

Appendix 4. Written notes accompanying intervention suggestions powerpoint presentation

Notes accompanying ppt presentation

INTERVENTIONS TO REDUCE THE DISTRESS OF MEN WITH CANCER:

Discussion suggestions from the Psycho-Oncology Research for men

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February 2013

Document purpose:

This document accompanies the ppt of the same name which was presented to a meeting organised by the Central Cancer Network in Palmerston North on 18 February. The first 7 of 9 slides in the ppt were presented on that day, and the eighth and ninth were added afterwards to show the action suggested by attendees of the meeting, by way of applying the findings and suggestions derived from the research. A matching commentary has been added to this document. Before that meeting, a discussion paper was also sent to participants, detailing a large range of intervention suggestions. The main thrust of those suggestions is discussed in the present presentation but the detail should be referred to also.

Slide 1: Background... as described in introductory paper you have had:

- Under Massey; Movember funding through CSNZ
- Supervisors
- Involved in-depth one-on-one interviewing 27 men incl 6 Maori, Horo/Otaki/Whanga/ST → thematic analysis → return to 7 men of vulnerable SES to validate and discuss solutions + 2 men higher SES to discuss solutions
- Now have a model of types of distress, means of coping, and process, which inform intervention

Slide 2: Research purpose: address inequality suffered by men:

- All the wrong health/cancer stats: e.g. 15 leading causes of death, 3x suicide rate, more unhealthy lifestyle behaviours *and* less health knowledge, less GP use... ignorance re health and health systems i.e. traditionally the role of women/nurturers
- Men's shorter lifespan and lower use of health services are symptoms of broader neglect of the inequality they suffer (e.g. there is no sufficient biological explanation for men's shorter lifespan and it should be a scandal, but we have accepted this as 'the way things are')
- 'Strong and silent' masc cultural norms prevent self advocacy: Men underreport distress sx / suffer in silence do not wish to plug a case based on vulnerability

- Meta-analyses show men can get twice the benefit from psycho-social intervention – probably because of greater need

Slide 3: Kinds of Distress

'No distress' + range of distress reported + ambiguous

'No distress' *associated w a range of factors*: incl acceptable time to die; misunderstanding or denial regarding seriousness of condition; optimism/pragmatism/get-on-with-it rationality; classic masculine aversion to any emotion that might be akin to self-pity which is shameful (give it a wide berth to the point of not conceding any negative emotion - dichotomy) i.e. this expresses the dilemma that masc norms put traditional men in whereby any expression of vulnerability inherently damages their identity as men, so is to be avoided/denied. Men who reported no experience of distress generally still often acknowledged being shocked upon diagnosis and also feeling empathic distress about their wives' distress.

'No distress' reporting *associated with* other talk that showed adherence to trad masc norms e.g. a reverential attitude towards medical expertise, talk of status and work prowess etc, and tended to be associated with less education but not exclusively. This suggests that it is an expression of trad masc norms rather than a fully accurate reflection of emotional experience.

Ambiguity reflected this also: men saying two things at once, perhaps by contradiction in the same breath or where words are at odds with body language and non-lexicon utterances etc

'Distress reported' fell into 4 main categories:

1. *Loss of control/uncertainty*: shock; uncertainties of prognosis and tx and impact on family and work etc; worry about dependents (emotions and finances); anxiety re interventions; loss of control of sexual function and continence; a general disturbing lack of control
2. *Substantive loss or anticipation of it*: life span; time with family/performing family roles e.g. financially providing or morally supporting; relationships (e.g. girlfriend) and social life (e.g. contacts assoc with sports)
3. *'Black' feelings* of guilt/regret (e.g. lung cancer, will not be there for granddaughter), degradation (doctor communication style or aspects of tx e.g. wearing a catheter), anger and self pity
4. *Empathic distress for wives* i.e. being distressed about their distress

Note: Uncertainty or lack of good info can cause or exacerbate a lot of these feelings: e.g. the uncertainty and worry around treatments and prognosis and effects of family and work → loss of control; and exacerbation of losses bc imagine greater loss bc no knowledge of how to manage things (e.g. loss of sexual function). *Men worried and grieved about things that I knew there were answers to, but they had not been informed.*

Slide 4: Processing distress metaphor of being dumped by a wave:

Washing machine: sea of uncertainty / avalanche 'which way is up'? / so many unanswered questions

Get feet on ground: realise 'I'm still alive'/hope/life to be lived → *engage* with problem solving of how to do this best

Hard slog of persisting through tx and all the losses and uncertainties and identity adjustments that have to be resolved → *equilibrium/achievement* i.e. regained sufficient control that cancer was no longer the 'big bogey'

Note how obtaining *information has a critical role* in 'getting men's feet on the ground' and beginning to engage and get traction on distressing issues

Slide 5: Means of coping i.e. strengths that can be built upon in any intervention. 4 main ones plus a group of others:

1. *Positive attitude*: men want to make the best of their situation
2. *Active and practical orientation*: men want to get up and do something to help themselves
3. *Being rational and taking control*: men want to think logically and coolly through options, they want information and they want to use it to solve problems and bring issues under control
4. *Social support and helping others*: Men enjoyed the practical support of others, most enjoyed the emotional support of wives, and some from a broader group - notably Maori, who had whanau including a number of women who guided them through the health process. More traditional Pakeha men were more likely to lean solely on wives and daughters for practical and emotional support and for information. Helping others was universally important, but only Maori took it to the level of a change in role in that two of the Maori men stepped up into roles as mentors of young people (passing on practical skills where they could no longer engage in the physical work and activity that they used to) and organisers of small beneficial projects (fishing, firewood cutting)
5. *A group of minor ones*: using withdrawal/crying, spiritual resources, social services (MCC, CSNZ transport), and satisfaction at personal growth e.g. growth in empathy for others and appreciation of life and family, health improvement (e.g. cessation of substance abuse)

There are downsides to some of these (e.g. positive and active to the point of being in denial)

But note some great opportunities for intervention in positive, active, rational attitude, wishing to take control of problems and solve them.... so, they have the motivation and desire to make good use of information

Slide 6: This research indicates that information is of central importance to men's wellbeing for several reasons:

- **Men's distress:** Two main types of distress feature a lack of information: uncertainty and consequent loss of control cause much anxiety, and lack of knowledge exacerbates losses and prevents their resolution, e.g. lack of knowledge about how to manage loss of erectile function and the relational implications of that
- **Men's coping strengths** require information as a base to work from: these are in taking control with an active and positive attitude and rational analysis.
- We know that **men have a health knowledge disadvantage** generally (i.e. women could benefit by well delivered and targeted information but men will benefit more because of their deficit in this area)
- **The disadvantage of men from vulnerable SES groups** can be addressed by empowering them with information i.e. men with lower education and therefore poorer access to information and less knowledge; men with lower income, by informing them of free or cheap services; single men, who do not have wives to inform them (!); and Maori men, who may find services and means of communication foreign and who may well also have lower education and income.

Slide 7: So the main thrust of the interventions discussion paper *is about informing men and connecting them* with what is available, and doing that comprehensively (rather than spasmodically and unreliably) and at appropriate times and in a quality way, e.g. learning about transport services when you are diagnosed, not part way through radiation when a radiation therapist mentions it, or learning about the MCC when you are diagnosed, not just before discharge from hospital after 3 weeks worrying about how to pay the rent, and not by a chance meeting when visiting a relative who had cancer. At the moment we appear to have very haphazard means of connecting people with psycho-social services, and it is men who are most vulnerable to missing out because they don't know how to get that information, or even that it exists, and yet they stand to gain most from having it.

The interventions suggested *assume that information is vital* to the well-being of patients, particularly men – i.e. information is not to be seen as a helpful addition to the real treatment, but as a vital part of the treatment for patients' overall well-being. In fact, a well informed patient is likely to do better medically, not only due to less distress and the dysfunction associated with that, but also because patients who understand what is happening are more likely to be treatment compliant and are in a position to make more efficient use of the time of their medical professionals: everyone wins! So I am suggesting that we need a new attitude towards informing patients which *recognises information as a number one treatment priority*, rather than as helpful add-on to medical treatment. A paradigm shift is needed.

The discussion paper, suggests 6 ways of ensuring that men are better informed:

(1) that **co-ordination** is established to ensure that information about the disease, its treatment (including 'the system' that delivers it), and psycho-social services, is provided comprehensively and at appropriate points in the diagnosis and treatment journey *i.e. that there is some central planning to ensure patients are informed* (with the expectation that men will benefit disproportionately from this)

(2) that a clause be incorporated in the **hospital admission form** to obtain permission for CSNZ and Maori Cancer Coordinators to be given contact details so they can explain their services to patients, unless the patient elects to 'opt out' *i.e. the onus is not put on men to seek out the services that they need, but the services are explained to them as a matter of standard practice, unless they chose to opt out;*

(3) that a set of **informational DVDs** be incorporated into standard treatment pathways – *this is the single most important part of the set of proposals and I will explain it further shortly;*

(4) that **other specific information-providing interventions be created** to address particularly distressing side effects (notably sexual function and the wearing of ostomy bags) and to facilitate the obtaining of a rapid response to questions – *these suggestions target particularly acute areas of distress. At the moment most men get very little information about the loss of erectile function as a side-effect of treatment, and this is the worst part of cancer for many of them, yet they are left to quietly become depressed in isolation since they do not feel comfortable raising the matter. Also, men find it difficult and worrying when they don't know of a professional who knows their case who they can readily access to put brief specific questions to – there is a lot of unnecessary worry as a result;*

(5) that existing **connection points** be better utilised to provide men with information about services and their health (including CSNZ transport drivers and ward visitors, and radiation therapists) and that new connection points be established (including an information sheet about CSNZ services upon admission, CSNZ volunteers connecting with men in radiation therapy waiting rooms and chemotherapy day wards)..... *and I understand that just recently Radiation Oncology is beginning to take advantage of the opportunity while patients are waiting to put messages up for them on TV monitors: there is masses of potential here for good communication, although, of course, it is not comprehensive since patients will only be watching for as long as they have to wait; and*

(6) that **male volunteers** who are survivors be connected to new male patients as 'buddies' and through Maori men's groups (new, to take advantage of networking). *Men in the research showed great respect for two sources of information: medical professionals, and peers who had personal experience. Male volunteers could become organised to reach out to newly diagnosed men to help them understand all aspects of what they are going through. For Pakeha men, a 'buddying' system is easily understood, and for Maori men, a collective/networking approach to tackling problems is natural and appreciated. So there is a great opportunity here for CSNZ to develop its services for men.*

Returning to the set of informational **DVDs....** This is the single most important intervention suggestion as it would equip men to understand what is happening to their bodies, how treatments work (including what the main side-effects are and how they can be managed), how the process of treatment unfolds and what they should expect of their relationship with their doctor, and what services are available to support them. **Introductory information** would be provided on a DVD seen at a hospital appointment after diagnosis but before treatment planning, and then more detailed information would be provided on **DVDs specific**

to the treatment type(s) applicable to the individual (including palliative care). The idea is to integrate these informational DVDs into standard treatment.

I showed a *similar DVD already in use for RT* to the discussion teams, and the Foxton team, who were all Maori and two of whom had limited literacy, found the presentation format very acceptable and useful. But note that some men who had been given the RT DVD had not seen it, and others had been given it a bit late. So there were problems with delivery, and the content is limited. What I am proposing would be comprehensive in content and delivered as a part of standard treatment, rather than seen as a helpful optional extra.

The discussion paper includes some **other intervention suggestions** which are peripheral to these aims but have the potential to make a significant impact on the wellbeing of individual men e.g. the suggestion regarding Menz Sheds could be a life line for men who are socially isolated, and the suggestion for a brief spiritual intervention has a piece of good research behind it which suggests it could make a significant difference for many palliative care patients.

Slide 8: Actions suggested by the PN meeting of 18 February.

A meeting was called by Central Cancer Network involving reps from itself, CSNZ, new Cancer Nurse Coordinators, and my practice oriented supervisors, in order to consider a way forward for the intervention suggestions emerging from this research. The meeting was enthusiastic about the research and made suggestions addressing a number of the six strategies, and also strongly urged that the research be presented at national level to influence men's health and cancer treatment strategies.

Meeting suggestions regarding the six strategies were:

1. **Coordination/planning:** The Cancer Nurse Coordinators may well have a role here. Perhaps the RCTS needs an Information Officer to ensure information provision is effective and kept up to date.
2. **Hospital admission 'opt out' clause:** This research will inform an initiative along similar lines which has already been advanced by CCN (Privacy Commissioner approval to this approach has been obtained).
3. **Informational DVDs as standard treatment:** There is a range of DVD material already available around the country and a stock take of it is needed to see what would be suitable to build into a DVD package along the lines of that proposed; The new Information Network could possibly advance this proposal, but would that involve too much delay?; CSNZ 'Get the Tools' website and RT waiting room TVs can run such material, but many men do not have the technology or prompt to see the website and the RT TVs are a snapshot opportunity only, not sufficient to provide the needed 'full dose' of information to all patients. We will need the cooperation of consultants regarding the content of the DVDs regarding treatments, but the level of detail will be very general so hopefully will not give cause for objection. There is also a problem with finding suitable space for

screening DVDs at hospital... could CSNZ rooms be used? (They run a regular orientation programme of their own, but this is not a standard part of treatment pathway.)

4. Other specific information interventions [no suggestion made]
5. **Improve connection points:** CSNZ Support co-ordinators will discuss suggestions at their upcoming meeting
6. **Utilise male survivors:** CSNZ Support co-ordinators will discuss suggestions at their upcoming meeting; men's stories have already been incorporated into CSNZ 'Get the Tools' website following an earlier presentation regarding this research where it was emphasised that men respect personal experience; It was noted that there is a need for CSNZ male volunteers to make personal connection with men rather than expect them to ring Cancer Connect service cold – many men may see that service as they do the men's support groups, i.e. as supports for weak self-pitying people. Lower SES men (eg all six Maori research participants) do not have computers, so do not expect them to see 'Get the Tools' material, but if their whanau can be attracted to it, the resources could be well used.

Slide 9: Actions to promote 'paradigm shift' at national level and inform work force

7. **A Paradigm shift is needed at national level**, so that influential people can demand that information provision be made a foundational and standard part of treatment. This research should be presented to CSNZ National Men's Health Strategy Group; other Cancer Networks; Men's Health Week; National Maori Leaders' Cancer Group. Also notify Cancer Control NZ
8. **Workforce training opportunities:** CSNZ Support managers; Oncology social workers; new Cancer Nurse Coordinators; other branches of Central Cancer Network