

Cancer and identity: An exploration of people's
understanding of cancer identities and their mass
media representations

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Bachelor of Psychology (Hons), Bachelor of Science

A thesis submitted for the degree of

Doctor of Philosophy

School of Psychology

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The University of Adelaide

April, 2017

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KEY TO ABBREVIATIONS

ACS	American Cancer Society
AIHW	The Australian Institute of Health and Welfare
FIT	Faecal immunochemical test
GBD	Global Burden of Disease
GP	General practitioner
IARC	International Agency for Research on Cancer
NCI	National Cancer Institute (The United States of America ¹)
NCCS	National Coalition for Cancer Survivorship (The United States of America ¹)
NGO	Non-government organisation
PBS	Pharmaceutical Benefits Scheme (Australia ¹)
SCS	Singapore Cancer Society
USA	The United States of America

¹The country is specified for organisations whose country affiliation is not obvious from their names.

ABSTRACT

With the increasing length of cancer survivorship, a rising number of clinicians and researchers are turning their focus to the long-term outcomes or side effects of cancer and its treatments, including the impact on an individual's identity – which is defined as an individual's self-construal that is inclusive of how one construes oneself in the present, past and future (Weinreich, 2003). The aims of the research project presented in this thesis were (1) to examine the understandings of individuals with cancer and the community for cancer identities (and in particular the "survivor" identity); and (2) to investigate media representations of individuals diagnosed with cancer that may not only affect the formation of cancer identities in these individuals, but also influence public perceptions and policies. To address these aims, four independent but related studies were conducted.

Study 1 addressed the first aim through a systematic review of 24 independent studies, consolidating the current literature about the understanding and endorsement of various cancer identities, in particular the "cancer survivor" identity, in individuals diagnosed with cancer. Analysis of these studies revealed that though "cancer survivor" is a widely accepted term, not everyone diagnosed with the disease would take on the label.

Study 2 presented the findings of an online survey that examined lay understandings of cancer identities and survivorship in a sample of 263 crowdsourced adult residents of United States of America (USA) who self-reported not having been diagnosed with cancer. The term "cancer survivor" was mostly viewed as an individual who has beaten cancer, is cancer-free and/or is in remission, an understanding resembling that of individuals diagnosed with cancer rather than reflecting the views of health professionals. Only 57.4% of the respondents considered someone

who is 5 years in remission to be a “cancer survivor” and some felt that the term was unnecessary or unhelpful.

Study 3 addressed the second aim in a sample of Australian print newspapers published in 2015; Study 4 explored the possibility of cultural differences whereby the Australian study was replicated, using a selection of Singaporean newspapers, which allowed for cross-national cultural comparisons. In both countries, certain cancers were over-represented in the media whereas others were under-reported. The most common portrayal of an individual diagnosed with cancer was that of a female adult under the age of 50 and diagnosed with breast cancer. Although psychosocial issues were the second most frequently mentioned sequelae of cancer, cancer identity issues were not as frequently reported ($n = 9$ [Australia]; $n = 2$ [Singapore]). In line with the findings of Study 1, individuals with a cancer diagnosis reported having a lack of cancer identity or refusing to consider the cancer experience as being central to their lives. The “cancer survivor” identity was mostly used by journalists to describe people who have finished treatment, have survived cancer, or are in remission, and also used to describe those who are carrying out cancer-related activities such as fundraising or advocating for better care of those currently undergoing treatment. As hypothesised, Singaporean newspapers had significantly more human interest stories than Australian newspapers, possibly reflecting the greater collectivism of Singaporean culture.

In conclusion, this research project highlighted the different understanding of cancer identities within two different populations (individuals with cancer and lay people), an understanding that was reflected in the media studies but not shared by advocacy groups or policymakers. With the term “cancer survivor” being shown not to be endorsed by everyone diagnosed with cancer, the various sectors involved in cancer care should take caution when using it – or use alternative terms that are more sensitive and acceptable. The mismatches between print media depictions of cancer and the actual statistics, and the under- or over-representation of certain

cancers, demonstrated the need for accurate dissemination of information from researchers and health professionals to the public when using the media. Future research conducted in non-English speaking countries will be helpful to extend the current findings, because they might have a different understanding for the term “cancer survivor” and/or use other more culturally-accepted terms, and the way cancer and the individuals diagnosed with it are presented in the media will give an indication of public perceptions in those countries.

DECLARATION

I, Sze Yan Cheung, certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Sze Yan Cheung

Signed: _____

Date: 21/04/2017

ACKNOWLEDGEMENTS

I owe my greatest gratitude to my supervisors, Professor Paul Delfabbro and Dr Linley Denson, who have provided me invaluable guidance throughout this research project. To Paul, thank you for your support over the last few years, especially during the period when I had to make drastic changes to the research topic. To Linley, your energetic approach is inspiring and thank you for always being there whenever I need a listening ear. Without the both of you, this thesis would have never come to fruition.

I would like to extend my gratitude to Dr Jane Mortimer who encouraged me to take the first step towards research. Thank you to the staff and friends within and outside the School of Psychology. Special thanks to Donna for assisting me as an independent coder. Suzanne, you are a blessing and thank you for dragging me out whenever I seemed lost to the world. Michelle, my sister from another mother, thank you for your constant encouragement.

To Andrew, words can never be enough to express my gratitude. Thank you for being my rock. To Linda and Carla, thank you for being my family away from home and thank you for always ensuring that I am well fed.

Lastly, I would like to thank my parents. Thank you for always believing in me and for being a phone call away. Your unwavering support has allowed me to boldly face any adversities in my path. I dedicate this work to you.