



**Realities of Living with a Life-threatening Illness:  
An Analysis of the Influences of Discourse  
on Illness Experience and Imagined Futures**

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To Christine

Without whose boundless love,  
patience, continuing selfless support,  
encouragement and numerous sacrifices  
this thesis would not have been possible.

CERTIFICATION OF AUTHORSHIP

I certify that the substance of this thesis has not already been submitted for any degree and is not currently being submitted for any other degree or qualification.

I certify that any help received in preparing this thesis, and all sources used, have been acknowledged in this thesis.

(Signed)



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(Date)



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## **Publications and Conference Presentations**

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- Fulton, G., Madden, C. and Minichiello, V. (1996). The social construction of anticipatory grief. *Social Science and Medicine*, 43(9), 1349-1358.
- Fulton, G., Madden, C. and Minichiello, V. (1996). The social construction of anticipatory grief. In *Dying, Death, and Bereavement 98/99* 4<sup>th</sup> Ed. G.E. Dickinson, M.R. Leming and A.C. Mermann. Connecticut. Dushkin/McGraw-Hill, pp. 202-211.
- Minichiello, V., Fulton, G., and Sullivan, G. (in press) Posing interpretive research questions, In *Handbook of Research Methods in Health*, eds. V. Minichiello, G. Sullivan, K. Greenwood and R. Axford, Addison Wesley and Longman

#### **Conference papers presented**

- Fulton, G. (1991). Anticipatory grief: Fact of fiction? paper presented to the Third International Conference on Grief and Bereavement in Contemporary Society, Sydney, July.
- Fulton, G. (1991). The ABC of grief, paper presented to the Third International Conference on Grief and Bereavement in Contemporary Society, Sydney, July.
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## ABSTRACT

Anticipatory grief is routinely accepted within the grief literature as an integral component of the process of facing an impending loss. It is widely assumed that the experience of anticipatory grief is a positive adaptive response to expected loss. However, previous research has resulted in the accumulation of inconsistent information about whether the effects of anticipatory grief are benign, adaptive or emotionally harmful. However, a critique of the literature reveals that anticipatory grief is socially constructed and not a phenomenon intrinsic to the process of confronting an impending loss.

This thesis uses symbolic interactionism to examine how individuals respond to the experience of living with the life-threatening illnesses of cancer and HIV/AIDS, how they constructed imagined futures and how they respond to these ideations. The study reveals that although individuals are influenced, initially, by the common sense and medical discourses associated with these diseases, neither discourse reflects their actual experiences. In discussing their experiences individuals provide symbols indicating that their subjective reality differs from the dominant discourses. If these symbols are acknowledged and a non judgmental environment provided, individuals disclose how they make meaning of their experiences via an experiential discourse. This discourse is marginalised by both the common sense and medical discourses. When constructing imagined futures individuals focus on a range of issues related to the progression of the disease, how they will cope, the event of death, how it might occur and expectations after death. Individuals respond to these imagined scenarios with fear and anxiety.

The results reveal that diagnosis of a life-threatening disease creates a crisis of self definition. For individuals diagnosed with cancer, the uncertainty surrounding the cause of the disease prompts a search for meaning which is reflected in the question 'why me?' In an effort to make meaning of an apparently random and senseless event these individuals develop self-images as important through making some form of 'history', having a rare form of cancer, 'proving' the hereditary nature of cancer, being lucky or being presented with the opportunity for personal growth. In contrast, individuals with HIV/AIDS, where the cause is known, the crisis in self definition is expressed in 'what now?' type questions. How individuals with HIV/AIDS respond to their diagnosis depends on their pre-diagnosis perspective on life.

The major implication arising from this thesis is that anticipatory grief is not intrinsic to the process of individuals facing their impending death. When constructing imagined futures individuals do not focus on anticipated losses. Instead, they focus on a range of dreaded issues and events.