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Construction of Male Identity: The Relationship between Cancer Support Groups and Identity for Men who are Living with Cancer

Kathryn M. Chegwidden

A Report Submitted in Partial Fulfilment of the Requirements for the Award of Bachelor of Arts Honours in Psychology, Faculty of Community Studies, Education and Social Sciences, Edith Cowan University.

Date of Submission: October, 2004

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

- i. incorporate without acknowledgement, any material previously submitted for a degree or diploma in any institution of higher education;
- ii. contain any material previously published or written by another person except where due reference is made in the text; or
- iii. contain any defamatory material.

Signature:

Date

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Construction of Male Identity: The Relationship between Cancer Support Groups and Identity for Men who are Living with Cancer.

A Review of the Literature.

Kathryn M. Chegwidden

Edith Cowan University

Bachelor of Arts (Psychology) Honours

Construction of Male Identity: The Relationship between Cancer Support Groups and Identity for Men who are living with Cancer

A Review of the Literature

Abstract

A diagnosis of cancer may have many meanings for a man in terms of the impact that cancer has on various aspects of his life, including his identity as a man. Subsequent membership of a cancer support group may support men negotiating their changing identity. A review of the relevant literature examines the impact of cancer and its treatments for men, and the various changes resulting from men's experiences with cancer and cancer treatments. An overview of support groups, their function, composition, and benefits is provided with a discussion of the advantages and disadvantages of professional and member facilitated cancer support groups. Men and their membership in various support groups and the role of support groups in the renegotiation of men's identities is explored. The lack of literature regarding the role of cancer support groups in the renegotiation of men's identity following a diagnosis of cancer indicates a need for research in this area.

Construction of Male Identity: The Relationship between Cancer Support Groups and Identity for Men who are living with Cancer.

A Review of the Literature.

It is estimated that at least 1 in 3 Australian men will be diagnosed with cancer by the age of 75 years (National Breast Cancer Centre and National Cancer Control Initiative [NBCC & NCCI], 2003), During 2001, 4122 new cases were diagnosed in Western Australia, 3206 of which were in the Perth metropolitan area (Threlfall & Thompson, 2003). The most common new incidences of cancer reported for men in 2001 were prostate cancer (22.7%), followed by colorectal cancer (14.8%), melanoma (11.5%) and lung cancer (11.3%) (Threlfall & Thompson, 2003).

A cancer diagnosis impacts on practical, emotional and psychological areas of living as well as having physical effects (NBCC & NCCI, 2003). Impacts such as altered body image and changed body functions, may require men to renegotiate their identity because they no longer 'fit in' with their previous perception of masculine identity (Ofman, 1993). Also, support needs for men who have cancer may be high (Steginga, Pinnock, Gardner, Dunn, & Gardiner, 2002). For example, men who have prostate cancer may have a high need for comprehensive information due to the range of treatments available (Steginga et al., 2002). Additionally, those patients who have a disfigurement resulting from their cancer or associated treatment frequently have high needs for a support network (Richardson, Lee, & Birchall, 2002). A range of supports including behavioural therapies and psychotherapy should be available to assist men alleviate the psychological ramifications of a cancer diagnosis. Additionally and/or alternatively, membership of a cancer support group may provide the needed support through education and assistance with psychological

adjustment to changes wrought by disease (Butler & Beltran, 1993; Kornblith et al., 2001; Johnson, 2000).

The purpose of this review is to argue that cancer support groups may be valuable in assisting men to renegotiate their identities following a diagnosis of cancer, as men may be confused about their masculine identities and be otherwise isolated in their distress. In this literature review, the changes and adjustments that men may make following a diagnosis of cancer are discussed followed by an examination of the function and benefits of support groups in general and cancer support groups specifically. Men and their membership in support groups will then be explored, followed by a discussion of the role of support groups in facilitating men's renegotiation of identity.

Impact of Cancer Diagnosis on Men

A diagnosis of cancer may impact on roles in all facets of men's lives, and may also challenge their beliefs and values, such as their belief that they are the family provider and producing an income takes precedence over nurturing and maintaining relationships (Foltz, 1987). For example, results of a qualitative study of men living with testicular cancer undertaken by Gordon (1995), suggest that many men experience a change in their perceptions of the importance of their personal relationships and a change in their belief that work is a more important priority for them than their family. This suggests that the men feel that their lives prior to the diagnosis of cancer no longer provide what they really want and so re-evaluate their lives and values accordingly (Gordon, 1995).

For some men the physical impact of cancer on their lives necessitates a reevaluation of their future. For example, interviews by Znajda, Wunder, Bell, and

Davis (1999) with men who had been diagnosed with soft tissue sarcoma established that many of the men had to re-evaluate their future working life, especially if they were engaged in physical work that required them to be physically strong and able. Some men also realised that they no longer took their health or life for granted following their diagnosis of cancer (Znajda et al., 1999). As a consequence of this reevaluation, the men in Znajda's study took one day at a time and were more inclined to seek advice and support from their health care team than they had prior to the diagnosis of cancer (Znajda et al., 1999).

As well as re-evaluating their lives, men may need to restrict some social activities either because of the cancer or treatment (Charmaz, 1995; NBCC & NCCI, 2003; Templeton, 2003). For example, the side effects of treatment may cause debilitating fatigue and nausea, which, by necessity, require the men to 'slow down'. Feelings of embarrassment because of altered bodily appearance including feminisation of appearance from cancer treatments, may impact on the social activities that some men feel comfortable in continuing to undertake (Templeton, 2003).

Psychological changes resulting from a diagnosis of cancer and/or treatment may include a crisis in identity, often manifest by anxiety or depression, resulting from altered roles associated with, for example, changes in work activities or loss of work and increased reliance on family (Foltz, 1987). Obvious physical changes that can occur with male cancers, such as loss of facial hair and feminisation of appearance resulting from testosterone depleting hormone treatment (Templeton, 2003), can also result in a crisis in identity. This may be exacerbated by the embarrassment some men experience resulting from their feelings about their

changed body appearance compared to other men (Boehmer & Clark, 2001; Clark, Jones, & Newbold, 2000; Fan, 2002; Kiss & Meryn, 2001).

Findings from studies of male identities following a diagnosis of cancer, in particular testicular and prostate cancer, show that men are often distressed by the effects of cancer and/or treatment and this distress can be exacerbated by uncertainty that the treatment being undertaken will not cure the cancer. Effects such as feminisation of appearance (Ofman, 1993), lack of sexual functioning (Kiss & Meryn, 2001), decreased libido (Fan, 2002), and altered abilities leading to changes in identities (Adamsen, Rasmussen, Midtgaard, Pedersen, & Sonderby, 2001) all may cause distress by, for example, adding strain to marital relationships. Further, sexual dysfunctions such as impotence, infertility and ejaculatory problems may challenge a man's identity particularly if it is associated with side effects of hormone treatment causing lowered libido or feminisation of appearance (Chapple & Ziebland, 2002).

The extent to which this challenge to masculine identity occurs, however, depends on many factors including the severity of the cancer and type of treatment, its duration and the psychological state of the individual man (Foltz, 1987) as well as the man's personal relationships and age (Chapple & Ziebland, 2002). This complexity is further borne out by the multifaceted responses Chapple and Ziebland's study evoked from men living with prostate cancer. For instance, some men reported that, although they were impotent, they still felt masculine, primarily because they still had sexual desires. However, other men who experienced lowered libido and were impotent, expressed feelings of no longer being masculine (Chapple & Ziebland, 2002).

Recent guidelines for psychosocial care of adults with cancer recommend that clinicians attend to the support needs for those who have cancer, while understanding that there may be gender differences in actual needs (NBCC & NCCI, 2003). This can be accomplished by clinicians maintaining awareness of appropriate support services available, assessing support needs and then referring their clients to appropriate agencies or individuals (NBCC & NCCI, 2003).

Although individuals with cancer have access to their medical team and are often referred to other services (NBCC & NCCI, 2003), another way of supporting adjustment to changes and relieving distress following a diagnosis of cancer is through membership of a cancer support group (Clark, Bostwick, & Rummans, 2003; Lepore, Helgeson, Eton, & Schulz, 2003). A comprehensive review by Fawzy, Fawzy, Arndt and Pasnau (1995) of numerous studies involving cancer support groups, indicates that support groups are useful in providing information about specific cancers, living with cancer, including coping with the changes that follow a diagnosis of cancer, managing pain, and exploring issues such as death and dying. Further, Fallowfield (1995) suggests support groups alongside other forms of psychosocial interventions such as psychotherapy, behavioural therapy or educational therapy, are essential to the overall well being and care of cancer patients as many facets of living are affected by cancer.

Support Groups

Although support groups vary considerably in their level of organisation, management, funding, available resources and membership numbers (Health Issues Centre, 1991), many function to meet the needs of individuals that are not met by mainstream society or service providers (Parkinson, 1979). Support groups can be

defined as groups of people with similar needs who come together to offer mutual assistance in order to reach common goals or relieve distress caused by challenges such as illness or hardship (Bartalos, 1992; Davis, Pennebaker, & Dickerson, 2000; Katz & Bender, 1976; Levine & Perkins, 1987). The advantages of a support group over professional care include usually being community based, they are formed as a response to the needs of specific groups of people, and are generally run at little cost to the members of the groups (Levine & Perkins, 1987). Additionally, support groups provide a reference group for the individual where their problem or needs are considered normative rather than unusual (Levine & Perkins, 1987). Further, the reciprocity that often occurs in support groups can assist in lifting the individual's self-esteem by giving them a sense of self-worth (Levine & Perkins, 1987).

Membership in a support group can promote a sense of community as described by McMillan & Chavis (1986). Sense of community incorporates such features as membership, influence, integration and fulfilment of needs and connectedness. Other features of support groups include providing a space for role modelling, and for sharing skills and strategies to deal with emotions, and day-to-day concerns (Reddin & Sonn, 2003). Support groups can also be a place where members can safely expose emotions or concerns (Levine & Perkins, 1987). Further, support groups can provide meaning to the experiences of the members within the group when those experiences are not the norm in mainstream society (Levine & Perkins, 1987).

Support groups adopt differing foci in the services they offer members. Support groups may provide self help (Levine & Perkins, 1987), peer discussion, social support, emotional support (Helgeson, Cohen, Schulz, & Yasko, 2000) and/or educational and psychoeducational support (Fawzy et al., 1995). Self help focussed support groups usually comprise two or more people with similar problems or concerns and are run by the members themselves (Self-Help Resource Centre, 2004). Peer discussion focussed support groups are similar but commonly have a trained facilitator to direct discussion (Helgeson et al., 2000). Self help and peer discussion support groups can provide social and emotional support through discussion of concerns and fears with someone who has had similar experiences and understands the emotions associated with those fears and concerns (Helgeson et al., 2000).

Support groups that focus on education and psychoeducation may also be beneficial beyond their educative value, as members may benefit emotionally as they become more informed and use the support group as a resource for continued well being (Coscarelli, 2004). According to Helgeson and Cohen (1996) educational or psychoeducational groups that are professionally facilitated, often provide better outcomes for cancer patients than discussion groups in terms of lessening distress and anxiety by assisting group members to become empowered through knowledge of their illness (Helgeson & Cohen, 1996).

Support groups are beneficial by being an affordable service that enables the individual to feel empowered through getting needs met (Hedrick, Isenberg, & Martini, 1992). This can be especially important for those who are experiencing serious illnesses such as cancer, as often adequate emotional support is lacking and financial resources can be strained through costs of treatments and care (Tedder, 1998). The major benefits of support groups however, that regularly occur in the literature, are the provision of information, alleviation of isolation, and development of a support network of people with similar problems and needs.

Major Benefits of Support Groups

Provision of Information

Studies such as those conducted by Scordo (2001) of a mitral valve prolapse support group and Butler and Beltran's (1993) examination of a sickle cell disease support group reinforce the notion that provision of information regarding serious illness is important. Both studies indicate that provision of information assists seriously ill individuals to understand the implications of their illness, to plan their lives and empowers them to make informed decisions (Butler & Beltran, 1993; Scordo, 2001).

Alleviation of Isolation and Development of Support Networks

Scordo (2001) highlights the importance of the support group in teaching coping skills for individuals to live with their disease and providing a space for individuals to talk to others with similar experiences. The result is, according to Scordo (2001), that the individual feels less isolated in his or her illness.

Likewise, Vareldzis and Andronico (2000) found from informal discussions with three college men's support groups that feelings of isolation are alleviated and support networks develop through attendance at support group meetings. Even though men come from different cultural backgrounds and differing sexual orientations, members of groups feel safe in sharing information and exploring emotions. Further, a sense of belonging to the group emerges as a result of shared similar experiences among group members (Vareldzis & Andronico, 2000).

Results from a study by Davis et al. (2000) suggest that people with illnesses that result in isolation caused by social stigmatisation, fear of rejection or prejudice are more likely to seek membership in a support group than those who are not subject

to effects of social stigma or prejudice. The findings from the Davis et al. (2000) study are reflected in a mixed method study by Stewart et al. (1995) involving 30 men with haemophilia and Human Immunodeficiency Virus/Acquired Immunological Deficiency Syndrome (HIV/AIDS), Results from the Stewart et al. study indicate that individuals with HIV/AIDS are often reluctant to seek support from friends and colleagues because of fear of rejection, prejudice and loss of confidentiality. However, belonging to a support group allows the group members to receive emotional support without fear of rejection and stigmatisation (Stewart et al., 1995).

Cancer Support Groups

Given that people with cancer often have informational needs unmet by their medical providers, are frequently emotionally isolated through fear of rejection or embarrassment and may be confronted by important decisions regarding their treatments and altered lifestyles (Sanson-Fisher et al., 2000), cancer support groups may provide the necessary support to meet these needs by providing a support network, and a venue for sharing information (Hedrick et al., 1992). Cancer support groups may be either facilitated by professionals such as nurses or psychologists, or by the members themselves. Both may present some advantages for the members of the group and also have some disadvantages. For example, advantages of professionally facilitated groups include being usually based on information provision with the facilitator keeping group members 'on track' in discussions (Tulsky & Cella, 1992). According to Gray et al. (1997) men appear to be more likely to attend groups that focus on information. A disadvantage, however, is the greater likelihood of the facilitator being regarded as an 'expert' by the members and therefore, members may lose out on the value of experiential knowledge of particular issues (Health Issues Centre, 1991).

Advantages of member facilitated groups which are usually emotion focussed (Lepore et al., 2003) include the establishment of friendships and social networks (Clark et al., 2003; Gray, Fitch, Davis, & Phillips, 1997; Helgeson & Cohen, 1996). However, disadvantages may include an increase in member distress through lack of direction in discussions and perhaps instillation of fear as a result of inaccurate information being provided (Helgeson & Cohen, 1996).

There is no one particular type of cancer support group that appears to work best for men. However, literature indicates that men may initially prefer to attend an informational cancer support group although the focus may change to one of receiving or providing emotional support (Gray et al., 1997; Steginga et al., 2002). Steginga et al. (2001) suggest that men may, therefore, benefit from support groups that offer a balance of both information and emotional support.

While it appears that many cancer support groups may be beneficial to both men and women, both in terms of informational support and emotional support, the majority of research involving cancer support groups and their efficacy has involved women (Lepore et al., 2003). This being said however, increasingly, research is being conducted among men, particularly those men living with prostate cancer (Steginga et al., 2002). According to guidelines published by the National Breast Cancer Centre and National Cancer Control Initiative (2003), the needs of men may differ from those of women and as such, further research is needed to gather evidence to determine what works best for men.

Helgeson et al. (2000) suggest that, although research would need to provide further confirmation, results of studies involving women living with cancer can possibly be generalised to men living with cancer. Although results from a study by Hunt, Bond, and Pater (1990) found that similar benefits, such as lessened distress, were gained by both men and women in support groups, there is scant evidence that supports Helgeson's claims. Indeed, studies such as those by Harrison, Maguire and Pitceathly (1995) and Znajda et al. (1999), indicate that men and women have different issues and needs, as well as different ways of dealing with a cancer diagnosis and its treatments.

Men and Cancer Support Groups

Having the opportunity to receive pertinent information regarding cancer and to discuss treatment options with other men who have cancer can help to allay some fears for some men who are living with cancer. For example, in a study by Steginga et al. (2001) of 206 men attending prostate cancer support groups in Queensland, it was concluded that men would benefit from receiving educational interventions regarding prostate cancer and treatments as well as being given the opportunity to voice concerns about their disease and receive support from peers. Steginga et al. found that this was especially salient for those men who were offered several options of treatment or were uncertain of outcomes of treatments, particularly in regard to sexual function.

Results from a study undertaken by Lepore et al. (2003) involving 250 men with prostate cancer, found that support groups offering education and emotional support, had positive benefits for members. These benefits included increased knowledge about the disease, provision of a place where the development of coping

strategies to deal with changed physical functioning, such as sexual dysfunction, could be facilitated, and a place where continued stable employment was enabled. These results are favourable when compared to those men who had no group intervention or to those men who had educational support only. Further, the Lepore et al. (2003) study results suggest that cancer support groups offering combined informational and emotional support may cater for a wider range of needs among male cancer patients.

Men frequently gain positive benefits from belonging to a cancer support group, even though the initial intention is to only seek information (Gray et al., 1997). Gray et al. interviewed men from a prostate cancer support group, the majority of whom stated that they often first attended the group in order to gain information about their illness. However, they then continued to attend for further information and to offer support to new members of the group (Gray et al., 1997). Further, the diagnosis of cancer often coincided with retirement from work and the men found that attendance at group meetings afforded them some feelings of usefulness to others. For other men it meant that they were able to transfer skills, such as organisational skills, to benefit the group. Involvement in the cancer support group also enabled some of the men to become more responsible for their own health and feel more able to question the doctor's decisions and take control over their treatment decisions (Gray et al., 1997). Some men also found that they were able to become more open to others and to offer empathy to those who were experiencing hardships in their lives (Gray et al., 1997), thus giving them the feeling of being able to contribute to the wellbeing of others in the group. Although the amount of research into the value of cancer support groups is encouraging, and there is an

increase into the research into prostate cancer support groups, there appears to be little research that focuses on male identity construction in the context of the cancer support group. Research in this area will benefit organisations that run cancer support groups catering for men by providing information to aid in their development of support groups.

Support Groups and Masculine Identity

By examining research into other types of men's support groups it may provide a template as to what is needed to attract men initially to cancer support groups, and to facilitate their continued attendance. Additionally, benefits that men may gain from regular attendance such as a feeling of belonging to a group of likeminded men, and being within a safe environment in which to explore emotions and learn skills such as effective communication may become apparent. For example, Reddin and Sonn (2003) who studied men involved in a men's group, conclude that men often discover their authentic or 'true' male identity through membership to a men's support group, rather than suppressing it by trying to live up to the dominant socially constructed hegemonic masculinity. For example, some men in Reddin and Sonn's study stated that they had changed since becoming members of the group by becoming less resistant to asking for emotional support and more accepting of their individual frailties and changes happening in their personal lives. As a result, individual men feel that they are more aware of, and more comfortable with, who they are as a person (Reddin & Sonn, 2003). Similarly, Flood (1995) maintains that men's groups offer a place for personal growth, and affirmation of manhood through improved communication skills necessary in a group setting and increased selfawareness. Similar findings are apparent from other studies. For example, a study by Stewart et al. (1995) of men living with haemophilia and HIV/AIDS found that men are more likely to manage changes that occur as a result of infection with HIV, if they are attending a support group. This may occur because the men feel safer and less isolated when with peers who have similar problems (Kaufman, 1994).

Being a member of a group where the other men have similar problems helps members normalise their experiences and problems (Addis & Mahalik, 2003; Steginga et al., 2001). According to Addis and Mahalik (2003) if men are in the company of other men who have similar concerns or problems, for example lack of sexual function or altered physical appearance, then those men follow the norm in terms of masculinity for that group. Therefore, in a setting such as a prostate cancer support group where sexual dysfunction is common, men may feel that their masculinity is less threatened and be able to negotiate the changes in their masculine identities more successfully.

The above findings are encouraging as masculine identities are often challenged by the sequale of a diagnosis of cancer including sexual dysfunction and changed roles. As such, a cancer support group may be valuable for men negotiating changes in their identities.

Masculine Identity Construction, Cancer, and Cancer Support Groups

Cancer support groups may provide a social context in which men living with cancer are able to renegotiate their identities, resulting in lessened conflict and distress arising from changes that have occurred as a result of cancer and its treatments. According to post structural explanations of gender, gendered identities are not innate (Coltrane, 1994), but are constructed from experiences in social and cultural contexts through relationships, language, power balances and imbalances

and individual situations (Hare-Mustin & Maracek, 1988). Hegemonic masculinity is often the 'Mandard' against which marginalised masculinities such as physically weak or emotionally expressive men, are often compared. This results in the popular notion that being a 'real' man is an identity that must be earned (Kimmel & Kaufman, 1994). Men are, thus, portrayed as tough, emotionally stoic, family providers, heterosexual and devoid of any feminine characteristics (Alsop, Fitzsimons, & Lennon, 2002).

Masculine identities can be diverse, influenced by many states such as age, ethnicity, occupation, sexuality, abilities and leisure pursuits (Hearn & Collinson, 1994). Moreover, they represent what is perceived as real for the individual and as such are random, complex, may be paradoxical and, importantly, subject to change (Hare-Mustin & Marecek, 1988) as may occur in the sequale of cancer diagnosis and/or treatment. How men undertake this renegotiation has been the subject of research. Gerschick and Miller (1995) report three styles of masculinity construction in their study of physically disabled men. Some of the men reformulated masculinity to fit in with how they functioned as men who were not able-bodied. Some men fought to gain or maintain hegemonic masculine qualities such as strength and emotional stoicism, and other men adopted a third style of constructing masculine identities by rejecting common views of masculinity and its importance and instead placed emphasis on the status of being a person rather than a gendered identity (Gerschick & Miller, 1995).

Wade (1998) suggests that male identities are influenced by 'membership' of a reference group. Men will feel connected with and secure among members of that group. However, men who have no reference group may feel unconnected to other

men and experience confusion and conflict regarding their identity. Support groups then, can provide a reference group for men, and give them a connection to others and at the same time provide a place in which to feel secure in their identities (Katz & Bender, 1976).

Even so, men who have a serious illness such as cancer can have their masculinity challenged by portrayals of hegemonic masculinity (Charmaz, 1995). For example, a man's sexual functioning and physical appearance is often associated with his masculine identity (Montgomery & Santi, 1996) and these can be altered by cancer and/or cancer treatments (Templeton, 2003). Further, many men reappraise their lives and values as their very existence is threatened (Charmaz, 1995) and may consider changing previously held beliefs and values such as placing more emphasis on the importance of relationships (Foltz, 1987; Gordon, 1995). These changes may develop as a process. For example, in Gordon's (1995) interviews with 20 men diagnosed with testicular cancer, three distinct stages to adjusting to life with cancer were detected. These stages are fear following diagnosis encompassing fears of death, disfigurement and suffering, finding personal meaning within the experience, and finally making sense of what happened from diagnosis through to resolution (Gordon, 1995). Further, Gordon found that the men either used strategies to confirm their masculinity by 'fighting' the cancer, emotional stoicism, and being physically active, or alternatively, men changed their perception of masculinity by, for example, acknowledging the importance of their close relationships and being able to be emotionally expressive.

Men who do not conform to society's portrayal of hegemonic masculinity, or only partially conform, such as those with perceived effeminate qualities or who

display emotions, however, are often marginalised or subordinated by other members of society (Connell, 1995). As men with cancer frequently experience body and psychological changes such as changed appearance, altered abilities and emotional distress (Gordon, 1995), there is appreciable risk of men living with cancer being perceived, either by themselves or others, as being less masculine than men who enjoy good health (Chapple & Ziebland, 2002). Support groups may, therefore, provide a safe place for men to overcome limits set by hegemonic masculinity (Reddin & Sonn, 2003). However, there is a lack of research into the role that cancer support groups may have in the renegotiation and construction of male identities following diagnosis of cancer. As cancer support groups have favourable outcomes in terms of relieving distress and anxiety caused by illness and treatments, it is possible that such groups will have some role in the construction of male identities. As such, further research is needed to examine the renegotiation and construction of male identities in the context of cancer support groups following a diagnosis of cancer.

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Running Head: CONSTRUCTION OF MALE IDENTITY

Construction of Male Identity: The Relationship between Cancer Support Groups and Identity for Men who are Living with Cancer.

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and Identity for Men who are Living with Cancer.

Abstract

A qualitative study was conducted to explore the relationship between cancer support

groups and identity for men who are living with cancer. The study involved 10 men

aged between 52 and 73 years old, diagnosed with cancer and regularly attending a

cancer support group. The men were recruited from five different cancer support

groups within the metropolitan area of Perth, Western Australia. Individual

interviews were used to gain an insight into each man's experiences of cancer, cancer

support groups and the impact on their masculine identity. Four recurring themes

relating to identity construction within the cancer support group context were

revealed. The themes were 'relief of isolation', 'emotional responses and coping',

'adjustment to changes', and 'empowerment'. Findings from the study indicate that

cancer support groups play a significant role in enabling men to negotiate identity

changes in a safe, supportive environment. Implications and recommendations for

future research are highlighted.

Keywords: masculinity; identity construction; cancer; support groups

Construction of Male Identity: The Relationship between Cancer Support Groups and Identity for Men who are Living with Cancer.

Despite the substantial literature on the mediating effects of cancer support groups on general life changes and information needs experienced following a diagnosis of cancer (see for example, Davis, Pennebaker, & Dickerson, 2000; Helgeson, Cohen, Schulz, & Yasko, 2000), there appears to have been little attention given to their role in facilitating more specific changes such as changes in gender identity. This has particular relevance for men as many cancer sequelae and treatments impact on men both physically and psychologically, and thus, on their masculine identity (Ofman, 1993).

Changes that appear to affect masculine identity following cancer diagnosis including, for example, feminisation of appearance (Ofman, 1993), lack of sexual functioning (Kiss & Meryn, 2001), decreased libido (Fan, 2002), and weakness (Adamsen, Rasmussen, Midtgaard, Pedersen, & Sonderby, 2001) have all been cited as possible threats to existing masculine identities. While adjustment to such changes may be difficult, one way of supporting men and relieving their distress may be their membership of a cancer support group (Clark, Bostwick, & Rummans, 2003; Lepore, Helgeson, Eton, & Schulz, 2003).

Support groups are groups of people who come together to offer mutual assistance through common needs arising from challenges (Davis et al., 2000; Levine & Perkins, 1987). The focus of support groups varies. For example support may be provided through education and psychoeducation (Fawzy, Fawzy, Arndt, & Pasnau, 1995), peer discussion, social support or emotional support (Helgeson et al., 2000).

Cancer support groups may have any or all of the above foci, and as such may help address any gaps in service provision which may exist for cancer patients. For example, cancer support groups can offer a support network of cancer patients who are cognisant of the particular issues that people experience following diagnosis and treatment for cancer (Johnson, 2000). Further, cancer support groups frequently provide comprehensive information relating to cancer which empowers the cancer patient to take a more active role in treatment decisions (Gray, Fitch, Davis, & Phillips, 1997; Johnson, 2000).

Whilst the literature on cancer support groups indicates that women are more likely to attend cancer support groups than men (Barton, 2000; Katz et al., 2002; Kiss & Meryn, 2001; Lepore et al., 2003), a diagnosis of cancer and subsequent treatments can have a major impact on men's identity such as diminished physical strength and a feeling of being different to men who are healthy (Adamsen et al., 2001).

Such changes are not congruent with the social construct of hegemonic masculinity, which is the 'benchmark' for Western society's perception of masculinity (Alsop, Fitzsimons, & Lennon, 2002). Men are thus, typically portrayed as tough, emotionally stoic, physically strong, family providers, heterosexual and devoid of feminine characteristics (Alsop et al., 2002). As such, men who are living with cancer may feel marginalised by other members of society when unable to live up to the standards set by hegemonic masculinity (Connell, 1995).

Cancer support groups may provide a safe place for men to renegotiate their masculine identities (Gordon, 1995), through discussion, information (Reddin & Sonn, 2003), and development of a reference group (Wade, 1998) and hence,

overcome limits of hegemonic masculinity. However, there is a dearth of research into the role that cancer support groups may have in this renegotiation. As such this study was conducted to address this gap in the literature and to answer the following research questions:

- 1. How do individual men construct masculine identities in the context of a diagnosis of cancer?
- 2. What role do individual men perceive that membership of a cancer support group plays in the construction of masculine identities following a diagnosis of cancer?

Method

Research Design

This research project was an in-depth qualitative study drawing upon a constructivist approach (Schwandt, 1994). This approach posits that individuals construct and attach meanings to experiences within the social and cultural context through interactions with others (Crotty, 1998) and there is no one dominant reality that arises from contextual experiences but rather, a range of realities that differ between individuals (Nagy & Viney, 1994). The participants were individually interviewed using a semi-structured interview design with open-ended questions to allow the men to give voice to their experiences. Individual meanings of their experiences with cancer and cancer support groups, and the impact of support group membership on their experiences could then be examined.

Participants

Participants for this study were a purposive sample recruited from cancer support groups within the metropolitan area of Perth, Western Australia. Although seven support groups were contacted, members from only five of the groups responded to the invitation to participate in the study. There were four inclusion criteria: participants needed to be male, be able to converse fluently in English, be aged between 21 and 80, as research indicates that most men who attend support groups are within this age range (e.g. Adamsen et al., 2001; Gray et al., 1997); and attend a cancer support group regularly. There is scant information on what constitutes regular attendance at support groups. McNair-Semands (2002), however, suggests that regular attendance can be calculated by the proportion of meetings attended. The cancer support groups attended by participants in this study met at

different intervals: monthly, fortnightly or weekly. For the purpose of this study, regular attendance was defined as attendance at, at least two thirds of meetings over the last three months, at least two thirds of meetings since joining the cancer support group if a member for less than three months; or if a member for more than one year, attendance at, at least half of scheduled meetings. This definition of regular attendance allowed for the participation of those men who may have missed meetings because of illness or treatment commitments (Adamsen et al., 2001).

A total of 10 men who met the inclusion criteria participated in the study. The age range of participants was 52 to 73 years. The cancer diagnoses of the men were prostate, upper gastrointestinal, bowel, breast, lymphatic, and myosarcoma. Of the 10 participants, two men had been diagnosed with terminal cancer, four men considered themselves to be recovered and four men still had cancer, however, the cancer was not immediately life threatening. All but two of the men had received some form of treatment for their cancer.

Procedure

Approval for this study was granted by the Faculty of Community Services, Education and Social Sciences Ethics Committee at Edith Cowan University, Perth, Western Australia. Facilitators of various cancer support groups were contacted initially by telephone to explain the aims of the study. Support group meetings were attended by the researcher if possible and the study explained to group members.

Two groups were not attended by the researcher and in these instances the facilitator was supplied with written details of the study. The facilitator then described the study to members as per the supplied details and information letters were given to

those men interested in participating. An appointment for an interview was made with men meeting the inclusion criteria and interested in participating in the study.

Interviews took place in the participants' homes with the exception of two that were conducted at the support group meeting venue. Prior to each interview commencing, informed consent was obtained from the participant. Participants were informed that they could withdraw from the study at any time without any consequences. A schedule of three open-ended questions was used to conduct the interview. Each interview was audio taped and transcribed verbatim, deleting or changing any identifying information. Participants were asked to check the transcripts for accuracy. The tapes were then erased.

Analysis

Each transcript was analysed using thematic content analysis. Thematic content analysis consists of data reduction by recognising recurrent emerging themes in the transcripts (Miles & Huberman, 1994). This allowed a context-based exploration of the experiences each man had in relation to his cancer, involvement within the cancer support group and identity construction. Individual transcripts were read through with the intention of capturing an overall impression of the participant's experiences (Creswell, 2003). Then, each transcript was examined line-by-line to detect descriptions of experiences, which were coded to reflect the meaning behind each experience (Morse, 1994). Coded items were then grouped together and placed into broader categories or themes according to their contextual meaning (Creswell, 2003). This procedure was repeated to further refine the themes to reflect the spoken and hence, lived experiences of the men (Creswell, 2003).

The rigour of the study was maintained by confirmation of data collected, careful documentation giving a comprehensive audit trail that included raw data, codes and themes derived from the data, notes made throughout the coding process and personal notes on researcher biases, and validity checks (Miles & Huberman, 1994; Morse, 1995). Validity checks were accomplished through researcher iterative reflection, review of codes and themes by the research supervisor and a summary of interpretations of each transcript forwarded to the corresponding participants to check for accuracy of interpretation (Nagy & Viney, 1994). Any changes requested by the participants were discussed with the participant if necessary, and changes were made as requested.

Findings and Interpretations

The five cancer support groups from which the participants were recruited had different foci. Two of the support groups focussed on making the group meetings a social event. Although cancer was discussed, the focus for the group was everyday living and social support. One group established for people with one specific cancer had an informational focus and the other two groups focussed more on emotional support through discussion of issues relating to cancer and everyday living. Three of the groups were facilitated by professional facilitators and two were facilitated by group members. All groups welcomed both men and women, cancer patients and their carers, to the groups.

Emerging from the men's interviews were four recurring themes that related to men's identity construction and the role that cancer support groups had in this construction following a diagnosis of cancer. The themes 'relief of isolation', 'emotional responses and coping', 'adjustment to changes', and 'empowerment' were intertwined in complex and dynamic ways, but for pragmatic purposes and clarity they will be discussed separately.

Relief of Isolation

People with a serious illness such as cancer may suffer from a sense of isolation (Davis et al., 2000). Indeed, cancer can cause significant psychological distress (Kiss & Meryn, 2001) which may result in emotional, physical and social isolation of the cancer patient.

Isolation was often described and experienced by the men in this study as experiencing a 'lack of intimacy among men', 'feeling alone', and as a 'lack of understanding from others'. However, for many of the men, relief from isolation

occurred through membership of a cancer support group. The cancer support group provided a 'common bond and shared experiences', 'companionship and friendships', and 'group support' for these men. Further, the cancer support group served to prevent or alleviate isolation that resulted from a diagnosis of cancer, by allowing the men to alter their perceptions of masculinity. One way in which this was accomplished was by providing them with a reference group that incorporated aspects of marginalised masculinities (Wade, 1998).

Lack of Intimacy among Men

Some of the men in this study spoke of lack of intimacy particularly in sharing of emotions and feelings among men, as being an isolating factor when diagnosed with cancer. Typically, the men described the lack of intimacy as being the 'norm' for men and how men were expected to behave. Buchbinder (1994) argues that the way men behave is a result of their culture, and their upbringing – in essence they have learned how to behave. This was reflected in the following excerpts of interviews.

...this is where us chaps are not very good. We don't talk easily. We don't show our emotions, we don't discuss them with other guys, because guys aren't interested in talking about anything but probably cars, booze, perhaps sport and various other sorts of very mundane aspects of life (Ricardo).

But there is a reluctance for men to talk about cancer or prostate cancer because it affects a part of the body that over

the years in their upbringing they've been taught not to talk about (Lionel).

The difficulties that men often faced when talking about problems and fears were further highlighted by one man's experience.

...difficult thing...for men to speak from the heart, it's very difficult for men to admit fear or failure or to show vulnerability (James).

Feeling Alone

Some men experienced a feeling of being alone and not connected to others who were important in their life. Feelings of being alone for some of the men in this study were exacerbated, however, by feeling different from other men.

I really felt out of place. I felt a bit different [from other men] I suppose (Nigel).

Lack of support from family was also a factor that led to feelings of being alone for some men (see also Taylor, Falke, Shoptaw, & Lichtman, 1986). One man stated that the lack of support from his adult child made him feel alone and unloved.

My [child] was incredibly unsympathetic, unsupportive, not nice at all...and so I found it difficult, I felt unloved. You know, nobody to talk to (Ricardo).

Feelings of being alone were not relieved by attendance at a cancer support group for all of the men. One man expressed his sense of isolation within the cancer support group as feeling alone and having no common bond with other group members due to his perceptions that his prognosis was different to those of the other members.

...they've had their operation and it's going good...So that's what sort of turns me off a bit [cancer support group].

Just sort of no-one, just sort of no help for me [from support group] because everyone else has got that light at the end of the tunnel sort of thing whereas I haven't got that (Bruce).

Although feeling isolated within the support group was not common among the men in this study, there is evidence in the literature to support these findings. For example, Steginga et al. (2001) suggest that men often have unmet needs including relief of their isolation, despite involvement in a cancer support group.

Lack of Understanding from Others

Most of the men spoke of the lack of understanding from people who did not have cancer, thus making them feel isolated. Other people's reactions ranged from avoiding the man regardless of whether they were acquainted or not, to saying that everything will be all right.

...I came back [to work] to sort of pick up where I had left off.

And no-one...would meet my eye. You know I'd sort of talk
to them and they'd turn away or pretend they were writing
something (Nigel).

A lot of people...[say] all you have to do is be positive and jeez it gets up your nose. Feel like hitting them sometimes (Charles).

Although it was often upsetting for the men to experience lack of understanding from others, they also recognised that it is difficult for others to understand just how cancer affects a person.

...having cancer is an extraordinarily stressful disease. Unless you've had it you probably wouldn't understand how stressful it is. Including financially (Terry).

Common Ground and Shared Experiences

The literature suggests that men who have been diagnosed with cancer frequently experience a sense of being separate from men who are healthy (Adamsen et al., 2001). As mentioned previously, the feelings of isolation that often result from a diagnosis of cancer are frequently relieved through membership of a cancer support group. Such membership can provide a reference group for men living with cancer, thus making their experiences with cancer a more 'normal' experience, thereby enabling many men to renegotiate their sense of identity (Addis & Mahalik, 2003). Many participants in this study spoke in such terms.

...it is a good thing to be a member of because you are with people who have the same problems as you (Lionel).

Attending a cancer support group can raise awareness of how many others are in similar situations and understand the experiences of others who have cancer (Clark, Jones & Newbold, 2000).

But we've all got a common bond. And if anybody is say in trouble, like you might say I've got to start chemo again next week, you're talking to people who know what you've been

through, what you're going to go through. You're talking to people who actually understand what it is (Terry).

Even though some of the men attended groups that had more female members than male members, they still had an important sense of having many things in common and shared similar experiences through their journey with cancer.

...you meet people there, people who have had bowel cancer and other, a lot of other cancers of course, breast cancer and stuff like that...I'm basically the only bloke who goes there...And that's what part of the support group is about is that the people that you are with, that you're actually socialising with have been there (Terry).

Companionship and Friendships

Having a common bond with others who had cancer, provided companionship and in many instances, close friendships were formed. In some ways the formation of close friendships was a departure from the limits set by hegemonic masculinity. Men may be socialised into hegemonic masculinity manifest through, for example, emotional stoicism, and toughness (Addis & Mahalik, 2003). As a result, some men may feel unable or unwilling to be intimate with others or to reveal their emotions (Reddin & Sonn, 2003). According to Gray et al. (1997), intimacy among men in cancer support groups may be lacking or at the very least, covert. While the Gray et al. (1997) study focussed on a men's prostate cancer support group, many of the men in this study, from a variety of groups, formed close bonds with other members of their groups.

...when you do come you feel like you are part of a real nice happy close knit family (Leo).

...you wouldn't want to give up the friendships you've made. It's as simple as that because there are a lot of friendships made (Nigel).

Group Support

Men may face rejection from their social reference group following a diagnosis of cancer particularly if the reference group has 'norms' of hegemonic masculinity, such as physical strength and toughness (Addis & Mahalik, 2003).

However, although men living with cancer may perceive themselves as dissimilar to other men following a diagnosis of cancer and a departure from the 'norms' set by hegemonic masculinity, they can reconstruct their identity in terms of masculinity normalised within the cancer support group (Wade, 1998). The support that the groups provided for men in this study was important in relieving the isolation resulting from a diagnosis of cancer and the threat to their masculine identity from the moment the men became members of the group, through, for example, providing help and advice to them if they were feeling confused and alone.

...we [wife and self] needed moral support because I felt that even before the actual diagnosis was made, confirmed through a biopsy; we needed desperately some moral support. Because there was no-one you could talk to (Wayne).

Group support can also be a social support for men with cancer (Clark et al., 2003). Being able to attend the support group meetings allowed some of the men to interact socially with other people with cancer, thus giving the men an opportunity to experience social acceptance in a safe, non-threatening way (Adamsen et al., 2001).

...it's become a social event these days for me. They are very nice people (Nigel).

The support group was judged to be an important aspect of their life for some of the men, particularly knowing that support was available if needed.

...they're a nice group...if you did need help...they'd be there...The support group definitely has a big place (Leo).

Furthermore, the group meetings and support provided the men with an emotional lift. For example one man said "It's ...a weekly charge" (Charles); while another said "It's a good medicine feeling" (Leo).

Emotional Responses and Coping

Men in this study demonstrated a range of emotional responses to a diagnosis of cancer and to the treatments that often followed. These are highlighted in the subthemes of 'reaction to diagnosis' and 'reaction to treatment'. Attendance at a cancer support group enabled some, though not all, of the men to cope more effectively with their emotional responses and to negotiate the changes in their identity through 'alleviation of fear', 'comparison to others with cancer', and 'psychological safety in expressing emotions'.

Reaction to Diagnosis

A diagnosis of cancer often causes distress (Clark et al., 2003) and it may be confronting for the cancer patient to be forced to consider their mortality (Ofman,

1993). For example, some men in this study were fearful about the uncertainty of

when they would die.

I think it was the fear, at one stage that dread...which everyone goes through I know, that fear of God, I'm going to die. When and what have I got to do before that. I actually got over that. There's an enormous amount of heartache. And you know you wake up in the morning and you think well is it

going to be today or tomorrow? (Ricardo).

Feelings of fear and a realisation of facing mortality among some of the men could also manifest themselves in actions that could be regretted later when emotions were less intense.

...at the very beginning when that [dying] is what we believed was going to happen, well we thought we don't need this, we don't need that. We sold all that [exercise] equipment and other things in the house which we felt were just superfluous.

And later on when we calmed down a bit, we realised we shouldn't have done that (Wayne).

For some of the men in the study, a diagnosis of cancer was not entirely unexpected. Consequently, the diagnosis of cancer was less of a shock.

...the actual diagnosis wasn't actually a great shock. I was pretty sure it was coming anyway (Lionel).

For other men the diagnosis was devastating to them and their families.

[it was like] the guy...took out one of those old hand
grenades, pulled the pin...it's live, and he passed it to me.

And then I had to...pass it to my family and to my friends and my workmates...it was utterly devastating (James).

One of the men found it difficult to believe that he had been diagnosed with cancer, as he had been very health conscious.

...always very health conscious in terms of not too much fat and not too much salt and watched always what we ate.

Exercised a lot...So when I got diagnosed the question was 'Why? Why?' (Wayne).

Similarly, two of the men spoke of feelings of disbelief and denial when their doctor told them they had cancer.

The first thing is that you don't want to believe it. You want to think they've made a mistake. You want to think that the doctor doesn't know what he's doing, that sort of thing (Terry).

I was really in denial I think. I didn't want to know (Nigel).

Reaction to Treatment

Treatment can also cause significant distress, resulting in depression and/or anxiety (Roth et al., 1998). For at least three of the men the treatments they received were thought of as distressing, with one man describing his treatment as "the trip to hell and back" (Charles) and another man as "he [oncologist] took all the stuffing out [of me]" (Leo). One man spoke of his feelings regarding a treatment.

...the only thing [treatment outcome] which in all of these things [treatment side effects] has depressed me...I absolutely

hated it, absolutely loathed it... You felt incomplete, you felt incredibly delicate. You felt embarrassed, you felt humiliated (Terry).

Alleviation of Fear

Apart from the fear of dying, men may also face the fear of not being able to maintain their masculine identity, for example through continuing employment after a diagnosis of cancer (Znajda, Wunder, Bell, & Davis, 1999). Fear of sexual dysfunction, which may also be perceived as a threat to masculine identity (Ofman, 1993; Stenginga et al., 2001) is also common, especially among men who have genitourinary cancers. In this study, attendance at a support group enabled many of the men to confront and relieve their fears by being able to talk to others with similar problems. Also, bearing witness to other men (and women) living with cancer and functioning well, reassured some of the men.

...a lot of people who apart from having ...cancer, are healthy and are leading normal lives...I think what I get out of it is the realisation that there are a large number of people there who've had ...cancer since the year dot and are still alive and healthy and generally getting on with life (Jason).

Talking to others within the support groups enabled men who were fearful to come to terms with what was happening and to gain other perspectives on the outcomes of cancer.

Had a talk to him [support group member] and he kind of allayed some of my fears at that time...we didn't know if we were coming or going...[there was] no real reason why I should fall off the perch in six months (Wayne).

Comparison to Others with Cancer

For some men in this study, comparing themselves with others in the group provided them with a sense of being fortunate and they were reassured that they were managing their illness well in comparison to others. This finding was consistent with Collins' (1996) assertion that people often compare themselves to others to evaluate their progress in terms of the severity of their illness and their emotional stability.

I thought to myself, I'm not that bad. So it's a sad thing to say that your reassurance comes from someone who's worse off than you but at the same time it does give you a little bit of a lift, an inspiration (Lionel).

...you need to go [to support group] because there's a constant endorsement of how fortunate you are at the moment (Ricardo).

Although comparison to others was largely a positive experience for many of the men, this was not always the case. For example, one man was distressed by attending a support group because of his perceived unfavourable comparisons with others in the group.

...get down in the dumps a bit afterwards...But going to those meetings brings it all back again you know...That's why I don't like going to them for that reason...I'm about the only one that nothing can be done (Bruce).

Feelings of depression and anxiety may persist for some time following a diagnosis of cancer for men whose masculine identity is threatened (Ofman, 1993). Consequently, some men may experience some depression when they compare themselves with those whom they perceive as more fortunate (Collins, 1996).

Psychological Safety in Expressing Emotions

Although research suggests that women are more likely to use the support group for intimate discussion (see for example, Adamsen et al., 2001), one man found that, although it was mainly women within his group who shared their emotions and expressed their needs, men also felt safe enough to share with the group.

It's mainly the women, mainly the women who can talk but even the guys there talk about what they are doing, what their needs are, how they are feeling (Ricardo).

The social portrayal of men being emotionally stoic imposes limits on some men in terms of exploring and expressing their emotions (Leyden, 2002). As such, a cancer support group can help overcome the limits set by hegemonic masculinity (Leyden, 2002) by providing a safe place in which to explore and release emotions.

...the support group is good ...for letting go of anger, or aggravation that I might feel at the time...it's a good place for me to admit my frailty...it's a good place to hash out about our problems (James).

...it's getting things off your chest instead of storing things up...it only stresses you (Charles).

Adjusting to Changes

For men, some of the myriad of changes that occur following a cancer diagnosis can be traumatic, especially when their perception of their own masculinity is challenged (Charmaz, 1995). Changes that often threaten masculinity include fatigue and weakness, altered physical abilities, changed roles and sexual dysfunction (Gordon, 1995; Ofman, 1993; Richardson, Lee, & Birchall, 2002; Templeton, 2003). In line with the published literature, some men in this study experienced changes such as those mentioned above as a result of their illness and/or treatment. Whilst men experienced 'temporary changes' they also experienced 'ongoing changes' to which they needed to adjust. Men in this study adjusted to the changes they experienced through 'redefining beliefs and values' and 'acceptance of illness'.

Temporary Changes

The men in this study were frank in discussing the changes that had occurred as a result of cancer or its treatment. The men were reassured knowing some changes were temporary and they would return to a more 'normal' state once their treatment had concluded.

So the only side effects [from the treatment] I did have was...some hair loss and shortness of breath...and there was a little bit of fatigue as well...Now that's gone since I've been off the...treatment (Wayne).

Ongoing Changes

For some of the men in this study, however, the changes they experienced were ongoing in line with continuing treatment or were a lasting effect from the

cancer itself. Changes included fatigue and weakness which appeared to diminish some of the men's feelings of being masculine. For example, according to Lionel, "it removes at least 50 percent of your male strength" and to Charles

I've lost a lot of strength...you don't know how much strength you've got until you lose it. I've never regained the strength (Charles).

Ongoing weakness and fatigue was a problem for men wanting to continue undertaking tasks they had been able to accomplish effortlessly prior to their cancer diagnosis and treatment.

What I reckon it's done though [cancer and treatment] is make me quite weak...I reckon it's wasted my muscles away. I could be wrong; I could just be very lazy. I go and do something now and everything is hard work, you know, digging in the garden, whereas it never used to be hard work (Bruce).

One man found that he was unable to concentrate enough to read, an activity that he had once enjoyed.

I used to read a lot...No, I can't read now because your concentration goes...it's just an effect. And an effect of the medication you're on too (Terry).

Lifestyle changes were made by some of the men to accommodate the limitations imposed on them from their cancer or treatment.

I was told how to live and to eat and what not to eat (Leo).

I can't lay flat anymore and I've got to sleep on my back and [head] elevated (Charles).

Although some of the men in this study had already retired from the workforce prior to their cancer diagnosis, other men were forced to leave their paid employment.

In the beginning it was absolutely appalling [leaving paid work]...to suddenly be here fulltime in the house, was an extraordinarily difficult transition, not just for me but for my wife. My wife was the housewife and she was happy being a housewife (James).

...won't be able to go back to work because no matter hard you try it will be too hard (Leo).

I can't go to work, um, you know I miss working but I just can't do it (Terry).

Cancers and treatments that affect the genitourinary system may cause changes in sexual functioning such as loss of libido and impotency. As sexual functioning is often associated with masculine identity (Ofman, 1993), some men found the threat or existence of sexual dysfunction disquieting.

...in the beginning that [impotency] was a big issue (Wayne).

I can't really decide whether it's age or...cancer but there's no doubt about it, my libido is lacking compared to what it used to be (Jason).

So you get impotency and then you get [treatment] and then you're completely sexless, I'll be quite frank...It's quite a thing really. Because if you think back in your younger life you never really realise how you [could] possibly live without some sexual input (Lionel).

Redefining Beliefs and Values

Different strategies are often used by men to adjust to the many changes that occur (Gordon, 1995) and to reconstruct their masculinity. One such strategy used by many of the men was redefining their beliefs and values. For example, one of the men redefined his beliefs and values concerning work. While work had been his foremost priority, he changed his priorities to focus more on his health rather than working.

After I was diagnosed with cancer...[I] came to the realisation...12-16 hour days...wasn't going to extend my survival...I chose to give up [work] (James).

Part of James' survival plan involved participation in a cancer support group.

...helps me [support group] in a whole host of ways, physically, mentally and spiritually...support group is not necessarily an easy process...that was what I had to do to stay alive (James).

As sexual functioning can be threatened with some cancers, a number of men in this study had to redefine its importance compared to their survival.

...there's a lot more to life than sex only...So if eventually I am totally impotent well then no big deal...you weigh it all up and ultimately you come to a decision. It is a trade off—if I want to live, and want to live for years, that's a minor inconvenience. That's the way I look at it (Wayne).

Cancer support group meetings can also help men who are having difficulty coming to terms with a lack of sexual functioning redefine their beliefs and values and facilitate their acceptance of the relative importance of survival and sexual functioning in their lives.

Unfortunately, this is one of the things [sexual dysfunction vs survival] at the [support] group that we have to hammer home occasionally (Lionel).

Redefining their beliefs and values encompassed an acknowledgement of the importance of the men's close relationships (see also Gordon, 1995).

...but having cancer and knowing that you are going to die, it does concentrate the mind a fair bit. You do think about things a lot. You think about the people that are valuable to you, people that stand by you and they are the most important things. Yeah, they are the real important things (Terry).

We appreciate our life more and we value life and we value each other. We're a very close unit...Really, in essence, I got cancer and all our lives began (James).

Many of the men spoke of appreciating life and living more fully rather than 'existing'.

I live every day now...well [support group] drums into you that you've got to live every day (Charles).

If I live well, then I will die well (James).

...you still don't know [if cancer is cured], so you tend to live every day the best you can (Ricardo).

For one man, the changes that occurred following his diagnosis and subsequent involvement with cancer support groups were profound and affected not only himself but his family as well.

...a time of incredible change for myself and for my whole family...Yeh, I'm probably the happiest I've ever been in my life (James).

Acceptance of Illness

Although many of the men were faced with their own mortality and changes to how they lived their life following their diagnosis of cancer, they came to accept their illness. Some of these men actually found relief in this acceptance. For one man acceptance came from categorising his cancer similar to any illness "So really, I've got ...cancer, it's an illness" (Jason).

One man stated that he had a choice of whether to accept his cancer diagnosis or to dwell on negative aspects of his illness, even though he did not experience the outcome he had expected.

I just assumed I'd got it and I'd get rid of it. I didn't but I'm not too bad... You either go one way or the other. You either get depressed with it or you accept it and get on with life. I've tried to do the latter (Lionel).

An acknowledgement that life was unpredictable and cancer was an aspect of life that he had no control over enabled one the men to accept having cancer.

It's not pleasant [cancer], it's not pleasant at all. It's just one of those things. That's life and there's no use sitting there crying about it, you've just got to get on with it...I think well this is just life, life is a lottery and you just get on with it (Terry).

Acceptance also meant that the men in this study needed to evaluate the costs and benefits of treatments in relation to surviving the cancer (see also Chapple & Ziebland, 2002). This evaluation and subsequent acceptance were frequently a result of being informed through the support group.

I accepted it [cancer treatment] as part of the deal; I mean I read up about it [treatments], I was informed about it [from support group]. And I knew about these side effects and you rationalise [having treatment] in your own mind by weighing up the pluses and the minuses...we're [self and wife] prepared

to put up with a relatively minor inconvenience for the greater good and the greater good was life (Wayne).

Empowerment-

Many men in this study initially found that they were powerless following a diagnosis of cancer. Powerlessness is the antithesis of qualities of socially constructed hegemonic masculinity, where control and strength are held in esteem (Kaufman, 1994). However, many of the men in this study considered they were empowered subsequently through their membership in their respective cancer support groups. This membership also afforded them the opportunity to renegotiate their masculine identity in the context of their current state of health and wellbeing (see also Gerschick & Miller, 1995). The sense of 'feeling powerless' that came through strongly as a theme from the men following their diagnosis of cancer, was overcome in several ways through the cancer support groups. Central to the men's empowerment was the 'provision of information' at the support group. Additionally, cancer support groups enabled the men in this study to feel empowered through 'reciprocity', as well as through 'learning and personal growth'.

Feeling Powerless

Men in this study who had previously thought they were in control of their lives, found that following their cancer diagnosis, they had lost that control and that they felt powerless.

...it [cancer] creeps up on you and when you do find out it zaps you, it takes total control of your life (Ricardo).

And all of a sudden, I wasn't [in control]. I was in command of nothing. Not even my own destiny (Nigel).

A sense of powerlessness often comes from a lack of knowledge (Echlin & Rees, 2002). Some of the men in this study felt that they were not given enough information by their doctors about their cancer and treatments, and so were either left ignorant of many factors involved with their cancer or were left with a false impression of possible outcomes.

It didn't mean much to me [...cancer]...Well, what is it? I had no idea...there's nothing I can do about it (Bruce).

...it was quite a very, very stressful time because at that stage I wasn't really fully informed. I just assumed from what the expert said that she [wife] would have to battle on her own without me (Wayne).

Provision of Information

Seeking information regarding cancer and its treatments is often a motivating factor for men to attend a support group meeting (Lepore et al., 2003) particularly so for men who have prostate cancer, as they are often offered a range of treatments (Stenginga et al., 2002). Treatments include prostatectomy, external beam radiation therapy, brachytherapy, and/or hormone therapy (Chapple & Ziebland, 2002). As different treatments are used at different stages of prostate cancer and a combination of treatments may be used, the choices can be quite confusing for some men.

Additionally, all of the treatments carry considerable risk of undesirable side effects such as impotence and incontinence (Chapple & Ziebland, 2002).

Information needs for many of the men in this study was a motivating factor to attend cancer support group meetings, so that they could build on information, which was often insufficient, provided by their doctor. Some of the men appeared reluctant to attend the support group meetings, however, they regularly attended to keep up to date with information regarding their cancer, "I just go along in case something's happened" (Bruce).

Information was provided through the men's cancer support groups in various ways. For example, a specialist nurse was available in a consultancy role for two of the groups' meetings to answer any questions or clarify information for the members.

...she's very knowledgeable and she keeps herself up to date with all the developments and treatments (Lionel).

...then explained to me in a bit more detail what I'd already read about...treatment and radiotherapy and surgery and so forth (Wayne).

Facilitators at two more of the groups were also able to offer advice if warranted and in one of the groups, the members took responsibility to gain information from other sources such as the Cancer Support Association of Western Australia to share with the group, Alternatively, another group used guest speakers to provide information through lectures.

I got into a support group...lecture once a week...I went down with the wife and that's when I realised what it [cancer] was all about (Bruce).

Attending a cancer support group can enable men to make informed decisions and take control of the course of their treatments (Gray et al., 1997). For instance, one man in this study found that information from the support group enabled him to challenge one doctor's advice and to move on to another doctor more open to listening to him.

...when I tried to pin him down [1st doctor], because I knew what I was talking about, I said well there is radiation that is another option. But I wasn't very impressed with the person [1st doctor]...we went to see [2nd doctor] and we did like him...he was open to suggestions (Wayne).

One man spoke of the cancer support group providing him with information to assist with problem solving.

But they [oncologists] can't solve any of your problems.

You've got to solve them yourself. That's where the support groups come in...I've learnt that much from support groups that I don't know where I'd be without it [support group] actually (Charles).

Reciprocity

Many of the men spoke about pleasure from helping others. Helping others enabled the men to retain some male power and independence, thus adding to the perception of strength (Addis & Mahalik, 2003) and reaffirming their perception of masculinity.

...one can get a little bit of pleasure...because the strange thing is that giving is often more pleasurable than receiving (Ricardo).

The notion of being able to contribute to the group as well as receive information and support was one of the reasons men gave for remaining involved with a support group. In this study reciprocity was often associated with feelings of self-worth (see also Levine & Perkins, 1987) and allowed the men to feel less in someone's debt (see also Addis & Mahalik, 2003). Being able to contribute after having received support was a positive experience as the men felt that they had repaid a debt.

So that [support] makes them [new members] feel good and makes me feel good because someone's helped me in the beginning and I can return the favour (Wayne).

... I would keep going to that [support group meetings] for as long as I felt I was contributing something. I can't see any reason to stop going. I get so much out of it [contributing to support group] (Ricardo).

One of the men suggested that reciprocity was a natural process and could take various forms, not just giving advice or information but also by being available to listen to those people in the group who needed to talk to someone.

What it means to you is the fact that you, from a selfish point of view, can get something out of it in terms of being with people that you can relate to. And that's helpful because

you're getting something out of it. You can put back in to help other people which is helpful again, because everybody...it's part of nature to...we like to think we are helpful. So you can put back in by talking or listening to them. Not necessarily by talking to people but sometimes by listening to people (Terry). Learning and Personal Growth

Support groups can serve as a venue for learning and personal growth (Flood, 1995). Many of the cancer support groups in this study provided the men with an opportunity to learn more about themselves and their personal growth. For one man personal growth centred on recognition that he was one of many others "I used to think I was the centre of the bloody universe but...I've learnt that I'm not" (James). For others personal growth was learning skills such as listening.

And going to the support group, I've done things I've never done before...I mean to go there and listen, to those people and sometimes I'm sitting there thinking, what is this stuff? This stuff isn't important to me and why are they going on about it. And then I'm saying – because they need to. (Ricardo).

Conclusions

The aim of this study was to explore the relationship between masculine identity construction and cancer support groups for men living with cancer. The men in this study were affected physically, emotionally and/or psychologically as a result of their cancer diagnosis and/or treatment and were confronted with many changes that impinged on their masculine identity. The experiences of these men led to many of them reconstructing their masculine identity to align with their changed circumstances. Integral to this reconstruction was their membership of a cancer support group.

Most of the men experienced feelings of isolation following their cancer diagnosis because of lack of support from family and friends or feeling different from other men. However, membership of a cancer support group fostered a sense of normality through shared experiences, friendships, and group support. Although this finding was common, one of the men experienced a feeling of isolation within the support group and was distressed by his perception that he had a less favourable prognosis than other members of the group.

Cancer support groups also offered the men in this study a place of psychological safety. Men who had hitherto been wary of displaying emotions found that, within the support group, they could express their emotions in safety. Although difficult for some of the men, they were able to share their concerns, problems, and feelings with others in the group, without fear of being perceived as less masculine.

The cancer support group was also a good place for the men to adjust to changes that were a departure from hegemonic characteristics, such as loss of work and sexual dysfunction, by redefining their values and beliefs. The men were able to

reconstruct their masculine identity to reflect those changes through evaluating their existing beliefs and values and redefining them as necessary.

Contrary to the standard set by hegemonic masculinity to exert power and control over others, the men in this study were able to reconstruct their masculinity in such a way that enabled them to find satisfaction and reward in the reciprocal giving and taking of support within the cancer support group. Further, the men were empowered through knowledge gained from the cancer support group meetings.

Accurate information provided at cancer support group meetings allowed the men to take responsibility and control over many of the ensuing decisions particularly in regard to treatment.

with cancer as opposed to men with a specific cancer, assumed that men with cancer are an homogenous group. However, all cancers carry with them, different effects and treatments that may impact on masculine identities in varying ways. Similarly, cancer support groups are not identical in their focus and as such may only meet a proportion of the needs of men with cancer. Consequently, although the findings give a comprehensive insight into the construction of masculine identities for the men involved in throughout, the results may not be transferable to men in other cancer support groups with different foci. Further, the results may not be transferable to men who attend 'men only' support groups, as all groups in this study were open to both men and women.

The implications of this study however, are that men do indeed construct their masculine identities within their social context and that cancer support groups may play an important role in men's identity reconstruction following diagnosis. As

such, more awareness of the benefits of cancer support groups, particularly in assisting men to negotiate changes in their masculine identities, is needed in the wider community. This could best be accomplished through such avenues as doctor's surgeries, hospitals and treatment centres. However, clinicians need to maintain awareness of the individual's mood and perceptions of their illness, to prevent possible distress resulting from comparison to others within the cancer support group.

Future research would be useful to examine the relationship between groups of men living with a specific cancer such as prostate or testicular cancer, construction of masculine identity, and cancer support groups that have a particular focus such as informational or emotional support. Such research that has more narrowly defined parameters would assist in determining what needs are met or unmet, thus aiding in the establishment and/or maintenance of effective cancer support groups.

In conclusion, the findings from this study provide evidence that men construct their masculine identity within a social context. As such, a cancer support group may provide a place where men can safely negotiate changes that lead to identity reconstruction following a diagnosis of cancer. However, this is dependent upon such factors as the type of cancer, support group focus and comparisons that are made with other members of the cancer support group.

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Appendix A

Male Cancer Support Groups Project

Interview Schedule

Question 1.

Can you tell me about yourself?

- Tell me a bit about your family
- What sort of things do you do through the day?
 - o What do you do for leisure?
- Can you tell me about what it was like to be diagnosed with cancer?

Question 2.

I would be interested in hearing about how you started coming to the support group.

Can you tell me about it?

Question 3.

What does it mean to you to be a member of the cancer support group?

- Can you tell me why you continue to be a member of the cancer support group?
- What supports do you perceive the group provides?

Appendix B

Male Cancer Support Groups Project

Information Sheet For Potential Participant

Dear Potential Participant

Thank you for offering to participate in my research study. My name is Kathryn Chegwidden and I am currently studying at Edith Cowan University. As part of Honours in Psychology, I am required to complete a research project. Formal approval has been received for this project from the Ethics Committee of the Faculty of Community Services, Education and Social Sciences.

In my study I will be looking at male identity following a diagnosis of cancer and exploring the value of the cancer support group to you. I anticipate that it will be beneficial to discover the value of cancer support groups for men who have cancer so that cancer support groups can be tailored for men's needs.

All information that you provide during the interview will remain confidential.

The proposed study will comprise of a taped interview of approximately 45 minutes to 1 hour. After transcription, a copy of the interview will be forwarded to you to ensure that the information is correct. A copy of the results of the study will be made available for you when completed.

Sometimes issues raised in interviews may result in discomfort. Hopefully this will not occur, but if you feel that you need to talk to someone either at the time of the interview, or at a later date, arrangements will be made to have a support person or counsellor on call should you need them. Additionally several telephone contacts are added at the end of this page that you will be able to call for support.

You are under no obligation to complete the study. If you wish to withdraw at any time for any reason, please let me know and the interview will stop immediately without any consequences or impact on any support you are receiving.

If you have any questions regarding the study, please call me on 9307 8180 or alternatively, you may like to call either of my supervisors, Dr Moira O'Connor on 6304 5593 or Dr Colleen Fisher on 6304 5715. If you wish to speak to someone in the university who is not connected with the project then please call Ms Julie Ann Pooley on 6304 5591.

Your assistance with this project is greatly appreciated.

Thank you Kathryn Chegwidden

Please keep this sheet for your own reference.

Cancer Council Support Centre: 9382 9338
Cancer Helpline 13 1120
Life Line: 13 1114

Appendix C

Male Cancer Support Groups Project	
Ihave questions that I have asked have been answer	
I agree to participate in this project, realising any time without consequences.	that I may withdraw from the study at
I agree that the research data obtained for this am not identifiable.	s study may be published provided that I
I understand that I will be interviewed and the I also understand that the recording will be enunderstand that all information is confidential	rased once the interview is transcribed. I
Participant:	Date:
Researcher:	Date:

Appendix D

Example of Question Ordered Matrix

Questions Participant	"Can you tell me what it was like to be diagnosed with cancer?"	"what does it mean to be a member of support group?"	"Why do you continue to be a member of support group?"	"What supportsthe group provides?"
Participant 3	'It was utterly devastating'	'A time for focus'	'If I want to live, I need to attend a support group'.	'Empathy'
Participant 6	'you drive away and you think, Oh my God'.	'I go because of the other bloke (neighbour).'	'To find out if I can discover anything more aboutcancer.'	'I get none really. I get satisfaction of knowing that there's a lot of people there who've hadcancerlead ing normal lives.'
Participant 10	'You don't want to believe it'	'Can get something out of it in terms of being with people you can relate to'	'I enjoy being a member'	'You can give so you can receive'