

Loss And Grief In General Practice:  
The Development And Evaluation Of Two  
Instruments To Detect And Measure Grief In  
General Practice Patients

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# Loss And Grief In General Practice: The Development And Evaluation Of Two Instruments To Detect And Measure Grief In General Practice Patients

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## Abstract

This study has developed and evaluated two instruments, a questionnaire, the Grief Diagnostic Instrument, and an interview, the Grief Diagnostic Interview to detect and measure the extant state of grief in general practice patients. These instruments investigate grief from past, present and impending death and non-death related losses occurring directly to the patient, as well as caused indirectly through experiencing grief in sympathy with the grief of others. The unique feature of these instruments is that they investigate grief from all losses rather than merely a single loss.

The questionnaire was demonstrated to be a concise, valid, reliable and sensitive measure, and acceptable to general practice patients. It is suitable for epidemiological studies to detect a broad range of losses and to investigate the prevalence and severity of grief in general practice patients. It is also suitable for comparing the course and severity of grief between losses and identifying commonalities and differences. The interview was found to be an acceptable and valid instrument for undertaking clinical studies. Suggestions for further evaluation of the instruments, and for their uses in grief research and as clinical tools have been proposed.

The findings that 2/3 of the general practice population studied were experiencing loss and that over 1/4 of all subjects were suffering moderate or severe grief, demonstrate grief to be a previously unrecognised significant mental health issue for general practice. The most frequently encountered loss categories were 'quality of life', 'death', 'separation' and 'job'. Non-death related losses accounted for 4/5 of all the losses detected. The lack of recognition of grief by subjects was demonstrated, particularly relating to migration and relocation. The hypothesis that loss and grief are under diagnosed and under treated in general practice is supported. This indicates the need for a new paradigm of loss and grief in general practice and for large-scale studies to investigate grief in general practice patients and the detection rate by general practitioners.

## Statement

This thesis contains no material that has been accepted for the award of any other degree or diploma in any other University and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

The Author consents to the thesis being made available for photocopying and loan if accepted for the award of the degree.

.....

Sheila Clark



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## Glossary

### ***Definitions used in this Thesis***

#### **Loss**

Loss is a perceived negative change by an individual due to the withdrawal of any valued person, object, commodity, state or opportunity from the life of the individual.

Modified from Miller and Omarzu (1996) (Chapter 2.2.1)

#### **Grief**

Grief is the response affecting the physical, emotional, behavioural, cognitive, social and spiritual domains of the individual that occurs in response to

- past present and future losses;
- death related and non-death related losses;
- losses occurring directly to the individual;
- losses caused indirectly through experiencing grief in sympathy with the grief of others.

Modified from Corr (1999) (Chapter 2.2.5)

#### **Grief: the state**

The state of grief is the state of the physical, emotional, behavioural, cognitive, social and spiritual domains of the individual in response to loss at an instant in time.

Modified from Corr (1999) (Chapter 2.2.3)

**The grieving process**

The grieving process is the process of adaptation to loss over time that may affect the physical, emotional, behavioural, cognitive, social and spiritual domains of the individual.

Modified from Corr (1999) (Chapter 2.2.3)

**The extant state of grief**

The extant state of grief is the state of the physical, emotional, behavioural, cognitive, social and spiritual domains of the individual over the two week window period up to, and including, the day of measurement in response to:

- past present and future losses;
- death related and non-death related losses;
- losses occurring directly to the individual; and
- losses caused indirectly through experiencing grief in sympathy with the grief of others.

(Chapter 2.2.6)

### **Other terms used in this Thesis**

BDI	Beck Depression Inventory (Beck, A.T., Ward, C.H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. <i>Archives of General Psychiatry</i> , 4, 561-71.)
CBI	Core Bereavement Items (Burnett, P., Middleton, W., Raphael, B., & Martinek, N. (1997). Measuring core bereavement phenomena. <i>Psychological Medicine</i> , 27 (1), 49-57.)
CI	Chief investigator
Clinical score	Grief measure score of the interview (i.e. no grief/ minimal grief/ mild grief/ moderate grief/ severe grief)
Evaluation interview schedule	The interview schedule format used in the evaluation
Evaluation questionnaire	The questionnaire format used in the evaluation
GHQ	General Health Questionnaire (Goldberg, D.P., & Williams, P. (1988). <i>A User's Guide to the General health Questionnaire</i> . Windsor: NFER-Nelson.)
Grief measure	That part of the interview or questionnaire that aims to measure the severity of grief resulting from the losses detected by the loss review (Section C of the questionnaire)

Loss review	That part of the interview or questionnaire that aims to detect grief and which consists of a list of categories of loss situations (Section B of the questionnaire)
Pilot interview schedule	The interview schedule format used in the pilot study
Pilot questionnaire	The questionnaire format used in the pilot study
SEC	Socio-economic cluster
Section C score	Grief measure score of the questionnaire
Section A	Demographic section of the questionnaire
Section B	Loss review of the questionnaire
Section C	Grief measure of the questionnaire
Trial interview schedule	The interview schedule format used in the trial (Chapter 8)
Trial questionnaire	The questionnaire format used in the trial (Chapter 8)

## Introduction

‘ “So death by leukaemia is now a local instead of an express. Same run, only a few more stops. But that’s medicine, the art of prolonging disease.”

“Jesus,” I said, with a laugh. “Why would anyone want to prolong it?”

“In order to postpone grief”. ’

This discussion between parents of dying children quoted from Peter DeVries’ (1969) autobiographical novel, highlights medicine’s failure to confront the challenges posed by the grief of its suffering patients. While the world’s literature, philosophies and music wrestle with the realities of loss and grief, medicine is still seen as prevaricating about these issues (Davis-Floyd & St John, 1998; Hauerwas, 1990).

Certainly, the palliative care movement of the past 50 years fuelled by the late twentieth century drive for euthanasia legislation, together with recent focuses on post traumatic stress and AIDS, has challenged general practitioners (GPs) to combine excellent medical competence with the humanitarian skills of caring. However, my clinical experiences since the late 1980s have substantiated the previous observations that there still appears to be a masterly evasion of dealing with loss and grief in the broader sense.

I became aware that a hidden agenda in the consultation common to many of my patients, was that of grief caused by loss. I realised that patients experience grief not only relating to the death of a loved one, but also because many conditions for which they normally consult their GP, such as chronic illness, disability, ageing, infertility, miscarriage, stillbirth and birth defect, are those of loss. Furthermore, more covert reasons for consultation included loss situations such as marital breakdown, unemployment, retirement, domestic violence, death of a pet, migration, adoption and being a caregiver. I concluded that whatever the loss, these patients were experiencing the common symptoms of grief, and that appropriate management

of them required that their loss and consequent grief be addressed. The concept of loss and grief, its causes, effects and management are the subject of a paradigm that is already established among the allied health professions of psychology, social work and nursing. The application of this paradigm to general practice seemed to me to provide a new approach which would greatly enhance patient care.

I became curious about how significant a problem grief might be in terms of the prevalence of grief in the wider general practice population, and also in terms of morbidity. My hypothesis was that:

- loss and its subsequent grief is under-recognised and under treated in general practice.

To investigate this, a tool was required, firstly, to detect grief and secondly, to measure its severity. For the convenience of prevalence studies on large numbers of patients, a tool in the form of a self administered questionnaire is the ideal. However, as there was no existing tool that fulfilled these requirements it therefore became necessary to develop such an instrument. Consequently, the first research question that is addressed in this Thesis is:

- Can a valid and reliable self-administered questionnaire be developed to detect and measure the extant state of grief in general practice patients?

One of the problems in developing a questionnaire was that there was no existing standard against which to evaluate it. In order to provide such a standard, a standardised clinical interview was also developed. The second research question that is addressed in this Thesis is:

- Can a valid and reliable standardised clinical interview be developed to detect and measure the extant state of grief in general practice patients?

These questions were addressed by a research study, which is the topic of this Thesis. The aims of the study were as follows:



1. to devise a self-administered questionnaire, the Grief Diagnostic Instrument, whose purpose was to detect and measure the extant state of grief in general practice patients;
2. to devise a standardised interview, the Grief Diagnostic Interview, whose purpose was to detect and measure the extant state of grief in general practice patients.

The objectives of both the questionnaire and the interview were as follows and have been designated by the letters A to D, which will be used throughout this Thesis:

- A. to detect the presence or absence of grief in patients attending general practices;
- B. to determine the categories of loss events causing grief;
- C. to measure the extant state of grief in these patients; and
- D. to demonstrate acceptable levels of validity and reliability.

This Thesis therefore describes the design and evaluation of two instruments to detect and measure grief in general practice patients: the Grief Diagnostic Instrument, which is a questionnaire intended for use in prevalence studies of general practice patient populations, and the Grief Diagnostic Interview, which was designed to be a gold standard against which the questionnaire could be compared. For the sake of clarity, these instruments will in future in this Thesis be referred to as the questionnaire and the interview.

The layout of the Thesis is described in the following paragraphs. Chapter 1 provides the background to the study. It gives evidence that grief from loss is generally unrecognised in general practice, and argues the need for an instrument to detect and measure grief from loss, in order to investigate this further. The chapter concludes by proposing the allied health paradigm of loss and grief as an appropriate resource to development such an instrument.

Chapter 2 describes the allied health paradigm of loss and grief from historical and present day perspectives. Current concepts about loss, grief and the grieving process that underpin the rationale of this Thesis are presented. It continues with giving the rationale for introducing this paradigm to general practice. The lack of a unified measure for the paradigm is identified and the chapter concludes with the need for a specific new instrument to be developed.

Chapter 3 describes the study design to create a self-administered questionnaire to detect and measure grief in general practice patients. It gives the rationale for also developing a standardised interview to detect and measure grief as a gold standard. Although both the questionnaire and interview evolved concurrently through these three stages, the evolution of the interview will be described first in Chapters 5 and 6, followed by the questionnaire in Chapters 7 to 13.

The methodological issues that arise from the study design are described in Chapter 4. Those relating to grief, such as the ethics of conducting research on grieving people, and the detection and measurement of grief, follow from the concepts of loss and grief described in Chapter 2. The issues relating to general practice are also discussed. The chapter focuses on recent research findings from which underlying principles were formed to guide both the format of the interview and questionnaire, as well as the conduct of the study.

The evolution of the interview, through the three stages of development, trial and evaluation described in Chapter 3, is addressed in Chapters 5 and 6. Chapter 5 describes, firstly, the design of the interview in the development stage and how this addresses objectives A to C. It continues by explaining how the design is improved through the stages of the trial and evaluation and concludes with a description of the final Grief Diagnostic Instrument.

Chapter 6 addresses objective D, that is, the validation of the interview. The methods and results are described and the chapter continues with a discussion about the validity of the interview as a gold standard against which the questionnaire will be compared later in the Thesis. The chapter finishes by describing the final Grief Diagnostic Interview and examines to what extent the second research question has been answered.

The questionnaire is addressed in Chapters 7 to 13. Chapter 7 describes the design of the questionnaire in the development stage and how this addresses objectives A to C. The subsequent chapters describe the trial and evaluation, which both fulfil two purposes: to demonstrate how the design of the questionnaire is improved through these stages; and to address objective D, that is, to investigate the validity and reliability of the questionnaire.

The trial of the questionnaire against the interview is described in Chapters 8, 9 and 10.

Chapter 8 details the method of the trial on a sample of general practice patients and provides the plan of analysis on which the validation of objectives A to D of the instrument is based for both the trial and the evaluation. The results of the trial are given in Chapter 9. Chapter 10 analyses these results in terms of objectives A to D, including comparisons of the questionnaire and interview data, and describes the modifications made to the instrument as a result.

The evaluation of the questionnaire against the interview is described in Chapters 11, 12 and 13. Chapter 11 details the method of the evaluation on a different sample of general practice patients. The results of the evaluation are given in Chapter 12. Chapter 13 analyses these results in terms of objectives A to D, including comparisons of the questionnaire and interview data, and describes the modifications made to the instrument as a result. The chapter finishes by describing the final Grief Diagnostic Instrument and examines to what extent the first research question has been answered.

The final chapter, Chapter 14, summarises and discusses the main findings from the study and suggests further avenues for research as well as clinical uses of the two instruments. The chapter finishes with recommendations and conclusions that come from the study.