

Appendix 2. Interventions suggestions paper

INTERVENTIONS TO REDUCE THE DISTRESS OF MEN WITH CANCER:

Discussion suggestions from the Psycho-Oncology Research for men

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Background

This research has investigated the distress and coping of men with cancer. Results were drawn from individual interviews with 27 men from the Horowhenua, Otaki, Whanganui, and South Taranaki. They were validated in follow-up discussions with small groups of the original participants (seven men) who had low income, were single, and/or were Maori. Ideas for interventions to address their distress and capitalise on men's coping strengths were developed with those men, and checked with another two men from the original participant pool who had tertiary education and managerial level experience (both had higher income, were married/partnered, and were Pakeha). I set out these ideas for change in this paper, for the purpose of stimulating discussion with relevant stakeholders.

Obviously, many of the needs that male patients have are the same as those of female patients. This research, and the suggestions made in this paper, focus on the needs of men, which have been neglected in the past. However, many of the suggestions are relevant to women also, and although I maintain the focus on men for present purposes, in most cases it would be appropriate to 'read in' women also.

Hospital services

'Opt out' clause in admission forms

Men were frustrated that the Cancer Society and Maori Cancer Coordinator did not contact them without their having to ask, or contacted them belatedly (e.g. the Maori Cancer Coordinator contacting a man after he left hospital when he needed her services from the point of diagnosis). All of the men in follow-up discussions were happy for the hospital admission form to carry a question requiring them to 'opt out' if they did not want to be contacted by these services.

Suggestion

The admission form could carry the following questions:

1. Do you live alone?
2. Do you have any objection to us providing your telephone number to the Cancer Society (and Maori Cancer Coordinator, where applicable) so they can telephone you to explain the services that they offer?

The first question is aimed at identifying those men who are most vulnerable i.e. who may lack social support. The second question is written in terms of an 'opt out' rather than 'opt in' to convey that being contacted by the Cancer Society (and the Maori Cancer Coordinator) would be the normal routine course. I understand from Jo Anson, manager of the Central Cancer Network (pers. com. December 2012), that any doubt about the legality of using such 'opt out' phrasing has been cleared up by the recent approval of the Privacy Commissioner. Note also the narrow purpose expressed in the second question: it does not give permission for men's details to be entered on the systems of these services for general purposes, but only for one contact to be made for one specific purpose. This is to avoid the fear some patients may have of being exposed to unwanted repeat contacts.

Men who live alone could be prioritised for early attention by the hospital social worker, as well as the Cancer Society field worker and the Maori Cancer Coordinator.

Incorporating information into standard treatment processes

The main components of men's cancer-related distress were to do with uncertainty and lack of control regarding the whole disease and treatment process, and losses, particularly of life expectancy and of important bodily functions. It was disturbing for me to discover that even after many months of treatment some men did not understand basic information about the disease (e.g. that cancer is not contagious, or that particular cancers progress to particular sites only) or about their prognosis / the purpose of their treatment (curative or palliative). These men were still quite 'at sea' and suffered unnecessary anxiety and despondency, including concern for the cancer risk of family members. Some also felt degraded by some treatments (e.g. wearing a catheter) and by the way in which some doctors communicated with them (e.g. blunt and truncated). Some men said that although they were kindly invited to ask questions, they understood so little about the disease, its treatment, and available services, that they did not know what to ask. The three Maori men comprising one of the small discussion groups had had "no idea" about Cancer Society services prior to their cancer experiences, and then only learned through their informal networks, or belatedly through the hospital social worker. The concerns that bothered them initially included paying the rent, ensuring the dog was looked after, and obtaining home help, but they had been reluctant to ask about assistance with these for fear of appearing to be "a bludger" and because of generally feeling whakamaa. They said that looking at the notice board in the hospital for information was "the last thing you're thinking of" and that they wanted to be told about services one-on-one, because that was the caring way. Other men also noted that their initial distress improved as they gleaned the information they needed over time. However, even the more educated men complained that desirable information was "not [spontaneously] forthcoming" from some doctors and the system generally.

An important strategy for combating anxiety and other negative feelings induced by uncertainty and lack of control is to provide timely and relevant information in a readily accessible form. Despondency and anxiety regarding loss can also be reduced by providing information that normalises the losses and presents strategies and resources for adjusting and coping.

Men expressed that they would be able to target important questions at consultations if they understood background information. Benefits should accrue to doctors also, who should be able to discuss treatments with their patients more efficiently, and expect better compliance with treatment regimes, because their patients will have a better understanding of the disease and its treatment.

Needed information can be provided efficiently in a number of forms, and several are suggested in this section. Good communication is achieved through the clear and repeated presentation of important messages at times when content is perceived to be relevant. It is therefore important that information is presented at multiple points during the diagnosis and treatment process. For many men (notably Maori) it is also important that information is

conveyed to whanau, especially since there are times when men are unable to absorb important information due to treatment effects (e.g. drug effects on memory) or their distress.

Following are a number of suggestions aimed at efficiently improving the communication of important information to patients.

Informative DVDs

A series of DVDs could be produced which address different aspects of the disease and treatment and difficult issues which may arise, delivering relevant information at pertinent points in the treatment process, delivered to patients as a part of standard procedure. One DVD of this nature already exists and has been used for several years to introduce patients to radiation therapy at Palmerston North RCTS and to the psycho-social services that may be helpful while undergoing radiation. I note that the three Maori men who participated in follow-up discussions viewed the RT DVD with me and found its 'virtual face-to-face' format perfectly acceptable.

That DVD has a number of very helpful features, most notably a detailed demonstration of the therapy process and an overview of psycho-social services. Men also were pleased that it used plain understandable language and showed real people – both professionals and patients. However, its delivery to patients appears to have been patchy (of the six men in the follow up discussions who had received it, only four had watched it, and one man who should have received it did not do so), and belated (men were given it to take home at the end of their initial visit to RT, although the purpose and procedure of that visit is demonstrated on the DVD), and men with prostate cancer found it frustrating that this DVD did not address – or even mention – the most serious side-effects associated with the treatment for them (incontinence and loss of sexual function), and that often their oncologist did not explain the sexual side effect either. However, the overall tone and clarity of the presentation on the DVD is very good, and it was accompanied by an attractive booklet which reinforced many points. If a series of similar DVDs (with booklets) is produced and embedded in a delivery protocol which ensures that patients get the full benefit of the information they provide, this method of relaying information could be both efficient and greatly beneficial.

I envisage that all patients (with whanau) would view a DVD providing background information on the disease and treatment and explaining basic terminology. Because an understanding of this material would be recognised as important, this viewing would be scheduled as a standard component of treatment, as an appointment at hospital after diagnosis but before the treatment planning consultation. Patients would then be offered the DVD (and accompanying booklet) to take home. Then, immediately after the treatment planning consultation or during the treatment planning process – but before treatment commences – patients would be given one or more other DVDs (with booklets) relevant to the particular treatments planned or under consideration. Because patients will now appreciate the importance of viewing the DVDs, they could be given the option of viewing these treatment DVDs at the hospital before they leave (which may suit men who do not have a DVD player) or at home. Detail about the proposed DVDs is as follows:

Introductory DVD: Introduction to cancer and its treatment. To be viewed by all cancer patients (and whanau), as part of standard treatment, after diagnosis.

As mentioned, this DVD would be designed for viewing at hospital at a special appointment timed between diagnosis and treatment planning consultations. This timing allows for patients to adjust sufficiently to the initial shock of diagnosis, and prepares them for their treatment planning consultation. The DVD might be 30-45 minutes long and would be accompanied by a booklet reinforcing main points and contact details. It would be introduced by the diagnosing doctor as a highly recommended component of standard treatment procedures, which explains basic facts about the disease and its treatment that are important to treatment planning and coping with cancer. (Patients who choose not to view it could still be offered a copy to take home for themselves or their whanau.) A viewing appointment could be made as the patient leaves his diagnosis consultation. The viewing itself could be conducted by an administrative staff member (little more would be required than simply settling the patient and whanau into a viewing lounge and starting the DVD), but ideally a nurse would be available after the viewing for ten minutes to answer any questions arising from it. Possibly regular viewing times could be scheduled to facilitate this, and a number of patients and their whanau could watch the DVD together.

This DVD would cover:

1. **What cancer is** and how it spreads, including its causes, and the fact that there are many types which have different courses and 'metastasise' to different organs. Basic terms would be described. The courses of the most common cancers – from possible causes right through to death or successful treatment – would be described by way of examples.
2. **What the main treatments for cancer are** and how they work. Explanation could use a simple analogy, e.g. of warfare: "In order to combat cancer you need to 'know your enemy': cancer's strengths are that it multiplies and it does so in ways which can be difficult to detect, therefore our treatments are designed to.... " It would explain terms like 'curative' and 'palliative' and would briefly explain how surgery, radiation, chemotherapy, and hormone therapy works. A useful analogy for these treatments might be that treating cancer is like killing gorse on your farm: "You can grub it out, you can burn it out, you can poison it, or you can starve it!" A typical treatment regime for a couple of common cancers could be provided by way of illustration.
3. **The treatment 'team' and process.** This would introduce men to the concept of dealing with cancer with a 'team' of supporters, including medical professionals, family and friends, and community organisations and members. It would explain the process of planning consultations, monitoring tests and consultations, and treatment. The patient would understand that the next step for him would be a treatment planning consultation, and that the role of the specialist is to advise and assist, rather than to direct treatment: it is the patient's right and responsibility to make treatment choices according to his own life priorities once the professional advice is understood. This is important because men often commented that they

did not feel 'on the level' with their doctor, and this could result in feelings of degradation and unnecessary anxiety which were damaging to their relationship and, sometimes, to treatment.

How to obtain further information would be an important part of this segment.

Men wanted to know what **questions to ask** "to be sure we're being told the whole story", so some questions could be suggested, such as, "What is the risk of my children getting this cancer and how should we deal with that?" and, "What signs of the cancer returning should I watch for after treatment, and what should I do if I am concerned?" The role of second opinions would be explained, and how to obtain one. Reliable supplementary information sources would be listed (e.g. the Cancer Society's website and helpline) and a comment could be made regarding the role and reliability of 'alternative' treatments. Patients would also be encouraged to make use of their 'home team' of family and friends to help talk issues and feelings through, as well as to make use of social services when needed.

4. **An introduction to cancer-related mental health issues, social services and care at home.** This section could start with an explanation of a typical cancer-related distress trajectory (such as has been described by the present research) by way of normalising distress and encouraging patients that they will 'come through' in due course. Then a few basic strategies could be mentioned e.g. talking with supporters, obtaining information, and having a positive active attitude that seeks to make the best of the situation and take advantage of any help that is available. A normal distress trajectory for family members (wives and dependent children in particular) could also be described, together with some suggestions regarding how the patient can assist family members with processing their distress. A brief overview of services and relevant contact details could be given, with the assurance that more detail will be provided in later treatment-specific DVDs and can also be obtained direct from the provider (or on the website that might be developed in accordance with the suggestion of a co-ordinator role, below). More detail could be provided regarding services that are relevant immediately, such as transport (Cancer Society drivers, Horowhenua shuttle, and reimbursement for using one's own vehicle) and the Maori Cancer Coordinator. Other services briefly described would include: social workers including Awhina and the Maori health unit/accommodation at hospital; Cancer Society services, including their fieldworkers, rooms, information line, accommodation, and buddying service (if our suggestion below is followed up); Cancer Psychology Service (noting its availability for relatives also) and John Kirwan's depression website; home help, and community based nurses, including hospice nurses. Patients could be encouraged to pay a visit to their Cancer Society rooms and discuss what is available. Note that men expressed concern for the emotional wellbeing of their wives and information for them as to where they could find support (e.g. Cancer Psychology Service, Cancer Society). An overview of benefits available from WINZ to assist with home help and financial burden or other needs would also be important.

Treatment DVDs: Four DVDs, covering surgery, chemo- and hormone therapies, radiation therapy, and palliative care. To be provided to patients according to their anticipated treatment regime.

Again, these DVDs would be 30-45 minutes long and would have accompanying booklets. Patients would be provided with the DVDs appropriate to the particular treatments anticipated at their planning consultation, with the invitation to view them before leaving the hospital if preferred. These DVDs would cover:

1. **How the treatment works** to combat cancer or, in the case of palliative care, to assist the patient with quality of life. This should include assurance regarding any common concerns, e.g. a fear of radiation could be addressed by a comparison of the dose of radiation used in RT with a lethal dose of radiation, or the dose victims of the Hiroshima bomb were exposed to.
2. **How the treatment process looks and feels.** In order to reduce anxiety, it is important to show and describe the *process* in sensory detail, and to explain the *purpose* of each step of the process. The viewer should feel as if he is personally experiencing the treatment. This is very well done in the extant RT DVD. In the case of the palliative care DVD, this section would show the use of common drugs (e.g. a morphine pump) and Hospice care, including home visitation by nurses.
3. **Main disease/treatment stressors and side-effects, and how they are managed.** Special sections of the treatment DVDs could be devoted to explaining the side-effects associated with the treatment of common or particularly problematic cancers, the likelihood of these side-effects being experienced and the range of severities commonly experienced, and the means by which they are dealt with, including guidance regarding further resources where the impacts are far reaching. For example, a section of the RT DVD would be devoted to the sexual and continence side-effects suffered by prostate patients; a section of the chemo- and hormone therapy DVD would explain hot flushes and the sexual side-effects suffered by prostate patients; a section on the surgery DVD would explain the effects of ostomy surgery and bag-wearing for those with bladder and bowel cancers (physical and social, with suggestions for further information), and detail about wearing a catheter for prostatectomy patients; and a section on the chemo- and hormone therapy DVD would explain how needle phobia could be managed, with other sections explaining hair loss and nausea. It would be important to cover all of the most burdensome commonly experienced side-effects and disease/treatment stressors, and resources for further information could be suggested. In the case of the sexual and continence or bag-wearing side effects affecting men with prostate and bladder or bowel cancers, one of those resources would be the course described below.
4. **The importance of taking care to comply with aspects of the treatment regime.** For example, on the RT DVD, patients would be clearly warned that they can experience permanent continence problems as a result of not drinking water as prescribed before treatment.

5. **Relevant social services and mental health strategies.** Each treatment DVD would dedicate significant space to (a) personal wellbeing and (b) a more detailed description of social services relevant to the particular treatment:
- (a) Wellbeing. Advice could be given for recognising and addressing depression and anxiety, explaining how depression symptoms can be 'masked' in men. The importance of staying socially engaged could be stressed, and some opportunities for doing so listed (e.g. Men's Sheds, charitable organisations, or mentoring young people in practical skills). Points of this nature are made in the extant RT DVD by patients who explain strategies they have used to cope, such as communicating closely with family. Services that help with depression and anxiety could be more fully explained in such a way, including the Cancer Psychology Service and John Kirwan's depression website. Because men have little experience with health related services, it is particularly important that services are described in explicit terms, e.g. explaining specifically that a service provides help with 'relationship issues *including* coping with disruption to your sexual relationship due to the sexual side-effects of treatment'.
 - (b) Services. The chemo- and hormone therapy and RT DVDs should detail transport and accommodation services (Cancer Society drivers, Horowhenua Shuttle, reimbursement of mileage) for attending treatment. The palliative care DVD should detail counselling, spiritual and Maori services based at hospital and in the community, and could also discuss issues and resources relevant to addressing end-of-life legal and financial matters (e.g. the importance of putting in place a power of attorney and of updating your will, and how to go about this), or managing young family members through the terminal illness of a parent. Such matters can have their own segments, so that patients can view only those relevant to their own circumstances. Services relevant to most treatment regimes could also be described in more detail in these DVDs, e.g. the Maori Cancer Coordinator, or Cancer Society massage, meditation, buddying and men's groups.

Younger men. The DVDs I have described mainly address the needs of older adults, who form the majority of cancer patients. However, sections should be incorporated which take into account the different perspective of younger adult patients. For example, material on testicular cancer and lymphoma treatment issues, and more 'high tech' ways that younger men may like to access support services

Course on side-effects impacting masculinity and sexual intimacy

I understand that there has already been some thought of addressing particular masculine issues relating to prostate treatment and ostomy surgery by means of a group seminar or course incorporated into standard treatment (pers. com. Dr Don Baken, psycho-oncologist, December 2012). Men need both medical and emotional / relational information on incontinence, impotence, and bag-wearing in order to soften the blow to their masculine self-image and self-esteem and to facilitate the adjustment of their sexual relationships. As noted earlier, it was the frequent experience of men participating in this research that loss of normal sexual function and its interference with intimate relations, was not thoroughly addressed by

their doctors before treatment was undergone. In some cases the matter was alluded to briefly and in vague terms (e.g. Arthur was told "in a round about sort of way... 'It may upset your sexual activities'"; Grant said "all I got told was it won't be any use any more!") and in other cases the matter was not mentioned at all. Even those men whose doctors were direct about the side-effects received no advice as to how to adjust in their sexually intimate relationships. As these are such personal matters, men are keen that they be raised by the professionals, and are dealt with openly, in a way that normalises them and makes them easier to discuss, as a part of standard hospital treatment. Adjusting to impact on physical lifestyle and associated social life (e.g. the loss of friends due to no longer being able to participate in contact sport) due to stoma surgery is another important topic that needs to be addressed.

Men who participated in the follow-up discussions were very keen on the idea of a group seminar or short course covering these topics as part of standard treatment. They wanted issues to be discussed openly and fully. They felt a group setting would help with normalisation and allow the opportunity to discuss particular problems. A course would directly and fully address both adjustment to living without particular functions (notably erection) and any options that are available to assist with regaining function (e.g. injections, implants, vacuum pumps) and how to obtain them, including funding. It would be valuable to include intimate partners in this discussion so that they understand the issues and discussion of them is normalised. A course would directly encourage and initiate such discussion, broach the most difficult topics in order to initiate couple discussions, and suggest services that can provide couples or individuals with further assistance. For some men the interference that treatment side-effects caused to their intimate relationships has been the worst part of their cancer experience, so assisting to bring about discussions with intimate partners is a vitally important component of any such course.

Such a course would need to be run by people with appropriate competence in both medical and psycho-social aspects. This may necessitate dual leadership (e.g. by a specialist nurse and a cancer psychologist), or sole leadership with the assistance of pre-recorded (DVD) material. If this is not feasible, then another informative DVD could be provided to individuals. While this alternative is not optimal in that it would leave men feeling isolated and without the immediate opportunity to ask questions, it could still convey a lot more information than men are receiving at present, and further resources and opportunities to ask questions could be suggested on it.

A 'go to' nurse for questions

Some men were concerned by unanswered questions many months after treatment, while others were invited to contact a local oncology nurse or their specialist surgeon or oncologist at any time to have concerns answered. It would be useful if all cancer patients were provided with the email and phone contact details of the relevant specialist nurse in order to resolve such concerns efficiently, as is the case for breast cancer patients at Palmerston North RCTS at present. One of the Whanganui men said he found the local oncology nurse excellent for such questions, but the other, although knowing who she was, had not

understood that he could have asked her the questions that troubled him. The role needs to be allocated and communicated explicitly.

Giving permission to RTs

Every man who experienced radiation therapy noted how superb the radiation therapists were in delivering the treatment with warmth and humanity. Some also noted their considerable respect for senior RTs and their gratitude for useful information about their treatment that these people passed on. However, where that information was given, men noted that the RT was running the risk of overstepping the parameters of their role in the interests of compassion, and was clearly uncomfortable with that. These men noted that the information forthcoming from their doctors was not sufficient to allay all of their concerns, despite regular consultations, and the information that the RTs provided (e.g. about side effects of radiation) was important to their peace of mind.

As part of a general policy of taking every opportunity to make relevant information available to patients, it could be helpful if RTs were formally permitted and invited to discuss the treatment, its side effects, and their management, with patients as part of their role.

Communication by doctors

Men noted unsatisfactory communication style from their specialists with disturbing frequency. This caused unnecessary distress and alienation, which could even effect treatment. All of those doctors whose performance was complained of were men, sometimes complaints were attributed to foreign cultural norms (doctors from countries where class hierarchies are more pronounced), and the most distressing problems were cold/blunt/truncated or directive/controlling ("rude and arrogant") approaches. As noted, men also often wanted more information than was volunteered by doctors, feeling that they did not know what questions to ask, and that doctors needed to be "pumped" for information (e.g. about the purpose and chances of success of their treatment, the significant side effects, and any genetic vulnerability applicable to their children). It needs to be recognised that uncertainty is a leading cause of anxiety in cancer patients, and although cancer is an inherently uncertain experience, advice can be given which minimises the uncertainty. Men worried needlessly when doctors were not forthcoming with information, fearing that bad news was being withheld from them. They want to be 'levelled with' about the range of possibilities and probabilities of outcome that were relevant to their treatments and overall prognosis.

In sum, men wanted an 'on the level', informative, and warm style of communication, which conveyed hope, but in realistic terms. For example, a straight explanation of the meaning of patient's diagnostic test results in terms of diagnosis and prognosis, but then hope – the assurance that while nothing is certain with cancer, there are options for treatment and assistance – and all said with caring warmth, with a simple explanation of treatments and the purpose of them. There were a few specialists who were exemplary at this and possibly they could contribute to professional development efforts. Also, based on men's interviews, I have drafted a paper for medical students listing 10 tips for treating men, and some of this material might be helpful to incorporate in professional development programmes for specialists.

Oncology social workers

Currently, an oncology social worker attempts to see every man who spends time as an inpatient as part of treatment. Unlike other psycho-social services (I have gathered snapshot data from a range of providers) this service successfully connects with a large number of men, proportionate with the gender balance expected amongst cancer patients. However, from my interviews, I know some men still 'slip through the net', and the service does not attempt to reach all outpatients. Those who saw the social worker found the visit useful, with these reservations: (1) the visit provided belated information about some services, which men had already learned about through other means, or would have liked to use earlier, either for practical support or to allay concerns about practical matters (2) although the meeting was genial, and questions were invited, the man did not understand the system and his future needs well enough to know what questions to ask the social worker.

Suggestions

1. The role and contact details of the oncology social workers could be explained in the introductory DVD viewed by all new cancer patients (described above).
2. Oncology social workers could make priority early phone contact with men who have indicated that they are 'living alone' on their hospital admission form.
3. Oncology social workers could include information about other services (e.g. Cancer Society and Maori Cancer Coordinator) in their standard initial contact with patients. This information could be elaborated on in written material or a DVD on social services made for the purpose. Oncology social workers could also encourage inpatients to watch the informational DVDs while they are 'laid up' in hospital.

Booking systems for high frequency treatment

Several men who were working or self employed mentioned significant difficulties they had with the scheduling of RT appointments. Two of them said they had sharp exchanges with the booking person concerning this, and one took the matter to a superior. By contrast, the chemotherapy booking system did not pose any problems.

A system is needed (perhaps it is now in place?) which affords some convenience and regularity of time for men who need that, due to work or other commitments. Those without such commitments could 'fill in the gaps'. Also, patients who come from a distance and stay at Osnam house during the week would be best served if given appointments late in the day on Monday, and early on Friday, to allow them to travel at convenient times. These patients' appointment times could flex around the needs of others in the middle of the week.

Brief spiritual intervention

In the spiritual context, one of the Maori men commented that cancer can be a "lonely time" (Beau). A very brief intervention delivered by oncologists (one delivery, adding two minutes to one normal consultation time) can give permission for a patient to indicate that they would value discussing the issue, and provide some human resource options. The intervention I suggest would be along the lines of that developed and tested by Kristeller et al. (2005), which assisted palliative care patients to suffer less depression (a clinically small-moderate statistically

significant effect size at three weeks, rising from negligible at immediate measure, and potentially rising higher over time). This simple intervention involves the oncologist asking after the patient's spiritual wellbeing in the context of suggesting that the issue is relevant to many people with their presentation of cancer, and offering a referral to someone skilled in spiritual matters if desired. A list of such people, covering various faiths and beliefs, could be offered, or, alternatively, the oncologist could offer to email the person selected from that list, providing them with the patient's phone number for contact. Whether they wanted such a referral or not, most patients in the Kristeller study received this enquiry as an expression of caring, and it strengthened their relationship with their clinician. In New Zealand spiritual matters can be difficult for people to raise, and such an intervention may provide a very important opportunity to some patients.

Cancer Society services

The following points are additional to those in my paper to the Cancer Society of 3 August 2012 entitled *Health Promotion and Psycho-Social Service Use*.

Cancer Society services are not well known amongst men, who tend to feel less competent and knowledgeable regarding health and social services generally. Maori men, in particular, expressed the value of being told about services personally, and had very little knowledge about the Cancer Society (Beau: "I wouldn't know who to ring"). The following are suggestions for improving the connection between men and Cancer Society services:

Contact new admissions.

A Cancer Society volunteer could phone all new admissions to hospital treatment, following-up on the admission form 'opt out' clause suggested above. In the case of men who are living alone, contact by a more expert person such as a field worker would be appropriate since there is a greater likelihood of significant need. It is important that contact phone numbers provided to the Cancer Society for this purpose are not entered on general databases but are used only to make this connection and then disposed of if no further assistance is required by the patient.

Transport drivers.

Men felt that Cancer Society drivers, who typically 'knew the ropes' very well and empathised from personal experience, could do very well at conveying information about other Cancer Society (and other) services to the patients they carry (Colin: "Word of mouth is often the best advertising"). This could include an offer made to all new service users that they call in at the local Cancer Society rooms and familiarise themselves with the services offered there. The Maori men emphasised how they felt cared for when people told them personally about services, and given their scant knowledge of such services, this would be a particularly valued opportunity for them.

Volunteers in RT waiting rooms and chemo wards.

Men felt that clearly identified (tee shirt or badge) Cancer Society volunteers attending RT waiting rooms and chemotherapy wards in order to make men familiar with the services available to them would be well received. This would be a good opportunity to connect men to transport, buddies, and men's groups in particular. Their presence would also provide men

with an opportunity to ask questions of someone who, though not an expert, is familiar with many cancer-related issues.

Volunteers in inpatient wards.

One man had experienced a Cancer Society volunteer visit while he was in a hospital bed, but the opportunity was not used to familiarise him with Cancer Society services, which he felt was wasteful. As has been shown by the success of oncology social workers in connecting with male inpatients, these visits could be a valuable opportunity for the Cancer Society to connect men with relevant services.

Admission information pack.

This could contain an attractive brief note (one page) listing Cancer Society services and inviting men to drop in to Cancer Society rooms or ring the 0800 number or visit the website and find out more

Men's group 'buddies'

Men who are alone are particularly vulnerable to distress and often need help to understand the medical system and available services. A man who has already 'been there' can be a safe and knowledgeable friend to provide both practical tips and emotional support to a new cancer patient. According to one of the participants, older men at his men's group often informally 'buddy' new members with particular needs, such as concerns about stoma surgery. Men can easily relate to the 'buddy' role.

Suggestions

Men's groups could adopt buddying as a lead agenda. Such a move would be consistent with the views of many research participants, that to be relevant to them, men's groups need to be outward looking and action focussed. Particular priority could be given to men living alone.

Once a patient has indicated interest, buddying could involve an initial phone call from buddy to patient, during which the two decide on an initial meeting time and place. Where distance or other factors prohibit meeting, it may be appropriate to refer to the telephone service, Cancer Connect). The objective would be to provide patients with a friend with whom they can freely discuss their condition and treatment with a view to receiving tips on 'how the system works' and useful services, as well as an opportunity to air feelings and concerns. Ideally buddies should have training, as Cancer Connect volunteers do, and as part of such training they should be made aware of the masked presentation of depression symptoms that can occur in men, and some resources available to address depression (e.g. John Kirwan's web site, counselling through the Cancer Society, and coaching through the Cancer Psychology Service). However, as one participant said, the important thing would be simply that the buddy had been on this journey himself and was willing to walk through it again with the new patient.

Connecting with Menz Sheds

In earlier communications with the Cancer Society I have already suggested that it develop a close association with Menz Sheds. This opportunity for social support could be of great

benefit for the mental health of men who have cancer. Menz Sheds could also provide a valuable health promotion opportunity. Attending a Menz Shed could be encouraged through men's groups and through buddies, as well as in the Cancer Society's general advice to patients.

Maori men's group

The three Maori men of the Foxton discussion group all relied heavily on their informal extended whanau networks to get them through their cancer experience. Not only were these contacts vital in helping them process cancer information and make treatment decisions, but they also connected Maori men with much needed services such as transport and home help. Now that their treatment is well behind them, these men rely on their informal networks to provide them with important roles and purpose. The two men whose lives had been most radically affected by the extent of their surgery (both wore bags and had ceased sexual relations) had 'changed gear' and become mentors to younger people, since they were no longer able to live the active physical lifestyles they had been used to. These men found it very rewarding to pass on their skills in music, mechanics, fishing, and other practical work. Such a change in role sits comfortably with Maori expectations of older age. All of these men also spoke highly of the help that they had received from others while working through cancer: "You can't do it on your own" (Ricky).

Suggestion

These men said they would be interested if the Cancer Society were to invite a group of Maori men with cancer to get together simply to extend their networks so that they could assist each other, their whanau, and the community in ways that arise naturally from that connection. Such a meeting would be quite informal and may involve a minimum of organisation by the Society as men would probably organise themselves once they got under way. Their on-going relationship with the Society could be discussed.

One of the men said how he found talking with other cancer patients like meeting with whanau, and that he imagined his own whanau would soon become involved in any such get togethers. Meeting together like this could be a very natural and productive intervention that benefits both the men themselves and the wider community, for example, by raising awareness about cancer early detection, as well as by encouraging and supporting each other. Men also said that this would be a good setting to process darker feelings like self pity and sadness, since it would provide a safe place to cry and an opportunity to think of and help others ("its not just all about me"). One of the men said that he had "hidden" from the world after his major surgery, and a group like this would have provided a safe place to get over the whakamaa barrier and back into circulation.

Domestic skills mentoring

Men expressed their concern that if their wife dies, they would not have sufficient domestic skills to look after themselves (e.g. cannot cook or run the dishwasher or washing machine). They need to be able to learn the sort of cooking and cleaning skills that 'Supergrans' currently teach young mothers.

Suggestion

Perhaps a connection could be made with the Supergrans Service to enable men who are alone to be referred to them by the Cancer Society or social workers.

Further health promotion suggestion

Further to the health promotion suggestions made in the August 2012 paper to the Cancer Society.... One participant noted that at his hobby club (machinery/automotive related, attracting mostly men of retirement age, I understand), he could often find himself speaking with half a dozen men about prostate cancer. One or two of these had had cancer themselves and would tell of their feelings and their treatment, but the others would be men who were suspicious that they had symptoms and ought to be doing something about it, and were being encouraged to do so by those who had 'been there'. He noted that although there were a couple of men in the club who had been cancer patients but remained silent, it was much easier these days to discuss such things (he referenced John Kirwan's work) and many did. Another man spoke similarly regarding his interactions with fellow members of his sports club, and another regarding interactions at his work place. In particular, both mentioned the considerable and serious interest other men showed in cancer awareness generally.

In my earlier paper to the Cancer Society I noted the credibility and persuasive power of personal story to men, and I suggested it be made more use of in health promotion. I should add that men also have a strong motivation to help others – nearly all of the men who participated in this research did so with such a motivation. Perhaps the Cancer Society could take advantage of these dynamics by encouraging men who have had cancer to 'come out' (as men have termed it to me) and use the power of their stories to help their club/work mates. In the past, the opportunity to educate men through such male hubs may have been recognised as an opportunity to distribute literature or to educate men with some kind of presentation. However, they could be targeted with the potentially more powerful additional / alternative agenda of inspiring survivors to share their stories as an ongoing commitment, thereby taking advantage of the respect that men have for the voice of experience and the motivation men have to help others, as well as the personal links that exist in these social contexts. Although for some men being known by others may heighten their sense of vulnerability, many appear to feel safe enough with these people – who already respect them – to discuss such 'personal' matters. In the case of Maori, their wide informal links and deep concern for whanau could be similarly harnessed for this health promotion purpose.

The main question would be how to connect with survivors to inspire them to do this work. Perhaps the Cancer Society could use and expand existing links with men's clubs and work places and with Maori groups to advocate this work. However, it must be borne in mind that the Maori men who know least about cancer are likely to be least well connected with the formal structures of their own society as well. Perhaps the Cancer Society's own lists of service users could be used as means to contact men with the suggestion that they could exploit the opportunities that they have to do this work. Or perhaps a mass media campaign could provide inspiring examples. This would be in keeping with the kinds of television advertising that have been running in recent years about supporting friends through mental

health problems or talking with friends about their violence or their drinking problem. The message would be something like, "Save a mate: talk about your cancer".

Cancer Psychology Service

Men liked the terms 'coaching' (instead of therapy or counselling) and 'team' and found the new name for the Cancer Psychology Service preferable to the Psycho-Oncology Service.

It would be useful if the nature of Cancer Psychology Services were described in concrete and specific terms for men, who often have no idea of how such services actually work.

Maori Cancer Coordinator Service

I suggest that Maori Cancer Coordinator services alter their procedures in a similar way to that suggested in relation to the Cancer Society and the oncology social workers, to provide for follow-up on the proposed hospital admission form 'opt out' clause. Again I note that it is particularly important that men who are living alone are contacted promptly, and also that phone numbers provided to the Service for this purpose are used only to make this initial contact.

Psycho-social service coordination

A significant issue for extant psycho-social services is the lack of coordinated delivery of them – and information about them – to patients. Men often learned about services belatedly and/or through 'random' means such as personal networks or a nurse's 'by the way' comment, or did not learn about them at all. Maori may have been particularly vulnerable, due to their generally poorer level of education and literacy, and their preference to have information communicated face to face. Furthermore, there seemed to be very little referral from one relevant service to another. The picture is one of a lack of coordination in how patients are advised of relevant services.

Suggestion

From a patient's point of view, there may be considered a need for central coordination of information regarding psycho-social services. I am not sure who could undertake the tasks that would contribute to such coordination, but possibilities that occur to me include the new 'care coordinator' role that the government recently announced, the RCTS, the Central Cancer Network, the Cancer Society, or a one-off role contracted to one of those with some provision made for periodic updating of work.

Essentially, the co-ordination needed would require a stock-take of extant services and planning to enable patients to be connected with them in timely and effective ways. A number of suggestions to this end have been made above, but central coordination could ensure that work of this nature is done, and that any new services are 'plugged in' to connection opportunities appropriately. Such a role would reflect an awareness of the importance of psycho-social services to the wellbeing of patients, including to both their mental health and to the effectiveness of their medical treatment.

I imagine that such a coordinator might work closely with the Central Cancer Network and with service providers to:

- Stock take extant services, placing them on a publically available website
- Plan and initiate contact/information points so that patients are informed about services repeatedly, at relevant stages in their cancer treatment, and by effective means. These arrangements would include incorporation of information into standard treatment procedures (including the insertion of an 'opt out' clause in admission forms), and incorporation of more information in the procedures of service providers as well (e.g. oncology social workers encouraging men to visit the Cancer Society).
- Undertake the task of creating the informative DVDs described above, arrange for them to be incorporated in standard treatment pathways, and periodically update them (say, every five years).

Conclusion

The scale of the suggestions put forward in this discussion document is significant, and suggestions are made at both structural and implementation levels. The most significant structural changes rely upon recognition of the psychological importance of information, and are aimed at providing comprehensive information about both disease and social services ('opt out' clause in admission form, DVDs, course re impacts on masculinity, and various suggestions aimed at better connecting men with relevant information and services), and the psycho-social service coordination suggestion.

The degree of effort required to implement changes of this nature would require recognition of the importance of psycho-social issues to the well-being of male cancer patients. In the past, the great bulk of cancer service and research resources have been spent on bio-medical intervention. The importance of psycho-social factors – both to optimising the effect of medical treatment and to the general wellbeing of patients – is now beginning to be recognised. It is also only recently that the health inequities suffered by men are beginning to be recognised. The present research is an example of both of these recognitions. Applying the necessary changes to the daily work of medical professionals and the lives of patients requires recognition and change of a fundamental and structural nature. However, although the effort required to implement the suggestions in this paper would be significant, it is by no means overwhelming. Furthermore, the opportunity exists for cancer services in a particular region – probably the MidCentral Health region – to pilot new systems which could eventually benefit men (and women) all over the country, and which could be adapted for patients of other serious and chronic illness.

From the patient's point of view, cancer is “*primarily* a psychosocial and existential experience”
– cancer psychiatrist Alistair Cunningham, 1988, p. 150.