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Abstract

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The cancer good news project

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Project Overview

'The Cancer Good News Project' (2012-2013) utilised a social marketing framework to address cancer related stigma and improve cancer screening rates amongst Macedonian and Serbian community members in the Illawarra. Research insights were translated into a tailored, integrated and evidenced based program to promote 'good news' about cancer survival and screening behaviours for two priority cancers – breast and bowel. Multiple strategies were utilised to address literacy and language barriers including: the recruitment of community champions, community events, paid radio ads, community newsletters, interactive PowerPoint community education resources, and a multilingual project website. The sharing of the stories of 'community champions' regarding experiences of cancer survival and screening were critical to facilitating open discussion and promoting screening norms. The project was successful in promoting discussion about cancer and decreasing associated fears, fatalism and stigma. Preliminary survey results also indicate success in promoting positive screening norms within both the Serbian and Macedonian communities.

Background and Policy Context

Research suggests that members of Culturally and Linguistically Diverse (CALD) communities strongly associate cancer with certain death and fatalism. Misconceptions about cancer and cultural taboos also inhibit the open discussion of cancer and cause delays in help-seeking and low attendance for screening (FECCA, 2010; Phillipson, Larsen-Truong, Jones, & Pitts, 2012). To ensure equitable access to cancer information and to improve cancer outcomes in CALD communities it is important that tailored interventions are developed which both address literacy and language barriers as well as the cancer related stigma and misconceptions that exist within communities (FECCA, 2010; Phillipson et al, 2012).

Case-study Benchmark Criteria

Behavioural Goals

Awareness, belief and behavioural objectives were developed to address fatalistic attitudes towards cancer and the taboos associated with talking about cancer. For adults in both communities, behavioural goals included: promoting use and uptake of project resources (e.g. website, newsletters); participation of more than 200 community members in forums/events; the recruitment of 5-10 community champions to share cancer screening and survival stories within the intervention materials; and the promotion of discussion about cancer and screening in more than 80% of participants. Breast cancer screening objectives for women (50-74 years) included: promoting agreement in a majority of participants (> 50%) that mammogram is important to detect breast cancer early and to reduce the risk of dying from breast cancer; and to increase intention to have a mammogram in current non-screeners by 25%. Similarly, for men and women (>50 years) target objectives included: promoting agreement in a majority of participants (>50%) that FOBT is important to detect bowel cancer early and reduce the risk of dying from bowel cancer. Finally, the program aimed to increase intention to conduct an FOBT in current non-screeners by 25%.

Customer Orientation

Focus groups were undertaken to gain insight into the nature of cancer related stigma and existing beliefs, knowledge and behaviours about cancer and cancer screening within the target audiences. Eight focus groups were conducted with 69 male and female members of the Serbian and Macedonian communities with an age range of 20-81 years.

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Focus group discussions also identified preferred strategies for the dissemination of project resources and activities. Development of the program was informed by ongoing consultation with community members via two community panels to test resources for content, readability (i.e. use of plain language) and cultural appropriateness. An iterative research and consultation process allowed for the project resources and activities to be tailored to the needs of the target audiences.

Insight

Formative research revealed that there was a notable absence of 'good news' or survival stories associated with cancer from within the target communities. Cancer was not openly discussed and was seen as a death sentence – and not associated with treatment or survival. Stories of cancer survival and cancer prevention were largely inhibited within these cultural groups. Based on this key insight, the project focused on 'reframing' the community cancer narrative, highlighting the good news about survival and early detection through screening for two priority cancers; bowel and breast cancer. Collecting and promoting personal stories of cancer survival through timely screening from community champions was an important strategy to facilitate open discussion about cancer and influence uptake of cancer screening tests.

Segmentation

The target audiences were defined as Macedonian and Serbian community members in the Illawarra region. These two cultural groups have a significant presence in the region and have been identified as high priority CALD groups in terms of health outcomes and needs. Further segmentation of these two audiences occurred through specific targeting of; women aged 50-74 years regarding breast cancer initiatives and men and women aged >50 years regarding bowel cancer initiatives. In order to reach these segments in a culturally appropriate manner, health service personnel with cultural and linguistic skill were engaged as cultural brokers. Tailored project resources and engagement activities were developed for each of the Macedonian and the Serbian audiences.

Exchange

Significant psycho-social barriers to discussion around cancer and to participating in cancer screening tests were identified. The key barriers related to; a shared, culturally embedded fear that talking about cancer or undertaking screening tests can precipitate the disease, lack of knowledge around screening procedures, a belief that screening and treatment doesn't improve outcomes, and strong fear about negative screening results ("I would rather not know"). An approach that sought to maximize the benefits of cancer screening tests was developed by promoting current, improved bowel and breast cancer survival rates and the important relationship of screening to survival rates. Personal stories about cancer survival and screening positioned the benefits of screening as realistic, appealing and achievable for the target audience.

Competition

For the target audiences, the key competitive behavior was not engaging in open discussion about cancer and/or delaying or avoiding screening and help-seeking in the absence of signs and symptoms of disease. The main benefits of avoiding discussion or screening were a level of 'personal comfort' associated with not discussing, thinking or engaging with cancer ("It's the worst thing you can mention"). There was also a level of 'cultural comfort' associated with adhering to existing social norms around cancer.

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For these audiences it was easier and more comfortable not to encounter the fear and anxiety commonly triggered by cancer dialogue and screening experiences. In response to the competition, all project resources featured the 'Cancer Good News' branding to promote comfort and reduce fear around discussing cancer, developed positive, accessible information and captured personal stories about breast and bowel cancer screening and survival. The project also provided opportunities to reframe existing cultural norms through discussion and the sharing of personal narratives.

Theory

Goffman's theory of stigma (1986) was utilized to inform the development of the Cancer Good News project. Goffman's theory provided a framework for understanding cancer related stigma where it is experienced as either 'felt' stigma (the fear of being discriminated against, internalised shame and a sense of inferiority) or 'enacted' stigma (actual experiences of discrimination)(Goffman, 1986). The theory provided understanding of the 'silencing' effect of cancer related stigma and the related impact on screening behaviours. This guided the development of multiple strategies designed to reduce stigma and 'reframe' cancer in a positive way by facilitating open, positive dialogue about cancer.

Marketing Mix

Product - The core product or benefit for the target audience was reduced fear and stigma surrounding cancer through open discussion about cancer, cancer survival and screening. Augmented products included community newsletters, radio scripts, a multilingual website (http://cancer-goodnews.com.au), community education sessions and interactive PowerPoint resources. Price - Perceived barriers to discussing cancer included beliefs that discussing cancer or even saying the word cancer can precipitate the disease, strong associations with fear and cultural positioning of cancer as a 'taboo' topic. Strategies focused on decreasing the nonmonetary costs associated with the desired behavior by providing a range of mediums, including public forums, for discussing cancer within a positive framework. Involvement of community champions who modelled the desired behaviors was also influential. These strategies served to decrease fears and fatalistic views and challenge cultural taboos around discussing cancer and beliefs that cancer was a death sentence. Place – To decrease barriers to the desired behavior community members were encouraged to 'start the discussion about cancer' by participating in public discussions/ forums about cancer survival and screening tests. These were delivered in culturally appropriate venues, e.g. church halls, with influential community leaders and medical professionals contributing to the discussion. The suite of project resources was available at these events and encouraged to be shared and discussed amongst family and friends. The inclusion of a multilingual project website and radio messages via local ethnic radio allowed the key messages to achieve widespread reach. Promotion – Key messages were tailored to be culturally specific and appropriate for each of the Macedonian and Serbian target audiences and promoted positive cancer survival rates (Good News Facts) emphasized the importance of cancer screening tests (Good News Tests) and modelled open discussion and testimony about cancer survival (Good News Stories). Promotional activities included radio messages, bilingual newsletters, a multilingual website and interactive PowerPoint presentations designed to be used sustainably by a broad range of health service providers.

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Partnerships

Strategic partnerships were established at the start of the project to ensure a sense of common purpose and shared ownership of the project (Abercrombie, Sawatzki, & Lotenberg, 2012). The University of Wollongong (UOW) in partnership with the Multicultural Health Service (Illawarra Shoalhaven Local Health District) as lead agencies, then involved Cancer Care nurse consultants (ISLHD), and the Cancer Council NSW as key partners in the project. Community and cultural organisations associated with each community were also engaged as key stakeholders in the project, including the local Orthodox Church leaders. These partnerships facilitated effective engagement of the target communities, appropriate delivery of resources and activities and the provision of culturally appropriate medical and technical expertise.

Evaluation and results

The first phase of the Cancer Good News Project has achieved high community engagement and success in promoting discussions around cancer, reducing stigma and promoting screening intentions. For adults in both communities, behavioural goals related to reducing stigma and promoting community discussion were achieved or exceeded including: the participation of more than 391 community members in community forums/ events; the use and uptake of project resources (e.g. 317 website visits, 7,000 breast cancer newsletters); and 93% agreement in a survey of n=114 participants that Good News Stories and Information about screening had promoted positive discussion about cancer with family or friends. In relation to breast cancer screening knowledge, beliefs and intentions, for women (50-74 years) objectives were achieved or exceeded including: 93% agreement that mammogram is important to detect breast cancer early and to reduce the risk of dying from breast cancer; 51% of women who had never had a mammogram also indicated they were likely or very likely to have one within the next 3 months. As for bowel screening knowledge, beliefs and intentions, for men and women (50-74 years), 92% agreed that FOBT is important to detect bowel cancer early and to reduce the risk of dying from bowel cancer; and 45% of people who had never had a bowel screen test (FOBT) indicated they were likely or very likely to have one within the next 3 months.

Lessons Learned

Project success was underpinned by the strategic partnerships between the University, the Local Health District's Multicultural Health Service, Cancer Care Services and Cancer Council NSW. Of particular importance were the involvement of local bi-cultural health workers and the engagement of community champions to share their stories of screening and survival. The emphasis on engaging community members in participatory research was significant in promoting the participation of both community groups and leaders.

Appendix 1

Please see the project website for examples of cross cultural resources http://cancer-goodnews.com.au

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