

Unmet supportive care needs of rural men with cancer: a qualitative study

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Abstract

Background A cross-sectional medical record audit and self-report questionnaire study of a rural supportive care cancer program found that when compared with women, men were more likely to be older; perceive health care information to be unhelpful; receive fewer referrals to services; were reluctant to join support groups and experienced a poorer quality of life.

Aim The aim was to explore unmet supportive care needs of rural men with cancer to inform improvements in service delivery.

Method Twenty-two men were invited to attend a focus group. The focus group was audio-recorded, transcribed verbatim and field notes were taken. Data were analysed thematically.

Results Ten men participated. Six key themes describe how these rural men perceive deficits in the cancer care support.

Conclusion There are unmet supportive care needs experienced by rural men with cancer. Gender-informed support is important when individualising care for men.

Background

Many people with cancer encounter severe physical, existential, and emotional problems¹. In recognition of this, most Australian health care facilities have included supportive care screening (SCS) in their cancer care programs. SCS is a systematic, evidence-based approach intended to identify and prioritise care needs for cancer patients. Supportive care is defined as *“the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement”*².

Screening for care needs is recommended to be routine and periodic at various stages of the cancer experience³. A validated and widely used screening tool, developed by the National

Comprehensive Cancer Network, is the Distress Thermometer (DT) and Problem Check List⁴. The level of distress experienced is identified on a 0–10 scale; a score ≥ 4 may indicate significant distress. The score identified on the DT is intended to guide clinical decision making. The Problem Check List enables identification of issues in the past week related to practical, family, emotional or physical problems and spiritual/religious concerns. The ideal outcome of screening is that individual risk factors are considered and appropriate actions and referrals to specialised services are matched to the patient-identified needs.

Poor quality of life (QoL) post-cancer treatment is common for men⁵. Previous studies have shown that men with cancer experience some very specific unmet needs⁶. A large systematic review focusing on the supportive care needs of men living with and beyond prostate cancer describes problems related to intimacy, lack of clear information, physical and psychological

distress⁷. Significantly, while men view information needs as most important, the greatest unmet need in one study, again focusing on prostate cancer, is the type of information — specifically the recurrence of cancer and side effects of cancer and its treatment⁸.

In an optimal patient-centred approach, greater patient satisfaction and improved outcomes is more likely when care is tailored to the whole context⁹. Depending on the environment, men or women may adjust their behaviour in certain ways. Recent research recognises the importance of understanding the interaction between gender and other variables, such as age and class when experiencing cancer¹⁰. Further, there are key cultural expectations of what it is to be a cancer patient¹¹; negative thoughts and expressions are generally not acceptable and 'thinking positive' is viewed as a moral imperative.

Concomitant with culture is the role of gendered expectations of behaviour. There is evidence internationally that medical institutions 'gender' their practice in the care of men and women with cancer¹⁰ in a way that can, at times, subconsciously stereotype men and women into traditional expressions of masculinity and femininity¹⁰. Problematic too is that the majority of research on counselling in cancer care has been with women and breast cancer. Past research reports that counselling is universally seen as beneficial to cancer patients, *especially* women¹².

Survival rates for cancer are lower for rural-dwelling Australians than urban dwellers¹³ and thought to be linked to their higher rates of socio-economic disadvantage, more advanced cancer stage at diagnosis and limited access to specialist cancer treatment. People living in rural areas have less access to health services, with shortages in almost all health professions and health-related infrastructure¹⁴. Lower levels of education in rural areas also results in poorer knowledge and negative health behaviours, which predispose rural Australians to cancer¹³. Although survival rates for rural Australians have improved in the past 30 years, the incidence of cancer continues to increase¹⁵.

This study was part of a larger project which aimed to evaluate the effectiveness of SCS in a rural ambulatory cancer care service in Northern Victoria¹⁶. Primarily males were found to have poorer QoL, with characteristics, such as needing to rest in a "bed or chair", "feel[ing] weak" and experiencing "shortness of breath" more than females¹⁶. Moreover, men found that the information provided by the cancer support team was "less helpful" than women did, despite having more visits to the health service¹⁶. Men were also more likely to be older than women and less likely to receive a referral through the SCS process¹⁶. Added to that, men were less likely than women to declare any positive benefits from the cancer experience, nor attend support groups or ask for information¹⁶.

The aim of this study was to follow up on the findings from the previous study and describe the unmet needs of these rural men with cancer to ultimately inform improvements to the SCS program.

Recruitment

Twenty-two men in treatment or remission from cancer consented to participate in further research as part of the evaluation of SCS research conducted at a rural ambulatory cancer service in Victoria, Australia. This evaluation has been reported elsewhere¹⁶ and provides the background to this study. Participants were contacted by telephone and invited to participate in a focus group at a time that suited the majority.

Method

The focus group was held in a local community library and facilitated by a faculty staff member who had no previous role in the research study or relationship with the focus group participants. The facilitator was a male academic with a nursing background and previous qualitative research experience. The principal researcher and a co-researcher (both nurses and rural health research academics) also attended the focus group interview and field notes were recorded by both researchers. The focus group followed a semi-structured question framework drawn from the findings of the first study, which aimed to stimulate discussion about individual men's experiences of cancer while living in a rural area. The duration of the focus group was 78 minutes and was audio-taped and transcribed verbatim.

Data analysis

The transcript was coded by two researchers to identify themes related to distress, against the contextual backdrop of rurality. Participants are not identified to preserve confidentiality and quotations are presented to illustrate themes. Field notes are provided to further illustrate and support the identification of the themes.

Results

Eleven men agreed to participate and 10 attended the focus group. Reasons for non-attendance were not sought. The major themes identified included the need for support groups specifically for men, financial distress as a result of their illness, relationship breakdown, cancer myths, knowledge gaps about cancer and treatment, and coping with physical limitations resulting from their illness or treatment.

Focus group demographic and descriptive profile

On average, the men in the focus group were 70 years of age (range 53–84). One man did not provide further demographic characteristics. Of the remaining nine, seven lived within 25 km of the health service where SCS took place, four had multiple diagnoses, three colorectal cancer, one melanoma and one lung cancer; all had been diagnosed more than 24 months earlier,

five had received treatment at another hospital other than the health service in which the study was conducted, five had more than 21 visits to the local health service.

Support groups for men

There was a clear and repeatedly expressed desire for a support group specifically designed for men. Field notes record that many focus group participants mistakenly believed that the focus group itself was intended as a support group. Participants perceived that formal support groups were available for women, yet in their experience no formal or informal support existed for men.

"There's nothing else around really for blokes to sit down and have a yarn, is there?" (Participant 2)

"Getting a group of blokes like this sitting around you can all have a yarn, let out some of your problems and it helps, I reckon." (Participant 4)

"... you have these things for women where they go in to have nails done and their hair done and that. I said there's nothing for blokes, what about getting something like that going for us blokes?" (Participant 5)

The men expressed feelings of seeking yet resisting support. While agreeing that support groups were something they wanted, they also were mindful not to appear too needy. Negative terminology such as "complain", "whinge" and "sook" were used throughout the dialogue. They appeared to be 'checking in' with each other that it was OK to want to meet and talk about their experiences. Field notes during this discussion recorded *"... the group have erupted, all talking over the top of each other, there is much ad lib humour, laughter and comical agreement, a form of 'pack camaraderie', almost as if there is a fear of seeking help as a consequence of appearing weak"*. (Interviewer 3)

Financial stress

Financial distress was raised by many of the participants. Several told stories of seeking help, but were frustrated by the process and their inability to change their circumstances. The men described strong emotions of powerlessness in the face of bureaucracy. Comments included:

"I had six months of chemo. Got no insurance, no nothing so I was six months unemployed ... we had to go around and see everyone that we owed money to, the banks and yeah, six months of chemo ... we went from two incomes to none. We had no money. The time we met there, well interest only on the house loan, still had three kids living at home out of five — by the time with food and a bit of fuel we had nothing to come back over here [health service for treatment]. That's the hardest part. I couldn't get unemployment benefits. I couldn't get nothing. Even though the doctors said you're entitled to this you'd go to Centrelink [Australia's national welfare agency], [they] don't want to know you." (Participant 4)

"... my missus was only getting holiday pay or long service the first five months I was crook. She was at home looking after me, so she went to that mob and said well I should be able to get a carer's pension or something. At the end of it after six or eight months of fighting and yelling and screaming and scratching and biting and stuff I was getting \$64 a week." (Participant 2)

Field note records detected a sense of anger during this discussion, particularly expressed by the younger men in the group, who were suddenly unable to work and thus contribute to the household income during treatment. The group agreed that the Ambulatory Cancer Service had on occasion provided 'petrol' and 'bills' money, a mere insignificance it seemed amid the enormity of the financial stress felt.

Relationship breakdown

Some of the participants related stories of relationship breakdown, during or after their cancer treatment. It was unclear if they had sought counselling or emotional support during this period. Comments included:

"... my wife told me it was all over and done with, so I walked away from a 33-year relationship with her..."

"... when the ex-told me it was all over I just — it wasn't the end of the world because I'd been to the end of the world."

(Participant 4)

Field notes record a sense of 'impotence' related to the loss of agency and control as well as loneliness and despair experienced during phases of the cancer journey.

Cancer myths

Many of the participants demonstrated that they had a poor understanding of cancer, associated risk factors and causation. It was clear that education or information relating to cancer may have been useful to increase their understanding. Comments included:

"Where's it come from? ... well, it's in our bloods somewhere, DNA." (Participant 2)

"One of my mates years ago, footy player, he got a flick in the gonads with a towel after training one night. Cancer not long after." (Participant 5)

Knowledge gaps

As well as a poor understanding of cancer aetiology, many participants expressed that they had little knowledge of the treatment they had received, the reoccurrence of illness, or where to access information about their illness and treatment. Comments relating to this include:

"When I was told I had leukaemia I said yeah, yeah, fine what's leukaemia?" (Participant 1)

"I didn't have much of a clue about it ..." (Participant 2)

"I don't know if it's true or not, that cancer ..." (Participant 3)

"I had a lung removed ... and I don't even know the name of the doctor that did it. Never ... I was never told ... well I didn't know who to ask." (Participant 6)

Physical distress

Physical symptoms related to cancer or treatment was discussed in light of the effect this had on their day-to-day life and interests. Comments illustrating this were:

"You get up to do something and you might be alright for half an hour then you just run out of puff and go and sit down." (Participant 2)

"Sometimes I've just got to go to bed for a couple of hours in the middle of the day." (Participant 5)

"I've never slept during the day in my life. I can't go to sleep in a car when it's travelling [normally]. The last three months I can sit down in the chair at five o'clock in the afternoon and have a 10-minute nap" (Participant 2)

"I had to give up golf because my right leg would collapse every time I tried to hit the ball. That was the end of the golf." (Participant 5)

Recorded field notes indicate that during this discussion, men appeared in genuine shock at how tired they felt and their subsequent inability to participate in the activities that were routinely a part of their life before their cancer diagnosis. More than this, men appeared to be frustrated with a need to alter their activities of daily living to accommodate their physical changes:

"... I've got this app on my phone ... — now I know every toilet in every town because ... if I eat the wrong thing now 20 minutes later I've got to find a loo." (Participant 4)

The focus group concluded, with many of the men asking when another gathering would be held, some again mistakenly believing that the focus group was, in fact, a support group meeting.

Discussion

This study aimed to explore the experiences of a group of men in a rural Australian region who had undergone SCS during their treatment for cancer. Six themes emerged in the research: the need for support groups for men; financial stress; relationship breakdown; cancer myths; knowledge gaps; and physical distress.

Many people diagnosed with cancer are receptive to informal supportive care¹⁷. The men in this focus group perceived emotional and social support via a specific men's group as desirable, but lacking in comparison to that available for women in the region. In common with our findings, a large international study identified that men felt less informed about psychological support; however, in contrast to our study, the men expressed

fewer needs than females¹⁸. While informal caregivers, such as partners, close family members, or friends, have been shown to provide essential support to cancer patients along the illness trajectory¹⁹, the men in this focus group seemed quite clear that they needed something outside of the family. Cancer patients report benefits in sharing experiences with others²⁰. Rural people, men in particular, are portrayed as being more stoical and less likely to ask for help²⁰. This may explain why in tandem with identifying limited access to informal support as a contributor to their isolation, the men were careful to ensure that they were not being perceived as weak. They expressed this in the use of colloquial terms such as "wimps" or "sooks". It could be that while wanting to have similar supports as women's groups they were keen to ensure this was not in conflict with their "masculine identity"^{21,22}. For this group of men there was an obvious tension of wanting to have what the women had but ensuring that they were "not being like women"²³.

It is well known that cancer places a financial and economic burden on individuals^{24,25}. A study of patients with colorectal cancer highlighted the adverse impact of treatment and employment²⁶. Moreover, McGrath *et al.*²⁶ demonstrated work limitations resulted in financial hardship for those recovering from cancer. Economic stress experienced by the men in this focus group was related to an inability to attend to their usual employment as a result of their symptoms from cancer or the treatment they received. The anger of finding oneself in extreme financial chaos was described by one man with the words "fighting and yelling and screaming", illustrating a loss of control over the circumstances that a diagnosis of cancer had put him in. The men in this group shared a common difficulty in reconstructing a former sense of themselves as powerful, strong men and breadwinners. The negative financial impact of cancer seems to be well known, yet the men in this focus group expressed extreme frustration at the barriers they faced in seeking timely and adequate monetary assistance. The need to travel for treatment for those living in rural areas compounds this financial hardship²⁰, and this was expressed by the men in this group. Addressing cancer-related financial burden has been identified as improving overall QoL²⁷. Improved access to financial assistance may have ameliorated stress related to cancer diagnosis and treatment for these men and is an area that needs urgent attention from social services.

A lack of control or agency was evident in other aspects of life, aside from financial control for the men in this focus group, which may be related to their age. On average, these rural men were around 70 years. Moynihan's¹⁰ early research identified a paucity of evidence of how older men with cancer respond to formal support, despite the knowledge that prostate cancer patients exhibit untreated distress. Moynihan¹⁰ also proposed that assumptions about older men and their self-perceptions when experiencing illness in addition to the clear lack of services

for men may be a contributing factor for distress. The rural location of this study means that, although 70 years of age, many of the men may still be self-employed in agriculture, adding another layer of complexity for distress that does not exist in urban studies.

The men in this focus group reflected on their changed intimate relationships and, in some cases, relationship breakdown. There is good evidence from a previous Australian study that cancer does impact on intimate relationships, with changed roles, communication, intimacy and sexuality²⁸. The changed roles frequently results in sadness, anger and frustration, but can result in relationship enhancement for men, more so than women. The feelings expressed by men in this study support these earlier findings of relationship changes, although for one man in particular his relationship deteriorated irreconcilably rather than improved. Gilbert *et al.*²⁹ describe these changes as "biographical disruption" and are, in part, a result of the physical impact of cancer, which forces men to adjust their daily life to accommodate physical needs. The stoical characteristics of rural men mean they may not adjust as well as their urban counterparts to "biographical disruption", increasing their level of distress.

It was evident in this focus group that there was a very poor knowledge of cancer and subsequent treatment. An Australian study focusing on prostate cancer showed similar issues with men's knowledge, concluding that informational support is a priority for men⁶. Interestingly, a small recent study reported that written information is less useful to men compared to clinical consultations, which may have implications for ways in which clinicians communicate information to men¹⁶. This may account for the high number of visits to the health service by some of the men. Informational support is shown to be a short-term need³⁰, but is associated with quality care³¹. Informational needs include the stage of disease, treatment options and side effects of treatment, as well as the trajectory of recovery³¹. Health professionals are the most frequent source of information in cancer care³¹. Irrespective of gender, patients who are less satisfied with the information they receive report more anxiety, depression, and lower QoL¹⁸. The comments in the focus group, such as, "I don't even know the name of the doctor that did it" suggest a real power imbalance and lack of information sharing. While research confirms that older age groups are less likely to engage in, or demand, shared decision making about treatment options³² this can result in future decisional regret. In addition, rural people are more accepting of a paternalistic culture of care and express less preference to be involved in treatment decisions³³. For this cohort of men, both older age and rurality, mean there may have been greater acceptance of the lack of information sharing about their illness and treatment.

Cancer care, like all health care, requires a person-centred approach. An Australian study showed that oncology nurses who

provide supportive care should be aware of differing attitudes among their patients³⁴. Our study supports these findings and strongly suggests that when considering the 'apparent' attitudes of men to suggested supportive care services and resources, clinicians ought to reflect that attitudes are highly influenced by the broad cultural context which includes, age geographic location and gender. Rural men, especially older men, are unlikely to request information about their illness or demand greater involvement in decision making about treatment. A model of shared decision making in SCS, including ascertaining the patient's preferred level of involvement, their understanding of illness and treatment pros and cons and their values and preferences regarding treatment is essential for providing quality, person-centred care, specific to individual needs. Regardless of the model of care utilised, this study highlights that changes to SCS in cancer is required to better meet the needs of rural men.

Conclusion

Cancer has physical and psychosocial implications for men that extend to their masculine identity and may force them to renegotiate their constructions of themselves. Physical issues appear to overlap with gender issues, whereby the impact of loss of income, physical discomfort and changed intimate roles were found in this study to be linked to masculine ideals. Men that identify with more traditional gendered roles therefore may be impacted by cancer more profoundly than women — this may be particularly true in rural settings. This study showed that rural men with cancer have unmet needs. Although the SCS captures the domains of physical, emotional, family and spiritual/religious concerns, it does not capture the patients' understanding of these aspects in a formal way or help to tailor learning needs.

Research impact

This study highlights the importance of ongoing evaluation of service delivery, in particular the importance of consumer perspectives of outcomes of the quality of care.

Indirectly, the rural ambulatory cancer service employed a prostate cancer nurse following this study. The results were able to inform how the service could tailor care provisions to the unmet needs of men with cancer, including the implementation of a support group.

Ethical approval

Ethics approval to conduct the study was granted by the Goulburn Valley Health Human Research Ethics Committee (approval number HREC/GVH44/15).

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Competing interests

The authors declare that they have no competing interests.

Consent for publication

All focus group participants were over the age of 18 years and gave written consent for participation. The consent form clearly states the intention to publish findings of the study.

Authors' contributions

CO and HH collected data. CO and KE analysed the transcripts. KE wrote the first draft, CO, HH, AK and LJ contributed to subsequent drafts. All authors read and approved the final manuscript.

Availability of data

De-identified transcripts of the focus groups and field notes are available from the corresponding author.

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