Research Summary:
Health literacy: addressing the silence about and absence of cancer discussion among Aboriginal communities in NSW

Introduction

Cancer is the second most common cause of death for Aboriginal people, with Aboriginal people 60% more likely to die from cancer than non-Aboriginal people. Despite this difference, there has been little previous research into Aboriginal people’s experience of cancer.

Health literacy refers to how people understand health and health care information, how they apply that information to their lives, use it to make decisions and act on it. Differences in health literacy may be a reason for why Aboriginal people have different cancer outcomes to non-Aboriginal people.

Why is this study important?

This study provides important insights into the individual, social and cultural aspects of health literacy and its impact on cancer for Aboriginal people in NSW. These insights could be used to inform future Aboriginal health programs and communication strategies, which could more effectively engage Aboriginal communities and people in cancer care and treatment.

What were the results?

Limited cancer awareness, knowledge and experience were common themes among all the people interviewed. Many of the people interviewed described cancer as new to their community, and said that they did not expect to experience cancer in their lifetimes. These beliefs and a strong community fear of cancer as a ‘death sentence’ silenced discussion of cancer in Aboriginal communities.

Recognising susceptibility to cancer

Study participants identified that the lack of Aboriginal faces in public cancer campaigns also suggested that cancer was not a priority health issue for them. Many interviews with Aboriginal people described cancer as a ‘big silent word.’
This silence around cancer allows myths to quickly develop, making people hesitant to have surgery or get treatment.

Opportunities to learn from each other

Myths can be powerful as they influence the way people think about things of which they might not have direct experience. This study also provided opportunities for health workers to understand the psychological barriers that may prevent Aboriginal people accessing proper cancer care.

How was this study done?

This study was part of the Aboriginal Patterns of Cancer Care Project (APOCC) and was conducted by a team of Aboriginal and non-Aboriginal researchers with expertise in understanding human behaviour and investigating the ‘why’ and ‘how’ of decision making.

For this study Aboriginal interviewers invited participants to talk at length about their understanding and thoughts about cancer as well as their personal and/or professional experiences of cancer. Interviews were conducted with 22 Aboriginal people who had experienced cancer, 18 carers of Aboriginal people (14 identified as Aboriginal) and 16 health care workers (8 identified as Aboriginal) with a range of professional roles in cancer care and Aboriginal health. The interviews were conducted through visits to a number of Aboriginal Medical Services, hospital cancer and palliative (end of life) services across NSW.

To ensure that appropriate cultural protocols were followed, a senior Aboriginal researcher was employed to act as cultural advisor and mentor to the study team.

Recommendations

- Conduct grass-roots education within community settings to provide information relevant to communities and bust myths about cancer.
- Provide education for health workers in both Aboriginal community-controlled health organisations and specialty cancer services on how to better engage with Aboriginal communities.
- Initiate programs to bridge the transition of people from community-based primary care to cancer treatment services.

**Key message:** This silence around cancer has allowed myths to develop, making people hesitant to have surgery or get treatment. Cancer awareness campaigns targeted at the Aboriginal community are required to position cancer as a key health issue.
Further information

This research summary has been developed from "Health literacy in relation to cancer: addressing the silence about and absence of cancer discussion among Aboriginal people, communities and health services." Treloar C, Gray R, Brener L, Jackson C, Saunders V, Johnson P, Harris M, Butow P & Newman C. E. (2013) Health and Social Care in the Community, 21(6), 655-664


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