



Prostate Cancer
Foundation of Australia

ENGAGING ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES IN PROSTATE CANCER HEALTH CARE PROGRAMS

OCTOBER 2015

MONOGRAPHS IN
PROSTATE CANCER

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Prostate Cancer Foundation of Australia (PCFA) is a broad-based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners and families, recognising the diversity of the Australian community.

We do this by:

- Promoting and funding world leading, innovative research into prostate cancer
- Implementing awareness campaigns and education programs for the Australian community, health professionals and Government
- Supporting men and their families affected by prostate cancer, through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses.

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ENGAGING ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES IN PROSTATE CANCER HEALTH CARE PROGRAMS

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FOREWORD

Prostate Cancer Foundation of Australia (PCFA) has been working with Aboriginal and Torres Strait Islander communities and specialist workers to develop prostate cancer resources for the community since 2012. It is a strategic priority for PCFA to ensure that evidence-based, culturally appropriate, and easily accessible prostate cancer information and support is available to all Australians.

It is known that there is a paucity of prostate cancer information available covering Aboriginal and Torres Strait Islander communities. It is also noted that Aboriginal and Torres Strait Islander men have poor knowledge of prostate cancer issues and this is a barrier to improving prostate cancer services and support for these men. In an effort to bridge these gaps, PCFA commissioned a research activity into Aboriginal and Torres Strait Islander prostate cancer men's issues and began responding to these community findings.

Leading from this research PCFA has now worked extensively with the Aboriginal and Torres Strait Islander communities and health practitioners around Australia to develop educational resources intended to improve prostate cancer awareness in Aboriginal and Torres Strait Islander men and their communities. These resources are part of the 'Supporting men with prostate cancer through evidence-based resources and support' project which is a Cancer Australia initiative, funded by the Australian Government.

The aim of this publication is to engage Aboriginal and Torres Strait Islander health experts to discuss current health issues and raise awareness about prostate cancer amongst Aboriginal and Torres Strait Islander men.

PCFA trusts that the monograph and educational resources will provide Aboriginal and Torres Strait Islander men, their communities and practitioners with information that is evidence-based and culturally appropriate.

Associate Professor Anthony Lowe
Chief Executive Officer

INTRODUCTION

Despite lower rates of diagnoses in comparison to non-indigenous Australians, prostate cancer is the second most commonly diagnosed cancer in Aboriginal and Torres Strait Islander men after lung cancer and thus represents a significant health issue. Aboriginal and Torres Strait Islander men are also 60% less likely to be hospitalised as a result of their prostate cancer and experience poorer survival outcomes. The Australian Institute of Health and Welfare reports that in 2004 – 2008 Aboriginal and Torres Strait Islander men had a lower chance of surviving five years following a diagnosis of prostate cancer than the general community (63% compared with 72%)⁽¹⁾.

Most men in the general community live on after a prostate cancer diagnosis either monitoring or managing their disease⁽¹⁾. It is envisaged that enabling Aboriginal and Torres Strait Islander men, their communities and health practitioners to improve prostate cancer awareness with culturally appropriate information and support will help close the current gap in prostate cancer outcomes.

There are strong cultural practices affecting prostate cancer in Aboriginal and Torres Strait Islander communities. Many Aboriginal and Torres Strait Islander men see prostate health and cancer as men's business and associate prostate cancer with 'shame' and death. This has led to reluctance to engage on the issue⁽²⁾.

The aim of this monograph is to examine the barriers to improving awareness of prostate cancer as a health issue amongst Aboriginal and Torres Strait Islander men and their communities, and to present culturally appropriate strategies for overcoming them. It draws together the current state of knowledge, qualitative research and expert opinion on strategies to improve the present situation. It specifically addresses:

- Aboriginal and Torres Strait Islander prostate cancer in context
- Cultural, community, and men's issues related to prostate cancer
- Community attitudes and knowledge about prostate cancer
- Culturally competent strategies for dealing with men presenting with prostate issues.

This monograph will be of specific interest to those with a concern for Aboriginal and Torres Strait Islander men's health and/or prostate cancer. This includes:

- Peak bodies and organisations involved with planning and service development for Aboriginal and Torres Strait Islander people
- Those presenting men's business and prostate cancer education programs such as Health Promotion Units, Aboriginal Medical Services and primary health organisations
- Those delivering prostate cancer clinical services to Aboriginal and Torres Strait Islander communities
- Educators and researchers in Aboriginal and Torres Strait Islander health, community medicine, health promotion, men's health and primary health care
- Aboriginal Health Workers and Practitioners, clinical and community staff training in men's health, health promotion and prostate cancer.

ABORIGINAL AND TORRES STRAIT ISLANDER PROSTATE CANCER STATISTICS

Rajah Supramaniam, Cancer Council NSW

This chapter provides a description of known prostate cancer statistics for Aboriginal and Torres Strait Islander men in the context of those for the general population. It provides a synopsis of the evidence on factors influencing Aboriginal and Torres Strait Islander health outcomes.

BACKGROUND

Until very recently almost all of the research conducted did not examine differences in diagnosis and treatment between Aboriginal and non-Aboriginal men. This absence of information means that it is difficult for health services to cater for the specific needs of Aboriginal men with prostate cancer.

The small evidence base for Aboriginal and Torres Strait Islander prostate cancer is widely acknowledged^{(1) (3) (4) (5)}. This is consistent with the overall gap in health information about Aboriginal and Torres Strait Islander people. It is also acknowledged that the quality of information and data varies significantly from State to State and that current data collections are hampered by under-reporting and non-identification of Aboriginal and Torres Strait Islander status on medical records⁽⁶⁾.

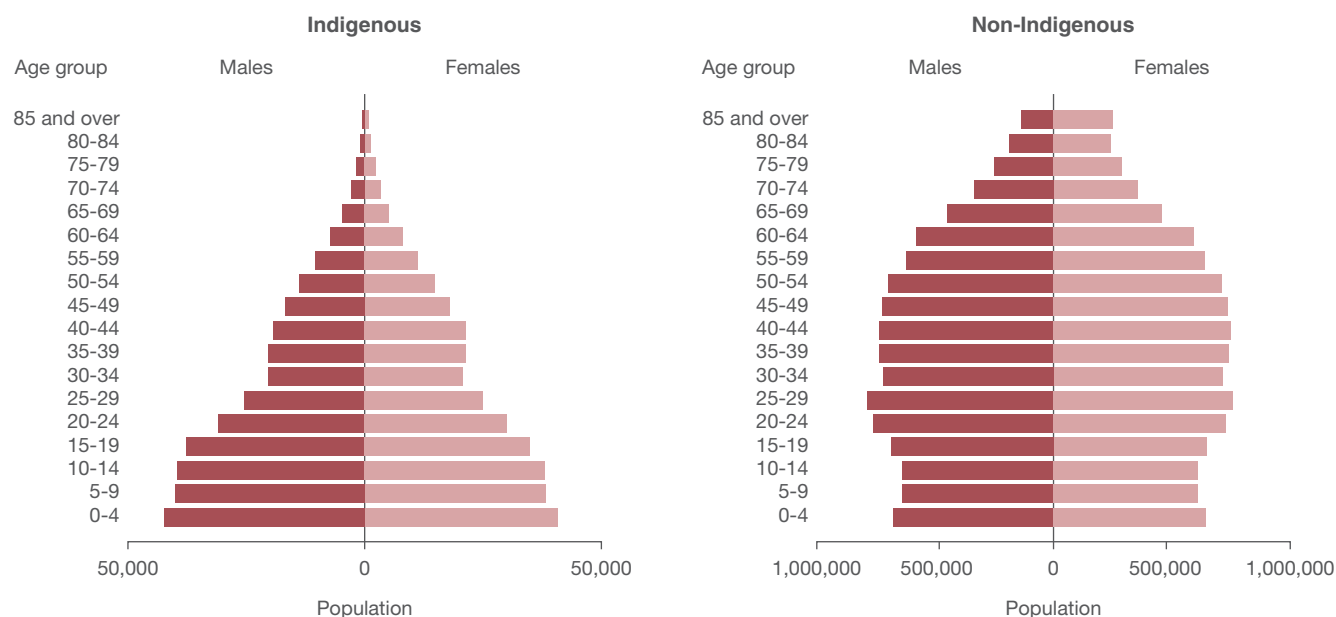
In response to this lack of research and data, the Commonwealth Government has developed the National Strategic Framework for Aboriginal and Torres Strait Islander Health Implementation Plan 2007 – 2013⁽⁷⁾. NHMRC has also produced Ethical Guidelines for Research with Aboriginal and Torres Strait Islander Communities to assist people working with Aboriginal and Torres Strait Islander communities⁽⁸⁾.

POPULATION

The Australian Bureau of Statistics reports that at 30 June 2011, the preliminary estimated resident population of Indigenous Australians was 669,900 people, comprising 3% of the total population. The distribution of the Indigenous population was notably different from the population as a whole⁽⁹⁾.

The Indigenous population has a younger overall age structure than the non-Indigenous population. In 2011, Aboriginal and Torres Strait Islander people under age 15 constituted 36% of the Indigenous population, whereas this age group represented 18% of the non-Indigenous population. Those aged 65 and over comprised only 3% of the Indigenous population, compared with 14% of the non-Indigenous population.

AGE STRUCTURE, BY SEX AND INDIGENOUS STATUS, AUSTRALIA, 2011⁽¹⁾



Source: ABS 2013

Indigenous population estimates by remoteness areas are not yet available from the 2011 Census. The latest available data from 2006 shows just under a third of Indigenous people lived in major cities (32%), which was much less than the proportion of the general people living in major cities for

Australia (68%). A further 43% of Indigenous people lived in Inner or Outer Regional areas, 10% lived in Remote areas and 16% lived in Very Remote areas. Indigenous people comprised 48% of the total population in Very Remote areas, and 16% of the total population in Remote areas ⁽¹⁰⁾.

ABORIGINAL AND TORRES STRAIT ISLANDER AREA OF RESIDENCE AT 30 JUNE 2006 ⁽¹⁰⁾

	Aboriginal and Torres Strait Islander population (ABS 4704.0) numbers by area of residence	Aboriginal and Torres Strait Islander population (ABS 4704.0) % by area of residence	Total Australian population (ABS 4102.0) numbers by area of residence	Total Australian population (ABS 4102.0) % area of residence
Major Cities	165,800	32%	14,159,825	68.4%
Inner Regional	110,600	21%	4,078,196	19.7%
Outer regional	113,300	22%	1,966,643	9.5%
Remote	47,900	9%	310,523	1.5%
Very Remote	79,500	15%	165,612	0.8%

ABORIGINAL AND TORRES STRAIT ISLANDER PROSTATE CANCER STATISTICS

(continued)

INCIDENCE

Prostate cancer is the most commonly diagnosed cancer in Australia (excluding non-melanoma skin cancer), and accounts for 25-30% of new cancers diagnosed each year in men ⁽¹¹⁾. In 2010, more than 19,800 new diagnoses of prostate cancer were reported ⁽¹²⁾.

In Aboriginal and Torres Strait Islander communities, where incidence rates are believed to be under-recorded, prostate cancer has second highest incidence of cancers in men after lung cancer and the fourth highest incidence of cancers overall (after lung cancer, bowel cancer and breast cancer in women) ⁽¹⁾. In 2004–2008, there were 291 new cases of prostate cancer diagnosed among Aboriginal men in New South Wales, Queensland, Western Australia and the Northern Territory. This was a standardised rate of 27 new cases per 100,000 men ⁽¹¹⁾.

The age-standardised incidence of prostate cancer in Australian men has increased over time, from 79 new cases per 100,000 men in 1982 to 194 per 100,000 in 2009. This increase is expected to continue, reaching 25,000 new cases per year Australia-wide in 2020 (up from 19,800 in 2012) ⁽¹¹⁾. The increases are mainly due to the number of men having tests, increased sensitivity in diagnostic biopsies and an ageing population.

When differences in age structure were accounted for Aboriginal and Torres Strait Islander males were less likely to be diagnosed with prostate cancer compared to non-Aboriginal males, but it is reasonable to expect a similar rising trend ⁽¹⁾ ⁽¹¹⁾.

MORTALITY AND SURVIVAL

In 2011 3,294 men died from prostate cancer, making it the second leading cause of male cancer deaths and the fourth leading cause of death overall for Australian men, accounting for 4% of all deaths and 14% of all cancer-related deaths in men ⁽¹¹⁾.

The age-standardised prostate cancer mortality rate for Australian men decreased from 34 deaths per 100,000 men in 1982 to 31 per 100,000 in 2011. By 2020 the number of prostate cancer deaths is predicted to increase to over 3,900 per year. In the same time period the age-standardised mortality rate is projected to decrease to 26 deaths per 100,000 men ⁽¹¹⁾. Generally over time until 2020 it is expected that for Australian men the number of deaths will increase, but as a proportion of the total number of prostate cancer cases the proportion will decrease.

In 2006–2010, there were 66 prostate cancer-related deaths among Aboriginal and Torres Strait Islander men in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory which is a rate of 6 per 100,000 men ⁽¹⁾. Prostate cancer mortality among Aboriginal men increased with age from less than 1 death per 100,000 men aged 0–44 to 170 per 100,000 males aged 65 and

over ⁽¹⁾. No projections have currently been calculated for Aboriginal and Torres Strait Islander men.

In the period 2001–2005 Aboriginal men had a 5-year relative survival of 83.6% (95% CI: 72.5–93.2) following a diagnosis of prostate cancer compared to non-Aboriginal men who had a 5-year relative survival of 91.0% (95% CI: 90.6–91.4) ⁽¹³⁾.

The 5-year Crude Survival Rate for Aboriginal men diagnosed with prostate cancer in 2004 – 2008 was 63% compared to the 5-year Crude Survival for the comparable general population of 71% ⁽¹⁾.

TESTING AND TREATMENT

PSA testing has become very common for Australian men since the 1990s ⁽¹⁴⁾ with almost 780,000 tests being performed on Australian men in 2012 ⁽¹¹⁾. There are no official statistics on prostate cancer testing available for Aboriginal men. Although rates of prostate cancer testing among Aboriginal and Torres Strait Islander men are missing from existing cancer data there is some evidence to suggest that testing rates are low ⁽⁴⁾ ⁽¹⁵⁾.

A study of 293 Aboriginal men from Queensland and the Northern Territory reported lower rates of testing for prostate cancer (blood test or digital rectal examination) among Aboriginal and Torres Strait Islanders compared with non-Aboriginal men. The authors suggest that “additional barriers may be operating, despite similar levels of concern and equivalent likelihood of visiting a doctor in the preceding year”. Barriers that they identify are a lack of gender-specific services and other chronic health conditions that may take priority for health services ⁽¹⁶⁾.

The optimal management of localised prostate cancer is difficult to define as evidence showing a clear survival benefit of one treatment over another is sparse ⁽¹⁷⁾. It is unknown whether treatment factors explain higher mortality for Aboriginal and Torres Strait Islander men with prostate cancer as little is known about their treatment patterns. One recent New South Wales study identified lower rates of surgical treatment for Aboriginal men with localised or regional spread of disease compared with non-Aboriginal men with similar prostate cancer ⁽¹⁸⁾.

RISK FACTORS

There are no known causes of prostate cancer although the risk of being diagnosed increases with increasing age and if a man has a family history of prostate cancer. Lifestyle, particularly dietary, environmental factors are also considered possible risk factors for developing prostate cancer ⁽¹⁹⁾.

The risk of developing prostate cancer increases with age. Men aged under age 50 are not commonly diagnosed with prostate cancer. However it is estimated 1 in 5 men will be diagnosed by the age of 85 in the general population ⁽¹²⁾.

Prostate cancer incidence among Indigenous men also increases with age from 10 cases per 100,000 men aged 45–49 to 586 per 100,000 men aged 65 and over ⁽¹⁾.

Men with one first-degree relative (parent, sibling or child) with prostate cancer were 2.2 to 2.8 times as likely to develop prostate cancer compared to men without a first degree relative with prostate cancer. For males with two first-degree relatives with prostate cancer, the risk was increased to 3.5 times ⁽²⁰⁾. However, it should be noted that higher rates of PSA testing amongst men whose close male relatives have been diagnosed with prostate cancer is a possible confounding factor.

Lifestyle factors that are commonly studied by researchers as risk factors for cancer include tobacco smoking, diet, exercise and alcohol consumption ⁽¹⁹⁾. It has been suggested that consuming diets high in calcium and processed meats may increase the risk of developing prostate cancer. However, the evidence for these factors is inconclusive ^{(19) (21)}. Physical activity has been shown to be associated with lower recurrence and higher survival after a diagnosis of prostate cancer ^{(22) (23)}.

Tobacco smoking has been shown not to affect the risk of being diagnosed with prostate cancer ^{(19) (23)}. However, one study has shown smoking at the time of diagnosis to be associated with increased recurrence and decreased survival from prostate cancer ⁽²³⁾. Aboriginal and Torres Strait Islander people are known to have a higher smoking rate than the general community ⁽²⁴⁾.

REMOTENESS

The incidence of all cancers is lower for people in regional and remote areas compared to those in major cities. This may be partly due to lifestyle factors. About one third of people diagnosed with cancer live outside the major population centres where the majority of tertiary level cancer care is available. There are significant disparities in cancer outcomes between people living in metropolitan versus non-metropolitan regions. Cancer patients who live furthest from a large treatment centre are at the highest risk of a poor treatment outcome ⁽¹³⁾.

Research has also found that people living with cancer in regional and rural areas have poorer survival rates than those living in major cities, and the further from a major city patients with cancer live, the more likely they are to die within five years of diagnosis ^{(3) (4) (5)}. This is also true for Aboriginal and Torres Strait Islander people ^{(1) (25)}.

The incidence of prostate cancer is higher in non-metropolitan than metropolitan regions and mortality rates are also higher ^{(3) (4) (5) (19)}.

The possible reasons for the disparity in non-remote and remote cancer survival, include:

- More difficult access to cancer treatment due to poor transport links and shortage of healthcare providers in non-metropolitan regions
- Higher proportion of Aboriginal and Torres Strait Islander peoples in non-metropolitan regions who are generally more economically disadvantaged than other populations
- A higher proportion of people from lower socioeconomic backgrounds living in non-metropolitan regions.

This leads to:

- Differences in cancer knowledge and health behaviours
- Later tumor stage at diagnosis
- Issues with affordability of care
- Reduced ability to access the full spectrum of cancer detection and care ⁽²⁶⁾.

Poor access to cancer treatment is also a major contributor to lower survival rates among people living in non-metropolitan regions ⁽¹⁾.

SOCIOECONOMIC STATUS

Resident location and socioeconomic status affects health. Incidence and mortality rates rise and survival from all cancers falls as a person's socioeconomic status decreases. Further, a study of the NSW rural and remote residency relationship to prostate cancer survival found that socioeconomic disadvantage was significantly related to prostate cancer survival ⁽²⁵⁾. Indigenous Australians experience disproportionate levels of educational, employment and social disadvantage. Many Indigenous Australians also experience poorer health than other Australians, often dying at much younger ages ⁽²⁷⁾.

Two-thirds (65%) of working-age Indigenous Australians were in the labor force in 2008, compared with nearly four out of five (79%) non-Indigenous Australians. In 2008, Indigenous households were nearly two and a half times as likely to be in the lowest income bracket and four times less likely to be in the top income bracket as non-Indigenous households. Nearly half of all Indigenous children were living in jobless families in 2006. This is three times more likely than Australian children in general.

“The neighbourhood in which we live has a profound impact on our choices and our health by access to services, exposure to poor sources of nutrition, less scope for exercise, employment status, job type and the social and cultural influence on our health.” ⁽¹⁹⁾

ABORIGINAL AND TORRES STRAIT ISLANDER PROSTATE CANCER STATISTICS

(continued)

CONCLUSIONS

Reliable and current information about the prostate cancer journey and prostate cancer research in Aboriginal and Torres Strait Islander men is sparse. It is known that Aboriginal and Torres Strait Islander men are less likely to be diagnosed with prostate cancer than men in the general population. However, they are more likely to die from their prostate cancer within five years of diagnosis. Suggested reasons for the disparities are reported however there is currently insufficient information to support detailed conclusions.

More research is needed into the diagnosis and medical treatment for Aboriginal and Torres Strait Islander men with prostate cancer. Ongoing monitoring of prostate cancer diagnosis and treatment can also provide timely and population based information needed on the effects of rurality, socioeconomic disadvantage and comorbidities on the diagnosis, treatment and survival of Aboriginal and Torres Strait Islander men with prostate cancer.

Specific prostate cancer research on epidemiology, service delivery, barriers and cultural impacts on prostate cancer outcomes need to involve the Aboriginal and Torres Strait Islander communities for the known gaps in prostate cancer outcome information to be overcome.

CULTURAL, COMMUNITY AND MEN'S ISSUES RELATED TO PROSTATE CANCER

Dr Michael Adams, Australian Institute of Aboriginal and Torres Strait Islander Studies

This chapter outlines cultural issues relevant to prostate cancer from an Aboriginal and Torres Strait Islander male perspective.

There is limited research investigating Aboriginal and Torres Strait Islander men's prostate cancer issues to guide the development of community interventions. Aboriginal and Torres Strait Islander men, and most medical health professionals, are not comfortable in discussing issues associated with sexual and reproductive health including prostate cancer ⁽²⁸⁾ ⁽²⁾.

CULTURAL CONNECTION – DEFINING COMMUNITIES

Aboriginal and Torres Strait Islander people are custodians of some of the most biologically diverse territories in the world. They are also responsible for a great deal of the world's linguistic and cultural diversity, and their traditional knowledge has been and continues to be an invaluable resource that benefits all of mankind ⁽²⁹⁾.

Each Aboriginal community is different, with different customs and protocols, systems of organisation, languages, and relationships to each other. There is no single Aboriginal culture – Aboriginal society is very diverse. Aboriginal culture is dynamic and continuously evolving ⁽³⁰⁾. Torres Strait Islanders are a separate group with their own distinct identity and cultural traditions ⁽³¹⁾.

Significant issues in the cultural identity for both Aboriginal and Torres Strait Islander people include family and kinship; recognition and respect as a distinctive people; relationship to land and sea as well as preservation of traditional customs, laws and language. Some communities, usually in urban areas and regional centres, are made of people from different traditional groups. Over 200 languages have been identified, in some areas the language is dying with the Aboriginal elders. There are more than 120 languages still in use today, language use is very sophisticated, with a system of languages or dialects that are used by each community ⁽²⁸⁾. Millennia of culture, language and traditional health knowledge development, as well as recent colonial history and discrimination affects the health of Aboriginal and Torres Strait Islander people ⁽³²⁾.

MEN SUPPORTING MEN – CULTURAL MENTORING

The family structure is important in Aboriginal and Torres Strait Islander communities. The Uncle-Nephew system is a cultural way of teaching and relating through family kinship and ceremonial responsibility ⁽³³⁾. This supports and affirms values and beliefs that are fundamental to the Aboriginal male's view of the world, and Aboriginal society. The 'Uncle-Nephew relationship' is a system based on the obligations of the mother's brother (uncle) to her son (nephew). The relationship between the uncle and nephew is very strong, at times closer and more important than the Father-Son relationship.

The 'Uncle-Nephew relationship' is based on an Aboriginal cultural framework that has the potential to resolve very many issues, including dealing with conflict situations. 'Uncle-Nephew' is put into action by senior men and elders who have the authority to impose traditional law and negotiate outcomes. It continues on in the close family relationships, values and priorities in many contemporary Aboriginal and Torres Strait Islander families ⁽³³⁾.

The process of Kanyirninpa, or holding, exists as a deeply embedded value amongst desert Aboriginal peoples (Puntu). It is disclosed as authority with nurturance, where older generations assume the responsibility to care for and look after younger people. Kanyirninpa holds in balance two other key cultural patterns of desert life, autonomy and relatedness. These values are transmitted across generations, where they provide desert society with identity, cohesion and strength ⁽³⁴⁾.

While Kanyirninpa can be identified in the nurturance provided a child after birth, its presence and power is particularly disclosed at ceremonial time ⁽³⁴⁾. For example, when Aboriginal boys (marnti) become men (wati) the manner of Kanyirninpa changes. No longer do young men seek to be held by their mothers and female relations. Instead, they seek to be held by older men: brothers, uncles and other males. By holding them, older men induct younger men into the social meanings and behaviours of desert, male adulthood. A generative and generational male praxis is disclosed ⁽³⁴⁾ ⁽³⁵⁾ ⁽³⁶⁾.

The deeply embedded Aboriginal and Torres Strait Islander values of family and kinship, the practice of relationship responsibilities such as Uncle-Nephew and being "held" and nurtured by elders has strong implications for ongoing cancer treatment particularly for men's cancer interventions such as prostate cancer support groups.

In Australia there exist Aboriginal and Torres Strait Islander male support groups, who within their limited resources, aim to adopt broad, multi-strategic programs. They empower participants and advocate for changes that improve the broader social determinants of health and community development by developing personal capacity and improving the orientation of health services ⁽³⁷⁾. These groups rely on the strong bonds between Aboriginal and Torres Strait Islander men.

In an attempt to provide culturally relevant support to Aboriginal and Torres Strait Islander males, the National Community Controlled Health Organisation (NACCHO) identified a responsibility to take a coordinated approach to address male issues ⁽³⁸⁾. They acknowledge that in many situations Aboriginal and Torres Strait Islander

CULTURAL, COMMUNITY AND MEN'S ISSUES RELATED TO PROSTATE CANCER

(continued)

male identities and self-esteem have been significantly diminished. It is therefore necessary to establish appropriate holistic programs that could assist Aboriginal and Torres Strait Islander males to rebuild their cultural and spiritual strengths, which define their identity and pride ⁽³⁹⁾.

This rebuilding is critical for Aboriginal and Torres Strait Islander male empowerment and self-determination. It strengthens self-esteem, quality of life, health status and spiritual wellbeing for men, their families and their communities ⁽³⁹⁾. Integration of prostate cancer programs with community services is therefore important.

Those Aboriginal community controlled health services and other organisations who have invested in setting a platform of principles and services that engage Aboriginal and Torres Strait Islander men on health and wellbeing show a positive indication of improvement. They establish an Aboriginal and Torres Strait Islander male safe environment that commits to working alongside communities to address the social determinants associated with Aboriginal and Torres Strait Islander male health and wellbeing ⁽⁴⁰⁾.

In Australia the use of support groups for information and support of men with prostate cancer and their carers is a widespread and valued practice ⁽⁴¹⁾. Prostate cancer support groups may be a valuable model for Aboriginal and Torres Strait Islander support given the existing health practices using men's groups.

PROSTATE CANCER AS AN ISSUE FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

Male health has in recent years become a key concern not only to Aboriginal and Torres Strait Islander communities but also for healthcare professionals and Governments ⁽¹⁶⁾. Statistics reporting the generally shorter life-spans of Aboriginal and Torres Strait Islander men compared with women, together with the reluctance amongst men to talk about health matters, are worrying ⁽⁴²⁾ ⁽⁴³⁾. Differences between men and women with regard to access to health information and willingness to seek medical advice have been reported clearly indicating the importance of addressing health issues from a gender perspective ⁽⁴⁰⁾. Quality information availability and awareness is crucial to early identification and decision making in prostate cancer.

The broad spectrum of issues covered at the first World Conference for Men's Health demonstrated that the area of men's health is highly complex. However, the potential for improvement of male health is great ⁽²⁹⁾. Increased benefits through targeted dissemination of information, promotion of preventive measures in health-care, and increased gender specific research can lead to marked improvements in mortality in highly prevalent illnesses such as cardiovascular disease and cancer ⁽¹⁾ ⁽³²⁾.

The lack of evidence based research on Aboriginal and Torres Strait prostate cancer has been widely reported. Although research on men (and boys) health has seen some increase in recent years.

One reason for the small amount of literature covering prostate cancer about Aboriginal and Torres Strait Islander men is the sensitive nature of reproductive health which is a particular concern, especially in remote communities. These matters are traditionally seen as taboo, requiring culturally appropriate and gender-specific research and services ⁽³²⁾.

The remaining gap in research capacity is a significant barrier to advancing evidence-based programs, interventions and policies that support improvements in men's (and boys) health ⁽²⁸⁾, particularly in prostate cancer.

Community based research studies have found that Aboriginal and Torres Strait Islander men have low levels of help-seeking behaviours compared with non-Indigenous men ⁽⁴⁴⁾ ⁽¹⁶⁾. While prostate cancer rates were low in these studies, testing for prostate problems was found to be less frequent in Aboriginal and Torres Strait Islander men than in non-Indigenous men, despite similar levels of concern about prostate cancer. Barriers to help-seeking included shame, culturally inappropriate services and lack of awareness ⁽²⁸⁾ ⁽²⁾. Domestic tension and conflict related to prostate cancer or erectile dysfunction issues have been reported by Aboriginal and Torres Strait Islander men ⁽¹⁶⁾. This situation was attributed to the participants' lack of knowledge of prostate health and erectile dysfunction issues. Lack of knowledge has significant impacts for Aboriginal and Torres Strait islander people ⁽⁴⁵⁾.

Aboriginal and Torres Strait Islander men have difficulties talking to health professionals, a particular concern is breach of confidentiality within the community and stigma attached to sexual problems ⁽⁴⁾. The lack of culturally appropriate health services for males has been highlighted as a barrier for men with reproductive problems — specifically, the predominance of female health professionals, as well as health workers and services not encompassing cultural aspects of family and gender ⁽³⁹⁾.

Further, the focus on the earlier onset of chronic health disorders may mean that prostate disease is not given high priority in health services. Cancer statistics show that Aboriginal and Torres Strait Islander people are more likely to have cancer diagnosed at a later stage, are less likely to receive adequate treatment and more likely to die from their cancer than other Australians^{(4) (15)}. This is attributed to location, disadvantage and environmental factors⁽¹⁾.

PRIMARY HEALTH CARE CHALLENGES AND PROSTATE CANCER

Strategies of dialogue and consultation are the most relevant and culturally appropriate way to increase community understanding and dissemination of research and educational resources for Aboriginal and Torres Strait Islander males and health service providers^{(46) (47) (48) (49)}. Central to this concept is the need for specific programs and educational resources for male Aboriginal Health Workers. Evidence exists to support the notion that when specific Aboriginal and Torres Strait Islander male friendly health programs are available, improved health behaviours and outcomes occur^{(2) (26)}.

Working in the Aboriginal and Torres Strait Islander health sector can be challenging for doctors and other healthcare professionals who have been educated in a Western approach. Aboriginal and Torres Strait Islander men can find it hard to open up and discuss personal and sensitive health issues, particularly if they see someone other than their usual doctor. If a man is seen regularly and feels comfortable with the doctor he is more likely to initiate discussion⁽²⁾.

For some men going to a health service can be a negative experience, sometimes it can be months or years before a man feels comfortable enough to open up about his health concerns, particularly on more sensitive and personal problems. Men may not open up in first consultation—it may take time to build trust—but balance is also needed to take advantage of opportunistic discussions^{(2) (43)}.

There are a number of defined issues associated with the poor sexual and reproductive health of Aboriginal and Torres Strait Islander men. These include the lack of gender-specific health education in Aboriginal and Torres Strait Islander communities, and the fact that most Aboriginal and Torres Strait Islander men lack the knowledge of their own bodies necessary to assess the merits of treatment options, or even to understand the implications of male health disorders. Few Aboriginal and Torres Strait Islander men are aware that supposedly unrelated medical conditions can cause or contribute to male reproductive-health problems. This is not surprising, because an assessment of men's health rarely includes the sexual and reproductive areas^{(38) (39) (40)}. NACCHO has developed a 10 point plan for Men's health 2013 – 2030⁽⁵⁰⁾. This plan strongly emphasises primary health care and empowering Aboriginal men. Primary health care prostate cancer interventions for Aboriginal and Torres Strait Islander men fit well to this plan.

ENGAGING ABORIGINAL AND TORRES STRAIT ISLANDER MEN IN DEVELOPING PROSTATE CANCER AWARENESS RESOURCES

Tim Earnshaw, Prostate Cancer Foundation of Australia, NSW

This chapter reports on a community based research activity commissioned by Prostate Cancer Foundation of Australia to engage the Aboriginal and Torres Strait Islander community in the development of culturally appropriate educational materials intended to raise the awareness of prostate cancer as a health issue for Aboriginal and Torres Strait Islander men.

The activity engaged Mibbinbah Limited to run a prostate cancer yarning session at the Mibbinbah 8th National Camp at Mt Kiera near Wollongong, NSW held in 2012. The purpose of the Mibbinbah national camp is to bring Aboriginal and Torres Strait Islander men together to discuss men's issues, hear what is happening and support each other's activities. Mibbinbah Limited is a long established Australian Indigenous male health promotion charity.

The yarning session aim was to establish:

- What are the information and resource needs people may have about prostate cancer?
- What are the best ways to provide this information?
- What are the best networks in the communities to communicate information about prostate cancer?

METHOD

A yarning session is where Aboriginal people have an open group discussion on an important topic. Ninety five men attended the prostate cancer yarning session. The yarning session was held as an individual session within the four day camp program.

The format for the yarning session included a general introduction, a twenty minute prostate cancer presentation covering general prostate cancer awareness information, followed by a men's discussion in response to some prompt / trigger questions. Participants were encouraged to range as widely as necessary in their discussions and comments. A senior Aboriginal men's health doctor attended to present information and provide clarification or assistance as required.

The participants were mainly Aboriginal men, including elders, from communities around Australia who responded to the Mibbinbah Annual Camp Application advertised on the Mibbinbah website advertisement through the Mibbinbah Facebook and distribution list.

FINDINGS

The discussion ranged widely and the following is a summary of the participants' recorded responses.

GENERAL INFORMATION LEVELS

Several questions were asked of the group to gauge their prostate cancer knowledge levels. Humour was significant in releasing some of the tension around this topic and the questions being asked.

When the men were asked about their knowledge of the function of the prostate gland, 16 men said they didn't know what the prostate was or what it actually did and there were a small number who didn't know that only males have a prostate. The responses from some of the younger men were that you only need to worry about your prostate when you are older. There were a significant number of men who did not know basic information about the prostate gland. There was an impression of prostate cancer as an old man's disease.

The men were asked what their response was to the word cancer. Language used to describe cancer included 'doom and gloom', 'death' and 'shame'. Other comments included "nothing you can do about it if you get it" and "you are better not to know that you have it". Whilst the responses to the word cancer were negative, an elder telling his story was able to have a positive impact of the group's perception of a man's prospects when diagnosed with prostate cancer. This was reinforced by a presentation of some prostate cancer facts by the doctor.

When the men were asked about their understanding of prostate cancer and its causes, there was great uncertainty in how to respond to this question. The doctor was able to give some instruction around what may cause prostate cancer. He explained that nobody is really sure of what the specific causes are. There are many possible factors, including age, race, lifestyle, medications, and genetics, to name a few. This was regarded as helpful by the participants. There was a general consensus that more education would be appropriate as long as this education was presented in a well facilitated way and a safe space.

The men were asked about their experience of prostate cancer. Forty eight percent (48%) of the group knew someone who had prostate cancer. It was an emotional time for some who retold what they, their family or mates, had been through with prostate cancer. One in two men were able to relate a personal story about prostate cancer. This was regarded as a high proportion by the group. The question had a strong impact on the discussion.

INFORMATION CHANNELS

The men were asked who in the community should be delivering information about prostate cancer. Local service providers such as health workers, nurses and doctors from the local Aboriginal Medical Service were considered appropriate to disseminate the information as these are trusted people in the community. A ‘mates program’ was considered useful, where everyday local men are able to talk to the community. There was a big discussion on enabling Aboriginal and Torres Strait Islander men to start the discussion. The main theme was that information should be delivered through trusted people in the community including leadership and support from community men.

INFORMATION ABOUT PROSTATE CANCER

The men were asked what information should be given about prostate cancer to the community. Education was considered necessary for everyone in the community. The respondents thought men, women and all of the community need to be educated about the disease. The prostate cancer information presented to the yarning session was considered a great start as it included information that is easily explained in a non-threatening manner. Other ideas were about presenting to local men’s and women’s groups; having the flexibility to go out and sit with such groups and educate in their environment; and that the information needs to be easily explained, non-threatening and delivered in the community environment.

The group acknowledged that there are a large number of men in the community who have experienced sexual abuse. Due to the nature of prostate cancer testing, particular strategies and sensitivity are needed when dealing with the issue.

The men were asked what information should be given to women in the community about prostate cancer. It was agreed that women need to be educated as well.

“We learn about breast cancer and other cancers that primarily affect women. There is a need to spread the word. When someone dies from cancer there are so many people affected by the loss.”

“Everybody is affected, everybody needs to be informed.”

RESOURCE FORMAT

The group was asked what was considered the best way to deliver information and what the considerations were in developing content. It was considered essential that any resources take into account the vast diversities between Aboriginal groups. One solution proposed was to have a template so that local and regional communities could then tailor it appropriately. Ensuring resources account for diversity and a program that can be tailored and delivered locally was considered useful. This includes accommodating people who do not speak English as their first language.

There was concern among the group for a large portion of community members who are unable to read and write. The men wanted it known that this is where they can start to assist their own communities. Resources need to be easily explained, contain no jargon with plenty of pictures. Resources need to be written in terms the community member can understand, graphic presentations and presented by community members.

Resources that can be handed out to those attending education sessions were considered useful.

ENGAGING ABORIGINAL AND TORRES STRAIT ISLANDER MEN IN DEVELOPING PROSTATE CANCER AWARENESS RESOURCES

(continued)

CONCLUSIONS

The research reached the following conclusions:

1. Prostate cancer is regarded as a significant issue by Aboriginal and Torres Strait Islander communities with 50% of men attending the Prostate Cancer Yarning Session reporting they were diagnosed or knew someone who had been diagnosed with prostate cancer.
2. Aboriginal and Torres Strait Islander men are likely to think of prostate cancer as a fatal disease with men attending the Prostate Cancer Yarning session associating cancer with death and 'shame'. This was a strong theme.
3. Prostate cancer is a men's disease that affects the whole community. Men in the Prostate Cancer Yarning Session reported a significant cancer impact in their communities, "there is a need to spread the word – when someone dies from cancer there are so many people affected by the loss".
4. Prostate cancer information is needed in Aboriginal and Torres Strait Islander communities. The Aboriginal and Torres Strait Islander participants in the Prostate Cancer Yarning Session valued the concept of an information program. A significant number within the Prostate Cancer Yarning Session did not know basic information about the prostate or prostate cancer.
5. There are community concerns which relate to how prostate cancer should be discussed. There were two main concerns raised by the representatives at the Prostate Cancer Yarning Session. The group acknowledged that there are a large number of men in the community who have experienced sexual abuse. Due to the nature of prostate cancer testing, particular strategies and sensitivity are needed when dealing with the issue. Concern was also expressed that "so many times previously people and organisations have asked how we can assist, never to be seen again". There was a general consensus at the Prostate Cancer Yarning Session that close consultation and co-operation was necessary for an Aboriginal and Torres Strait Islander prostate cancer project to be successful.

ENGAGING ABORIGINAL AND TORRES STRAIT ISLANDER MEN IN HEALTH CARE INTERVENTIONS

Dr Keith Gleeson, Biripi Aboriginal Medical Service, Taree, NSW

This chapter presents strategies for engaging Aboriginal and Torres Strait Islander men in health care interventions to maximise opportunity for better outcomes.

Aboriginal men regard their genitals as an important cultural symbol of manhood. The cultural transition of boys leaving their childhood behind occurs with the circumcision of males during initiation ceremonies from 8 years and older⁽⁵¹⁾. This as a tradition is still practiced in some areas of Australia today. At this time in their life young boys are seen to move from being 'held' by their mothers and female relatives to being 'held' by their male relatives and elders⁽³³⁾. Culture and responsibility plays an important role in defining men's business and a man's place within his Aboriginal community. The role of men's business is extremely strong and should not be underestimated by non-indigenous health staff^{(34) (28)}. Clinicians treating an Aboriginal or Torres Strait Islander man should seek to understand these issues when engaging them in the investigation and treatment of prostate cancer.

A health professional should never believe they are treating an Aboriginal or Torres Strait Islander man separate from the community, they should see it as treating the man in his community. An individual Aboriginal or Torres Strait Islander man seeking treatment or investigations for any medical condition, including prostate cancer, will have broad connections and there will be a significant influence of the community in a person's treatment and engagement with the service.

Aboriginal and Torres Strait Islander males are more likely to avoid men's health consultations based on what they have previously heard about a service in their community^{(46) (47)}. Negative community feedback is difficult to combat and it may take health service providers and elders considerable time and effort to change this community perception^{(2) (52)}.

ENGAGEMENT AND COMMUNICATION

Introductions are important in Aboriginal and Torres Strait Islander communities as can be seen by the significance placed on Welcome to and Acknowledgement of Country⁽⁵³⁾. Cultural training often helps the health practitioner to make a good impression when first encountering a local community. This is essential to ensure continued follow up and treatment.

Aboriginal males are less likely to engage health service providers on sensitive issues when dealing with female clinicians^{(47) (28) (2)}. Discussing prostate issues with women will lead men to feelings of shame and vulnerability. Even though a man is willing to seek help for their medical complaint, staff gender and what is perceived as a women's place may lead to delays in a man seeking treatment^{(28) (2)}. Early recognition of this by a female doctor and clinic staff not only shows respect, but will leave a lasting impression on the person, thereby opening the door for future clinical engagement.

Confidentiality is a fundamental health practice. Aboriginal and Torres Strait Islander males will often skirt around sensitive issues involving men's business, particularly when consulting a doctor for the first time. They often raise secondary matters, before they feel comfortable to discuss the primary or underlying health issue with the clinician⁽²⁸⁾. This can be more poignant because confidentiality is a key concern for men given that most Aboriginal and Torres Strait Islander people utilise community controlled health organisations where there might be family as employees or female workers that know them personally⁽⁵⁴⁾.

Developing an open rapport with an Aboriginal or Torres Strait Islander client is the key to improving clinical engagement and building mutual trust and respect. There is a lot of stigma associated with digital rectal examination in Aboriginal communities⁽⁵⁵⁾. Similarly, loss of culture, disempowerment, previous sexual trauma, erectile dysfunction leading to family disharmony and domestic violence are potential barriers that impinge on the clinical engagement with Aboriginal and Torres Strait Islander males⁽⁴⁵⁾.

Clinicians should approach the investigation and physical examination involving the prostate of an Aboriginal male carefully – particularly with digital rectal examination. Clear explanation and plenty of time is needed for the male to consider the options. Avoid any impulse to pressure an individual this may have an opposite effect.

ENGAGING ABORIGINAL AND TORRES STRAIT ISLANDER MEN IN HEALTH CARE INTERVENTIONS

(continued)

A good clinician will identify the barriers and overcome them to achieve the assessment, diagnosis and treatment that will lead to successful outcomes and improved quality of life.

Clear explanation of prostate cancer and treatment applying the Keep It Short and Simple (KISS) principles are essential in Aboriginal and Torres Strait Islander engagement ⁽²⁸⁾ ⁽²⁾. The key is to have patience and commitment. Aboriginal and Torres Strait Islander people do not like to be rushed or forced, they see this as threatening. A history of imposed solutions has left a legacy of suspicion that lingers from past practices among Aboriginal and Torres Strait Islander people. Understanding these practices and their impact on Aboriginal and Torres Strait Islander people will help the clinician develop a sound foundation in which to approach community health care.

Clinicians should not assume that when the patient nods their head an Aboriginal or Torres Strait Islander person understands what is being said by the doctor. This is a polite way of showing respect, but is often misconstrued by the doctor to mean yes. Hence in some instances consent for treatment may not have been given and the person feels powerless to speak up or does not want to make a fuss.

The ethics of informed consent is complex and very important when working in Aboriginal and Torres Strait Islander communities. A man may be suffering from past trauma that may affect clinical engagement in the screening, treatment and management of prostate cancer. Compounding issues such as previous sexual trauma, abuse, mental health problems, loss of empowerment are some potential issues one should consider.

CULTURAL SECURITY

A culturally safe and secure environment is one where our people feel safe and draw strength in their identity, culture and community ⁽¹¹⁵⁾.

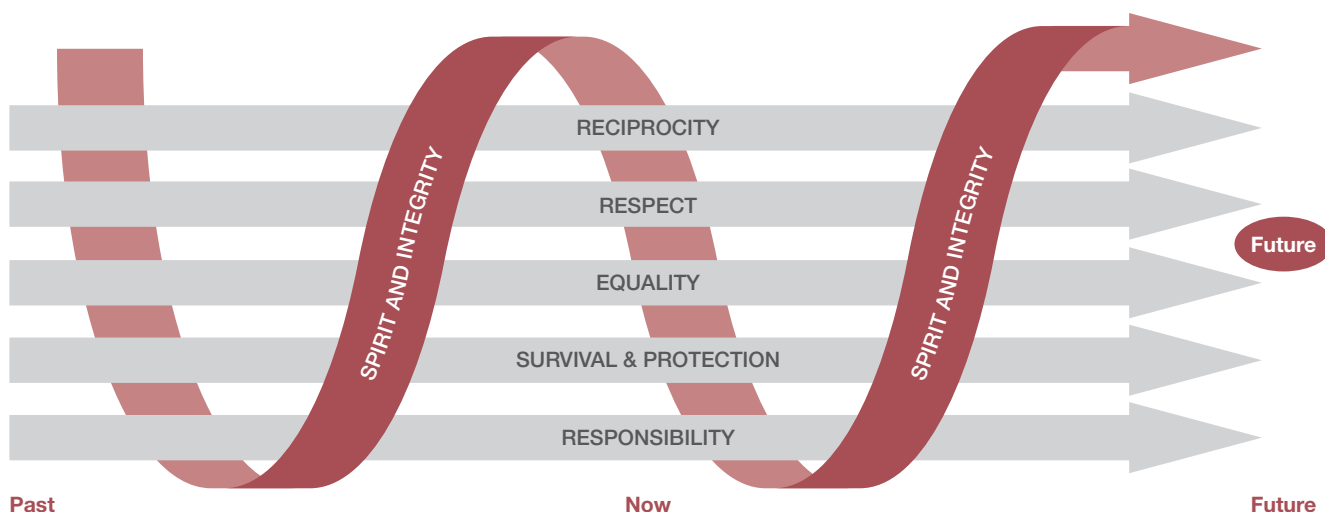
It is now accepted that doctors and health staff need cultural safety and cultural security training for the particular region in which they are working prior to their engagement with their local Aboriginal and Torres Strait Islander community ⁽²⁾ ⁽⁵²⁾. This helps the clinician understand their own culture and health assumptions, informs them of the culture and context they are about to work within and provides skills in delivering health services to the community ⁽⁵⁶⁾. This is important when working with Aboriginal and Torres Strait Islander people.

Clinicians should undertake a cultural training course appropriate for their particular region. Aboriginal people are culturally diverse and the cultural norms differ from region to region.

Clinicians should ask the patient how they would like to be treated, what is the culturally appropriate way ('proper way'), what is considered taboo and what is not.

The National Health and Medical Research Council has endorsed a values and ethics framework developed by Aboriginal people for culturally appropriate conduct in Aboriginal and Torres Strait Islander Health communities ⁽⁸⁾. This framework demonstrates the community values that health workers will find themselves working with.

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES VALUES RELEVANT TO HEALTH RESEARCH ETHICS



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Working with cultural perceptions and expectations requires a fundamental shift in professional practice^{(54) (57)}. Doctors and medical staff need to appreciate the significance of culture on health outcomes for Aboriginal and Torres Strait Islander people, the need for community involvement in service planning and decision making, and an acknowledgement of the wide range of Aboriginal and Torres Strait Islander diversity across Australia⁽⁴⁰⁾. One model fits all will never work for this cultural group.

ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH WORKERS AND COMMUNITY HEALERS

Aboriginal Health Workers and Practitioners are professionals who have a unique insight into the working of their local community and provide the clinician with valuable information that often assists in health service delivery. They are a 'cultural bridge' between the medical service and the community.

Utilisation of Aboriginal Health Workers is a particularly rich resource that can be over looked by clinicians^{(2) (58) (59)}. Guidelines recommend consultation with the patient about involvement of Aboriginal Health Workers as confidentiality through community or cultural relationships can be a concern for some people⁽⁵⁴⁾.

Consider using Aboriginal Health Workers and Traditional Cultural Healers to assist you in communicating and supporting your treatment goals. However, be mindful about confidentiality as these people may be related to the patient in question.

Aboriginal Health Workers can often communicate important information, particularly in those regions where English is not the primary language⁽⁵⁸⁾. They are trained to relay and explain complex information and assist in medical procedures. It is often the Aboriginal Health Worker or Aboriginal Health Practitioner who can identify the compounding social issues that are more likely to have a major impact on engagement and outcomes.

These issues include distance to high quality health care, transport, financial hardship and strong cultural beliefs that would prevent a man seeking or complying with medical advice^{(2) (58)}.

Additionally when communicating information a clinician should not have an expectation that all first Australians can read or write, they may have a low literacy level or poor vision. A man's comprehension of what is going to happen to him is often over looked by many treating doctors, and time should be permitted for the patient to absorb the information before treatment is started. Aboriginal or Torres Strait Island Health Workers and Practitioners can be the crucial link in communicating this information. This may often involve informing the extended family, and Aboriginal and Torres Strait Islander Health Workers and Practitioners should be engaged if the patient requests it⁽⁵⁸⁾. Involving the family and other community members is far more common in Aboriginal and Torres Strait Islander communities.

One study showed that a majority of Australian cancer patients had used complementary medicines in conjunction with their cancer treatments⁽⁶⁰⁾. There has been a traditional holistic healing practice among Aboriginal and Torres Strait Islander communities for many thousands of years⁽⁵¹⁾. Use of traditional medicines and foods affirms people's identity with their culture. It is good practice to assess a patient's lifestyle and health practices when managing a health problem including use of complementary and traditional practices.

Traditional healers may also be encountered in some regions of Australia, and will need to be considered in the holistic approach to the treatment of Aboriginal and Torres Strait Islander men in those regions^{(28) (61)}. In such cases, traditional healers may be an ally that will foster good health care in their communities and may assist in the facilitation of men accessing western style medicine including prostate cancer treatment. Aboriginal Health Workers can assist in understanding and liaising with traditional practices in a region.

ENGAGING ABORIGINAL AND TORRES STRAIT ISLANDER MEN IN HEALTH CARE INTERVENTIONS

(continued)

The importance of culturally safe practice is paramount in Aboriginal and Torres Strait Islander communities and needs to be delivered in an environment that is not pressured for time ^{(2) (28) (61) (62)}. Patient preference is primary in determining the cancer treatment and what a clinician believes to be important for the individual person may not be what they value as essential at that time ⁽⁶³⁾.

Aboriginal and Torres Strait Islander people will often have added community and cultural considerations as well as the normal health decision to balance. Personal and community responsibilities or priorities can often affect Aboriginal and Torres Strait Islander people's attendance to important medical appointments ^{(64) (65)}. This can delay treatment and may have devastating consequences, not to mention the work load required by the General Practitioner to renegotiate further follow up.

DISTANCE AND ISOLATION

Specialist cancer services are located in larger regional centres to provide high level, technical health care for cancer patients. This approach is not without its disadvantages for some people. Rural and remote areas of the country are where poorer prostate cancer outcomes have been shown to occur, and patients face greater costs to access treatment and health services ^{(25) (3) (5) (19)}. Rural and remote areas also have a greater proportion of Aboriginal and Torres Strait Islander residents than urban centres ⁽¹⁰⁾.

Treatment often requires an Aboriginal or Torres Strait Islander person to leave their traditional country, their family and their community. The prospect of an isolating long stay and the costs for carers to support the patient whilst they get their treatment in hospital, places a significant mental health burden on an already traumatised individual and family. This can often impact on recovery time follow-up and treatment for the person. Clinicians should ensure that support services for Aboriginal men attending these major treatment centres also have facilities to cater for their family and / or extended family if they are to achieve a good health outcomes ⁽⁶⁶⁾.

Clinicians should understand that Aboriginal and Torres Strait Islander patients living in regional/ remote areas of Australia and requiring treatment for their condition in major regional centres are often isolated from family and suffer great expense. They should endeavor to link people to suitable support services. Their extended family can assist with this.

Engagement of Aboriginal and Torres Strait Islander Support Workers in hospitals can be a valuable resource for doctors and can often identify support services for patients attending these medical facilities. Additionally, Aboriginal Support Workers and interpreters can also assist when communication problems between the individual person and the treating medical team become apparent. Misunderstandings often result in Aboriginal and Torres Strait Islander people leaving the hospital against medical advice.

The extended family can assist in issues to do with isolation, stress and minimising the risk of the patients leaving the hospital against medical advice.

An Aboriginal person may need an interpreter given that English could be their second or third language. This role often falls to the immediate family which is not best practice and is generally used when it is the only alternative in the absence of suitably qualified interpreters ⁽⁶⁷⁾. Family is an important component of the culture and essential to improving health outcomes for the client. Family support will help with engagement, and family endorsement will lay important ground work with other members in the community that are likely to need these services at a later date.

Information and understanding is essential for consent. Clinicians should recognise the use of a suitable linguistic interpreter may be essential in some Indigenous communities where English is a second language. It is important to be mindful that family members are by no means a suitable alternative for conveying medical information or details to patients.

SORRY BUSINESS

Non-indigenous doctors and health staff should understand that Sorry Business (death) and the dying patient is extremely important for Aboriginal and Torres Strait Islander people ⁽⁶⁸⁾ ⁽⁶⁹⁾ ⁽⁵⁶⁾. Dying has a profound effect on indigenous families ⁽⁶⁸⁾ ⁽⁷⁰⁾ ⁽⁷¹⁾. It is likely to be felt throughout the wider community because of the extended family and cultural connections. This is often a sad time for the family and the local community to recover from, given that many people die at young age or die from premature causes. Mourning can take a long time and in some regions there will be cultural practices and ceremonies that need to be completed ⁽⁷⁰⁾.

It is not uncommon for large communities to travel hundreds of kilometres to attend Sorry Business which is often a significant challenge given the financial difficulties they encounter ⁽³⁹⁾. It is important in the healing process for people and should be a major consideration when dealing with an unwell Aboriginal patient wanting to leave the hospital against medical advice to attend such services or ceremonies. Clinicians who understand the significance of a patient wanting to leave a hospital for cultural reasons are flexible in their treatment of the patient, and will provide far better quality of care than if they are rigid and not compromising ⁽⁵²⁾ ⁽⁷⁰⁾.

Many Aboriginal and Torres Strait Islander people do not like being placed in rooms where family or local community members have recently passed away, due to cultural spiritual beliefs. This often causes immense stress for the person who is more than likely to walk out of the hospital untreated. This belief may vary within Aboriginal and Torres Strait Islander communities around Australia, but understanding the need to have areas spiritually cleansed using the traditional smoking ceremony and traditional healers is an important aspect of the culture. In this matter it is important to work with the local community elders and healers. Knowledge of these cultural issues by doctors and health staff will help them understand why many Aboriginal families do not want their loved ones dying at home. Death is considered a natural process in Aboriginal and Torres Strait Islander culture, spiritual beliefs can determine the person's choice about where they would prefer to die and should be taken into consideration when treating the dying patient and supporting their family ⁽⁶⁸⁾ ⁽⁵⁶⁾ ⁽⁷⁰⁾.

Clinicians should understand the cultural reason for which an Aboriginal person is requesting to discharge from hospital against medical advice. This often relates to a culturally sensitive matter such as Sorry Business, family issues, past experience with medical staff and/or previous death of family members who may have used that room (presence of bad spirits).

In summary, clinicians should recognise the significance of culture when planning and undertaking health care interventions involving Aboriginal and Torres Strait Islander men. Lack of recognition of factors which influence uptake of health care must be addressed to ensure health programs are effective in their delivery.

SUMMARY

SUMMARY

There is limited data and research on prostate cancer amongst Aboriginal and Torres Strait Islander men to guide the development of community interventions.

The limited statistics available indicate that Aboriginal and Torres Strait Islander men are less likely to be diagnosed with prostate cancer than non-Aboriginal men. However, they are more likely to die from the disease within five years of diagnosis. Suggested reasons for the disparities are reported. However, there is currently insufficient information to support detailed conclusions.

Each Aboriginal community is different, with different customs and protocols, systems of organisation, languages, and relationships to each other. Culture, language and traditional health knowledge development affect the health of Aboriginal and Torres Strait Islander people.

Aboriginal and Torres Strait Islander men have difficulties talking to health professionals. A particular concern is breach of confidentiality within the community and stigma attached to sexual problems. The lack of culturally appropriate health services for males has been highlighted as a barrier for men with reproductive problems.

There are a large number of men in the Aboriginal and Torres Strait Islander community who have experienced abuse. Due to the nature of prostate cancer testing, particular strategies and sensitivity are needed when dealing with the issue.

An individual Aboriginal or Torres Strait Island man seeking treatment or investigations for any medical condition, including prostate cancer, will have broad connections and there will be a significant influence of the community in a person's treatment and engagement with the service.

Aboriginal males are less likely to engage health service providers on sensitive issues when dealing with female clinicians.

Those Aboriginal community controlled health services and other organisations who have invested in setting a platform of principles and services that engage Aboriginal and Torres Strait Islander men on health and wellbeing show a positive indication of improvement.

RECOMMENDATIONS

Further research is needed into the outcomes for Aboriginal and Torres Strait Islander men with prostate cancer following diagnosis and treatment.

Ongoing monitoring of the trends in prostate cancer in Aboriginal and Torres Strait Islander men is required to better understand and be alerted to any changes in prostate cancer diagnoses and care.

In developing information resources and education programs, the following should be addressed:

- Materials should provide factual information and deal with culturally sensitive issues appropriately
- Programs should deliver information through trusted people in the community including community leaders
- Programs should include culturally appropriate resources
- Resources should include easy explanations, containing no jargon and include pictures
- There is a strong oral tradition and values around “telling” information and this should be incorporated where possible
- National programs to improve outcomes for Aboriginal and Torres Strait Islander men should acknowledge diversity.

Health care providers should receive cultural safety and cultural security training for the particular region in which they are working prior to their engagement with their local Aboriginal and Torres Strait Islander community.

In delivering health care, the importance of culturally safe practice is paramount in Aboriginal and Torres Strait Islander communities. Health care needs to be delivered in an environment that is not pressured for time. Patient preference is primary in determining the cancer treatment.

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