best practice and may maximise the likelihood of such interventions being successful. How this can be done and the benefits of doing so, are outlined in the following paper.

Statement of contributors

Miss Kate Gunn (candidate) was responsible for the literature review, conception of the study, data analysis, drafting and submitting the manuscript. This paper is currently under review by the Australian Journal of Rural Health.

Signed: Miss Kate Gunn

Professor Deborah Turnbull, Ms Lindsay McWha, Dr Matthew Davies and Professor Ian Olver AM (co-authors) provided ongoing supervision throughout the research program that led to this publication. Their role included working with Miss Gunn to refine the direction of and methodology employed in the research, commenting on the material presented in drafts and providing editorial input. They hereby give their permission for this paper to be incorporated in Miss Gunn's submission for the degree of Masters of Psychology (Clinical) with Doctor of Philosophy from the University of Adelaide.

Signed: Professor Deborah Turnbull

Signed: Ms Lindsay McWha

Signed: Dr Matthew Davies

Signed: Professor Ian Olver AM

Connecting rural cancer patients and their families and carers with psychosocial support; the development of a website using a Participatory Action Research Framework and Behavioural Change Theory

Running title: Connecting rural cancer patients with psychosocial support

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Miss Kate McDonald Gunn= 40%

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Number of Figures/Tables: Figures: 5, Tables: 3.

Abstract

Objectives: A) To develop a website to provide rural-specific information on psychosocial care for rural South Australian cancer patients and their carers, families, friends and health professionals, and engage people with relevant life experience as well as knowledge from the psychological literature in the process B) document the lessons learnt from using this method.

Method: 10 rural cancer patients and one rural health professional/ rural cancer patient's carer, worked with the authors to develop www.countrycancersupport.com.au. Participatory Action Research (PAR) principles guided this process. Behaviour change theories were employed to motivate users to access psychosocial care. Other insights from the psychological literature (e.g. the tiered model of psychosocial interventions in cancer, Cognitive Behaviour Therapy) were also integrated into the design, providing they were acceptable to participants.

Results: An 84-page, interactive website producing widespread interest and use (4016 visits in the first five months) was developed. The participatory website development process also resulted in collaboration between a large number of stakeholders, increased awareness of the value of rural-specific information for rural patients and acceptance, trust and appreciation of the website by its users. Empowerment of participants involved in the website's development was also an important result.

Conclusions: This study demonstrates the utility of PAR in developing a solution to the psychosocial information needs of rural cancer patients. It also provides a framework to inform the development of other online, consumer-driven health-promotion interventions in accordance with best practice recommendations.

What is already known on this subject?

- Rural cancer patients experience high levels of distress, unique stressors and want more rurally-relevant information to help them access appropriate psychosocial care
- However, the exact types of information they require and how messages that encourage psychosocial help seeking could be appropriately communicated, is unclear
- Values and attitudes are known to affect help-seeking patterns in the rural population and require careful consideration when designing interventions for this group
- Involving consumers in intervention design is considered best practice and can improve the design's acceptability and implementation
- Participatory Action Research (PAR) is a well-established method that is particularly useful when there is scope for those who identified the problem to go on and help address it
- The more behaviour change techniques that online interventions incorporate, the larger effect the intervention has been found to have on user-behaviour

What does this study add?

- Provides a framework to guide consumers' collaboration with researchers in solving self-identified problems in their communities
- Demonstrates the particular value of using PAR when developing interventions for populations who are under-researched and have values and beliefs that need to be carefully considered
- Highlights how consumers can be empowered through participation in PAR and how using this approach can lead to interventions that are highly acceptable

Introduction

Rural cancer patients experience the psychosocial challenges associated with a diagnosis of cancer in any setting as well as a number of additional stressors arising from their place of residence (e.g. the need to travel to receive medical treatment) (Baldwin & Usher, 2008; Bettencourt et al., 2008). Evidence is emerging that rural cancer patients may be at risk of poorer mental health functioning (Burriss & Andrykowski, 2010; Girgis et al., 2000; Lyons & Shelton, 2004; Wilson et al., 2000). It is well documented that they generally have poorer treatment outcomes (Jong et al., 2004), lower quality of life (Butow et al., 2012) and higher levels of unmet psychosocial needs than their urban counterparts (Beesley et al., 2008; Butow et al., 2012; Harrison et al., 2009), which makes them a group worthy of special attention.

A recent study by the authors of this paper (Gunn, Turbull, McWha, Davies, & Olver, In press) identified the lack of rural-specific information on psychosocial care as a major barrier to service use in the rural cancer population. It also highlighted that the provision of this information may help overcome attitudinal barriers to service use (e.g. the belief that help is unnecessary and concerns about confidentiality and/or stigma).

Previous research widely acknowledges the potential for online interventions to deliver psychosocial care to rural cancer patients (Butow et al., 2012; Lawler et al., 2011) and has also raised the problem of a lack of rural-specific information for these patients (Bettencourt et al., 2007; Butow et al., 2012; C. Davis et al., 2003). However, until now, very few examples of comprehensive online information sites tailored to the specific psychosocial needs of rural cancer patients have existed in Australia or internationally and little research has been done to discover how rural cancer patients would like to receive information and/or education of this type (Butow et al., 2012). Therefore, the present paper reports on the involvement of several South Australian rural cancer patients and one carer/health professional in developing rural-specific online information on 'how to cope and who can

help', when faced with a diagnosis of cancer. The website also aims to help reduce feelings of distress, perceived isolation and encourage psychosocial help-seeking.

Best practice guidelines for developing health communications highlight the importance of understanding key aspects of the culture that influences the intended audience, and building that into the communication strategy (National Cancer Institute, 2008). More specifically, involving consumers in intervention design has been found to increase the usability, effectiveness and cultural appropriateness of interventions (Bridgelal Ram, Grocott, & Weir, 2008). It also assists in the development of information that is more relevant, readable and effective at improving patient knowledge (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006), and can empower participants (Kidd & Kral, 2005) and lead to a sense of ownership among users and more successful implementation (Waller, Franklin, Pagliari, & Greene, 2006). The involvement of people with relevant life experience can foster trust in the intervention (Cugelman, Thelwall, & Dawes, 2009) and is particularly important when an intervention aims to bring about behavioural change, which this website seeks to do. Therefore, a Participatory Action Research (PAR) Framework was chosen to guide the content development process.

The essential elements of using a participatory method are “understanding, mutual involvement, change, and a process that promotes personal growth” (Kidd & Kral, 2005, p. 187). Put simply, to ‘do’ PAR “you get the people affected by a problem together, figure out what is going on as a group, and then do something about it” (Kidd & Kral, 2005, p. 187). It enables people to solve a practical problem (in this case the need for a new information resource) and meet the knowledge generation goals of social science through collaboration in a mutually acceptable way (Rapoport, 1970) and is increasingly accepted in the field of Psychology (Herr & Anderson, 2005).

The specific objectives of using the participatory approach in this study were to (1) develop relevant and acceptable website content and (2) empower participants by directly involving them in this process.

In addition, insights from models of voluntarily behaviour change shaped the website's design to increase the likelihood that it would lead to more psychosocial help-seeking among users. This is an important goal, particularly in this population, because as Henshaw and Freedman-Doan (2009) say, "By attending to public perceptions of treatment and systematically developing approaches to reduce barrier-producing beliefs... progress can be made in closing the gap between those who would benefit from treatment and those who receive it" (pp. 434-435). Previous research has found online interventions that incorporate more behaviour change techniques have larger effects compared to those incorporating fewer techniques (Webb et al., 2010). Other academic literature also informed the website design, providing that the additions were acceptable to participants.

Given the lack of research and guidelines in this field (Bridgelal Ram et al., 2008; Potvin, Cargo, McComber, Delormier, & Macaulay, 2003), the purpose of this paper is to inform the development of similar consumer-led online interventions, in particular for under-researched groups.

Method

Participants

Four men and seven women residing in 'accessible' to 'very remote' rural areas of South Australia according to the Accessibility/Remoteness Index of Australia (Australian Institute of Health and Welfare, 2004) took part in the participatory website development process.

Seventeen people took part in the author's prior study (Gunn et al., In press) which identified the need for this rural-specific information resource. Of these, 10 gave permission to be recontacted and 9 of the 10 agreed to take part in the project. One person declined because he felt it would be "best to leave it to others". An additional participant was recruited through personal networks. A rural health care professional who had also cared for her own cancer-affected rurally-based father, was recruited after she expressed interest in participating. Figure 1 details the recruitment process. In accordance with PAR it was important that those who identified the problem were involved in developing the

solution to it. The two additions were included as they were thought to offer unique perspectives (i.e. that of a carer/ health professional and a younger male cancer patient).

Demographic characteristics of all participants are presented in Table 2. Table 3 outlines the medical characteristics of those who had had a diagnosis of cancer. All five of the most commonly diagnosed types of cancer in Australia were represented in the sample (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2008), as were the four most remote Accessibility/Remoteness Index of Australia categories (ARIA) (Australian Institute of Health and Welfare, 2004). The more remote categories were deliberately over-represented due to the rural focus of the research employed in the prior and present work. While the sample is considered representative of rural and remote cancer patients in South Australia, this will be tested by evaluating the resulting website to determine whether it reflects the needs of a larger, new sample, at a later stage.

Procedures

After consulting with key government and non-government stakeholders, funding to create this resource was secured and a draft website plan was developed based on what participants in the previous study had said they wished they had known earlier. Also shaping the plan were a review of other patient websites, clinical practice guidelines and as previously stated the academic literature (e.g. the tiered model of psychosocial care by Hutchinson et al. (2006) and information on how to do cognitive behaviour therapy with cancer patients by Moorey and Greer (2010)).

Ethical approval was granted by the University of Adelaide Human Research Ethics Committee and Cancer Council SA's Human Research Ethics Committee. The PAR method used to design the website was informed by Hart and Bond's framework (1995). As Figure 2 illustrates, a consent form, permission to recontact form, a demographic questionnaire, website outline and list of questions to consider were mailed to those who agreed to participate. Once they had considered the questions, the principal author rang them to discuss the website plan. Participants' feedback was then systematically documented in memos, as were the next actions to be taken/ changes to be made.

Where possible, revisions to the website plan were made after each interaction so that a new version was reviewed by the next participant. The preliminary research by the authors (on what patients wished they knew earlier) was validated using a similar technique employed by White and Verhoef (2005) (i.e. by asking whether these findings accurately represented their experience and whether they felt anything had been overlooked). Smith, Rosenzweig and Schmidt's guidelines (2010) assisted in documenting the process.

Participants were viewed as active participants in the research project and the driving force in developing a solution to an important problem they had raised. As the researcher who worked closely with the participants had not personally experienced cancer, according to Herr and Anderson (2005)'s conceptualisation, the mode of participation employed was considered 'co-learning' whereby "Local people and outsiders share their knowledge to create new understanding and work together to form action plans, with outsider facilitation" (p. 40).

Although every effort was made to work with participants as equals, they were not involved in every decision or with every task (e.g. reviewing literature). Participants' suggestions included information on topics such as what to take and what to expect at accommodation facilities, how to use public transport and advice on how to deal with the reactions of others on return to their rural community post-treatment.

As detailed in Figure 3, information was also gathered from service providers on what they offer to help people affected by cancer. 'Expert reviewers' (e.g. an Oncologist, Cancer Council SA Helpline Nurse Counsellors, Psychologists) reviewed printed website content and relevant changes were made.

Behaviour change theory was used to design elements of the site that targeted attitudinal barriers to service use in an effort to maximise the likelihood of motivating users to access psychosocial care. Techniques from a broad range of theoretical frameworks (e.g. Social Cognitive Theory, Theory of Reasoned Action, Theory of Planned Behaviour) were selected from Abraham and Michie's (2008) taxonomy of behaviour change techniques, based on what was deemed effective for online

interventions in a recent meta-analysis by Cugelman et al. (2011) and what was acceptable to PAR informants (i.e. if they considered them usable, helpful and relevant). Aspects of the transtheoretical model (Noar, Benac, & Harris, 2007; Prochaska, DiClemente, & Norcross, 1992) and the recent work of Henshaw and Freedman-Doan (2009) who have conceptualised mental-health care utilisation using the Health Belief Model, were drawn upon, as were barriers to service use identified in the authors' previous work (Gunn et al., In press). This resulted in the inclusion of an interactive distress screening tool linked to a rural health and support services directory which provides feedback tailored to the user's readiness to access support and level of distress. Figure 4 illustrates this and how other behaviour change techniques look in practice. Table 1 outlines examples of the behaviour change techniques incorporated into the website's design and explains the theories that informed their inclusion.

Several participants then viewed an online version of the website. Suggestions were accommodated (e.g. having an adjustable font size) before the *Country Cancer Support* website was launched via the media, with assistance from several stakeholders and participants (e.g. one participant took part in radio interviews and several distributed pamphlets in their local areas).

The preliminary research by the authors (where the need for this resource was established) was carried out between June and September 2010, the participatory website development process unfolded between February 2011 and June 2012 and the website was launched in June 2012.

Results

This collaborative approach to developing an online information resource resulted in:

a) The *Country Cancer Support* website

The interactive, self-help, 84 page website includes practical written information and video clips featuring 'John' (a participant) explaining to newly diagnosed rural South Australian patients what to

expect if they need to travel for treatment. An online distress screening tool is linked to tailored feedback and a rural health and support services directory. CBT-based self-help material is also offered to help users deal with cancer-related distress. Refer to figure 5 for further details on information the website contains.

As illustrated by the following representative comments volunteered by several users of the website, this method also resulted in:

b) Collaboration between a range of stakeholders

This included participants, other rural cancer patients and their families and carers, rural cancer support groups, Cancer Council SA, Country Health SA, The University of Adelaide, the former Spencer Gulf Rural Health School (now UniSA), Cancer Council Australia and both rural and urban-based health professionals.

"The website is a great example of what can be achieved when organisations and members of the community come together with a common purpose"

Feedback included in media release by Professor Brenda Wilson, Chief Executive, Cancer Council SA

c) Acknowledgment and wider acceptance of the need for more rural-specific information for rural cancer patients and their families, carers and health professionals

"This website is much better for country patients/carers to use than other resources as it is specific to them and what they are going through and what they require... it is a much needed tool for patients and carers. It will be a welcome relief to a lot of people."

Feedback provided by email from daughter-in-law of a rural cancer patient

"What a fantastic website, exactly what people need. I have already discussed it with a friend who needs to have a skin cancer taken off her nose in August and another friend who's Mum is heading to Adelaide in a few weeks for chemo and rang asking me about where to stay today. Before yesterday I would have only been able to give them the helpline number and the info that I know myself however it was great to give them a tool which they can use in there (sic) own time and answer there (sic) own individual questions. The helpline is fantastic but must

be very overwhelming for people when they are stressed and confused, this website allows them to look and absorb the information in their own time.”

Feedback provided by email from rural support group leader

d) Widespread interest in the resource (between 12 June 2012 and 12 November 2012)

- 24 newspaper articles, 5 radio interviews
- 4016 visits to website (2827 unique visitors)

e) Acceptance, trust and appreciation of the resource by its users

“This website is fantastic. I know it has been a lot of work for you, but it is very worthwhile. The site is easy to navigate, full of practical advice, and well set out. I am very proud to have been able to help in the small way that I have.”

Feedback provided by email from ovarian cancer survivor/ participant in the present study

“What a fabulous resource you have created. Congratulations! Thank you, on behalf of country patients (and health staff), for the work you have done.”

Feedback provided by email from Clinical Services Co-ordinator, rural hospital

f) Empowerment of participants

“[Dad] considered that being involved as a role model with [the] website project was just another way he could fight cancer by educating and assisting other patients. Even when he knew his personal battle was coming to an end, he was determined to leave a legacy for others and help prepare them for the battle ahead and hopefully increase their chances of beating the disease. Dad also saw being involved with the website as an opportunity of giving something back to the people who had assisted him for so long during his battle with cancer. His family and friends will draw comfort from the knowledge that his message will continue to be a great support for other cancer sufferers.”

Feedback provided to local newspaper by daughter of participant (now deceased) in present study

Given the objectives of using PAR in this study were to develop relevant and acceptable website content and empower participants by directly involving them in this process, these are pleasing results.

Lessons from the process

Key lessons learnt include the importance of identifying the unique strengths of stakeholders, allowing participation to evolve over time and accepting that participation takes various forms (some wanted to be project drivers or ambassadors while others were happy taking more subservient roles). The most challenging aspect of this method was its time consuming nature as other authors have found (e.g. Owens et al., 2011). However, it resulted in a far more comprehensive and interactive resource than initially envisaged.

Insights also emerged into how the positionality of the researcher who interacts with the participants can impact upon the quality of the relationships formed with them and upon the authenticity of the final intervention design. In this case, as previously stated, the principal author initially considered herself to be an ‘outsider’ as she had not personally experienced cancer. However, over time, it became clear that with a rural background she was considered an ‘insider’ by participants. This facilitated the growth of close relationships, mutual pride and importantly, trust and openness about knowledge, beliefs and experiences.

The privileging of particular sources of knowledge in different contexts (e.g. that generated from consumers’ experience versus traditional empirical research) also became evident through this work. The positivist approach employed in the preliminary research by the present authors enabled funding to be obtained to develop the website. The humanistic approach to the website’s development outlined in this paper appears to have helped the website win the approval of its users. However, a positivist evaluation is required by decision makers to determine whether the website will continue to gain funding to be maintained in the future.

Discussion

Working flexibly and utilising both the literature and lived experience to guide the development of interventions can foster trust, empower participants and help deliver results that are acceptable to those in both the academic and ‘real’ worlds. Although many of the lessons learnt have also been raised in participatory work with other populations (e.g. Gittelsohn et al., 2010; Nelson, Pancer, Hayward, & Kelly, 2004), this project highlights its value in developing interventions for rural populations, whose unique needs, values and attitudes are under researched, need careful acknowledgment and can easily be overlooked or misunderstood. It also highlights how the principles can be adapted to create web-based solutions to community-identified problems and may act as a model to solve similar problems in other locations.

Using technology to deliver health information to rural populations has great potential (wide reach, low cost) (Cugelman et al., 2011) and involving consumers in intervention design is known to have several benefits. However, successful examples of interventions that combine the two are scarce, as are critical reflections on their development, which makes this paper an important contribution to the field.

Acknowledgments

The authors gratefully acknowledge the assistance provided by participants, Country Health SA, Cancer Council SA, Cancer Council Australia and the Spencer Gulf Rural Health School (Primary Health Care Research Evaluation and Development Bursary) (now UniSA).

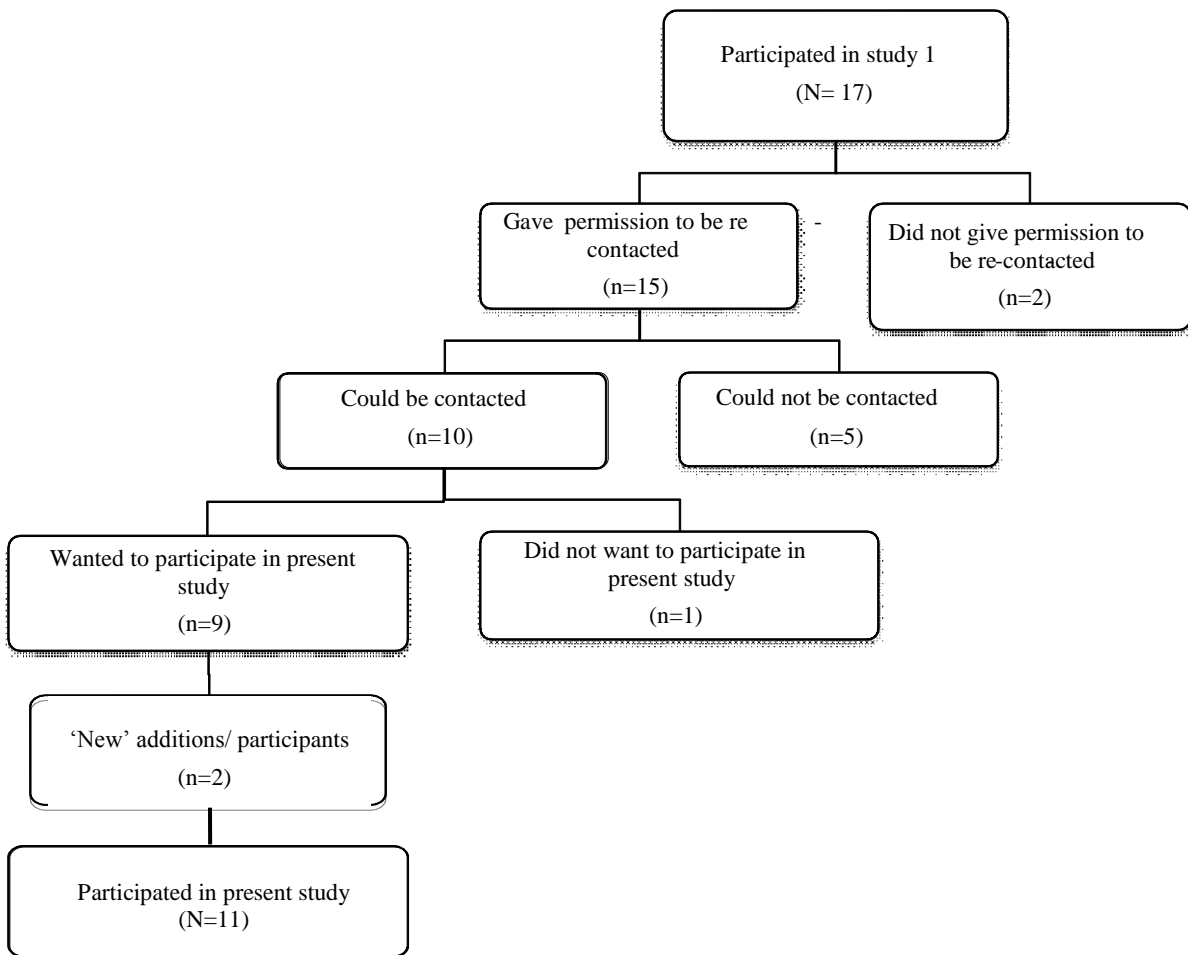


Figure 1. Recruitment method

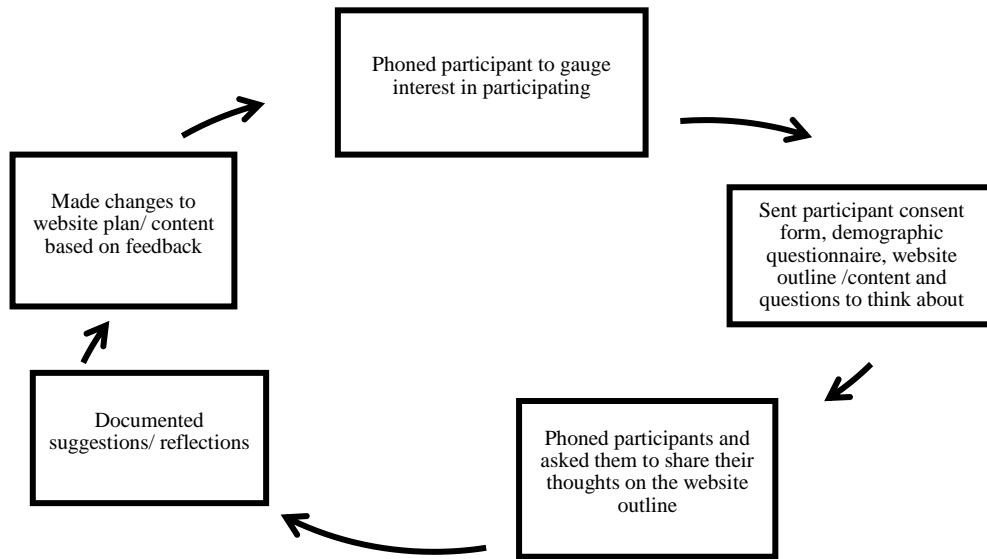


Figure 2. The Participatory Action Research cycle

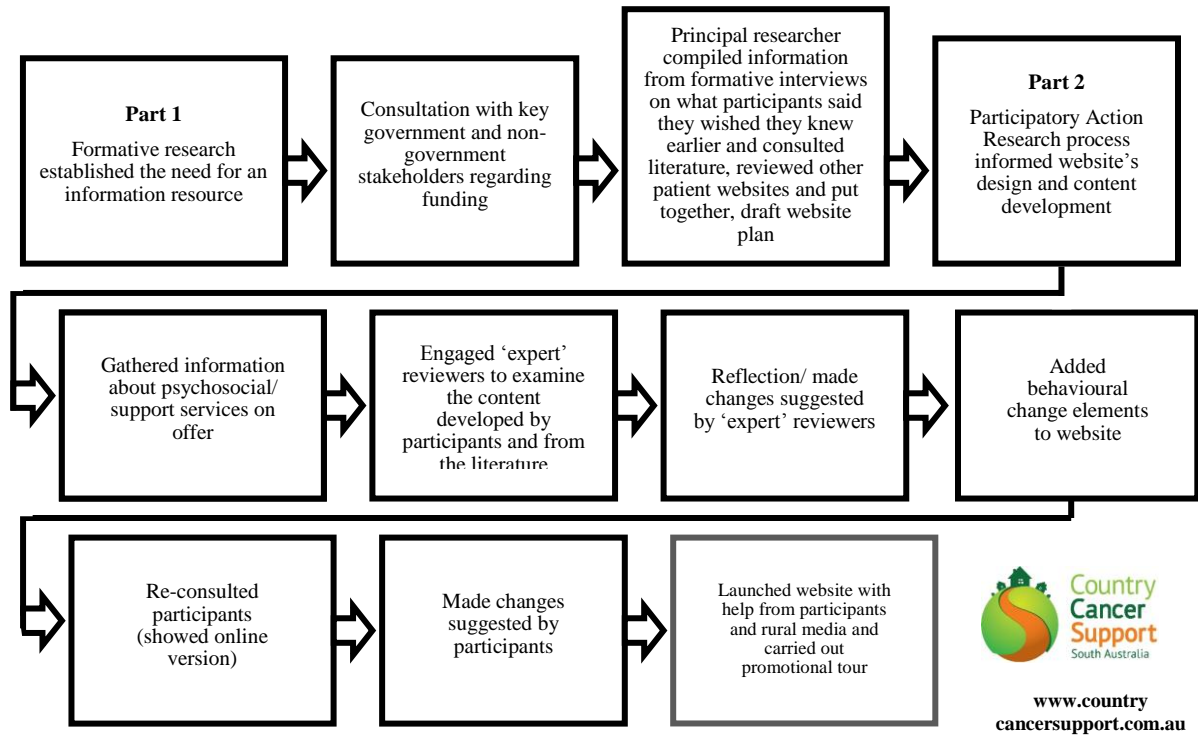


Figure 3. Method

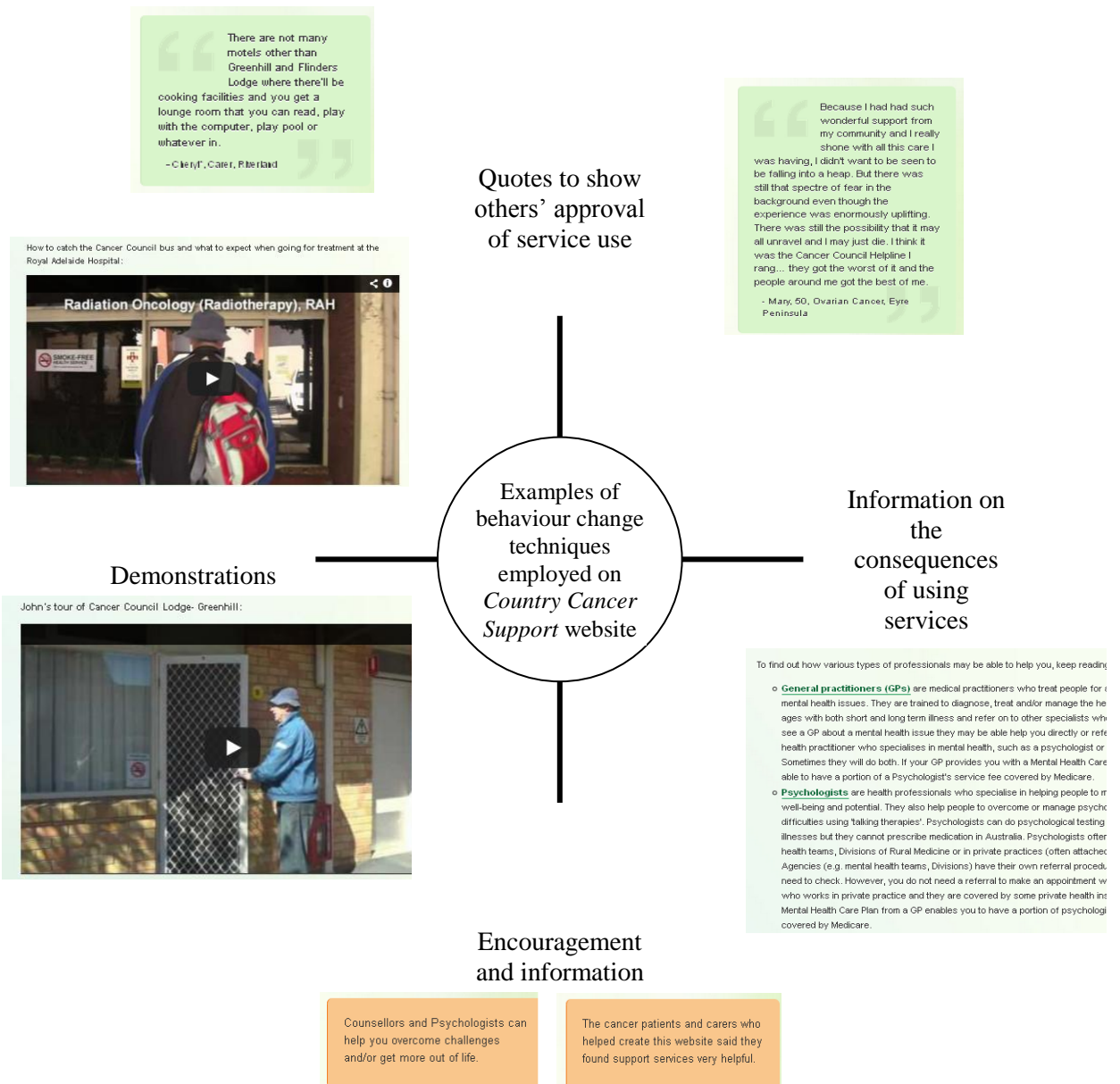


Figure 4. Examples of how behaviour change elements have been incorporated into Country Cancer Support website

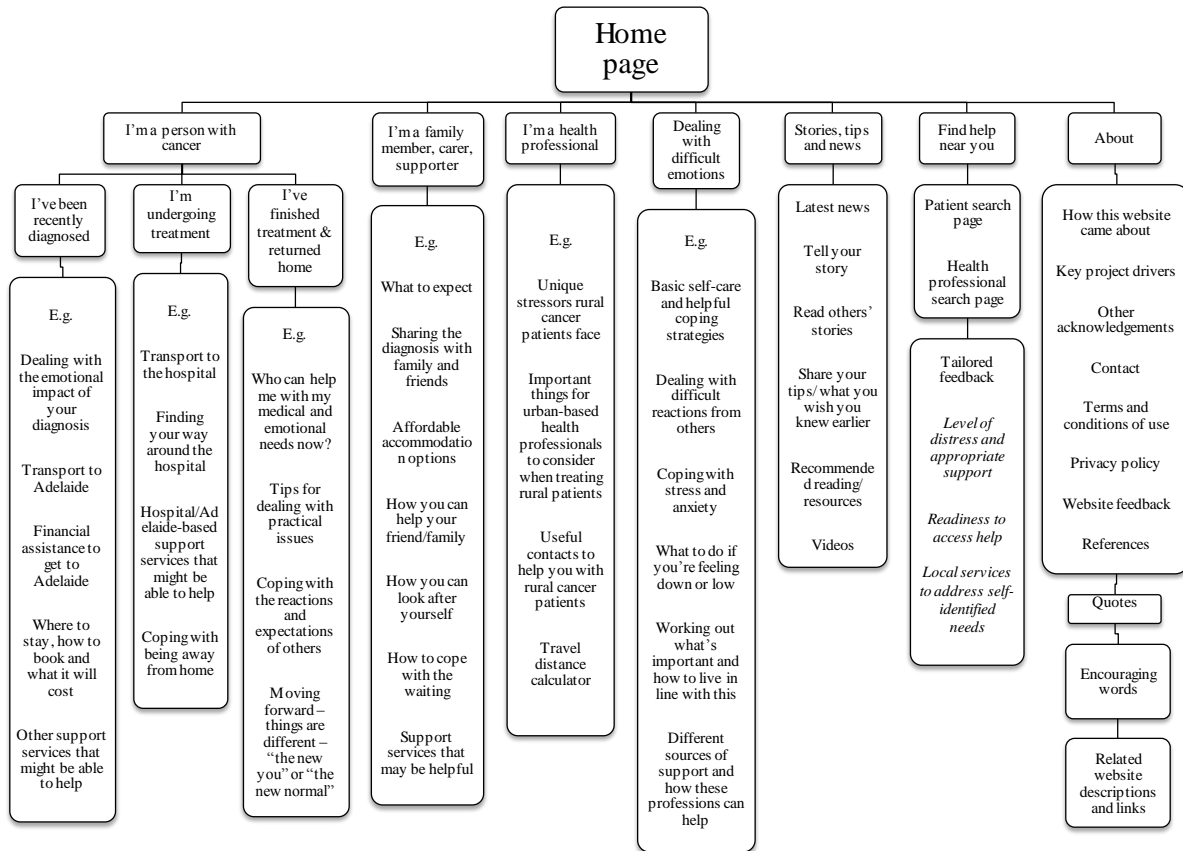


Figure 5. Resulting Country Cancer Support website content and structure

Table 1

Examples of Behaviour Change Techniques Incorporated into Website Design and Their Theoretical Basis (adapted from Abraham & Michie, 2008)

Technique	Theoretical basis
Provide instruction	Social Cognitive Theory
Provide information about others' approval	Theory of Reasoned Action, Theory of Planned Behaviour, Information-Motivation- Behavioural Skills Model
Model or demonstrate the behaviour	Social Cognitive Theory
Plan social support or social change	Social support theories
Provide information on consequences	Theory of Reasoned Action, Theory of Planned Behaviour, Social Cognitive Theory, Information-Motivation- Behavioural Skills Model

Table 2

Demographic Characteristics of Participants

<i>Age in years</i> <i>M</i> (<i>SD</i>)	47.27 (13.45)	range 25-69	<i>n</i>
<i>Marital status</i>			
Single/ never married			1
Married/ living with a partner			8
Widowed			0
Separated/ divorced			2
<i>Education level</i>			
Finished primary school			1
Finished high school			3
Trade certificate, apprenticeship, diploma/certificate from a college or TAFE			4
Degree/ diploma from a university			3
Postgraduate degree			0
<i>Employment status</i>			
Full time			6
Part time			1
Casual			0
On leave			0
Not working- not looking for work			0
Not working- looking for work			2
Not working- retired			2
<i>Household income (per week)</i>			
< \$ 500			0
\$ 500-999			5
\$ 1000-1999			3
\$ 2000+			0
Do not wish to disclose			3
<i>Level of remoteness (ARIA)¹²</i>			
Highly accessible			0
Accessible			3
Moderately accessible			1
Remote			4
Very remote			3
<i>N</i> = 11			

¹² The Accessibility/Remoteness Index of Australia (ARIA) is a standard index of remoteness that is based on accessibility by road to services. Classifications range from “Highly Accessible” (areas with scores between 0 - 1.84 where there is relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction) to “Very Remote” (areas with scores >9.08 – 12 with very little accessibility to goods, services and/or social interaction).

Table 3

Medical Characteristics of Participants Diagnosed with Cancer

<i>Patient-reported site of disease</i>	<i>n</i>
Bones	1
Breast	3
Cervix	1
Colorectal/ bowel	1
Lymphoma	1
Lung	1
Melanoma	1
Ovaries	1
Prostate	1
Testicles	1
Brain	1
NB Total= >10 as some participants reported multiple sites	
<i>Patient- reported state of disease</i>	
No activity	9
Recurrence	0
Metastases	1
Do not know	0
<i>Patient-reported cancer treatments received</i>	
Chemotherapy	8
Hormone therapy	2
Radiotherapy	6
Stem cell transplant	1
Surgery	8
<hr/> N= 10	

CHAPTER VI: STUDY THREE

Preface

The primary purpose of Study 3 is to determine how acceptable providing rurally-relevant psychosocial cancer information via a carefully designed website, is to rural cancer patients, their supporters and health professionals. How well the *Country Cancer Support* website meets its objectives of increasing psychosocial service help-seeking intentions and decreasing self-perceived levels of distress and isolation are also explored. It is hoped that these lines of enquiry will help to answer Liaw and Humphrey's (2006) important question; "How ready is rural society for information technology insertion?" (p. 97).

Despite the evidence that online mental health interventions are efficacious, assessable and acceptable for many general and medical populations, there is a particular shortage of studies that have examined the capability of these interventions to address cancer patients' mental health (Shepherd et al., 2008). The need to develop and evaluate education and information materials specifically for rural people affected by cancer has also been acknowledged (Wilkes et al., 2000).

However, as alluded to previously, developing these sorts of interventions is not easy and nor is evaluating them. As a result, very few studies have examined how sites are used and/or perceived by their target audiences (i.e. whether they are acceptable and feasible) (Sciamanna et al., 2002; Vandelanotte & De Bourdeaudhuij, 2003). Pakkala, Presser and Christensen (2012) believe evaluation of this type is so difficult that, "It is perhaps overambitious to measure whether websites are able to contribute to solving problems in public health, but we should be able to measure whether we produce understandable information that is easy to find" (p. 511).

However, despite the acknowledged difficulty in undertaking an evaluation of this type, and the lack of established measures to assist in the process (Vandelanotte & De Bourdeaudhuij, 2003), completing this evaluation is crucial to help inform the development of similar interventions for other

populations. Evaluating the contribution of consumers to the development of interventions (Entwistle et al., 1998) and the process of research (Boote et al., 2002) via measures of acceptability is thought to be important and particularly novel aspect of this research. Very few examples of the evaluation of the impact of consumer involvement in intervention design currently exist (Entwistle et al., 1998), despite the recent widespread push for consumer involvement in healthcare planning and research. See Appendix 8 for the resulting online survey.

Statement of contributors

Miss Kate Gunn (candidate) was responsible for the literature review, conception of the study, data analysis, drafting and submitting the manuscript. This paper is currently under review by the Journal of Medical Internet Research.

Signed: Miss Kate Gunn

Professor Deborah Turnbull, Ms Lindsay McWha, Dr Matthew Davies and Professor Ian Olver AM (co-authors) provided ongoing supervision throughout the research program that led to this publication. Associate Professor Nirranjan Bidargaddi (co-author) also helped to supervise the research contained in this publication. Their roles as supervisors included working with Miss Gunn to refine the direction of and methodology employed in the research, commenting on the material presented in drafts and providing editorial input. They hereby give their permission for this paper to be incorporated in Miss Gunn's submission for the degree of Masters of Psychology (Clinical) with Doctor of Philosophy from the University of Adelaide.

Signed: Professor Deborah Turnbull

Signed: Ms Lindsay McWha

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Running title: *Country Cancer Support* website evaluation

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Abstract

Background: People affected by cancer who live in rural areas face several challenges, but often have difficulty accessing psychosocial services. Providing rural-specific information on psychosocial care may help this unique patient group and their supporters to overcome barriers to use. Although websites offer new opportunities to provide health and mental health information to rural communities, little is known about whether they will be acceptable to, or helpful for this population.

Objectives: To determine how acceptable providing rurally-relevant psychosocial cancer information via a website (designed using a Participatory Action Research framework and the psychological literature) is to rural cancer patients, their supporters and health professionals. It also seeks to determine how well the *Country Cancer Support* website meets its goals of increasing psychosocial service help-seeking intentions and decreasing self-perceived levels of distress and isolation. Levels of use, favourite features, areas for improvement and how it compares to other resources, are also explored.

Method: 111 people who were rural South Australian cancer patients, their family, friends, carers (i.e. “supporters”) or health professionals, participated in the online website evaluation. Quantitative data were analyzed using SPSS, qualitative data with Content Analysis and usage data with Google Analytics.

Results: There were 3957 visits to the website in its first 5 months of operation. Participants reported that the website was easy to use, helpful and relevant. Most participants who were rural cancer patients or supporters indicated that they thought the website had been written by people who understood what they were going through and (if relevant) that it made them more motivated and confident to access professional psychosocial support services and/ or travel to Adelaide for medical treatment. 73.33% of patients and supporters (to whom it was relevant) said using the website made them feel less isolated and 53.57% felt less distressed. All health professionals reported that the website provides relevant information about the services available to address cancer-related distress in their rural patients and that it provided them with new knowledge about things to consider when treating rural patients. Particularly valued aspects of the website include the depth and breadth of information it contains and that it is easy to navigate, read, understand and relate to. It was generally considered superior to existing resources for this patient group.

Conclusion: This unique research demonstrates the acceptability and efficacy of a carefully designed website in meeting the rural-specific psychosocial information needs of rural cancer patients and their supporters. It also highlights the ability of a website to increase users' help-seeking intentions, reduce their feelings of distress and isolation and improve health professionals' understandings of the unique needs of rural patients and the services available to support them.

Introduction

Providing rural cancer patients with adequate psychosocial care is a key challenge in many sparsely populated parts of the world (Shepherd et al., 2008). Despite being exposed to several stressors, few rural people affected by cancer access psychosocial services (C. Davis et al., 2003; Koopman, Angell, Turner-Cobb et al., 2001).

Reviews have concluded that online self-help interventions can be an effective method of delivering interventions that target conditions such as anxiety and depression (K. M. Griffiths et al., 2010) and are thought to offer unique opportunities to assist those who find it difficult to use face-to-face services due to concerns such as stigma, service availability, distance or physical, time and economic constraints (Munoz, 2010). More specifically, they offer cancer patients opportunities to access information about their illnesses as well as the benefits of peer support such as practical advice and emotional support (Winefield et al., 2004). However, very few online mental health self-help trials have involved rural residents (K. M. Griffiths et al., 2010). Further, little is known about how rural users will accept such technology (Liaw & Humphreys, 2006), whether their infrastructure is sufficient (Jameson & Blank, 2007), or whether online interventions can encourage this population to access traditional face-to-face psychosocial services.

Formal evaluations of such web interventions are essential to identify areas for improvement, unexpected outcomes and to justify further investment (O'Connor-Fleming, Parker, Higgins, & Gould, 2006). Systematically determining the most and least helpful aspects is vital to inform future online health interventions (Webb et al., 2010), particularly as comprehensive evaluations of this type are rare in the academic literature.

This paper evaluates the *Country Cancer Support* website/ web-based intervention (specific to rural South Australia), which provides information on 'how to cope and who can help' when facing a diagnosis of cancer. It seeks to determine website usage, acceptability (including ease of use,

relevance, necessity, helpfulness, likelihood of recommending the site to some and returning on another occasion), areas for improvement, and impact on users psychosocial service help-seeking intentions and perceived isolation and distress. Favourite features, areas for improvement and how it compares to other resources, will also be explored.

Methods

Website development

Several rural South Australian cancer patients who helped identify the need for the *Country Cancer Support* website in a previous study by the authors of this paper (Gunn et al., In press), collaboratively developed the website with the authors. This process was informed by a Participatory Action Research (PAR) framework which aims to involve people experiencing a problem in developing a solution to it and to meet the knowledge generation goals of social science through collaboration in a mutually acceptable way (Rapoport, 1970). PAR methodology is increasingly accepted in the field of Psychology (Herr & Anderson, 2005).

Insights from models of voluntary behaviour change also shaped the design of the web intervention to increase the likelihood that it would lead to more help-seeking among users to manage cancer-related distress. Greater effects have been found in online interventions that incorporate more behaviour change techniques, than in those incorporating fewer (Webb et al., 2010). Therefore, several techniques from a broad range of theoretical frameworks (e.g. Social Cognitive Theory, Theory of Reasoned Action, Theory of Planned Behaviour) were selected from Abraham and Michie's taxonomy of behaviour change techniques (Abraham & Michie, 2008), based on what was deemed effective for online interventions in a recent meta-analysis by Cugelman et al. (2011) and what was acceptable to PAR informants. Examples include demonstrating the behaviour (i.e. psychosocial help-seeking) and providing instruction and information about others' approval of the behaviour. In addition, aspects of

the transtheoretical model (Noar et al., 2007; Prochaska et al., 1992) and the recent work of Henshaw and Freedman-Doan (2009) who have conceptualised mental-health care utilisation using the Health Belief Model, were also drawn upon and barriers to service use identified in the authors' earlier work were considered. Clinical practice guidelines and academic literature (e.g. Hutchison et al., 2006; Moorey & Greer, 2010; National Comprehensive Cancer Network, 2011) also informed the content and design.

Website description

The resulting interactive, 84-page website includes practical written information (on topics such as financial assistance for travel and coping with being away from home), low-intensity Cognitive Behaviour Therapy (CBT) self-help material, video clips featuring 'John's' experience of travelling for treatment, a distress screening tool linked to a rural health and support services directory and feedback tailored to the user's readiness to access support and level of distress. The feedback provided by the distress screening tool about what types of interventions might be useful is consistent with the National Comprehensive Cancer Network distress management guidelines (National Comprehensive Cancer Network, 2011) and the tiered model of psychosocial care (Steginga et al., 2006). The website also features space for users to share their stories and tips, testimonials by rural cancer patients that normalise the experience of distress, and short statements that encourage psychosocial service use. All information can be easily downloaded in Portable Document Format (PDF). The home page which can be found at www.countrycancersupport.com.au is displayed in Figure 1. The website went live on 8 June 2012.

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Figure 1. Screen shot of Country Cancer Support home page

Evaluation design

The design chosen to describe the demographics of the sample and determine the website's usage, acceptability, areas for improvement and impact is outlined below. A Randomised Control Trial was not employed to determine the website's impact on variables such as perceived distress and isolation as ethical issues would have been raised by denying some people access to the website given that the participants involved in developing the website wanted their work to be shared for the benefit of others as soon as possible.

Google Analytics

Website usage

Google Analytics was used to derive quantitative metrics of website usage. Website administrators often use this free, external tracking system to improve website content and design (Bennett & Glasgow, 2009; Plaza, 2011). Usage has previously been considered an outcome measure of "success" in setting up a similar website (Winefield et al., 2004).

Web-based survey

A custom web-based survey was modelled on existing questionnaires and scales. However, as Heesch, Velasquez and Sternberg (2005) point out, “no instruments exist to assess patients’ readiness to engage in mental health treatment” (p. 533-534) and as Vandelanotte & Bourdeaudhuij (2003) highlight, “there is no theory or model about how to measure acceptability or feasibility of tailored interventions. Nor are there guidelines about what acceptability or feasibility scores are ‘good’ or ‘bad’, or what level of acceptability is needed to predict behaviour change in tailored interventions” (p. 309).

The survey was formatted to maximise ease of comprehension and response. Adaptive questioning reduced the complexity of the questions (e.g. health professionals were not asked about their levels of distress). Participants were reminded to complete a page before moving on to the next and could ‘go back’ and review their answers. The functionality of the questionnaire was tested by a small number of users before it was made public and only minor changes were made. Where necessary, existing measures were adapted to the context of the research to improve face-validity and reduce demand on participants, as detailed below.

Demographics

Demographic information and the users’ role when visiting the website was gathered to describe the sample). Users who did not identify as health professionals also had their current level of *distress* measured with the widely used “Distress Thermometer” (National Comprehensive Cancer Network, 2011). Whether they were *currently receiving treatment for anxiety, depression or any other mental health issue* was also measured using a one-item, self-designed measure, to help describe the sample.

Acceptability

The degree to which participants found the website acceptable was measured using single items on *ease of use* (adapted from F. D. Davis, 1989; Flavian, Guinalau, & Gurrea, 2006; Muylle, Moenaert, & Despontin, 2004), *relevance* (Flavian et al., 2006; Muylle et al., 2004; Vandelanotte & De

Bourdeaudhuij, 2003), *necessity* (self-designed), *helpfulness* (Muyllé et al., 2004; Sciamanna et al., 2002), *likelihood of returning to the website* (National Cancer Institute, 2011) and *recommending it to others* (National Cancer Institute, 2011). Participants were also asked *what impressed them most* and *how the site compared to other resources* (F. Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006). A one-item, self-designed measure also gauged whether users felt their *situation was understood by those who wrote the website*, as perceived expertise of authors can predict ‘active trust’ in online interventions and, in turn, behavioral impact (Cugelman et al., 2009). Developing the website content with PAR was expected to promote this outcome.

Health professionals were asked whether the website provided them with *relevant information on psychosocial services* and *new knowledge about rural patients* using self-designed measures.

Areas for improvement

This was determined by simply asking participants “How do you think this website could be improved?”

Impact

The website’s perceived impact on patients’ and their carers’, family members’ and friends’ (i.e. “supporters”) intentions to access support services and medical treatment was measured by adapting the behavioural impact items developed by Cugelman et al. (2009). *Readiness to access professional, peer, family and friend support before and after website use* (i.e. progression through stages of change from the Trans-theoretical Model) was assessed with a version of the Readiness to Change ruler. Originally designed to quickly assess a person’s present motivational state towards changing a specific behavior (Zimmerman, Olsen, & Bosworth, 2000), this was adapted to measure readiness to seek additional support. Layman’s descriptions of the five stages of change by Zimmerman et al. (2000) were incorporated to aid comprehension.

The website's perceived influence on patients and supporters' levels of cancer-related distress and isolation were also self-designed but important measures of success in setting up this site.² Survey Administration

The voluntary, self-administered online survey was open to users of the *Country Cancer Support* website who gave informed consent, spoke English, were over 18 years, had been given a diagnosis of cancer whilst living outside metropolitan Adelaide, or were the family member, friend, carer or health professional of a rural South Australian who had been given a diagnosis of cancer. Participants accessed the survey via an email (sent to employees of rurally-based government health services by the Chief Executive of Mental Health) from an SA Health contact list), or via a link/ button to the survey situated on the *Country Cancer Support* website. The website was available in the public domain and anyone who fitted the criteria could participate. Some also completed it when a screen popped up alerting them to the survey during site use, or accessed a version embedded in a website page. The survey was publicised on radio, in the written media and through personal and professional networks.

Respondents were informed that participation was voluntary, would not affect their medical advice and they could stop at any time. The purpose of the study and time required for completion (15 minutes) were also detailed. Participants could remain anonymous. However, at the end of the survey, the option to go into the draw to win a voucher and participate in further research was provided; on acceptance, participants were asked to provide their email address. All responses were captured electronically. Data was password protected. Incomplete questionnaires were included if demographic details and role (e.g. patient, carer) were provided. Ethical approval was obtained from the School of Psychology Human Research Ethics Subcommittee (The University of Adelaide).

Participants

There were 111 participants between 8 June 2012 and 6 November 2012. Their demographic details are outlined in Table 1. More women than men took part, but a range of educational backgrounds were represented. Only one participant was of Aboriginal or Torres Strait Islander origin.

Table 1. *Demographic Characteristics of Participants*

	<i>n</i>
<i>Age in years M (SD)</i>	
48.02 (13.47) range 18-74 (n=108)	
<i>Role (when visiting website)</i>	
Person who currently has/ has had a cancer diagnosis	24
Family member/ friend/ carer/ supporter of person with cancer	29
Health professional	53
Other	5
<i>Education level</i>	
Finished primary school	6
Finished high school	20
Trade certificate, apprenticeship, diploma/certificate from college or TAFE	23
Degree/ diploma from a university	30
Postgraduate degree	32
<i>Level of remoteness (Accessibility/Remoteness Index of Australia)</i>	
Highly accessible	42
Accessible	35
Moderately accessible	14
Remote	11
Very remote	9
<i>Country of birth</i>	
Australia	97
UK or Ireland	8
Italy	1
Germany	3
Other	2

N= 111

Of 111 survey participants, 53 were rural South Australian cancer patients or the supporters of a rural cancer patient. 18.18% of this group were receiving treatment for anxiety, depression or another mental health issue at the time. According to their scores on the Distress Thermometer and the tiered model of psychosocial intervention in cancer (Hutchison et al., 2006), 6.67% of these participants were experiencing severe levels of distress (and required assistance from a specialist mental health professional), 44.44% were experiencing moderate to severe distress (and could benefit from specialist care from a mental health professional), 17.78% were experiencing mild distress and 31.11% were experiencing minimal distress. In the present study, 47.73% of cancer patients scored 5 or higher on this measure which is similar to that of Tuinman et al.'s (2008) participants (43%) in a study of cancer patients treated at 9 different hospitals in the Netherlands.

Health professionals who participated included Psychiatrists, Psychologists, Registered Nurses, Practice Managers, Community Health Nurses and Social Workers. 47.17% were urban-based and 52.83% were based rurally.

Data analysis

Quantitative variables were analysed using the Statistical Package for the Social Sciences (SPSS). The measure of remoteness was calculated using the Accessibility and Remoteness Index of Australia (ARIA), based on participants' postcodes. This is a standard index of remoteness that is based on accessibility by road to services. Classifications range from "Highly Accessible" (where there is relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction) to "Very Remote" (areas with very little accessibility to goods, services and/or social interaction) (Australian Institute of Health and Welfare, 2004). Qualitative feedback was analysed using the conventional qualitative content analysis method described by Hsieh and Shannon (2005).

Results

Website usage

Between 12 June 2012 and 8 November 2012, there were 3966 visits to the website. Of these, 2749 were unique visitors (30.69% returning visitors). Users viewed a total of 20011 pages (an average of 5.05 pages per visit). The mean time spent on the site was 4.55 minutes. Of these visits, 487 were from mobile devices (including tablets).

The most frequently visited pages were the home page (21.72%) (see Figure 1), 'I'm a person with cancer' page (8.09%) (see Figure 2), 'I'm a health professional' page (5.95%) (see Figure 3), 'I'm a family member, carer or supporter' page (5.42%) (see Figure 4), 'Dealing with difficult emotions' (4.82%) and 'Find help near you' page (3.19%). 52.57% of users accessed the site directly; 34.52% found it via a search engine. Of the 95.11% from Australia; 64.86% were from within the state. Website use peaked on Tuesdays and Wednesdays between 8am and 5pm.

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Figure 2. Screen shot of the 'I'm a person with cancer' page on *Country Cancer Support* website

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Figure 3. Screen shot of the ‘I’m a health professional’ page on *Country Cancer Support* website

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Figure 4. Screen shot of the ‘I’m a family member, carer or supporter’ page on *Country Cancer Support* website

Website acceptability

Most participants (96.4%) reported finding the website easy to use (Table 2), while 97.3% agreed that it was relevant to their needs, 99.1% believed it necessary and 98.2% found it helpful. All participants said they were likely to return to the website. All but one (99.10%) would recommend the website to someone else. Most patients and supporters (98.11%) felt the website was written by people who understood what they were going through.

The most impressive features reported were:

- Depth and breadth of information (n=40)

“The amount of information provided. Covers everything that may be needed”

“It's content...very informative and comprehensive” (sic)

- Easy to navigate (n=35)

“Easy to navigate and very well set out”

- Easy to read, understand and relate to (n=18)

“Language is great and not "jargon"”

“The depth of information and the tone of which it is delivered. This is easy for all ages to read and understand, it has a kind feel behind it which I am sure is what many people in difficult situations appreciate”

- Easily accessible because of online format (n=13)

“The vast amount of information in one easy to access place”

- Information is available in printable sheets (n=12)

“The printable sheets are a great idea”

- That it is specifically for rural people (n=9)

“That it is FOR country people”

- John’s virtual tours/ videos (n=9)

“John’s video clips are excellent... John is a real star”

- Like it all (n=7)

“It was all most helpful. Many thanks to all who contributed”

- Real life stories are incorporated (n=6)

“Reading the stories of others”

- Information on emotional issues/ supportive care (n=5)

“The breadth of information provided, especially the mental and emotional information/considerations”

Participants interpreted the question on comparing the *Country Cancer Support* to other resources in different ways, but responses could be divided into five categories, shown in order of prominence below.

- The *Country Cancer Support* website is superior to other information sources
 - More comprehensive (n=11)
 - Rural/ country South Australia specific (n=10)
 - A one stop shop (n=8)
 - Easy to use/ access/ navigate (n=6)
 - Language is easier to read/ understand (n=3)
 - Can easily pick and choose what to look at (n=4)
 - Can print off information easily (n=2)
 - Up to date (n=2)

- Relevant ($n=2$)
 - Contains videos ($n=2$)
 - Contains links to more information ($n=2$)
 - Makes users feel that their questions have been asked before ($n=1$)
 - No login required ($n=1$)
 - Interactive ($n=1$)
- Websites are more useful than printed resources
- Convenience (any time, any place) ($n=12$)
 - Don't need to wade through paper ($n=3$)
 - Anonymity ($n=2$)
 - Can go back to it ($n= 2$)
 - Can't lose a website like you can lose a brochure ($n=1$)
 - Less overwhelming ($n=1$)
- Information provided in any format is helpful
- Websites are useful in conjunction with printed information and face to face services
- Another resource was more helpful
- Breast Cancer Network Australia forum (set out easier and user's questions get answered by more than one person) ($n=1$)
 - Cancer Council website (no explanation given) ($n=1$)
 - Online forums (more input from cancer survivors going through the same thing as me) ($n=1$)

Areas for improvement

Participants were given the option to provide feedback on how the website could be improved.

Themes from the 52 responses to this question include:

- Great as it is ($n=24$)

“I think it is one of the best websites I have seen, no improvement necessary”

- Ensure it is updated frequently ($n=6$)

“Ongoing maintenance to ensure information remains relevant”

- More stories/ tips from people with cancer ($n=5$)

“More stories and contributors”

- More videos/ virtual tours ($n=2$)

- More information for patients having ongoing treatment/ who are terminal ($n=2$)

Impact

Health professional specific outcomes

All health professionals agreed that the website provided relevant information about the services available to address cancer-related distress in their rural patients (see Table 2 below). They also all agreed that it provided them with new knowledge to consider when treating rural patients.

Table 2

Online Survey Response Frequencies for Acceptability Items

	Not at all	A little	A moderate amount	A lot	A great deal	% that agree	<i>n</i> (Participant type)
Easy to use	4	2	10	34	61	96.40	111 (All)
Relevant to needs	3	4	16	54	34	97.30	111 (All)
Necessary	1	2	2	28	78	99.10	111 (All)
Helpful	2	2	6	38	63	98.20	111 (All)
Likelihood of returning to website	0	5	5	42	59	100	111 (All)
Likelihood of recommending the website to someone else	1	2	4	22	82	99.10	111 (All)
Written by people who understand what I'm going through	1	2	8	20	22	98.11	53 (Patients, carers, family, friends)
To what extent do you think this website provided you with relevant information about the range of services available to help deal with cancer-related distress?	0	2	4	19	21	100.00	46 (Health professionals)
To what extent do you think this website provided you with new knowledge about things to consider when treating rural patients?	0	2	4	19	21	100.00	46 (Health professionals)

Self-reported influence on patients and supporters' psychosocial service help-seeking intentions

Table 3 shows that of those patients and supporters to whom it was relevant, 66.67% agreed that using the website had motivated them to access professional support services in their rural area, 67.65% agreed that the website had motivated them to access professional support services in Adelaide, and 75.86% were motivated to travel to Adelaide for medical treatment.

A Wilcoxon Signed Rank Test was employed to test the significance of changes to participants' self-reported readiness to access various forms of support as a result of website use. Participants were significantly more willing to access *professional* support after using the website than before using the site, $z = -2.40$, $p < .05$, $r = -0.3$. According to Cohen's criteria, this is a medium effect size. Participants were also significantly more willing to access *peer* support after using the website, $z = -3.44$, $p < .01$, $r =$

- 0.4 (also a medium effect size). Significant changes were not detected in willingness to access family support, $z = -1.58, p=.115$ or willingness to access support from friends, $z = -1.70, p=0.90$.

Self-perceived influence on on patients and supporters' self-perceived distress and isolation

Of the relevant patients, carers, family members and friends, 53.57% felt less distressed after using the website. 73.33% reported feeling less isolated.

Table 3
Patients and Supporters' Online Survey Response Frequencies for Impact Items

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	% that agree	n
Because of this website I am now more motivated and confident to access professional support services at home (in my rural area)	1	3	7	15	7	66.67	33 (Patients, carers, family, friends to whom it was relevant)
Because of this website I am now more motivated and confident to access professional support services in Adelaide	0	5	6	14	9	67.65	34 (Patients, carers, family, friends to whom it was relevant)
Because of this website I am now more motivated and confident to travel to Adelaide for medical treatment	0	2	5	16	6	75.86	29 (Patients, carers, family, friends to whom it was relevant)
Because of this website I am now feeling less distressed	2	1	10	9	6	53.57	28 (Patients, carers, family, friends to whom it was relevant)
Because of this website I am now feeling less isolated	4	2	2	13	9	73.33	30 (Patients, carers, family, friends to whom it was relevant)

Discussion

This study demonstrates that the *Country Cancer Support* website is deemed acceptable by rural South Australian cancer patients and their supporters and health professionals. In particular, the fact that it is considered easy to use is very important. Interventions like this must be inclusive and not

further marginalize existing socio-demographically disadvantaged groups with a digital divide (Liaw & Humphreys, 2006).

This evaluation also shows that a website can motivate users to access professional support services rurally and, where appropriate, even promote confidence to travel for psychosocial and medical treatment. Given the aforementioned low uptake of psychosocial care among rural cancer patients (C. Davis et al., 2003; Koopman, Angell, Turner-Cobb et al., 2001) and that inferior rates of survival for rural patients partly stem from a frequent reluctance to travel for optimum medical treatment (Jong et al., 2004; Sabesan & Piliouras, 2009), this is a significant achievement. Previous research has found that online interventions incorporating more behaviour change techniques have greater effects compared to those incorporating fewer techniques (Webb et al., 2010). Therefore, the present study attributes *Country Cancer Support*'s success in encouraging service use to the website's incorporation of behaviour change techniques, and indeed is further evidence of the value of also incorporating theory in intervention design. Corboy, McDonald et al. (2011) suggest that some stigma about service use might be because people lack understanding of what is offered in a psychosocial support service. Therefore, it is possible that simply overcoming this knowledge barrier is a possible mechanism through which the *Country Cancer Support* website assists.

The fact that this website made users significantly more likely to access peer and professional support, but no more likely to access support from family and friends, is unsurprising, as accessing professional services was deliberately emphasised in the development of the website. Lay support is already well utilised by this population (McGrath et al., 1999b; Rogers-Clark, 2002). The apparent reduction in isolation and distress among participants is considerable, given its prevalence in this population (Burris & Andrykowski, 2010; Girgis et al., 2000; Lyons & Shelton, 2004; Wilson et al., 2000) and the recognised difficulty in addressing it (Lyons & Shelton, 2004; Shepherd et al., 2008). A large proportion of those who took part in the evaluation were experiencing high levels of distress. It is acknowledged that it is likely that the website helps those experiencing high levels of distress more

than less distressed users (Saner & Keller, 2007). However, even if web interventions only have small impacts on users, the minimal cost of delivering online ‘treatments’ and their potential to reach large numbers of people, mean they are still significant for patient and population health (Webb et al., 2010).

This study also demonstrates that this type of website can educate health professionals about the needs of rural cancer patients and the psychosocial services available to support them. This is an important finding as patients’ lack of awareness of psychosocial services, is at least partly, because medical professionals lack knowledge of these services (Hutchison et al., 2006; Mehnert & Koch, 2005). Further, as Elliott-Schmidt and Strong (1997) point out, “The health practitioner who is trained within a metropolitan context needs to be sensitive to cultural and behavioural differences when providing services, and needs to be able to adjust his or her expectations to fit in with the perspectives of rural clients” (p. 63). This website clearly supports them in doing this.

The fact that participants generally believed the website had been written by people who understood their situation can also be attributed to the use of PAR methodology in its development, and may explain why the website was more successful at reducing feelings of isolation than distress. Users particularly appreciated the website’s depth and breadth of information, its ease of navigation and readability, its accessibility online, the printable information sheets, the specific rural focus (which acknowledges they are different from their urban counterparts) and virtual tours. Participants generally preferred this website over other resources. Reasons included; it is more comprehensive, it is specific to their local area, rural South Australia, and it provides a ‘one stop shop’. As the stage of disease and level of emotional distress alters, the information needs of patients are likely to change (Fallowfield et al., 1995). This perhaps explains why the website format is welcomed by users- it gives them the opportunity to go back and seek different information, tailored to their new situation.

Areas for improvement/ things to consider included frequently updating content, posting more stories/ tips from people with cancer, incorporating more virtual tours and providing more information

for patients who are terminal or having ongoing treatment. These suggestions should be considered when developing similar interventions.

Despite high levels of traffic to the website generally, the discussion boards on the *Country Cancer Support* website were not as well-utilised as expected; static information pages were visited far more frequently. This is surprising, because many PAR participants insisted on the inclusion of discussion boards and they were found to be the most popular feature of Winefield et al.'s (2004) site. Other discussion boards (e.g. Cancer Council's Cancer Connections) may be filling this need, or perhaps rural values hinder enthusiasm to publicly air questions or comments. This would be an interesting area of further research. However, online support groups are not currently supported by empirical evidence (Leykin et al., 2012).

This website appears to have been better received than the only locally known comparable site, Winefield, Coventry and Lambert's now defunct website which aimed to "reduce the psychological distress and sense of isolation, and to increase the confidence and coping skills, of women with breast cancer" (2004, p. 177), but was not able to obtain funding to keep it going. Although today the internet is more widely accepted and utilised than it was in 2004 (Ewing & Thomas, 2012), it seems likely that the PAR framework used to develop *Country Cancer Support* promoted acceptance and adoption among its users. These findings reiterate the value of engaging consumers in intervention design.

Limitations of this study include the lack of standardised measures to evaluate the website and the measurement of intentions to use services post website-use, rather than actual use. However, the external validity of these findings is high because the website was the same during evaluation as it is under 'normal' circumstances (i.e. when not being tested, e.g. no technical support was provided). Although conducting a Randomised Control Trial (RCT) would have provided higher level evidence, the costs of this (in terms of depriving some people of the potential to benefit from the intervention) were considered too great given the high level of consumer involvement and their desire to make the site public as soon as possible. Further limitations are the small sample size, the small proportion of

cancer patients and participants from culturally and linguistically diverse populations, use of self-report measures and measurement of perceived (rather than actual) influence on distress, isolation and help-seeking intentions. The ability to respond anonymously is likely to have improved the validity of results. However, another possible limitation is self-selection bias (Eysenbach, 2004). In particular, those with higher levels of education are more likely to take part in research (Angell et al., 2003a), which was found to be the case in the present study and may mean the sample is not entirely representative of the wider population.

This research has demonstrated that it is possible to increase psychosocial service help-seeking intentions and decrease self-perceived levels of distress and isolation via a web-based intervention - its key goal. These findings are important given the high levels of distress, low rates of service use, poor knowledge about relevant services and the lack of research that addresses such problems in the rural cancer population.

As interest in e-health grows around the world, it is hoped that this body of research will inform the development and evaluation of other similar consumer-driven public health interventions in the future. In doing so it is hoped that it may help to reduce health disparities, in rural cancer populations and beyond, in Australia and around the world.

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CHAPTER VII: DISCUSSION

Summary and synthesis of findings

The purpose of the first stage of this research was to determine how rural cancer patients perceive psychosocial care and think access to it could be improved. It highlighted that psychosocial care is valued highly by this patient group and reiterated that attitudinal barriers and a lack of rural-specific information on psychosocial care were, at least in part, responsible for their low levels of psychosocial service use.

Armed with this knowledge and the philosophy that those directly affected by problems can make valuable contributions in the process of developing solutions to them, the purpose of the second study was to engage rural cancer patients in generating a rural-specific source of psychosocial information that would also target attitudinal barriers to service use, isolation and distress. Lessons learnt from this process could inform the development of similar interventions for other populations. This study resulted in the development and launch of the comprehensive *Country Cancer Support* website and participants reported feeling empowered as a result of this process.

The purpose of the final stage of this body of research was to check the validity of the earlier work with a broader sample and to determine the extent to which the *Country Cancer Support* website is acceptable to those affected by cancer in rural South Australian and to gauge how effectively it can reduce perceived barriers to accessing psychosocial care. It also sought to determine the extent to which an intervention of this kind can reduce distress and isolation among cancer patients and their carers and, as found to be necessary in Study 1, improve health professionals' knowledge of the unique needs of rural cancer patients and the services available to support them. High levels of use and perceived acceptability ratings suggested that interventions of this type can be useful and highlighted the value in engaging consumers in the development of interventions for their peers. The success of the website in increasing a user's self-identified intention to access psychosocial and medical treatment

services added validity to the finding from Study 1 that a lack of information was a barrier to psychosocial service use. This work also highlights that by carefully incorporating behaviour change theory into the design of online interventions, attitudinal barriers to service use can be reduced.

Problems encountered and potential limitations

Although a methodologically rigorous framework was employed throughout this research, several limitations should be noted. Firstly, in Study 1, the literature review was conducted before the interviews were analysed using thematic analysis. As a result, a more theoretical approach may have been applied to the analysis than intended. However, as Malterud (2001) points out, “Researchers who claim that they approach their material inductively, without applying any theory for analysis, fail to realise that their stance is unavoidably affected by theory” (p. 486). In practice, given the need to gain ethics approval alone, it is rare for researchers not to have read on a topic before they begin to analyse qualitative data on it.

Secondly, it is possible that the participants in Study 1 and Study 2 were more open-minded, self-reflecting and/or engaged than the wider rural cancer population. They had all used psychosocial services of some description and were willing to take part in this research. Therefore, to some degree, self-selection bias may limit the generalisability of these findings. However, the success of the *Country Cancer Support* website (derived from the results of Study 1 and 2) in meeting the needs of the broader cancer-affected rural population (as demonstrated in Study 3) suggests this effect was minimal.

In a different vein, the generalisability of the findings from using a PAR framework in Study 2 may be more limited than they would be using more traditional methods (as outlined in Chapter II). However, the priority of this study was to develop a locally acceptable solution to a locally identified problem, instead of generating findings that might also be applied to broader contexts. Nonetheless, lessons from using this particular method will be useful to help develop similar interventions in other localities, for other problems.

If we are to apply generalisations from any of this research to other states of Australia, differences in population density and service provision in other states should be considered. For example, the Clinical Oncological Society of Australia (2006) found that patient support services ranged in access from 35% in South Australia to 78% in Western Australia. Similarly, a study by White et al. (2011) noted that cancer support services are relatively satisfactory to rural Western Australian patients' needs. Further, contrary to findings in the present research with a South Australian sample, Corboy et al. (2011) found that knowledge of support services was high among their rural Victorian sample of cancer-affected men.

Marked differences between rural communities within the same state can also exist. For example Judd, Jackson, Komiti, Murray and Fraser (2007) found differences in the intention to seek help for mental health problems depending on the size of the town in which a rural person lives and, as Study 1 highlights, the availability of lay support appears to differ depending on the size of the rural community in question.

The fact that a randomised control trial (RCT), which is considered the 'gold standard' method of testing interventions, was not used to evaluate the efficacy of the *Country Cancer Support* website may also be viewed as a limitation. However, as Leykin et al. (2012) point out, it is difficult to balance the scientific design issues with the ethical concerns regarding controls, particularly when the group being studied is vulnerable and in need of services (i.e. cancer patients). As the participants involved in developing the website wanted their work to be shared for the benefit of others as soon as possible and these views needed to be respected, a RCT design was not feasible for this research. However, it is acknowledged that using a quasi-experimental design and thereby having a comparison group (using matching or reflexive/ pre-post comparisons) would have enabled stronger conclusions to be drawn about the impact of the online intervention on its users, without the ethical issues that randomising participants to control groups raises. Unfortunately limited time and resources meant that this type of

evaluation could not form part of this thesis, but subject to funding, it is something that may be done in the future.

A notable limitation of Study 3 is that the questionnaire employed was not validated due to time and budgetary constraints. In addition, it might have been better to employ the ARIA+ measure (Australian Population and Migration Research Centre, 2013) throughout as a measure of remoteness instead of its predecessor, the ARIA. However, the author was unaware of this new measure at the time the research was planned and conducted and the availability of information on it appears limited.

New findings from this research/ contribution to knowledge

Despite the aforementioned limitations of this work, it has undoubtedly been set in a unique context, employed a well-justified and appropriate method and made some important contributions to knowledge.

Study 1

The unique analysis of the factors that impact upon the accessibility to psychosocial services from the perspective of rural cancer patients presented in Study 1 will help inform the provision of culturally appropriate psychosocial cancer services. It will also aid in the development of new initiatives that aim to provide information and overcome attitudinal barriers to use, so that services are likely to be used.

A new finding from Study 1 is that rural cancer patients who have used psychosocial care value it highly and do not view lay support as an adequate substitute. The notion that lay support is preferred by rural cancer patients has been widely cited (Jameson & Blank, 2007; McGrath, 2001b; McGrath et al., 1999b; Silveira & Winstead-Fry, 1997). However, the present research questions this and suggests that increasing access to professional support should be a priority in rural areas.

Another novel finding is that lay support is not as available in populated rural centres as it is in more isolated areas – a reminder that not all rural communities are the same and not every rural

community requires the same sort of support. The finding that attitudinal barriers and a lack of information (rather than the lack of appropriate services) are the most dominant explanations for low levels of psychosocial service use also has obvious and important implications for the delivery of services.

The notion that there are many benefits of living in a rural community when faced with a diagnosis of cancer was raised in the present research. It is unfortunate that this could not be elaborated on because of the word limit imposed by the journal that Study 1 has been accepted by; as Rogers-Clark (2002) highlights, “This positive dimension of rural living tends to be ignored in scholarship and research about rural living” (p. 34). Rogers-Clark (2002) also notes that an overwhelming majority of the rural breast cancer patients involved in her study (N=9) “felt strongly that the positive aspects of rural living outweighed the difficulties” (p. 34).

Rural cancer patients’ desire to be differentiated from urban patients and for urban hospital staff to have a better understanding of their unique needs and the services available to assist them – which in turn would assist with recommendations and referrals – was also identified. This study also demonstrated the utility of involving consumers in identifying how services might be improved; they see things that health professionals do not, for example that lay support is not an adequate substitute for professional help.

Study 2

The development of an intervention with consumers that not only provides self-help psychosocial care, but also aims to connect people to existing services, is unique. As Van Scheppingen et al. (2011) suggest, “More attention should be concentrated on directing patients with meetable unmet needs to available services” (p. 655), which is what the present research aimed to do. The bold step to focus on reducing barriers to services that already exist, rather than focusing on how new services could be developed, could only be done with the novel insights about barriers to help-seeking from Study 1 as justification. As health professionals generally perceive structural barriers such as a lack of services as

more problematic than attitudinal barriers (Corboy, McDonald et al., 2011), the present work highlights the importance of consulting consumers and not merely relying on health professionals' reports. Similarly, as Nimegeer, Farmer, West and Currie (2011) point out, "while communities are often portrayed as laggardly and loathe to change, it is in fact often a lack of commitment to change, thinking differently and persistence in addressing the barriers of legislation and regulation *by service providers* that is a barrier to rural health service reconfiguration. Engaging community members as intelligent, equal partners who can deal with complex financial, health and service information is an educational and analytical process that can make community members partners in change" (p. 1006).

Study 2 also makes an important contribution to knowledge as it employs a consumer-led PAR framework (something which is widely recommended but rarely done or described) to develop an intervention that is the first of its kind. Furthermore, the integration of behaviour change theory and other academic insights with knowledge generated from lived experience and the description of how this can be achieved, also constitutes a new approach.

Study 3

Study 3 demonstrates that a website can be acceptable to rural cancer patients, their supporters and to health professionals, while also (where relevant) decreasing self-perceived distress and isolation and increasing self-reported help-seeking intentions and levels of knowledge. It provides novel insights into the preferences of patient groups, which could inform the development of similar websites and a framework to evaluate other websites. There is currently a lack of validated measures and accepted techniques. In addition, the present study represents another attempt at what others have suggested but few have done – to shift the focus of research from describing problems to developing and evaluating tailored interventions for this unique population (Butow et al., 2012).

Strengths

This research employed a methodologically rigorous framework, that is theoretically rooted and addresses a particular need in a particular place (rural South Australia), while also having implications for the psychosocial care of rural populations elsewhere and health promotion and help-seeking more generally. The multi-methods framework used to investigate and address the needs of an under-researched population ensured that the benefits of both qualitative and quantitative methods could be enjoyed. Using this method also enabled data to be gathered that was valued by both health professionals and consumers. As Nimegeer, Farmer, West and Currie (2011) suggest, “Service providers tend to use summarised area quantitative data and utilitarian evaluative frameworks to make planning decisions, whereas community members prioritise local, narrative and experiential dimensions” (Nimegeer et al., 2011, p. 1004).

A notable strength of this research is that it was not carried out in a treatment setting by anyone associated with the participants’ treating teams. As Dunn (2005) highlights, patients are generally reluctant to criticise the professionals who are involved in their current treatment, which makes measuring their satisfaction with cancer care difficult. However, in Study 1, participants seemed uninhibited to make criticisms of their treating teams. It is therefore likely that validity was added by having an independent interviewer and by not carrying out interviews in treatment centres.

Another strength of this research is that the results of Study 1 and Study 2 were shared with participants and they were given the opportunity to assess whether their views were accurately represented. None of the results were queried in either study. This process added validity to the findings.

The epistemology of privileging consumer knowledge and the corresponding use of a PAR framework are also strengths. Despite the push for involvement of consumers in health care, and the knowledge that “Community engagement in decision making has the potential to lead to more

egalitarian, contextually appropriate decisions and to shift the balance of power towards service users” (Nimegeer et al., 2011, p. 1004), successful examples of it actually being implemented are difficult to find in the literature.

The fact that the online intervention investigated in this research is wide ranging and meets the needs of a large range of people, affected by cancer in different ways, is also valuable. The low cost of developing and delivering such interventions is also undoubtedly advantageous.

Significance of this research

It is well established that emotional wellbeing can have an impact on cancer patients’ attitudes to treatment, treatment choices, the effects of treatment and final outcomes (Baldwin & Usher, 2008). Decreasing distress is thought to aid a patient’s perceptions of their ability to cope with physical ailments (McDowell et al., 2009). Further, as Pascoe, Edelman and Kidman (2000) point out “Patients with psychological morbidity experience more severe physical symptoms associated with treatment, poorer treatment compliance and greater use of health-care resources” (p. 790). This suggests that use of the *Country Cancer Support* website could improve both the psychosocial and physical health outcomes of its users. In a different vein, there is also mounting evidence that psychosocial interventions are not only effective, but also economical as they reduce GP and specialists visits (Carlson & Bultz, 2004), however, this particular benefit has not been investigated in the present research.

The evidence that the *Country Cancer Support* website can increase users’ intentions to access medical treatment is also obviously very important. Ensuring cancer patients get treatment as quickly as possible is crucial; with delay, conditions often become worse, treatment more complex and survival less likely (Elliott-Schmidt & Strong, 1997). The website’s ability to decrease users’ self-reported levels of distress is also important because, as Leykin et al. (2012) state, “Internet interventions aimed

at helping cancer patients and their providers identify and manage the most prevalent emotional symptoms (i.e. depression and anxiety) have the potential to help address the enormous unmet need for mental health services” (p. 1023).

Connecting rural cancer patients with professional services may be increasingly important in the future because, as Hoyt et al. (1997) suggest, as the rural population declines, there will be fewer people to offer lay support that is thought to help buffer rural residents from some difficult life events.

Although some caution should be exercised when making generalisations from this research, there are lessons that can be taken from it to help rural cancer populations interstate and overseas and to address help-seeking issues (in particular for mental health issues) more generally. Evidence of a need for more information has been found in both rural *and urban* cancer populations (Girgis et al., 2000), as have low levels of psychosocial service use. For example, Carlson et al. (2004) found that nearly half of the cancer patients who met the criteria for distress in their study had not sought professional psychosocial support, nor did they intend to. Similarly, among a variety of cancer patients (not necessarily rural) in a Sydney hospital, Pascoe et al. (2000) found that 75% of those experiencing clinically significant anxiety and depression were found not to have accessed counselling or psychological intervention. Clearly some of the issues raised in the present research extend beyond rural Australian cancer patients to the wider cancer populations in Australia.

It is likely that problems of accessing psychosocial services are not limited to the cancer population either. Work by Slade, Johnston, Browne, Andrews and Whiteford (2009) found that only one third of people with a mental health disorder had used relevant health services in the 12 months prior to being interviewed. The method employed to develop this help-seeking enhancing website could well be used to address the access to mental health care more generally.

The results of a recent review suggest that the problem of rural cancer patients receiving inadequate psychosocial care is a universal issue (Butow et al., 2012). It is considered a challenge that Australia shares with several other nations including the United Kingdom, the United States (Shepherd

et al., 2008) and Canada (Nekolaichuk, Cumming, Turner, Yushchyshyn, & Sela, 2011). For example, a recent Canadian study found that being a rural patient reduced ones chances of being referred to a psychological counselling service (Nekolaichuk et al., 2011) and similar issues such as long-distance travel are also experienced by rural cancer patients in this country. Further, a Canadian study of the transition of older rural people with advanced cancer and their families determined that a lack of information was a major stressor, resulting in them feeling as though they were “navigating unknown waters” (Duggleby et al., 2010).

Given the push for psychosocial care to be a standard part of cancer treatment (Fallowfield, 1995b), an aim supported by participants in this study, interventions like the *Country Cancer Support* website make it easier for health professionals to do so. Before this website was established, a complete list of services to support rural cancer patients in South Australia did not exist. This obviously made it very difficult for health professionals to know who to refer the patients to if a problem was raised and as a result, they were possibly less likely to screen for distress.

The present research is an important step towards Munoz’s (2010) recommendation; “To bring the benefits of evidence-based internet interventions to the underserved, public sector clinics should establish eHealth resource centres, through which patients could be screened online for common disorders and provided with evidence-based Internet intervention services not currently available at the clinics” (p. 1). As other examples of this type of intervention are few, this is clearly a significant contribution, particularly as it has been successfully realised to meet the needs of under-researched, and often misunderstood, rural cancer patients. As Angell et al. (2003a) point out “Developing interventions for underserved populations, however, is fraught with difficulty. Assessing the needs of underserved patients using traditional assessment instruments and procedures often misses key elements of the problem. Developing an intervention that is accepted, culturally appropriate, and locally endorsed is an enormous challenge” (p. 499). This makes the development of an intervention that addresses each of these issues an exciting and exceptional achievement.

Further research

The present research has generated some important findings. However, it would be useful to test these findings with larger samples. In particular, this would allow for comparisons to be made between the benefits experienced by different types of website users. For example, as previous research has shown that rural women are more likely to seek help for mental health issues than rural men (Judd et al., 2008), an interesting area of further research, would be to examine whether there are gender differences in the extent to which the website has an impact on help-seeking. It would also be useful to follow up the extent to which pure use of the CBT components versus pure use of the information components impacts on wellbeing post use (e.g. after 6 weeks) and to identify exactly which behaviour change techniques employed have the biggest effect and which pages and features are used the most, to aid the development of other interventions.

More generally, examining the differences in the mental health of rural and non-rural cancer patients and survivors would undoubtedly be beneficial (Burriss & Andrykowski, 2010). It would justify further investment into improving access to psychosocial care in rural populations and provide a baseline to determine if the introduction of new interventions is worthwhile.

In a different vein, as previously alluded to, given difficulties in accessing mental health care in rural areas, it would be useful to test whether the development of a similar self-help website that challenges attitudinal barriers to mental health help-seeking in a similar way to the *Country Cancer Support* website, could be helpful for those experiencing more general mental health issues. The potential for such an online intervention to not only reduce symptoms of mental illness but also increase feelings of fulfilment among the emotionally healthy members of rural populations would also be an interesting and useful endeavour. Consistent with this idea, Judd et al. (2006) have noted that to improve mental health help-seeking for rural people, we need to better understand and work out ways to address attitudinal barriers (e.g. the stoicism that is often assumed of rural values).

Further investigations into how best to meet the psychosocial needs of Indigenous rural Australians is also required. The level of unmet supportive care and barriers to treatment and support are likely to be even higher among Indigenous cancer patients from rural and remote regions (Whop, Garvey, Lokuge, Mallitt, & Valery, 2012). It would also be useful to investigate the experiences of rural people affected by cancer who are from culturally and linguistically diverse backgrounds and methods through which access to psychosocial care could be improved for this patient group.

Conclusion

This research identified a problem, focused on developing a multi-faceted solution to it, mobilised and empowered those affected to be part of the solution, combined knowledge from lived experience with that from the literature in developing the solution, elicited new knowledge from this process and importantly, found that simply providing information via a website can decrease self-reported feelings of distress and isolation and increase help-seeking intentions among rural cancer patients and their supporters.

The results also reiterate the importance of interventions being targeted (Girgis et al., 2000; McGrath et al., 1999b), creative and flexible (Lee, 2007) and considering the preferences, perceptions and existing strengths (Rogers-Clark, 2002), support and resourcefulness (McGrath et al., 1999b) of rural populations. In addition, they demonstrate that knowledge generated both through lived experience and scholarship can be successfully incorporated into an intervention's design. It provides a novel framework to help others engage consumers in this process (which has been widely recommended but rarely described) and reaffirms the value of consumer involvement, for the purposes of empowering participants, developing culturally acceptable interventions and efficiently developing solutions to difficult health-related problems.

This research will help shift the focus from a supposed lack of psychosocial services to increasing access to the services that already exist. The *Country Cancer Support* website is a good example of

how this can be done. It is also hoped that it will lead to greater acknowledgement of the substantial differences between rural cancer patients and their urban counterparts and wider understanding of the fact that rural cancer patients would like this to be acknowledged.

Despite the contribution that the careful development and evaluation of the *Country Cancer Support* website has made, developing information resources and online interventions alone will not solve all inequality in cancer care. As identified in Study 1, making psychosocial care a standard part of treatment and improving communication and referral pathways between health professionals are also imperative initiatives.

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APPENDIX 1

Psychological characteristics of participants in Study 1

Psychological Characteristics of Participants

<i>FACT-G M (SD)</i>	Participants in present study	Cancer population norm (Brucker, Yost, Cashy, Webster, & Cella, 2005)	General US adult population norm (Brucker et al., 2005)	Queenslan d general adult population norm (Janda, DiSipio, Hurst, Cella, & Newman, 2009)
<i>Physical well-being</i>	22.35 (5.2)	21.3 (6.0)	22.7 (5.4)	25.1 (3.7)
<i>Social/family well-being</i>	22.21 (5.7)	22.1 (5.3)	19.1 (6.8)	19.2 (6.6)
<i>Emotional well-being</i>	20.00 (2.7)	18.7 (4.5)	19.9 (4.8)	21.2 (3.7)
<i>Functional well-being</i>	20.70 (6.0)	18.9 (6.8)	18.5 (6.8)	20.3 (6.2)
<hr/>				
<i>K10 M (SD)</i>	Participants in present study		General Australian adult population norm (Andrews & Slade, 2001)	
<i>Psychological distress</i>	17.47 (4.86)		14.2	

N = 17

Cancer specific health-related quality of life. The FACT-G (version 4), a self-report measure designed for use with people who have any type of cancer, measures four domains: physical well-being, social/family well-being, emotional well-being and functional well-being (Webster, Cella, & Yost, 2003).

Psychological distress. The K10 is based on ten self-report questions about depressive and anxiety symptoms experienced over the past four weeks (Andrews & Slade, 2001).

APPENDIX 2

*References consulted to assist in generating
content for the Country Cancer Support website*

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APPENDIX 3

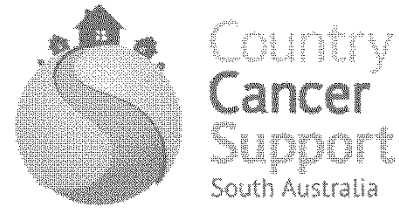
*Fact/ worksheets contained in the 'Dealing with difficult emotions'
section of the Country Cancer Support website*

Basic self-care/useful coping strategies



- Be proactive and take control of your health and care as much as possible.
- Do some gentle exercise (e.g. walking) if you feel up to it. If you are concerned, ask your doctor what is an appropriate level of activity for you.
- Eat a nutritious diet (usually this means more fibre, more dark green and orange vegetables, less fat, sugar and salt, unless you have been advised otherwise by a health professional).
- Avoid alcohol.
- Only do as much as you can, both physically and mentally. This may be less than you are used to.
- Have a rest/nap if you need to.
- Be prepared to just take one day at a time.
- Be kind to yourself. Remember it's okay not to feel positive all of the time. Treat yourself the same way you'd treat a friend in the same situation.
- Consider relaxing your housekeeping and gardening standards, making easier meals, using services such as Meals on Wheels and/or accepting offers of help.
- Keep doing as many non-cancer related activities as you can (e.g. seeing family and friends, having a massage, listening to music, going on holidays, gardening, volunteering). It is important to try to keep a sense of pleasure and achievement in your life. Doing things you enjoy and that are meaningful to you will help you take your mind off your health.
- Try to accept that this is not the way you'd like it to be, but it is the way it is for now. You can't change some things but you can choose to make the most of every day.
- Be open with your doctor and/or treating team about how you are feeling and if you are experiencing any difficulties such as worry, lack of sleep or pain. They are not only there to look after your physical health, but also your overall quality of life. Treatment is available to help with these sorts of issues.
- Share your feelings with those close to you. Remember it is okay not to feel positive all of the time.
- Consider joining a support group or speaking to someone who has been through a similar experience over the phone via Cancer Council SA's Cancer Connect program.
- If you are having trouble talking about the way you feel, document your feelings by keeping a journal, sharing your story online or by painting, drawing or finding some other way of expressing yourself.
- If you are having trouble with mobility or managing in your home, consider engaging an occupational therapist, physiotherapist, or contacting the Independent Living Centre for information and helpful equipment and aids.

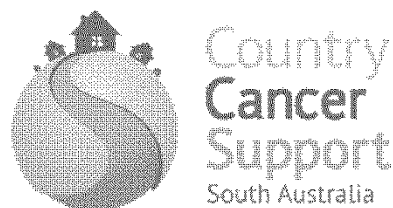
Managing fatigue



It's common for people undergoing cancer treatment to experience fatigue, because repairing tissue damaged by radiation or chemotherapy requires a great deal of energy. It doesn't mean your treatment isn't working or that your health is getting worse. However, it can go on for weeks or months after treatment has finished. Here are some tips that might help you reduce your fatigue.

- Drink plenty of water.
- Eat a variety of healthy snacks several times a day (instead of just having three big meals per day).
- Have short naps (long ones may make it difficult for you to sleep at night).
- Try having naps before you feel too tired.
- Try to avoid doing too much physical work. Sit whenever possible (e.g. when ironing, cutting up food, talking on the phone), take rest breaks and don't be afraid to ask for help (e.g. with laundry, or putting out the bins).
- Speak to your specialist doctor or GP about how you can incorporate some gentle exercise into your day. It can make you sleep better at night and feel more energetic during the day.
- If available, consider using online shopping or placing orders at your local supermarket so that your groceries are delivered to your door.
- If you find you are having difficulty remembering things, make lists (if you don't already).
- When you feel okay, make large quantities of food like casseroles or soup that you can freeze so that you have something ready for when you're not feeling so good.
- If you smoke, talk to your specialist doctor, GP or phone the [Quitline](http://www.quitline.com.au) on 13 78 48 for help with quitting. Smoking reduces your energy levels.

Improving the quality of your sleep



Many people with cancer say that they feel tired a lot of the time, but find it difficult to “switch off” and sleep. This is something you should mention to your specialist doctor and/or treating team. However, making some simple changes to your sleeping environment, lifestyle and your way of thinking about sleep, may also help too.

Adjusting your environment

- Remove any clocks that are visible or accessible from your bed. Knowing the time and/or being tempted to check it is likely to wake you up and make you more worried about not being asleep.
- Minimise the amount of light and noise in your bedroom (use an eye mask and/or ear plugs if necessary).
- Ensure your bedroom is the right temperature (consider using another blanket, opening a window, turning on a fan if necessary).

Adjusting your thinking

- Many people affected by cancer find themselves lying awake in bed at night, which is frustrating. While this may be caused by genuine concerns about your health and/or treatment, it often turns into worry about not sleeping, which in turn makes it more difficult to get to sleep. A good alternative is to get out of bed and do something distracting yet relaxing such as reading a book, listening to music or having a glass of water and only going back to bed when you feel really sleepy.
- If you find this doesn't work, another strategy you can try is to get out of bed and deliberately pay attention to the thoughts that show up in your mind and the feelings that show up in your body. If the thoughts are things you can do something about, write a note to yourself to remind you to deal with them in the morning. If they're feelings or thoughts about things that you cannot change, imagine putting each thought on a leaf, placing the leaf in a stream and watching it float away. Over time you may notice the same sorts of thoughts coming up again and again. You may like to give those thoughts a name such as the “I'm a burden story” or the “This is all too hard story”. You could try naming unhelpful feelings in the same way, like “There goes anger”. It's important to remember that these thoughts are just thoughts, not necessarily the truth. Our mind often plays tricks on us by replaying these thoughts over and over again and making us believe they are true. Often people find if they can notice when this is happening and name the ‘stories’ or visualise the thoughts, it's easier to let them go.
- Progressive muscle relaxation is another good way to help you relax if you are lying in bed, getting frustrated about being awake and find that you are tossing and turning a lot.

Adjusting your behaviour/lifestyle

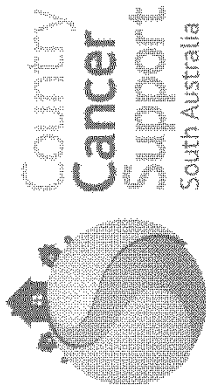
- Your bed and bedroom need to be things that you associate with sleep. Avoid doing other things like watching TV, eating or reading in bed, and only go to bed when you feel sleepy so that when you put your head on your pillow, your body is trained to associate it with going to sleep.
- Increase the amount of exercise you do (but not within a few hours of bed time).
- Avoid heavy meals, caffeine (coke, coffee, tea), nicotine (cigarettes) and sugar for a few hours before bed time.
- Avoid alcohol. Although it might make you get to sleep more quickly, it compromises the quality of your sleep in the second half of the night and as its effects wear off, it's likely to make you get up for the toilet or a drink of water.
- If possible, deal with upsetting or worrying things and do your problem solving early in the day. Plan to do relaxing activities in the afternoon and evening.
- Get out of bed at a similar time each day and if possible, expose yourself to some sunlight in the morning.
- Develop some pre-bedtime rituals such as doing breathing exercises or relaxing stretches for 15 minutes before bed, to help remind your body that it's almost time to sleep.
- Try having shorter naps during the day so you feel sleepier at night.
- Read more about how to manage the side effects of treatment. Effective management of these is likely to make it easier to sleep.

List five things you could change to try to improve the quality of your sleep:

- 1.
- 2.
- 3.
- 4.
- 5.

You may find it helpful to keep track of your sleeping habits and pre-bedtime activities using the following sleep diary for a couple of weeks. This can help you identify the lifestyle, attitudinal and environmental factors that are affecting the quality of your sleep. When you've filled it out for a few days or more, look for patterns in when you do and don't sleep well and adjust what you do accordingly.

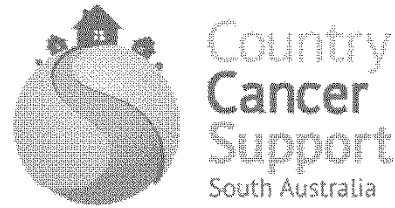
Sleep diary



	Significant events	Alcohol, caffeine & nicotine consumption	Naps (number & duration)	Activities before bed (e.g. dinner at 7, TV)	Activities in bed (e.g. read for ½ hour)	Time lights off	Amount of time to fall asleep	Time woke up	Number of times woke	Hours slept	Rest score (0= not rested, 10= well rested)
Mon											
Tues											
Wed											
Thurs											
Fri											
Sat											
Sun											

	Significant events	Alcohol, caffeine & nicotine consumption	Naps <i>(number & duration)</i>	Activities before bed <i>(e.g. dinner at 7, TV)</i>	Activities in bed <i>(e.g. read for ½ hour)</i>	Time lights off	Amount of time to fall asleep	Time woke up	Number of times woke	Hours slept	Rest score <i>(0= not rested 10= well rested)</i>
Mon											
Tues											
Wed											
Thurs											
Fri											
Sat											
Sun											

Dealing with difficult reactions from others



Support from family and friends can be very useful to help you cope with the stress of cancer. However, it's important to remember that your diagnosis will not only have come as a shock to you, but also to those around you. Unfortunately, when you tell some people, they might not react as supportively as you would like them to and the news may change your friendship. While it's difficult to know what may have caused this reaction from them, it's possible that they just don't know what to say, how to help, how to deal with changes in your appearance, or how to cope with their own feelings. They may even believe that cancer is contagious (which of course isn't true).

If you feel that some people are avoiding you because they are scared they might say the wrong thing, consider phoning them to 'break the ice'. You might also reassure them that they needn't talk to you about your health if they find it difficult, and that you would just appreciate their company. Another way to help them feel more in control of the situation is to give them a job (e.g. cooking your family a meal once a fortnight). It's likely that this will actually help both of you. People often feel privileged to be able to help.

On the other hand, sometimes people with cancer avoid their family and friends in an effort to minimise the chance that they will be asked about how they feel. You may need to be honest with yourself – are they avoiding you or are you in fact avoiding them?

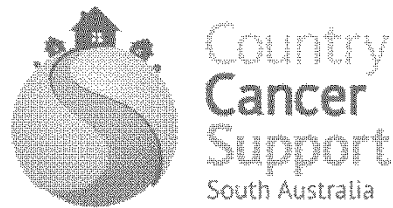
Children are likely to worry about a family member and react in all sorts of ways, from being disruptive (often to hide their fear), withdrawn, or clingy. It's important to try to give children as much attention and to stick to their normal routine as much as practically possible. Enlisting help from a family friend or relative to give them extra comfort, guidance and affection may also be useful.

Other suggestions:

- Be **open and honest** with people about how you feel and how you would like them to behave. Although you might find this difficult to do, it's better to do it calmly in the early stages, rather than letting your frustration build up and angrily confronting the person at a later stage. Reading about [how to be assertive](#) may help you do this constructively.
- Consider **joining a support group or speaking to a cancer survivor** via [Cancer Connect](#). It's likely that other people have had similar experiences and may be able to offer some advice, or simply reassure you that you're not alone.
- Be aware that **people around you may have had to take on new responsibilities**.

- ☑ Let your family and friends know that you realise things have been difficult for them and that you **appreciate their support**.
- ☑ Remember that helping during difficult times comes easily or seems like an obvious thing for some people to do, but this isn't always so obvious to others. **Some people lack the confidence to offer to help, while others genuinely believe they have nothing to offer.**
- ☑ If you find that difficult reactions from others are making you feel angry, **consider reading about managing anger**.
- ☑ If you feel that people don't understand the person that you have become, **consider reading about how to talk to others about your priorities or values**.

Coping with stress and anxiety



Stress is a natural response to being in challenging or dangerous situations. It's something that everyone experiences now and then. If you (or your family) have been affected by cancer, no wonder you're feeling stressed!

Identifying triggers and signs of stress

Knowing in advance exactly what triggers stress and how you tend to feel and think when you are beginning to feel this way can help you cope more effectively when faced with difficult situations in the future. This worksheet is designed to assist you with this.

Complete the sections below that are relevant to you. If you find it difficult, consider asking someone who knows you well to help.

When I'm feeling stressed...

I'm at (place):

E.g. At home, doctors surgery

I'm doing (activity/behaviour):

E.g. Sitting looking out the window, waiting to see the doctor

I'm with (company):

E.g. On my own, with Bob

In my body I'm feeling (physical sensations):

E.g. Heart racing, restless, hot, sweaty, tense muscles, difficulty concentrating

I'm thinking (thoughts):

E.g. "This is all too much", "I can't cope", "What if the doctor gives me bad news?"

Working out how others can help

It's not always obvious to the people around you when you are feeling stressed and it can be difficult for them to know the best way to help. It can be upsetting if you don't feel like your needs are being met, particularly during stressful periods. To help you avoid snapping at the people around you when you're feeling under pressure, consider asking yourself the following questions while you're feeling calm.

When you notice yourself feeling stressed, what could you do to let the people around you know how you feel?

E.g. Tell them you feeling a bit overwhelmed and need a bit of space or that you feel anxious about an upcoming appointment

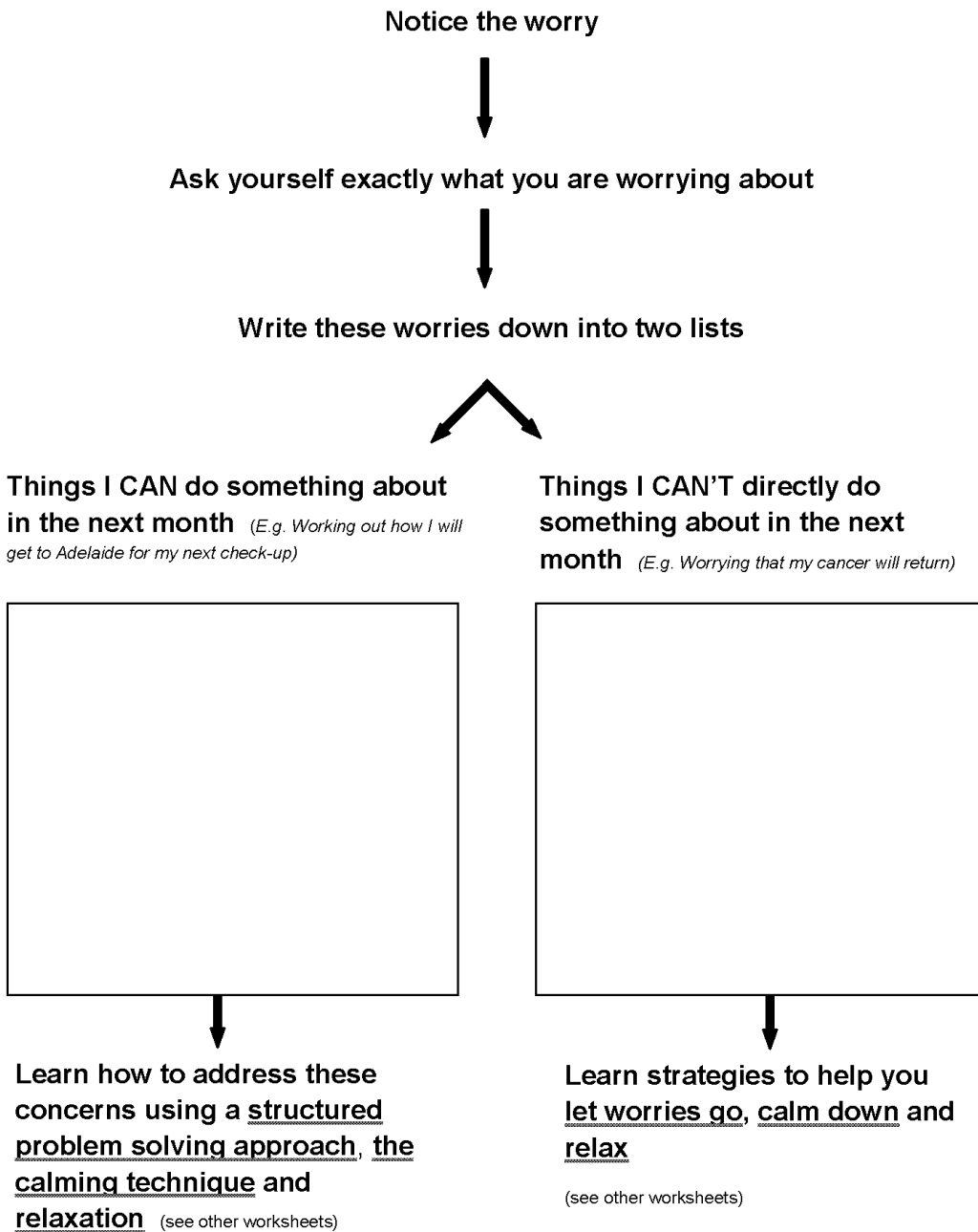
How can you constructively let the people around you know how you would like them to help?

E.g. Ask them if they would mind helping with a job, giving you some space, distracting you, accompanying you to an appointment

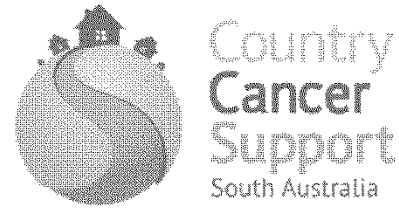
Even if you're upset or stressed, don't forget to let people know that you appreciate their help. It will make them feel good about what they've done and make them far more likely to help you again!

Working out how to best help yourself

Sometimes taking control of problems or worries can seem like an overwhelming task. If you feel that you have a number of things you need to deal with, but don't know where to start, using this chart may help.



Structured problem solving



The structured problem-solving method outlined below has proven very helpful in dealing with problems that people can do something about in the short term (e.g. working out how to get to Adelaide for your next treatment).

**** For worries that you can't easily do something about (e.g. wondering if the cancer will return), consider looking at the learning to let worries go worksheet.**

1. Write down the problem. (Be as specific as possible.)

(e.g. my car has broken down so I can't drive to Adelaide for my check-up on Thursday)

2. Write down all the possible solutions. (Think broadly – don't worry if they are not entirely realistic at this stage.)

(e.g. I could catch the bus, get a taxi to the airport and fly, ask someone if I could borrow their car, ask someone if they could drive me, send out a text to a few of my friends and see if they know anyone who will be travelling to Adelaide on Thursday anyway)

3. Write down the advantages and disadvantages of each option.

(e.g. if I fly I will get there quickest, but it will cost me a lot in taxi fares, if I ask someone to drive me I could go there and back in one day, but I find it difficult to ask people to help me, if I borrow someone's car and drive myself I won't feel as though I'm asking such a big favor, but I will have to stay the night in Adelaide and will be worried about getting a speeding fine in someone else's car)

4. Eliminate less desirable or unrealistic solutions and put the good ones (left over) in order of preference.

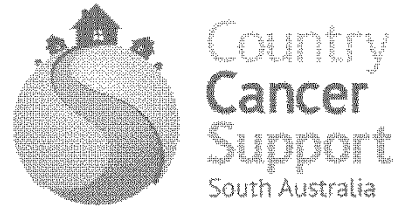
5. Decide on a solution and work out:

- Who will do what?
- How you will go about implementing it?
- When you will implement it?

6. Implement the solution.

7. Review your progress. If you're satisfied, start solving a new problem. If not, work out what still needs to be done or if an alternative solution may be more suitable.

Learning to let worries go



What strategies have you been using to deal with worrying or upsetting thoughts in the past?

Have people been telling you to 'be positive' or remember that you 'are lucky'?

How easy has this been for you?

As you've probably found, it's very difficult to try to control or avoid worrying and to block negative thoughts out of your mind. In fact, sometimes when you try to do this you end up directing more attention towards these negative thoughts and struggling with them even more. That is, the more you try not to 'be negative' or worry, the more you will be.

Fortunately there is an alternative. While you can't choose not to have negative or worrying thoughts, you can choose how you respond to them. One way to respond is by being 'mindful'.

Being mindful involves noticing when your mind is drifting off into unhelpful or negative thoughts and, instead of buying into or chasing them, trying to turn your attention back to what is happening in the 'here and now'. This might sound a bit complicated at first, but trust us on this one and read on!

When you are being 'mindful' you are aiming to:

- Notice what you are experiencing without judging or trying to avoid it
- Be open to the variety of experiences (internal and external) that you have
- Control your attention (but not what you see or think)
- Stay in the present moment

Busy lifestyles generally mean that people rarely do things 'mindfully' or stay entirely in the present moment.

How often do you plan what you are going to wear for the day while you are having a shower or, listen to music while going for a walk?

When you are doing these sorts of things you are not bringing your attention to one thing at a time and are not being mindful.

While learning to go about life mindfully is a difficult skill to learn, it has been proven to be a very useful strategy for many people, so it's certainly worth a go. The following exercise might help you get started.

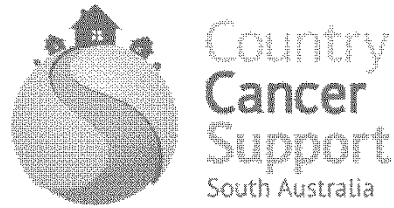
1. Sit in a chair with your feet on the ground.
2. Close your eyes and ask yourself “What thoughts, feelings and bodily sensations can I feel right now?” Spend at least 30 seconds acknowledging, observing and describing these thoughts to yourself without passing any judgements, trying to answer, avoid or change them.
3. Once you’ve noticed these thoughts, then you can choose to let them go. Your only response might be something like, “Oh here comes a worry, thank you mind”. You may like to visualise your worries as written words, clouds floating by or leaves in a stream, say to yourself “these are not facts, they are just thoughts” and watch them move or wash away.
4. Now for the next three minutes or so, focus your attention on your breathing. Notice your chest and stomach rising and falling. When you find you are distracted by a thought, label it as “a thought” and gently return your attention back to your breathing.
5. Finally direct your attention towards the sensations being experienced throughout your whole body while you breathe. Notice the chair you are sitting in, the temperature of the air around you and the sounds you can hear. Wiggle your fingers and toes and notice how it feels. Then again, focus back on your breathing.

What most people find when they do this exercise is that when they are concentrating on what is happening in the immediate moment, there is less room in their mind for unhelpful emotions such as worry or fear and when worries do come up, it's easier not to get caught up in them.

You can do exercises like this anywhere. For example while walking in a garden you could notice the feel of the lawn on your feet, the sun on your skin and the smell and colour of the flowers and trees.

Most people find this difficult to do at first because our minds have a tendency to wander off from the present moment. Rest assured this happens to almost everyone. Try not to pass judgement and get frustrated – instead, just congratulate yourself for noticing what your mind is doing and then focus back on the present.

To have someone talk you through this sort of process (by downloading a free mp3), visit http://contextualpsychology.org/free_audio The 'leaves on a stream exercise' might be a good place to start. Alternatively, try 'mindful breathing' by visiting http://emedia.rmit.edu.au/communication/media/audio/sec4Segments/SixACT_Conv4Part2.mp3 or 'mindfulness of thoughts' http://emedia.rmit.edu.au/communication/media/audio/sec4Segments/SixACT_Conv4Part3.mp3



Calming Technique

When people feel threatened or anxious they tend to over-breathe, which means they take in more oxygen than their body needs. This can result in physical sensations such as dizziness, confusion, breathlessness, increased heart rate, clammy hands, blurred vision and numbness and tingling in extremities. One of the most simple and effective ways to reduce these symptoms is to slow down your breathing.

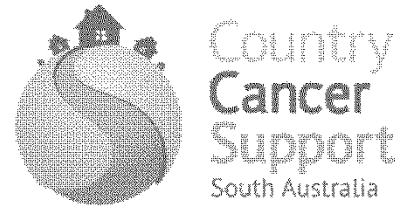
Here's how to do it:

- 1. Find somewhere comfortable to sit or lie down.**
- 2. Breathe in (through your nose if possible) for 4 seconds.**
- 3. Hold your breath for 2 seconds.**
- 4. Breathe out (through your nose if possible) for 6 seconds.**
- 5. Pause before repeating again until all the symptoms of over-breathing or anxiety have gone.**

It's best to breathe down into your stomach, not just into your lungs. To check that you're doing this, place one hand on your stomach and the other on your chest. If you can feel your stomach rising, then you're breathing deeply enough.

If you practice this technique a couple of times each day, it will become easy to remember and use when you face particularly anxiety-provoking situations (e.g. when you're waiting in a doctor's surgery to receive test results).

Progressive muscle relaxation

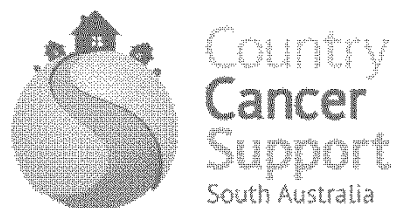


If you find you need some help to calm down and/or you have tight muscles from long periods of worry, stress or fear, this simple technique may be useful. Consult your specialist doctor or GP before you try this if you have concerns about any physical injuries.

1. **Find a quiet place where you won't be interrupted for about 15 minutes.** Sitting in a chair with comfortable clothing on, your shoes off and feet flat on the floor often works well.
2. **Close your eyes and take some long, slow, deep breaths.** It may be useful to use the calming technique. (See other worksheet if you don't know it.)
3. **Paying particular attention to how it makes you feel in your body and in your mind, tense each of the following muscle groups, one at a time, for 5 seconds and then relax them for 15-20 seconds and dwell on that feeling.**
 - Left hand and forearm *then repeat for...*
 - Left upper arm
 - Right hand and forearm
 - Right upper arm
 - Forehead
 - Eyes and cheeks
 - Mouth and jaw
 - Neck
 - Shoulders
 - Chest and stomach
 - Hips and buttocks
 - Left upper leg
 - Left lower leg
 - Left foot
 - Right upper leg
 - Right lower leg
 - Right foot
4. **Take a few slow, deep breaths then slowly open your eyes.**

Regular practice will help you get better at using this technique. Be careful when tensing your back and neck and don't do anything that is painful. When tensing your feet and calves, be aware that this may result in cramping.

What to do if you're feeling down or low



Being given a diagnosis of cancer comes with many challenges.

While everyone's experience is different, some of these challenges may include:

- Having to incorporate the illness/ diagnosis/ idea of being a 'cancer patient' or 'cancer survivor' into your self-concept (or way you view yourself) and keeping a sense of independence and control
- Needing to manage treatment side effects and the loss of some body parts or functions
- Living with the fear of cancer coming back or death
- Adjusting to changes in appearance
- Dealing with financial insecurity and changes in relationships and roles

So it's no wonder that many people who are faced with cancer feel down at times. However, it's important that you don't assume the following symptoms of depression are side effects of cancer, or things that you should tolerate.

If you experience the following symptoms, make sure you discuss them with your specialist doctor, GP, or speak to someone else such as a professional counsellor or psychologist:

- Depressed mood
- Loss of pleasure or interest in usual activities
- Inability to concentrate
- Feelings of guilt or worthlessness
- Disturbed sleep patterns
- Fatigue or loss of energy
- Change in weight or appetite
- Slowed movements
- Restlessness
- Thoughts of death or suicide

Identifying triggers/ difficult situations/ warning signs

When you are feeling down, it's useful to work out exactly what things are associated with feeling this way.

Consider asking yourself the following questions and writing your answers below.

<p>Are there particular days when you tend to feel down? If so, which?</p>
<p>Are there particular times of the day when you tend to feel down? If so, when?</p>
<p>What is going on around you when you are feeling down? <i>(E.g. you're near particular people, stressful events, there's a lack things to do)</i></p>
<p>Are there particular sorts of thoughts going through your head when you are feeling down? If so, what are they?</p>
<p>How would your life be different if you weren't feeling down? What would it look like? What would you be doing?</p>

Although people might have told you to try to 'think positive', chances are it hasn't been all that helpful. It's just not that simple. But there's good news – you don't need to get into arguments with yourself about the way you're thinking.

Instead, a useful strategy is to learn how to notice when you're getting caught up in certain thoughts and work out what effect this is having on you. Is it making you more depressed, or helping you work through a realistic problem? In short, if the thinking is helpful, keep going. If the thinking is unhelpful, keep reading!

If you spend some time working out the kinds of things you're thinking when you feel down, you might notice a pattern. Often the same topics come up and go round and round in people's heads. This is called ruminating.

Using the list of thoughts above as a prompt, write down a list of the five most common topics that go round and round in your head and make you feel down.

1.
2.
3.
4.
5.

You may have noticed that when you're ruminating about these things it's more difficult (and sometimes seems less desirable) to solve problems. It's also often more difficult to focus on what is happening in the world around you.

Disrupting rumination/ stopping difficult 'stories' from taking hold

One way to help distance yourself from these topics or thoughts is to give them a name – for example, the “I now have an ugly body story” or the “cancer is going to come back story”. Giving them a name like this can help you recognise when they spring up and help take some of the heat out of them. By calling them a “story” you’re acknowledging that they’re just thoughts and not necessarily reality.

After giving the story a name (or simply just acknowledging that your mind is getting caught up again), consider what you could be devoting your attention to instead. Many people find it helpful to pay particular attention to what is happening around them in the here and now (e.g. the sound of the birds, the wind on their face). You could also choose to focus on doing something that is important to you (e.g. phoning a friend) and making a particular effort to engage in what you are doing.

Consider this example:

Situation: Driving to check up

- **Rumination topic/story:** “The cancer is going to come back”
- **Consequence:** Feel more depressed, almost hit a cyclist

If this person could have noticed when the “story” came up and used this as a cue to change their behaviour and deliberately pay attention to what was happening around them, things may have been different.

An alternative:

Situation: Driving to check up

- **Rumination topic/ story:** “The cancer is going to come back”
- **Cue to action/ change attention:** Labelled the thought as just a thought or “story”, not a fact. Returned attention back to driving and made an effort to take particular note of the colours of the other cars on the road.
- **Consequence:** Feel more relaxed and in control when getting to appointment.

So, let's apply this to you

Rumination topic/ 'story'	Situations where this normally occurs	My typical reaction to this 'story'	My more present-focused way to respond	How did it go? Result?
<i>E.g. "The cancer is going to come back story"</i>	<i>E.g. Driving to checkups, resting in the afternoon</i>	<i>E.g. Let these thoughts go round and round in my head</i>	<i>(E.g. Go for a walk & notice the sights & sounds around you, call a friend & pay extra attention to what they are saying, look at a painting & notice the colours & brush strokes)</i>	<i>E.g. Calmer, less 'wound up'</i>

Acting the way you would like to feel

Another useful strategy when you're feeling down is to act the way you would like to feel. When people are down or sick, they tend to lose motivation, energy and interest in many of the things that have given them pleasure and meaning in the past. As a result, they usually become less socially, mentally and physically active, which makes their mood worse. While it can be difficult to find the motivation to do the things you used to enjoy and gain a sense of achievement from, research has shown that taking action even when you don't feel motivated to do so (if you're physically capable) is actually one of the most effective ways of improving your mood. Give it a try for yourself! It's okay to do this gradually, starting with small steps and working up to bigger changes in your routine.

The following questions will help you work out what to do.

What activities gave you a sense of achievement in the past that you aren't currently doing, but are capable of?

Which work tasks or jobs would you feel relieved to complete?

Which social activities did you previously enjoy and find important that you no longer do?

Are there any family or friends you now spend less time with that you could reconnect with? If so, who?

What sorts of activities did you previously find fun, enjoyable or relaxing, but no longer do? *(E.g. playing cards, walking the dog, painting, playing darts, gardening, riding your motorbike, playing a musical instrument)*

What types of physical activity did you previously enjoy?

From your list of *physical* activities, circle one that you could start doing again in the next week (given your current medical condition/state of health).

Now have a look over the other activities you've listed above and choose a few others (3 or 4) to try over the next week.

1.

2.

3.

4.

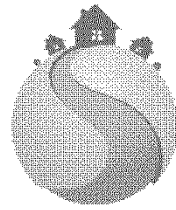
It's fine to spend small amounts of time doing these activities in the beginning (e.g. 10 minutes in the first week) and with time, work up to spending longer (e.g. 20 minutes in the second week).

To help make it easier to do these things, schedule a time to do each and write these in your diary.

You may then like to rate your mood out of 10 before and after doing each activity so you can keep track of which activities have the biggest impact on your mood.

At the end of each week, look at the list again. Reschedule those activities that improved your mood, consider doing them for a bit longer next time and try a couple of new ones from your list.

Working out what's important and how to live in line with this



Country
Cancer
Support
South Australia

Often a diagnosis of cancer challenges what people believe about their world, their relationships and themselves. It can also make them examine their life, think deeply about what's important to them and provide a new perspective on their life and priorities. This can bring about positive changes in the way they go about their life. If you haven't thought about this, that's okay – you might prefer to come back to this at another time. If you feel ready to start thinking about it, the following questions might be useful.

What has your experience with cancer told you about what really matters or what you really care about?

How can your experience with cancer help you to learn or develop new skills and strengths?

How can this experience help you to improve the way you relate to others?

What do your worries or fears show you that you care about and find important?

Understanding changes in your values and explaining them to others can be difficult. The following exercises are designed to help you do this.

Before you begin, it's important to understand exactly what values are. Values are statements or principles about what we want to do with our life, including what we want to stand for and how we want to behave. There's an important difference between values and goals. Values (e.g. creativity) are like a direction or process, not a destination – they can guide you through life, towards certain goals. Goals (e.g. to finish a particular painting) are like a destination or outcome in the future that once you've reached, you can't continue to strive towards. You never have to justify your values, but you may need to prioritise them.

Examples of values include: fun, flexibility, commitment, affection, accuracy, maturity, money, peace, professionalism, religion, service, tidiness, trust, warmth, wisdom, friendship, being caring, being bold.

You could make a list of your own values, or keep reading and use the following prompts to help you do this. Being clear about your values is likely to help you understand 'the new you' and work out how best to move forward with your life.

Below is a list of areas of life that are valued by some people.

To what extent do you value the following aspects of your life?

Please select a value between 1 (not at all important) **and 10** (extremely important). Remember that there are no right or wrong answers – this is an indication of how important they are to YOU now (not before you were affected by cancer).

	Not at all important ↔ Extremely important									
Family relations <i>(not parenting or marriage)</i>	1	2	3	4	5	6	7	8	9	10
Marriage/ intimate relationships	1	2	3	4	5	6	7	8	9	10
Parenting	1	2	3	4	5	6	7	8	9	10
Social life/ friends	1	2	3	4	5	6	7	8	9	10
Work	1	2	3	4	5	6	7	8	9	10
Education/ training	1	2	3	4	5	6	7	8	9	10
Fun/ recreation	1	2	3	4	5	6	7	8	9	10
Spirituality	1	2	3	4	5	6	7	8	9	10
Community work/ citizenship	1	2	3	4	5	6	7	8	9	10
Physical self care <i>(e.g. sleep, exercise, diet)</i>	1	2	3	4	5	6	7	8	9	10
Creativity	1	2	3	4	5	6	7	8	9	10

Thinking back over the **past week**, how consistent have your actions been with each of these values? Remember this is about how YOU think you've done, not about what anyone else thinks, or what you wish you'd done. Please select a value between 1 (not consistent) and 10 (completely consistent).

	Not consistent with my values in this area of my life					↔	Completely consistent with my values in this area of my life				
Family relations <i>(not parenting or marriage)</i>	1	2	3	4	5	6	7	8	9	10	
Marriage/ intimate relationships	1	2	3	4	5	6	7	8	9	10	
Parenting	1	2	3	4	5	6	7	8	9	10	
Social life/ friends	1	2	3	4	5	6	7	8	9	10	
Work	1	2	3	4	5	6	7	8	9	10	
Education/ training	1	2	3	4	5	6	7	8	9	10	
Fun/ recreation	1	2	3	4	5	6	7	8	9	10	
Spirituality	1	2	3	4	5	6	7	8	9	10	
Community work/ citizenship	1	2	3	4	5	6	7	8	9	10	
Physical self care <i>(e.g. sleep, exercise, diet)</i>	1	2	3	4	5	6	7	8	9	10	
Creativity	1	2	3	4	5	6	7	8	9	10	

** (Adapted from Wilson's Valued Living Questionnaire)

Now answer the following questions:

How consistent is your current lifestyle with your values? If your values aren't driving your actions, consider asking yourself – what is? Is it negative emotions such as sadness, guilt, worry or fear?

To what extent do you think your life might be more fulfilling if you let your values guide your actions instead?

If you started doing more things that are meaningful and important to you, to what extent do you think this could reduce some of the negative emotions you are experiencing?

Now list the aspects of your life that you value the most in order of importance and complete the following exercise:

	Valued area of life	What I'm currently doing that is consistent with this value	Things I could realistically do in the next week to live more consistently with this value	Things I could realistically do in the next month to live more consistently with this value
E.g.	<i>Social life/ friends</i>	<i>Attending weekly coffee catch-ups with a group of ladies from church</i>	<i>Ring Mary and have a chat to her over the phone</i>	<i>Make arrangements to go out to dinner with Susan</i>
1				
2				
3				
4				
5				
6				
7				
8				

Now schedule times in your diary to do them. You may like to rate your mood out of 10 before and after doing each activity so you can keep track of which activities have the biggest impact on your mood.

At the end of the week, if you find yourself unable to do what you've outlined above, ask yourself why? What got in the way? What strategies could you use to overcome these hurdles to living a more valued, meaningful life? Should you ask someone for assistance? Or would you benefit from using other worksheets? These could help you with problem solving (e.g. if you don't know where to start), or to learn the calming technique (e.g. if anxiety has been making it difficult).

Talking to others about what's important to you

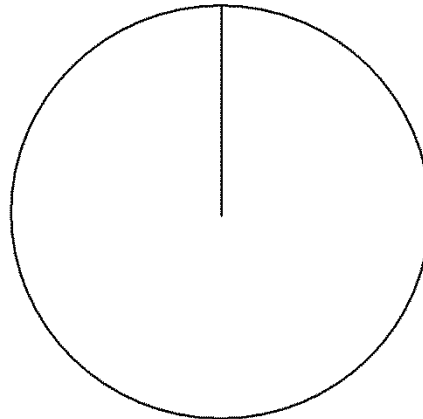


Use this worksheet to help you explain to other people how cancer has influenced your priorities or changed what is important to you. List your top ten priorities before and after cancer, give each priority a percentage (according to the importance that area of your life had/has to you) and divide up the pie charts based on these percentages to show this clearly.

My top ten priorities before I was diagnosed with cancer

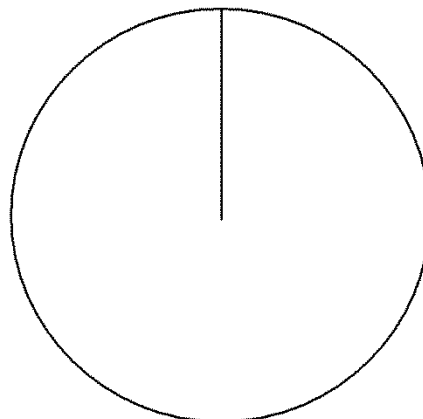
(E.g. Work- 30%, parenting- 40%, having fun- 10%, relaxing- 10%, eating healthily- 10%, exercising, socialising, cooking))

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.

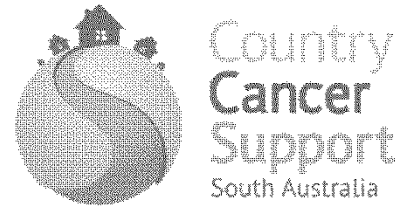


My top ten priorities after cancer/ now

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.



You may then like to consider asking your partner or family members to do the same. This may help open up some valuable conversations that help you all move forward.



How to be assertive

Being assertive can help you communicate more effectively with others, which can improve the quality of your relationships and help you ensure your needs are being met.

Being assertive means expressing your opinion clearly and directly. It doesn't mean being aggressive. Being aggressive often damages relationships and involves only considering your own needs, refusing to compromise, losing control and forcing your opinions on to others. On the other hand, assertiveness means respectfully expressing your needs in a controlled manner, being reasonable, equally considering the needs of others and using clear language to express your points. All of this often involves compromise.

When being assertive, you need to pay attention to your vocal tone, body language, content and actions. Here are some suggestions that might help you be assertive:

- Don't shout or whisper. Speak calmly and directly at a normal conversation volume and sound firm, but not aggressive or angry.
- Honestly tell the person how you feel and listen carefully to what they say in response.
- Stand tall and look the person in the eye while you're speaking. Your body language needs to reflect confidence in what you're saying.
- Don't exaggerate by using words such as "never" or "always", making threats or being sarcastic
- Avoid making judgments, state the facts instead.
- Try to avoid accusing the other person of things. You can usually reword "you statements" ("you're upsetting me") into "I statements" ("I feel upset when you don't ask me how my appointment was"). Statements beginning with "I want" or "I need" are also useful (e.g. "I want to go for a walk after dinner").
- Start off by stating that you recognise the other person's wants/situation/feelings or beliefs, and then assert your own. This means that you're being sensitive to others without disregarding your own needs
- Make an effort to listen to the other person's response. You can demonstrate that you are listening with your body language (by nodding, or looking them in the eye), or by paraphrasing what they've said when they've finished. If you listen to them attentively, they're more likely to listen to you.
- It's important to remember that although being assertive is likely to help, it doesn't mean that other people will necessarily respond the way you would like them to.

When have you been assertive in the past?

How did that go?

When have you not been assertive in the past and regretted it?

In what situations would you like to be able to communicate more assertively and effectively?

What could you say (remembering the difference between assertiveness and aggressiveness)?

This structure may help: *"I feel* _____
when you _____
because _____
I want/need _____."

When will you say it?

What do you need to do to arrange this conversation?

How do you think you will feel after saying it?

Managing anger



Anger is a normal emotion that everyone experiences now and then. Often anger is experienced when we feel powerless, mistreated, misunderstood, humiliated, embarrassed, fearful, or when we feel like things are out of our control. Sometimes there's no obvious trigger. Given that cancer frequently makes people feel powerless, it's no wonder that people affected by it often experience feelings of anger.

While anger might motivate us to do things like get the best treatment or fundraise to help cancer research, if it's not thoughtfully targeted, if it's very intense and/ or frequent, it can be destructive (both for you personally and those around you). If you find that anger is becoming a problem in your life, consider the following.

Exactly what tends to make you angry?
Where are you when you are angry?
What are you doing when you are angry?
What are you thinking when you are angry?

What prior experiences, beliefs or 'buttons' are being pushed that may contribute to this anger?

Is it possible to avoid any of these situations in the future? If so, what will the costs and benefits be?

What do you notice in your body when you are starting to feel angry?

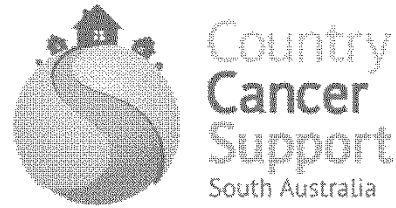
(E.g. tightness in chest, sweating, tense muscles, pounding heart)

Next time you notice these bodily sensations or thoughts coming on, consider stopping and asking yourself what is making you angry and then try one of the following strategies.

- Explain that you need some time to think (or 'cool down') and remove yourself from the situation. This will give you a chance to think things through and respond in a calm and controlled manner.
- Distract yourself from the situation by counting to ten, turning on the radio, going for a walk, or speaking to a friend (about something else).
- Ask yourself if you've made a genuine attempt to see this from the other person's point of view.
- Use humour to diffuse the situation.
- Acknowledge what the other person has said, tell them how you feel and respectfully communicate what you need or believe.
- Choose to just let it go.
- Try the calming technique.
- Try progressive muscle relaxation to relieve your muscle tension and help shift your focus elsewhere.

Learning techniques to help you sleep better, manage stress and be more assertive may also help reduce your chances of becoming angry (see other worksheets).

Loss and grief



Grief is a natural reaction to the loss of something significant. This could be the loss of your health, or of a particular role, status, goal or person. Grieving can encompass a wide range of thoughts, feelings and reactions.

Often the extent of grief reflects the extent to which you valued that part of your life. However, people grieve very differently and the ways in which two people respond to the same event may vary significantly.

There are many elements of the cancer journey that can cause feelings of loss and grief. These may include loss of:

- energy
- part of your body or function
- physical comfort
- sense of control or independence
- sense of security in your health
- future goals or ambitions
- routines
- sense of identity
- roles (e.g. main breadwinner)
- relationships
- financial security
- work opportunities

Grief often endures after treatment has ended and may be present for a large proportion of the time or triggered by certain events (e.g. medical appointments, special family occasions, hearing of others affected by cancer).

While most feelings of grief dissipate with time, one of the best ways to speed up this process is to talk to others about what you are feeling. Sometimes people affected by cancer find this difficult, because they believe that others will think they should be grateful to be alive, or that when their treatment has finished they should be able to “get over it”.

It can also be difficult because some people aren't familiar or comfortable with talking about grief and dealing with the feelings that come with it. However, remember that **expressing this grief is likely to help you to understand, accept and adjust to your losses**. It's worth persevering even if the first person you speak to doesn't respond the way you had expected or hoped.

If you find that this is too difficult to do and that grief is enduring and interfering with your quality of life, consider speaking to your specialist, GP, or a counsellor or psychologist who is trained to provide strategies to help you with the necessary adjustment. When grief is not resolved it can lead to depression, so seeking help early is important.

The following strategies may also help:

- Put aside some time each day to quietly reflect and fully experience your emotions.

- ☑ Allow yourself to cry.
- ☑ Keep a diary of what you're thinking and how you're feeling. Having a record of this journey may be interesting to look back on and examine your progress.
- ☑ Make the effort to see some close friends or family – it's likely to improve your mood.
- ☑ Avoid making important, major decisions soon after your loss.
- ☑ Seek professional help with things as varied as finances, jobs around the house, or coping emotionally – you don't need to do all of this alone.
- ☑ Learning relaxation, scheduling activities that are consistent with your values and problem solving may also be useful strategies to help you cope.

APPENDIX 4

Service provider online survey



Thank you for showing an interest in this survey which will be used to create an online directory of services to improve rural South Australians' access to health and support services.

If you (and/or your organisation) provide services to assist rural South Australians with their health and/or psychosocial needs (e.g. emotional, social, practical, physical, spiritual issues) we would love to be able to share information about your service with others and greatly appreciate the time you spare to complete this survey.

Kind regards

M. Psych (Clin)/ PhD Candidate
School of Psychology
The University of Adelaide

kate.gunn@adelaide.edu.au

*** 1. What would you like to do?**

- Start the survey now (It should take less than 10 minutes to complete)
- Read more about why the survey is being carried out

Previous research has shown that for many rural people, one of the most significant barriers to seeking psychosocial help is their lack of awareness of the types of local services that are available and their lack of understanding about how these services may be able to help. Therefore, to help address this issue, we are developing an online directory of psychosocial services with support from Country Health SA, Cancer Council SA, The Spencer Gulf Rural Health School and The University of Adelaide.

This online resource will enable consumers to rate their levels of distress and unmet needs and assist to connect them with appropriate services in their local area and relevant self-help material. The website will also include search functions to enable health professionals and other interested parties to easily and simply locate relevant services across rural regions of the state.

However, to make this website work we really need your help!

If you could please take the time to fill out this online survey about the services your organisation provides, it would be greatly appreciated.

If you have a good idea about what services your organisation offers, the survey should take less than 10 minutes to complete.

As people affected by cancer have been found to be in particular need of information on rural psychosocial services, you will notice that a few questions are specifically geared towards this group. The service directory will initially be housed in a website called "Country Cancer Support" which will be targeted at and evaluated by rural cancer patients and their families, carers and health professionals. However, the service directory will be available to everyone at all stages and eventually it is likely that (depending on the effectiveness of the initial website) the scope of the website will be extended by Country Health SA to help address the specific needs of other groups at risk of experiencing distress.

We look forward to hearing about the important services you and your organisation offer.

Thank you very much in anticipation for your assistance with this project.

Please click "next" to start the survey.

Other

Thanks again for agreeing to help with this important project.

If you could answer this on behalf of your WHOLE organisation, it would be great.

Please note that all questions marked with an * require an answer. However, if you could answer as many questions as possible it would be great.

Please also note that this survey won't take long to complete but if you exit before completion, your answers will not be saved.

***2. Organisation/ service name**

3. Former name (if applicable) OPTIONAL

***4. Street address**

***5. Suburb/ town**

***6. State**

- | | |
|--------------------------------|----------------------------------|
| <input type="radio"/> SA | <input type="radio"/> NT |
| <input type="radio"/> NSW | <input type="radio"/> Queensland |
| <input type="radio"/> Victoria | <input type="radio"/> Tasmania |
| <input type="radio"/> WA | <input type="radio"/> ACT |

Yes

***7. Postcode**

8. Organisation/service's email

***9. Directions (e.g. opposite the Post Office) OPTIONAL**

10. Postal address (if different from street address) including suburb/town OPTIONAL

***11. Phone number**

12. Fax number OPTIONAL

13. Web address OPTIONAL

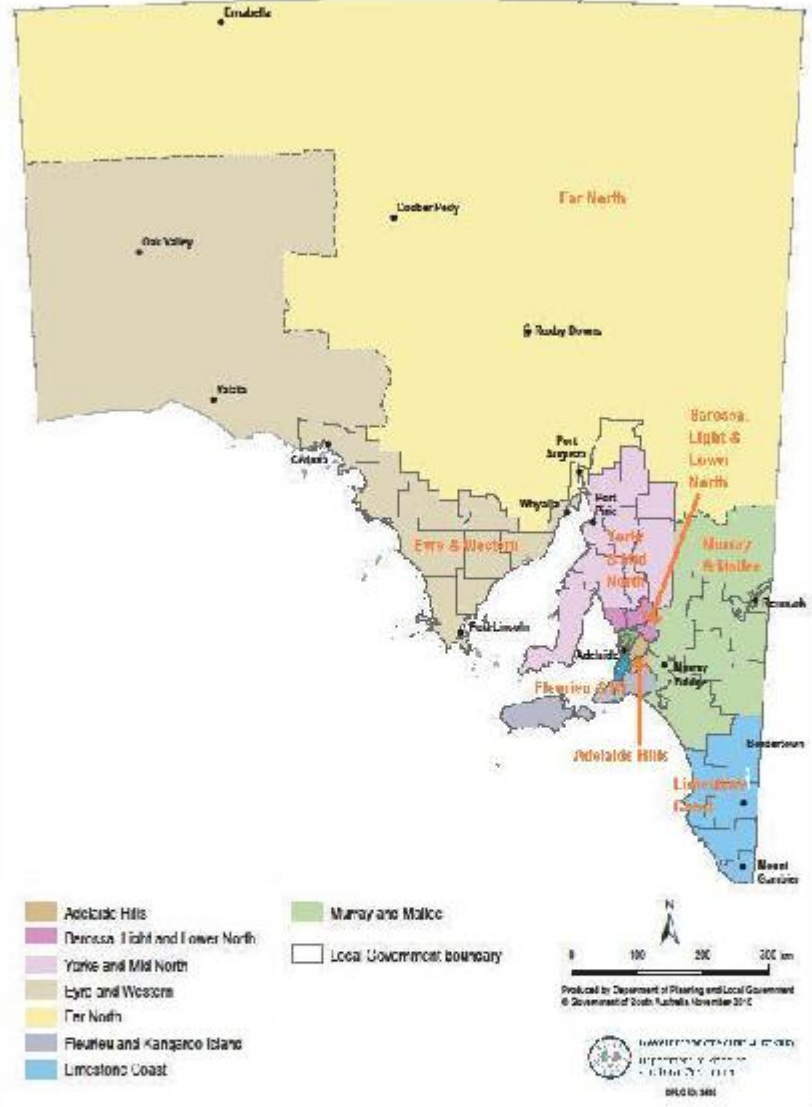
14. Postcodes of towns where outreach services are offered by your organisation (e.g. a counsellor may work primarily in Clare but visit Snowtown one day per week, so Snowtown's postcode should be listed here) OPTIONAL

YES

***15. Region(s) your organisation services (please refer to map below and select as many as are relevant)**

- | | |
|---|--|
| <input type="checkbox"/> Adelaide Hills | <input type="checkbox"/> Murray and Mallee |
| <input type="checkbox"/> Barossa, Light and Lower North | <input type="checkbox"/> Yorke Peninsula and Mid North |
| <input type="checkbox"/> Eyre Peninsula and Western | <input type="checkbox"/> Adelaide |
| <input checked="" type="checkbox"/> Far North | <input type="checkbox"/> Broken Hill |
| <input type="checkbox"/> Fleurieu Peninsula and Kangaroo Island | <input type="checkbox"/> Statewide |
| <input type="checkbox"/> Limestone Coast | <input type="checkbox"/> Nationwide |
| <input type="checkbox"/> Other (please specify) | |

South Australian Government Regions



***16. Days of operation (please select as many as relevant for your WHOLE organisation)**

- | | |
|------------------------------------|-----------------------------------|
| <input type="checkbox"/> Monday | <input type="checkbox"/> Friday |
| <input type="checkbox"/> Tuesday | <input type="checkbox"/> Saturday |
| <input type="checkbox"/> Wednesday | <input type="checkbox"/> Sunday |
| <input type="checkbox"/> Thursday | |

***17. Hours of operation**

- | | |
|--|--|
| <input type="radio"/> 8.30am- 5.00pm | <input type="radio"/> 9.00am- 5.30pm |
| <input type="radio"/> 9.00am- 5.00pm | <input type="radio"/> 24 hours per day |
| <input type="radio"/> Other (please specify) | |

***18. After hours service available?**

- No
- Yes (If so, please describe the nature of this service and provide relevant contact details)

***19. Wheelchair access?**

- | | |
|---------------------------|--------------------------------------|
| <input type="radio"/> No | <input type="radio"/> Not applicable |
| <input type="radio"/> Yes | |

***20. Disability parking?**

- | | |
|---------------------------|--------------------------------------|
| <input type="radio"/> No | <input type="radio"/> Not applicable |
| <input type="radio"/> Yes | |

***21. Disabled toilets?**

- | | |
|---------------------------|--------------------------------------|
| <input type="radio"/> No | <input type="radio"/> Not applicable |
| <input type="radio"/> Yes | |

***22. Service description (please give a detailed description in simple language about the WHOLE organisation- you may like to model it on the example below or copy it from somewhere such as your website)**

OCR EXAMPLE

"When you call Cancer Council Helpline you will speak to caring and experienced people who understand what you need to know. Our expert trained nurse/health counsellors provide confidential information and support for people with cancer and their families and friends about:

- how to prevent cancer or detect it early
- different types of cancer
- diagnostic tests and cancer treatments
- the services available to people with cancer
- the emotional aspects of cancer

Although we do not provide medical advice or recommend a course of action, our trained nurse/health counsellors can provide information to clarify medical terms, procedures and treatments.

Health professionals may also use the service to access up to date information or to refer patients to support services."

***23. Type of organisation**

- Private health-care provider (e.g. GP practice, private Psychologist)
- State community health service/ hospital
- State mental health service
- Division of General Practice
- Non-government organisation (e.g. Lifeline)
- Local government
- Other (please specify)

***24. Service type (please select as many as relevant)**

- | | |
|--|--|
| <input type="checkbox"/> Health | <input type="checkbox"/> Financial |
| <input type="checkbox"/> Emergency health | <input type="checkbox"/> Legal |
| <input type="checkbox"/> Psycho-education/ low intensity mental health | <input type="checkbox"/> Employment |
| <input type="checkbox"/> Mental health | <input type="checkbox"/> Practical |
| <input type="checkbox"/> Emergency mental health | <input type="checkbox"/> Indigenous |
| <input type="checkbox"/> Information/ referral | <input type="checkbox"/> Relationship/ parenting |
| <input type="checkbox"/> Peer support | <input type="checkbox"/> Helpline |
| <input type="checkbox"/> Social and emotional support | <input type="checkbox"/> Advocacy |
| <input type="checkbox"/> Allied health (other than mental health) | <input type="checkbox"/> Child protection/ family services |
| <input type="checkbox"/> Palliative care | <input type="checkbox"/> Disability support |
| <input type="checkbox"/> Transport | <input type="checkbox"/> Drug/ alcohol |
| <input type="checkbox"/> Accommodation (during treatment) | <input type="checkbox"/> Respite/ carer support |
| <input type="checkbox"/> Housing | <input type="checkbox"/> Religious/ spiritual |
| <input type="checkbox"/> Other (please specify) | |

** Mental health services only

25. If applicable, which psychotherapies and/or approaches are used by professionals within your service? OPTIONAL

- | | |
|---|--|
| <input type="checkbox"/> Acceptance and Commitment Therapy- ACT | <input type="checkbox"/> Interpersonal therapy |
| <input type="checkbox"/> Cognitive Behaviour Therapy- CBT | <input type="checkbox"/> Mindfulness-based cognitive therapy- MBCT |
| <input type="checkbox"/> Dialectical Behaviour Therapy- DBT | <input type="checkbox"/> Narrative therapy |
| <input type="checkbox"/> Family therapy | <input type="checkbox"/> Psychoanalysis |
| <input type="checkbox"/> Group therapy | <input type="checkbox"/> Schema therapy |
| <input type="checkbox"/> Hypnotherapy | <input type="checkbox"/> Supportive counselling |
| <input type="checkbox"/> Individual therapy | |
| <input type="checkbox"/> Other (please specify) | |

***26. Service delivery modes**

- | | |
|--|--|
| <input type="checkbox"/> Face-to-face at service provider's premises | <input type="checkbox"/> Email |
| <input type="checkbox"/> Home visits | <input type="checkbox"/> Skype |
| <input type="checkbox"/> School visits | <input type="checkbox"/> Web (other) |
| <input type="checkbox"/> Telephone | <input type="checkbox"/> Post (e.g. sending information) |
| <input type="checkbox"/> Other (please specify) | |

***27. Professions of those providing services within your organisation**

- | | |
|---|--|
| <input type="checkbox"/> General Practitioner | <input type="checkbox"/> Physiotherapist |
| <input type="checkbox"/> Registered Nurse | <input type="checkbox"/> Psychiatrist |
| <input type="checkbox"/> Enrolled Nurse | <input type="checkbox"/> Oncologist |
| <input type="checkbox"/> Mental Health Nurse | <input type="checkbox"/> Surgeon |
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Specialist doctor (other) |
| <input type="checkbox"/> Social Worker | <input type="checkbox"/> Volunteer |
| <input type="checkbox"/> Counselor | <input type="checkbox"/> Administration Officer |
| <input type="checkbox"/> Psychotherapist | <input type="checkbox"/> Dietician |
| <input type="checkbox"/> Occupational Therapist | |
| <input type="checkbox"/> Other (please specify) | |

***28. Appointment required?**

- No Yes
- Other (please specify)

***29. Referral required?**

- No
- Yes (please describe referral requirements)

***30. Payment arrangements (e.g. no fee, bulk billed, gap of \$10 unless have Health Care Card)**

***31. Other cards required?**

- No
- Yes (please specify e.g. Health Care Card)

***32. Age limits?**

- No
- Yes (please specify)

33. Other eligibility criteria (if applicable) OPTIONAL

***34. Waiting list?**

- No
- Yes (If so, please state approximate length of wait in weeks)

***35. Exclusion criteria?**

- No
- Yes (please specify)

***36. Services provided in any languages other than English?**

- No
- Yes (please specify which language/s)

***37. Which issues can this organisation assist PEOPLE AFFECTED BY CANCER with?**

- None
- Emotional health (e.g. depression, fears, nervousness, worry, sleep, loss of interest in usual activities)
- Physical health (e.g. mouth sores, fevers, diarrhoea, breathing, treatment decisions, sleep, sexual)
- Family/ relationship problems (e.g. dealing with children, dealing with partner)
- Appearance
- Bathing/ dressing
- Getting around/ mobility
- Eating
- Cleaning
- Gardening/ home maintenance
- Spiritual/ religious concerns
- Social support
- Transport
- Accommodation during medical treatment (e.g. Greenhill Lodge)
- Housing (other than during treatment)
- Insurance/ financial
- Childcare
- Work/ school
- Information/ referral
- Other (please specify)

38. Other services in your region that you believe should be included in this directory
OPTIONAL

***39. I can confirm that to the best of my knowledge all of the information provided above is true and correct and I understand that it will be published in an online database that will be maintained by Country Health SA.**

- No
- Yes

***40. Name of the person who completed this form (this will not be included in the online database)**

***41. Email address of the person who completed this form (this will not be included in the online database)**

Thank you for taking the time to complete this survey.

You will be notified about how to update your organisation's details via email at a later date.

If you have any comments about how it could be improved or information about exiting service directories that may be helpful, I'd love to hear from you via the email address listed below.

It would also be a great help if you could please pass on the link below to other relevant service providers.

<https://www.surveymonkey.com/s/ruraiserviceprovidershortversion>

We hope to have the website up and running in the next couple of months and will email you when this is the case.

Kind regards

M. Psych (Clin)/ PhD Candidate
School of Psychology
The University of Adelaide

kate.gunn@adelaide.edu.au



APPENDIX 5

Adaption made to the Distress Thermometer for

Country Cancer Support website

Problem checklist

Left out:

- Childcare
- Work/ school
- Ability to have children
- Family health issues

Added:

- Cleaning
- Gardening/ home maintenance
- Social support
- Accommodation during treatment
- Information/ referral

Grouped together under 'emotional health':

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

Grouped together under 'physical health':

- Treatment decisions
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Fatigue
- Feeling swollen
- Fevers
- Indigestions
- Mouth sores
- Nausea
- Nose dry/ congested
- Pain
- Sexual
- Skin dry/ itchy
- Sleep
- Tingling in hands/feet

APPENDIX 6

Promotional materials for Country Cancer Support website

NOTE:

This appendix is included on pages 270-273 of the print copy of the thesis held in the University of Adelaide Library.

APPENDIX 7

Media releases and example newspaper articles

Media Release

www.adelaide.edu.au/news



Tuesday 27 July 2010

Rural recruits needed for cancer study

A University of Adelaide researcher is seeking recruits for a study of cancer patients living in the State's rural areas to help improve facilities and support services for these people.

Masters of Clinical Psychology student Kate Gunn is hoping to identify the unique challenges faced by rural cancer sufferers, who comprise a third of all people living with cancer in Australia.

"The burden is disproportionately heavy for cancer patients in rural and regional areas," Kate says. "They usually have to travel long distances for treatment, which means they are away from friends, family and normal sources of social and psychological support."

"This isolation may increase their levels of distress and also persuade some patients to 'stay put' and not access the recommended treatment, which increases their risk of poor treatment outcomes.

"We need cancer patients to tell us how their experience can be made easier and what services are needed to help them cope."

The study will focus on patients' social, emotional and psychological needs.

Kate says her findings will pinpoint the specific services and resources lacking in rural areas for cancer patients.

Professor Ian Olver, Cancer Council Australia CEO and co-supervisor of Kate's project, says previous studies have shown that outcomes for rural cancer patients can be worse than for their city counterparts and this inequity must be addressed.

Professor Deborah Turnbull, Mrs Lindsay McWha and Dr Matthew Davies are also co-supervisors.

Confidential interviews will be done in either the patient's rural community or at the Cancer Council's offices in Adelaide.

"I am particularly keen to hear from cancer patients who are not coping well and who have suggestions for how the existing services in rural areas can be improved," Kate said.

For more information about the study, or to see if you are eligible to participate, please contact Kate Gunn on 0417 852 537 or kate.gunn@student.adelaide.edu.au

Cancer Council Helpline: 13 11 20 (phone lines are open Monday-Friday 8.30am-8pm).

Media Contact:

Candy Gibson
Media Officer

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Victor Harbor Times, 29/7/10, p. 9.

Media Release

Monday 18 June 2012



THE UNIVERSITY
of ADELAIDE



New cancer website to support country people

A new website has been launched to provide much-needed information and support to rural South Australians affected by cancer – and it's thanks to the work of a University of Adelaide student and a group of dedicated country cancer patients.

The new Country Cancer Support website – www.countrycancersupport.com.au – provides specific information to people in rural areas affected by cancer on how to cope and who can help.

The need for this website was identified by University of Adelaide Psychology student Kate Gunn, who has conducted extensive interviews with rural South Australian cancer patients and their carers as part of her PhD research.

"The people I interviewed emphasised the importance of being given information that is relevant to them, to enable them to cope better, access support services and find out more about getting to Adelaide for their recommended medical treatment," Ms Gunn says.

Many of the people who helped identify the need for the Country Cancer Support website have been working closely with Ms Gunn to develop its structure and content.

"This project has empowered several rural cancer patients by enabling them to be involved in a meaningful project that has the potential to be of benefit to their communities, and their input and guidance has been invaluable," she says.

One such dedicated person is Sharon Schroeter from Port Pirie, who was diagnosed with breast cancer in 2009.

"Being involved with the website has been extremely rewarding," Ms Schroeter says.

"I hope that this website will help people to learn and benefit from our experiences at what is a difficult time, especially for people living in the country."

The website includes practical information and interactive features, such as space to share tips and stories with others, and an online "distress screening tool" which is linked with a rural health and support services directory.

The website also houses short video clips that explain what to expect if patients need to travel to Adelaide for treatment, and self-help exercises for people working through difficult emotional issues.

"The content is tailored to meet the needs not only of rural cancer patients and survivors, but also those of their families, carers, supporters and health professionals," Ms Gunn says.

Professor Ian Olver, co-supervisor of Ms Gunn's PhD project and Cancer Council Australia CEO, says: "Previous studies have shown that outcomes for rural cancer patients can be worse than for their city counterparts, and accessing support services is often more difficult.

/continued

"This website offers information on practical ways rural people affected by cancer can help themselves, and important information about how to access relevant sources of help, which we hope will help address these inequalities," Professor Oliver says.

"The website is a great example of what can be achieved when organisations and members of the community come together with a common purpose," says Professor Brenda Wilson, Chief Executive, Cancer Council SA.

People who use the website and complete a brief online survey about their experience will be eligible to enter a draw to win a Coles Group and Myer voucher valued at \$400.

"The results of this survey will be used to determine how helpful the new site is and how it can be improved," says Ms Gunn, who will now travel around the state speaking to cancer support groups and hospitals about the website.

This project is supported by the University of Adelaide, Country Health SA, Cancer Council SA and the Spencer Gulf Rural Health School.

Media Contact:

Kate Gunn
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The University of Adelaide
Mobile: 0417 852 537
kate.gunn@adelaide.edu.au

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The Recorder, 12/07/12, p.

6.

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Adelaide Advertiser, 26/06/12, p. 29.

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APPENDIX 8

Country Cancer Support website evaluation online survey

If you are:

over 18 years of age,

have been given a diagnosis of cancer and live outside metropolitan Adelaide

OR are a family member, friend, carer or health professional of a person who has been given a diagnosis of cancer and lives outside metropolitan Adelaide,

and have viewed the Country Cancer Support website,

It would be VERY HELPFUL if you could please complete the following confidential survey. It is expected to take approximately 15 minutes for patients, carers and friends and 5 minutes for health professionals (their version is shorter).

If you choose to take part but change your mind once you have started, you may stop at any time.

Although participation is voluntary, on completion of the questionnaire, you may choose to enter the draw to win a \$400 Coles Group and Myer gift card. If you don't mind participating in a brief follow-up survey, you will have a second opportunity to win ANOTHER \$400 Coles Group and Myer gift card.

The information gained from this survey may be published, but at no stage will individual participants be identified- you will remain anonymous. While this research project is being conducted to improve the quality of patient care, please note that involvement may not be of any direct benefit to you and will not affect your medical advice, now or in the future.

There are not expected to be any adverse effects of participation. However, if you feel as though you need help coping in general, please contact either your general practitioner or one of the following service providers:

Cancer Council Helpline: 13 11 20 (cost of local call, 8.30am-8pm, Monday to Friday) for confidential information and support for people with cancer, their families and their friends, from expertly trained oncology nurses

Rural and Remote Mental Health Service: 13 14 65 (cost of a local call, 24 hours per day) for emergency mental health information and assistance

Lifeline: 13 11 14 (cost of a local call, 24 hours per day) for access to trained counsellors

This project has been supervised by Professor Deborah Turnbull (Chair of Psychology, The University of Adelaide), Professor Ian Oliver (CEO, Cancer Council Australia), Ms Lindsay McWha (Visiting Research Fellow, School of Psychology, The University of Adelaide), Dr Matthew Davies (Lecturer, School of Psychology, The University of Adelaide) and Dr Niranjan Bidargaddi (Manager of Mental Health Research & Observatory Unit, Country Health SA).

Ethics approval has been granted from The University of Adelaide, School of Psychology Human Research Ethics Sub-committee. However, if you have any concerns about the ethical aspects of this study, please contact either Kate Gunn (8291 4171 or kate.gunn@adelaide.edu.au), principal supervisor, Professor Deborah Turnbull (8313 1229) or the convenor of the School of Psychology Human Research Ethics Sub-committee, Associate Professor Paul Delfabbro (8303 4936).

TO START THE SURVEY PLEASE CLICK 'NEXT' (BELOW).

Supported by:



Thank you for agreeing to do this questionnaire. Your participation is GREATLY appreciated.

*** 11. What is your postcode at home (or where you work if you are a health professional)?**

*** 12. What is your age (in whole years)**

*** 13. Which gender are you?**

- Male
- Female

*** 14. What is your marital status?**

- Married or living with a partner
- Separated/ divorced
- Widowed
- Single/never married

*** 15. What is the highest level of education you have completed?**

- Did not finish primary school
- Finished primary school
- Finished high school
- Trade certificate, apprenticeship, diploma or certificate from a college or TAFE
- Degree or diploma from a university
- Postgraduate degree

***16. In which country were you born?**

- Australia
- UK or Ireland
- Italy
- Greece
- Holland
- Germany
- Other European
- New Zealand
- African Country
- Asian Country
- South America
- North America
- Oceania
- Other (please specify)

17. Are you of Aboriginal or Torres Strait Islander origin?

- No
- Aboriginal
- Torres Strait Islander
- Both
- Don't know

*** 18. On approximately how many separate occasions have you visited this website (use numerals e.g. '3')?**

*** 19. Approximately how long in TOTAL have you spent looking at this website or looking at material printed from it?**

- 0- 5 minutes
- 5- 10 minutes
- 10- 20 minutes
- 20- 30 minutes
- 30- 60 minutes
- 1- 2 hours
- 2- 5 hours
- 5- 10 hours
- > 10 hours

*** 20. Why did you visit this website?**

(E.g. "I wanted information on where to stay in Adelaide and where my husband could have counselling")

*** 21. Did you find what you were looking for?**

- Yes and more
- Yes
- Partially
- No. Please describe exactly what you were looking for so we can consider adding it in the future.

***22. Which components of the website have you read/used? (Please select all relevant)**

- Website links (to other websites)
- Quotes by other country people (In green boxes)
- Home/ first page
- 'I'm a person with cancer (recently diagnosed)' information pages
- 'I'm a person with cancer (undergoing treatment)' information pages
- 'I'm a person with cancer (finished treatment and returned home)' information pages
- 'I'm a carer/ family member/ supporter' information pages
- 'I'm a health professional' information pages
- 'Practical tips for dealing with difficult emotions' information page
- 'Practical tips for dealing with difficult emotions' fact sheets/ PDFs
- 'Find help near you' page (patient version)
- 'Find help near you' (health professional version)
- 'My story' page
- 'Read others' stories' page
- 'Share your tips' page
- 'Recommended reading/ resources' page
- 'About this website' pages
- 'How to catch the Cancer Council bus and what to expect when going for treatment at the RAI' video clip
- John's tour of Cancer Council Lodge- Greenhill video clip
- John's tour of Cancer Council Lodge- Flinders video clip
- Other (please specify)

***23. What impressed you MOST about this website?**

(E.g. printable sheets on managing emotional issues)

***24. To what extent do you think this website is:**

	Not at all	A little	A moderate amount	A lot	A great deal
... helpful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... difficult to understand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... relevant to your needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... visually appealing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... difficult to read	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... easy to use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... comprehensive/ complete	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... novel/ offers something new	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... clear	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... accurate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... user-friendly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... credible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... interesting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... not detailed enough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... necessary	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... confusing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... written by people who are knowledgeable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... written by people who understand what I'm going through	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... too complicated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***25. How likely are you to:**

	Not at all likely	Slightly likely	Moderately likely	Very likely	Extremely likely
... return to this website	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... recommend this website to someone else	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

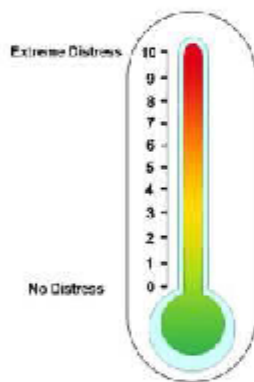
***26. What best describes your role when visiting this website today?**

- I am a person who has been RECENTLY DIAGNOSED with cancer
- I am a person who is UNDERGOING CANCER TREATMENT
- I am a person who has FINISHED CANCER TREATMENT
- I am a family member, friend or carer of a person who has been RECENTLY DIAGNOSED with cancer
- I am a family member, friend or carer of a person who is UNDERGOING CANCER TREATMENT
- I am a family member, friend or carer of a person who has FINISHED CANCER TREATMENT
- I am a health professional who primarily works in an URBAN SETTING
- I am a health professional who primarily works in a RURAL SETTING
- Other (please specify)

** Patients and supporters only (not health professionals)

***27. Please select the number (0-10) that best describes how much distress you have been experiencing in the past week, including today.**

- 10 (Extreme distress)
- 9
- 8
- 7
- 6
- 5
- 4
- 3
- 2
- 1
- 0 (No distress)



** Patients and supporters only (not health professionals)

***28. In the past 4 weeks:**

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
About how often did you feel tired out for no good reason?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel so nervous that nothing could calm you down?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel hopeless?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel restless or fidgety?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel so restless you could not sit still?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel that everything is an effort?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel so sad that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About how often did you feel worthless?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. Are you currently receiving treatment for anxiety, depression, or any other mental health problem?

Yes

No

** Patients and supporters only (not health professionals)

***30. To what extent did the following aspects of this website help to reduce your levels of cancer- related distress?**

(Please select "I didn't look at this section" if necessary)

	"I didn't look at this section"	Not at all	A little	A moderate amount	A lot	A great deal
Reading quotes about others' experiences (In green boxes)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading the fact sheets about how to manage difficult emotions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading information about what to expect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading information about what to do next	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding out about the sorts of help available to me using the 'Find help near you' page	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding out about the sorts of help available to me using the information pages	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding out about how serious my level of distress is considered to be and the types of services that might help someone with that level of distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Viewing the video clips	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading others' stories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sharing my own story	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading others' tips/ recommended reading	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sharing my own tips/ recommended reading	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>					

** Patients and supporters only (not health professionals)

***31. Please rate the degree to which you agree with following statements**

(Select **"Not relevant to me"** if necessary)

"Because of this website I am now:

	"Not relevant to me"	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
... feeling better informed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling better understood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling more frustrated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... more motivated and confident to access professional support services in Adelaide (e.g. accommodation, counselling)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... more motivated and confident to access professional support services at home (In my rural area) (e.g. transport, counselling)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... more motivated and confident to travel to Adelaide for medical treatment (e.g. chemotherapy, radiotherapy, surgery)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... more confident that I will be able to deal effectively with my own cancer-related distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... more confident that I will be able to deal effectively with others' cancer-related distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... thinking that transition into or out of treatment will be more manageable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling better equipped to deal with this diagnosis and/or treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling more worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling as though the unique needs of rural people have been recognised	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling more confused	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling more 'normal'	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling less distressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling less isolated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feeling as though I'm not the first person to experience these issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

** Patients and supporters only (not health professionals)

***32. Please select where you were in terms of your willingness to access the following sources of support BEFORE looking at this website.**

Email	I was not thinking about it	I was weighing up the pros and cons	I was making small changes in preparation to do it and was thinking about how to deal with the hard parts	I was already doing it	I had already made it a regular part of my life
Professional support (e.g. counselling, Cancer Council Helpline, social worker)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peer support (e.g. support group, Cancer Connect service, blogging)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support from friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***33. Please select where you are in terms of your willingness to access the following sources of support AFTER looking at this website.**

Email	I am not thinking about it	I am weighing up the pros and cons	I am going to make small changes in preparation to do it and think about how to deal with the hard parts	I am going to do it	I am going to make it a regular part of my life
Professional support (e.g. counselling, Cancer Council Helpline, social worker)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peer support (e.g. support group, Cancer Connect service, blogging)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support from friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

** Patients and supporters only (not health professionals)

***34. To what extent do you agree with the following statements?**

(Please select "I didn't notice this/ not applicable" if necessary)

After looking at this website, I am more likely to use support services because of the...

	"I didn't notice this/ not applicable to me"	Not at all	A little	A moderate amount	A lot	A great deal
... Information on when and where to access services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... Information on the consequences of using services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... Instructions on how to access services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... encouragement to make you think about barriers to service use and ways to solve these potential problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... video clips I watched that showed others using services and demonstrating how they can help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... Information on whether the issues you are facing are 'serious enough' to warrant using services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... Information on how much using services might help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... encouragement to think about whether the costs of seeking help are worth the benefits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... Information about others' approval of the use of services (testimonials)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... general encouragement to seek help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... reassurance that needing some support is 'normal' in these circumstances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... Information on how to communicate with health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... Information provided by others who have already used services/ sought help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... help with working out gradual steps towards accessing help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... Information on how seeking support is recommended for everyone affected by cancer (and nothing to be ashamed of)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... feedback about your level of distress and services that might be appropriate based on this (when using 'Find help near you' page)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... suggested things to do and think about, based on how ready you are to access support (when using 'Find help near you' page)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... stress management techniques	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... time management strategies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

** Patients and supporters only (not health professionals)

*** 35. Which of the following services:**

	... had you used before ever visiting this website?	... do you intend to use within the next month?	... do you intend to use within the next 6 months?
None	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist (e.g. oncologist, surgeon)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer patient accommodation facilities (e.g. Greenhill Lodge)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer care coordinator/ breast care nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rural liaison nurse (at urban treatment hospital)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group/ telephone peer support/ online peer support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport services (e.g. Community Passenger Network, PATS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helplines (e.g. Cancer Council Helpline, Rural and Remote Mental Health Service Line)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Religious/ spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Education programs (e.g. Look Good, Feel Better, Staying Healthy After Cancer)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial counselling/ assistance programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community nurses/ in-home care (e.g. bathing/ dressing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy groups (e.g. Cancer Voices)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other allied health professionals (e.g. occupational therapist, physiotherapist, dietician)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Childcare services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practical assistance (e.g. cleaning, home maintenance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="text"/>		

** Patients and supporters only (not health professionals)

***36. After viewing this website, to what extent do you think it:**

(Please select "I didn't notice this/ not applicable to me" if necessary)

	I didn't notice this/ not applicable to me*	Not at all	A little	A moderate amount	A lot	A great deal
... provides you with relevant information about the range of services available to help deal with cancer-related distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... clearly explains how to access relevant support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... challenges the belief that help is unnecessary	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... highlights ways that most people could benefit from the use of some services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... reduces the need to ask health professionals for information on non-medical (but cancer-related) issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes you feel less overwhelmed and more capable of seeking help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... provides you with the information you need on support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes you less worried about stigma associated with cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes you less worried about stigma associated with seeking help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes you feel less worried or embarrassed about having to ask for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes you less worried that you will know the service provider you choose to see from another setting (e.g. through sport, work or school)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... reduces your concerns about privacy and gossip resulting from the use of services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes you more aware that seeking help does not mean that you are a failure or a shameful thing to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes you more aware that it is recommended that everyone given a diagnosis of cancer uses support services of some description	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes you less concerned about using support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

** Health professionals only (not patients and supporters)

***37. To what extent has this website provided you with new knowledge about:**

	Not at all	A little	A moderate amount	A lot	A great deal
... how to help rural patients manage cancer-related distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... services that may be able to benefit your rural patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... the unique stressors rural cancer patients face	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... things to consider when treating rural patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... how to diagnose cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... how to connect your rural patients with relevant support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... what is meant by 'psychosocial interventions'	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... why it is important to consider cancer patients' psychosocial needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... why it is PARTICULARLY important to consider RURAL cancer patients' psychosocial needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... the distance your rural patients need to travel to access services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... the importance of screening for distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... the importance of regular bowel cancer screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... how to screen for distress (using this website as an aid)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***38. How do you intend to use this website with your patients/ clients in the future?**

- I don't intend to use it again
- By giving them a flyer about the website and suggesting they look at it
- By printing off information pages from the website and giving it to them
- By looking up things on the information pages and verbally telling them facts based on these pages
- By looking up things on the information pages and writing the information from them down for them
- By printing off results from the 'Find help near you' page for them
- By looking up things in the 'Find help near you' page and verbally telling them about the results
- By looking up things in the 'Find help near you' page and writing the results down for them
- By showing them the website during the consultation/ session
- By telling them about the website and suggesting they look at it at home
- Other (please specify)

***39. How many patients have you referred to this website?**

** Health professionals only (not patients and supporters)

***40. To what extent do you think this website:**

(Please select "I didn't notice this/ not applicable to me" if necessary)

	I didn't notice this/ not applicable to me*	Not at all	A little	A moderate amount	A lot	A great deal
... provides relevant information about the range of services available to help deal with cancer-related issues/ distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... clearly explains how to access relevant support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... challenges users' belief that they don't need help and highlights ways that most people could benefit from the use of some form of supportive care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... reduces the need to ask health professional for information on non-medical (but cancer-related) supportive care issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes users feel less overwhelmed and able to seek help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes users less worried about stigma associated with cancer and therefore less concerned about using cancer-related services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes users feel less worried or embarrassed about having to ask for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes users less worried that they will know the service provider they choose to see, from another setting (e.g. through sport, work or school)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... reduces users' concerns about privacy and gossip resulting from their use of services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes users more aware that seeking help does not mean that they are 'a failure' or a shameful thing to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... makes users realise that it is recommended that everyone given a diagnosis of cancer uses support services of some description	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***41. How many years of your life have you LIVED in a rural area of Australia?**

***42. How many years of your life have you WORKED in a rural area of Australia?**

43. Please briefly describe your profession/ job title

(E.g. "GP", "Community Health Nurse")

***44. How did you hear about this website? (Please select as many as relevant)**

- Pamphlet
- Poster
- Magnet
- Magnet board
- Family member or friend
- General practitioner
- Specialist
- Nurse or other health provider
- Social worker, counsellor, psychologist or other allied health provider
- Cancer support group
- Cancer Council Helpline
- Newspaper or magazine article
- TV/radio
- Web search engine (Google, Bing, etc.)
- Social networking link (Facebook, Twitler)
- Link from another web site
- Health organisation or association (hospital, clinic, etc.)
- Don't know
- Email (please specify who from)

***45. Please describe other sources of cancer-related information you have used in the past 6 months**

(E.g. "A Cancer Council SA pamphlet on treatment side effects I picked up in my GP's waiting room")

***46. When comparing these OTHER sources of information with the Country Cancer Support website, which do you prefer and why?**

(E.g. "I prefer this website because I can remain anonymous and it is more convenient" OR "I'd rather pick up a printed booklet from my local GP because I don't like using computers")

47. How do you think this website could be improved?

48. Any other comments?

Thank you very much for completing this survey. Your time and effort is greatly appreciated.

Just one more thing...

49. OPTIONAL- Please select all relevant and leave your email address if you would like to:

- go into the draw to win a Coles Group and Myer voucher valued at \$400
- be contacted again regarding participating in a quick follow-up survey (e.g. short, 10 question online questionnaire) and have another opportunity to win a \$400 voucher
- receive a summary of findings when this study is complete

Email address:

Thanks again!

Kind regards

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