

## Chapter 1: Background

This chapter provides the rationale for undertaking the study. It gives evidence that grief from loss is generally unrecognised in general practice and examines why managing patients' grief is highly relevant to improving patient care. It concludes by giving the rationale for constructing an instrument to detect and measure grief from loss in general practice patients, and by proposing the allied health paradigm of loss and grief as an appropriate resource for doing so.

### ***1.1 Grief from loss: unrecognised in general practice***

Research over the past 25 years has provided ample evidence from developed countries worldwide that there is a high prevalence of emotional problems in general practice patients as well as in the community. Studies in Australia have found that between 20% and 50% of patients in general practice have problems that are emotional in origin in Australia (Britt & Miller, 2000; Chancellor, 1977; Hickie, Davenport, Hadzi-Pavlovic, Koschera, Naismith, Scott & Wilhelm, 2001). Similar results were found in the United Kingdom (Goldberg, 1979) and in the United States (Hoepfer, Nycz, Cleary, Regier, & Goldberg, 1979). Anxiety and depression alone have been found in around 20 % of primary care patients (Harris, Silove, & Kehag, 1996; Zung, Broadhead and Roth, 1993). Similarly, audits of the community found the prevalence of psychiatric problems to be between 20 and 30% in the South Australian (Clayer, McFarlane, Bookless, Air, Wright, & Czechowicz, 1995), New Zealand (Oakley-Browne, Joyce, Wells, Bushnell, & Hornblow, 1989) and American populations (Robins & Regier, 1991; Kessler, McGonagle, Zhao, Nelson, Hughes, Eshleman, Wittchen & Kendler, 1994). However, most emotional problems remain unrecognised in general practice, as it seems GPs fail to recognise them in over half their patients (Goldberg, 1979; Hickie, Davenport, Scott, Hadzi-Pavlovic, Naismith & Koschera, 2001).

Similarly grief from loss, other than from the death of a loved one, appears to be generally unrecognised in general practice. Evidence that this is so comes from unproductive searches of data bases and classification systems of problems managed. Published clinical audits of problems managed in general practice make no mention of loss and grief (Bridges-Webb, Britt, Miles, Neary, Charles, & Traynor, 1992; Underwood, Ward, Fatovich, Wood, Gray, Prince, & McGee, 1992). Additionally, a Medline search for papers on primary care between 1991-2001 found no specific articles under the key words 'loss and grief', whereas 332 articles were found for the keyword 'psychosocial', 37 for 'life events' and 934 for 'depression'. Furthermore, apart from reference to conditions relating to bereavement and trauma, the classification system for primary care, the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (World Health Organisation, 1992) does not include loss and grief among its diagnostic categories. Even the Nottingham Health Profile (Hunt, McEwan, McKenna, 1986), a primary care clinical screening instrument, has no mention of grief. The exception to this is the International Classification of Primary Care (Lamberts and Wood, 1987) which does contain a category 'Grief' in addition to bereavement and trauma items.

Psychiatry, like general practice, also does not include grief from loss as a recognised problem, despite the association of loss events with mental ill health. Instruments designed for screening and diagnostic purposes, such as PRIME-MD (Spitzer, Williams, Kroenke, Linzer, deGruy, Hahn, Brody & Johnson, 1994), the Diagnostic and Statistical Manual of Mental Disorders: Primary Care version (American Psychiatric Association, 1996), the Composite International Diagnostic Interview (Robins, Wing, Wittchen, Helzer, Babor, Burke, Farmer, Jablenski, Pickens, Regier, Sartorius, & Towle, 1988) bear no mention of it. However, as grief itself is not a pathological condition there may be justification for not including the paradigm as a primary diagnosis in psychiatric instruments.

On the other hand, two psychiatric instruments do consider life events. The most recent version, the Fourth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), (American Psychiatric Association, 1994) is a multi-axial system of which the fourth axis is specific to psychosocial and environmental problems.

Additionally, the AMDP-System (Guy & Ban, 1982) does include an incomplete list of life events that ‘may have a significant bearing on patients’ psychiatric conditions’.

Nonetheless, life events are not the same as loss events, as will be explained in Chapter 2.

## ***1.2 The relevance of grief management to general practice***

There are several reasons why the management of patients’ grief may be highly relevant to general practice. Firstly, there are some early indications of a high prevalence of grief among general practice patients. Secondly, grief has known associated mortality and morbidity outcomes, and finally, patients see their GPs as a relevant source of help. These will be described in turn.

### **1.2.1 Pilot studies on the prevalence of grief**

Observations of patients’ grief in my clinical practice (Appendix 1.1: cases 1-4) led me to carry out two pilot studies to examine to what extent grief is an issue in general practice and in the community.

As an initial inquiry into the prevalence of grief in general practice, I undertook an audit of 200 patient encounters in my own practice. This was at a time when my interest in loss and grief was just beginning and inter-practice comparisons showed my practice to be representative of those of other women doctors. This audit found that while 33% of encounters had a psychological component, loss and grief was an issue in 27.5% of all

patients (36 patients) (Clark, 1986). Further, only 5 patients presented the loss as reason for the encounter and the other 31 presented with a variety of physical symptoms. The 55 losses suffered by the 36 patients, in descending order of frequency were: relationship breakdown; incapacitation (illness, injury, disability); death of a family member or friend; moving house; migration, loss of employment; losses associated with the birth of a baby; and death of a pet. Twenty-three patients were experiencing one loss, eight patients had two losses and five were suffering three or more losses. Furthermore, eight patients were suffering past losses and the others were experiencing concurrent or impending losses.

A second pilot study into the prevalence and nature of loss in the South Australian population using the South Australian Health Omnibus Survey (Harrison Market Research Pty Ltd., 1994), showed 24 % of the general population to be experiencing distress from a variety of losses. Losses (multiple categories) in descending order of frequency were: death of a loved one (8.9% of population); unemployment (4.0%); loss of quality of life from disability, illness or injury (3.7%); divorce or separation (3.4%); loss of significant personal property (1.9%); migration or moving house (1.2%); loss of pregnancy (0.6%); and retirement (0.5%). These studies indicate that both in the community and among general practice patient populations, grief is a significant issue.

### **1.2.2 Mortality and morbidity of grief**

Morbidity and mortality have been well researched for bereavement, one major category of loss. Poor outcomes from bereavement relevant to general practice include:

- mortality from cardiovascular disease (Hirsch, Hofer, Holland, & Soloman, 1984) and suicide (Brent, Perper, Goldstein, Kolko, Annan, Allman & Zelenak, 1988; Szanto, Prigerson, Houck, Ehrenpreis and Reynolds, 1997);

- autonomic reactions and endocrine changes (Roy, Gallucci, Avgerinos, Linnoila and Gold, 1988; Salopsky & Pulsinelli, 1985), that may provoke new disease or complicate existing conditions. These include palpitations, irritable bowel, hypertension, diabetes mellitus and menstrual irregularities;
- reduced immunity (Bartrop, Luckhurst, Lazarus, Kiloh, & Pennry, 1977; Goodkin, Baldewitz, Blaney, Asthana, Kumar, Shapshak, Leeds, Burkhalter, Rigg, Tyll, Cohen, & Zhen, 2001) which may lead to increased risk of viral infections such as of the upper respiratory tract;
- lifestyle changes, such as insomnia (Clayton, 1974; Martin, 1988), smoking, excess caffeine intake, dietary changes and decreased levels of physical exertion;
- mental ill health such as depression, anxiety and substance abuse (Clayton, 1998; Harlow, Goldberg & Comstock, 1991; Jacobs, 1993; Maddison & Viola, 1968; Mendes de Leon, Kasl & Jacobs, 1994; Mor, McHorney & Sherwood, 1986; Surtees, 1995; Wortman & Silver, 1989);
- social changes such as diminished social support and relationship breakdown (McNeil, Hatcher & Reubin, 1988; Tudball, 2001);
- somatisation (Clarke, Mackinnon, Smith, McKenzie & Herrman, 2000; Mallouh, Abbey, Gillies, 1995; Parkes, 1964); and
- diminished cognitive ability, such as poor school performance and work difficulties (Caplan, 1990; Seeman, Singer, Rowe, Horwitz & McEwen, 1997).

Similar morbidities have also been demonstrated in those experiencing non-death losses. Increased mortality rates, and poor physical and mental health have been found to be associated with unemployment (Mathers & Schofield, 1998). Carers of family members with Alzheimer's disease and stroke have been found to have impaired immunological functioning and higher levels of depression than controls (Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki & Speicher, 1987; Reese, Gross, Smalley & Messer, 1994). Marital separation was associated with higher levels of alcohol intake (Power, Rodgers & Hope, 1994) and psychiatric symptoms (Svedin & Wadsby, 1998). Depression and anxiety have been found to be associated with early-stage breast cancer (Kissane, Clarke, Ikin, Bloch, Smith, Vitetta & McKenzie, 1998). Studies such as these provide evidence that non-death loss situations, like bereavement, have themselves associated mortality and morbidity outcomes.

### **1.2.3 The GP's role**

Importantly, the general public see their doctor as the key professional for assistance with grief (Harrison Market Research Pty Ltd., 1994). A question in the South Australian Health Omnibus Survey asking those currently experiencing loss: 'What sources of help do you see as appropriate to your distress?', found that the GP was the professional of choice, and second only to family and friends. In another study of a small sample of 35 patients bereaved through suicide, 19 (54%) had consulted a primary health care doctor in the first nine months following bereavement but in only 7 cases had the death been discussed. Moreover the patients had wanted their doctor to initiate discussion about the death. In instances where the grief is hidden or disenfranchised there is unlikely to be the normal level of social and family support, so grieving individuals are often forced to seek outside help, such as their GP.

General practitioners are in a prime position to care for the grieving not only because of their personal knowledge of patients and their families but also because of their encompassing

roles of managing the physical symptoms and of providing emotional support, stress management, sick certificates and referral to social support and services. They are skilled in recognising the patient's hidden agenda when presented with physical complaints (Barsky, 1981; Daines, Gask & Usherwood, 1997). In their role of integrating the physical, psychological and social aspects of health into planned comprehensive and continuing care as directed by the Royal Australian College of General Practitioners (Royal Australian College of General Practitioners, 1991), they are well placed to manage any complications of the grieving process. They may be the only health professional accessible, especially in country areas. Importantly, they may be the only affordable practitioner, particularly if the doctor bulk bills, that is, directly bills the Health Insurance Commission for services, so the patient has nothing to pay.

Furthermore, much of the GP's work already concerns loss whether or not they recognise their patients' grief. More doctors are looking after an increasing number of patients dying at home (Dunlop, Davies & Hockley, 1989), suffering chronic illness (Knottnerus, Metsemakers, Hoppener & Limonard, 1992), and losses associated with ageing (Glover, 1999).

### ***1.3 Rationale for constructing an instrument to detect and measure grief***

Considering the findings from the pilot studies of sizeable prevalence of grief from loss, the health risks associated with grief, and that the GP is seen as the professional of choice for assistance, it would seem that grief management is relevant to the care of patients in general practice. By appropriately attending to the grief of their patients, GPs may be better placed to detect emotional disorders in their patients, provide appropriate information, support and treatment, and prevent many of the complications of grief.

There is clearly a need to investigate further the occurrence of grief in general practice. There needs to be a large scale epidemiological study of the general practice patient population to determine the prevalence of grief, its causes and severity. For this there needs to be an instrument that firstly detects and secondly measures grief from any loss. Although there exist measures of grief resulting from bereavement, no scales existed to measure grief from a variety of losses. In order to construct a measure, the concepts of loss, grief and the grieving process, needed to be understood and clearly defined. The paradigm of loss and grief, that is employed in the allied health professions such as psychology, social work and nursing, provides these frameworks and will be used as a resource for constructing this grief measure.

#### **1.4 Summary**

This chapter has argued that there is mounting evidence that grief is a neglected issue in general practice patients, that there is a need to explore the issue of grief further and of the necessity for an instrument to detect and measure grief from all types of loss. The chapter concludes with the need to understand the concepts of loss and grief in order to develop the instrument, and that the paradigm of loss and grief, that is applied in the allied health professions, is an appropriate source. This paradigm is considered in the following chapter.

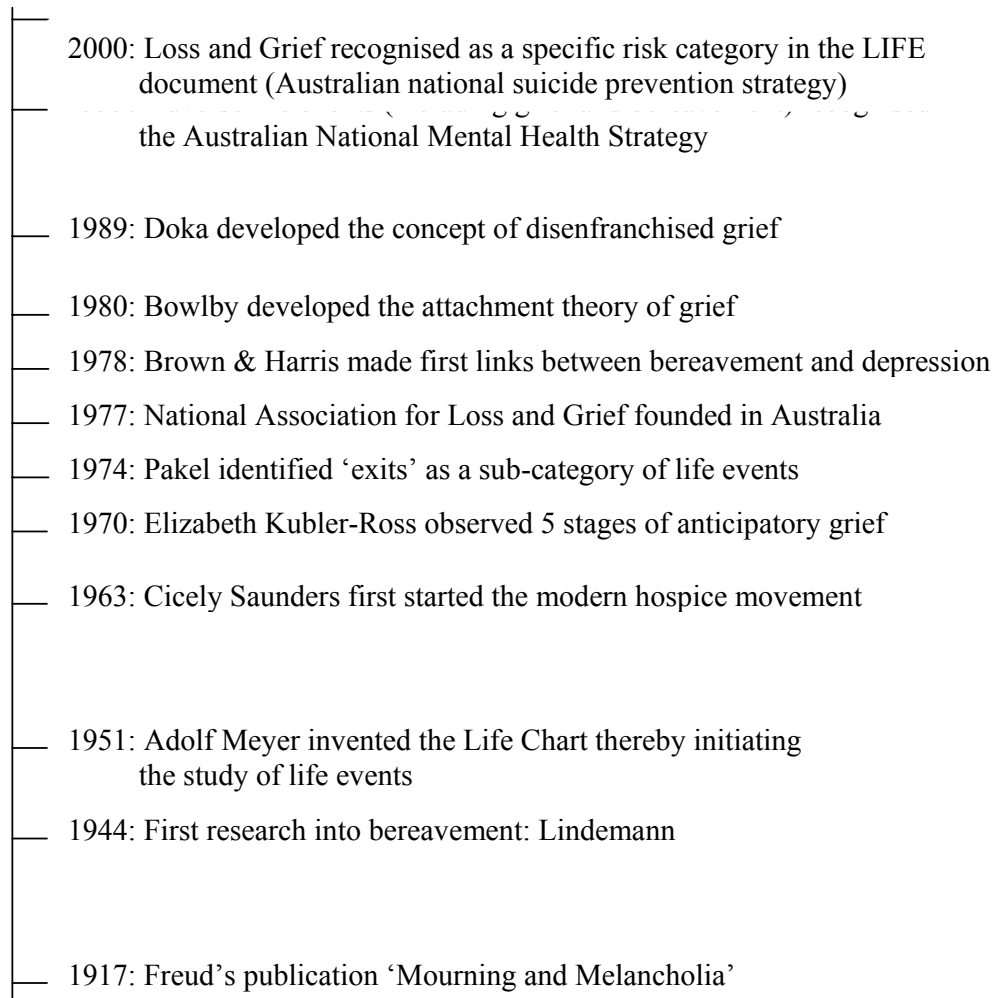


## Chapter 2: The paradigm of loss and grief and its measurement

This chapter describes from historical and present day perspectives the paradigm of loss and grief as it applies in the allied health sciences. The distinguishing features of the paradigm are described, and the current concepts of loss and of grief that are relevant to this study are detailed. Attention will be given to defining loss and grief as detected and measured in this study, and the ‘extant state of grief’, which the instruments aim to measure (Introduction), will be explained. The potential contributions of this paradigm to general practice are considered. The chapter continues by identifying the lack of a unified measure for the paradigm and concludes by positing the need for a specific new instrument to be developed.

### ***2.1 Historical perspective***

The paradigm originated through two main lines of inquiry - life events and bereavement; and contributions have come from a variety of disciplines including psychoanalysis, psychology, psychiatry, gerontology, social work and more recently, nursing. The account that follows should be read in conjunction with the time line which charts the main historical events (Figure 1).



**Figure 1: Main events in the development of the paradigm of loss and grief**

### **2.1.1 The contribution from life events**

The scientific interest in life events developed through the bio-psychosocial study of disease in the early and mid twentieth century. A life event is an event in the life of an individual that requires the person to make on-going adjustments to the changes incurred by the event (Holmes & Rahe, 1967). A heterogeneous mixture of situations make up this group such as marriage, birth of a baby, death of a family member and the onset of chronic disease. Adolf Meyer (1951) first seeded interest in the area of life events with his life chart. This tool for making medical diagnoses charted, chronologically, the changes in life situations and periods

of illness of an individual, and thereby attempted to make connections between illness and life events.

There followed a number of inventories of life events developed by various researchers that included a diverse range of life changes such as the death of a spouse, infertility, Christmas and promotion. These inventories attempted to scale life events according to the perceived degree of social adjustment (Holmes & Rahe, 1967), the amount of distress caused (Paykel, 1974), or to both social adjustment and distress (Tennant & Andrews, 1976).

The fundamental concept of loss was first mooted by Paykel, who observed in 1974 that 'exits' (now called 'loss events') produced more distress than other life events and he identified two thirds of the items in his life events inventory as exits. He found that social adjustment and emotional distress in relation to life events were distinct and independent entities. From this grew the concept that it is not merely the life event itself but its interpretation or meaning, in terms of the severity of the distress, which the individual attributes to the event that is the important factor.

Of relevance to medical practice is the subsequent demonstration of the associations between life events and physical, emotional, immune, behavioural, social and, particularly, mental morbidity (Brown & Harris 1978a; Brown & Harris 1978b; Goldberger & Breznitz, 1993; Katschnig, 1986; Stueve, Dohrenwend & Skodol, 1998). Depression, anxiety, post traumatic stress disorder, substance abuse and relationship breakdown may all be sequelae of life events. Further, risk factors were identified that were associated with poor outcomes, which included characteristics of the life events and of the individuals undergoing the events. These made it possible to predict those persons who were more likely to experience morbidity. Risk factors associated with poor outcomes included the suddenness and unpredictability of the event (Mrazek & Haggerty, 1994). A second set of factors that protected the individual from

these complications and increased their resilience included good self-esteem and financial security (Spence, 1996).

These discoveries were supported by research from a physiological perspective. Since Selye's (1956) foundation work, the study of stress has taught us much about the biochemical, neuro-endocrine, immune, physical and mental responses to stress and a whole discipline of stress medicine has developed (Hubbard & Workman, 1997a). However, the types of stressors studied vary between studies, so generalisation of the results needs to be done with caution. Like Paykel's distinction of exits as a particular category of life events, this research confirmed that it is the interpretation of the stressor by the individual and not the stressor itself that determines the outcome (Goldberger & Breznitz, 1993; Hubbard & Workman, 1997b).

These findings are all very relevant to GPs because they make it possible for the GP to identify those most at risk of adverse outcomes from life events and to initiate interventions to prevent complications arising in their patients. In fact, the issue of adverse life events is now recognised in various public mental health policies and guidelines including the Australian National Mental Health Strategy (Commonwealth Department of Health and Aged Care (1999; 2000a); 'Life Is For Everyone', the Australian national suicide prevention policy (Commonwealth Department of Health and Aged Care, 2000b); and the clinical practice guidelines, Depression for Young People (National Health and Medical Research Council, 1997).

Therapy has been focussed on identifying those at risk, strengthening the protective factors of the individual and providing interventions targeted at the specific needs of the individual life event. For example, when counselling survivors of sexual abuse, specific issues to address include the perceptions of guilt and shame (Long & Smyth, 1998).

The concept of life events is useful in that it provides a common approach to this group of health-related social issues. However, one of the major disadvantages is that the nature and implications of each individual event differ greatly from each other, thus prohibiting a cohesive approach to management. For example, although implying some elements of stress, getting married is usually perceived as being beneficial to the individuals concerned. Other events are perceived as negative, but even these can be sub-divided into those that are interpreted as loss by the individual and those that are not. For example, a court hearing may itself be perceived as a noxious stress but not a loss event, whereas a gaol sentence imposes many losses associated with incarceration. The heterogeneous group of life events therefore includes loss events as a subset.

### **2.1.2 The contribution from bereavement**

The study of the grieving process following bereavement has provided a detailed understanding of the principles pertaining to a particular life event that is also a major category of loss.

The effects of bereavement on the individual and the nature of grief have been studied by Freud as early as 1917 (Freud, 1934), and later by Lindemann (1944), Raphael (1984), Parkes (1986), Parkes and Weiss (1983), Stroebe, Stroebe & Hansson (1993) and Stroebe, Hansson, Stroebe, & Schut, (2001). Grief is now recognised as affecting the physical, emotional, cognitive, behavioural, social and spiritual domains of an individual's life (Corr, 1999).

Research using a variety of methods, including comparative controlled studies, has identified a number of demographic, personal, inter-personal, cultural and contextual variables similar to those found in relation to life events, that may affect the grieving process (Cleiren, 1993;

Sanders, 1993; Osterweis, Solomon & Green, 1984; Madison & Walker, 1967; Stroebe & Stroebe, 1987)).

The early finding that bereavement carries an increased risk of death (Rees & Lutkins, 1967), has been challenged by studies, of increasingly sophisticated methodology, controlling for the various confounders such as personal and environmental characteristics. However, a review of fourteen longitudinal studies (Woof & Carter, 1997a) suggests that the risk of mortality is greater in the first year of bereavement particularly for men. This increased risk is supported in the findings of a controlled study of over 12,000 bereaved spouses which found an increased mortality for both men and women (Schaefer, Quesenberry & Wi, 1995)

There is also evidence of increased morbidity associated with bereavement. In addition to the conditions described in Chapter 1.2.2 there is evidence of: an increased rate of consultations with GPs (Parkes, 1964), an increased number of sick days and hospital admissions (Parkes & Brown, 1972), increased rate of admission to hospital for mental health reasons (Clegg, 1988), and work-related difficulties (Smith, 1999). Further, the prevalence of morbidity is not insignificant: as many as one third of bereaved widows have been found to suffer clinical depression in the first year after the death of their husbands (Mendes de Leon, Kasl & Jacobs, 1994; Wortman & Silver, 1989).

In children, bereavement is associated with depression, sleep difficulties, decreased appetite, withdrawn behaviours, enuresis, abdominal pain, aggressive behaviour and a lack of interest in school (Van Eerdewegh, Beiri, Parilla & Clayton, 1982). Bereavement suffered in childhood has also been linked to depression and suicidal behaviour in adult life (Adam, Lohrenz, Harper & Streiner, 1982; Brown & Harris, 1978).

Bereavement therapy has focussed on providing management of physical symptoms, emotional and social support consistent with the social mores (Griffin & Tobin, 1982, Kellehear, 2000), education about grief and coping strategies (Parkes 1986; Raphael, 1984; Worden, 1991) and of facilitating psychological accommodation to the loss. There are a number of concepts from the study of bereavement that are pertinent to the paradigm of loss and grief which will be briefly described.

#### *2.1.2.1 Attachment theory*

John Bowlby's theory of bonds of attachment which arose from his study of bereavement was a major step forward in understanding loss (Bowlby, 1980). He explained bonds of attachment between individuals from a psychodynamic perspective: that these bonds create a set of distinctive lifelong behaviours whose aim is to maintain a homeostatic mechanism designed to preserve the safety of the individual through procuring care for that individual. These behaviours include subsets concerned with the formation, maintenance and disruption of the attachment relationship. It is those behaviours and experiences relating to the disruption of the attachment bonds that he describes as grief.

Although Bowlby consciously restricted his inquiry to bereavement in order to provide a template for investigating other losses which could disrupt an individual's homeostatic safety mechanism, he recognised similarities with grief associated with other forms of loss. These included the threat of death through serious illness, stillbirth and the separation of a young child from its mother. Bowlby refined the concept of loss, identifying two major types, one related to death and a second caused by loss events other than death. He further classified the latter into interpersonal loss, which involved loss between persons, such as divorce, and personal loss which involved the loss of objects and situations, such as the loss of a job. He also recognised the earlier findings of Brown and Harris (1978) that future as well as past losses could cause grief, and that an individual may grieve for another's grief.

### *2.1.2.2 Theoretical frameworks of the grieving process*

A symptom of medicine's negligence in failing to update itself with advances in bereavement care, is its continued misapplication of Elisabeth Kubler-Ross's (1970) five stages of grief in dying patients. This has since been replaced by a variety of working frameworks that provide the rationale and strategies for much of current grief therapy. Following on from Bowlby's attachment theory, there is now a general consensus that there are three main phases (Bowlby, 1980; Lindemann, 1944; Parkes, 1986; Raphael, 1984) consisting of an initial phase of shock and denial, a second of disorganisation and pining and a final phase of reorganisation and integration. Other contributions include the notion of grief being a disease that needs healing (Averill & Nunley, 1993; Engel, 1961), the concept of the grieving process as a series of four tasks (Worden, 1991), a psychosocial transition (Parkes, 1988), a dual process of grief work and restorative work (Stroebe & Schut, 1999), the rebuilding of the relationship with the deceased person (Rubin, 1999; Walter, 1996), meaning reconstruction (Neimeyer, 2000) and spiritual experience (Doka & Morgan (1993).

### *2.1.2.3 Variants of grief*

One of the grief issues of concern to GPs, has been what constitutes normal grief and what does not. There is still no consensus about what constitutes abnormal grief, that is, grief outside the cultural norm. By surveying the views of prominent experts in the field, Middleton et. al. have classified variants of grieving into delayed, chronic, anticipatory and absent grief ( Middleton, Moylan, Raphael, Burnett & Martinek, 1993). To this have been added the concepts of complicated grief (Prigerson, Maciejewski, Reynolds, Bierhals, News, Fasiczka, Frank, Doman & Miller, 1995) and grief reactions following trauma (Turnbull, 1998; Wolfe and Jordan, 2000). Grief is regarded as complicated when it is followed by any of the recognised morbidities, such as depression, described earlier.



Although the emerging discipline of traumatology is becoming increasingly prominent in medicine, its recent reunion with the field of grief is less well known. Research into grief and trauma originated together. In the United States, Lindemann's (1944) study of victims of a night club fire and, in Australia, research into the aftermath of the Granville train disaster (Raphael, 1977) resulted in the birth of the National Association for Loss and Grief. For several decades traumatology split off but is now returning with the recognition that grief is a coexisting condition in trauma victims.

Despite all the previous discussion, grief has been found to be a stressor that is not necessarily noxious but can create opportunity for personal growth and benefit the individual (Tedeschi & Calhoun, 1995; Schaefer & Moos, 1998). The study of how bereaved people accommodate loss into their lives has demonstrated that, in addition to the resilience and protective factors common with other life events, particular personal grieving strategies exist that facilitate the individual's adaptation to loss (Murphy, Gupta, Cain, Johnson, Lohan, Wu, & Mekwa, 1999; Gamino, Sewell, & Easterling, 2000). These include engaging in a process of closure with the deceased, seeing some good or meaning come from the death, maintaining an internal relationship with the deceased and the individual's innate spirituality. Grief therapy now places strong emphasis on interventions based on these factors (Klass, Silverman, & Nickman, 1996; Neimeyer, 2000).

#### ***2.1.2.4 Disenfranchised grief***

A major step towards a paradigm of loss and grief was made by Doka (1989) in his work on disenfranchised grief. Doka recognised that much grief lay outside the social norms and defined this as "the grief that persons experience that is not or cannot be openly acknowledged, publicly mourned or socially supported" (Doka, 1989: p4). In his later book (Doka, 2002: pp 10-14) he recognised five categories of disenfranchised grief:

- where the lost relationship is not recognised, such as a same sex or an extramarital relationship;
- where the griever is not recognised, as in children and persons with intellectual disability; and
- where the loss is not discerned, such as elective abortion and the death of a pet;
- where the dynamics of the grieving process are unrecognised, such as certain types of behaviour and cognitive styles rather than the societal norm of expressing emotions;
- where the circumstances of the death are not accepted. An example is the stigma attached to suicide bereavement that may result in lack of support for the bereaved, a painful process for the bereaved of ‘coming out’ about the mode of death, and contribute to the lack of research about this form of bereavement (Clark, 2001b, Clark & Goldney, 2000).

Doka’s work was also important in that it led to increased recognition of non death-related loss events. One result of this has led to the identification (from various methods) in the medical and allied literature, of a large number of conditions where the loss itself has been shown to be an important contributor to patient morbidity. Moreover, these conditions as outlined in Table 2.1 are problems frequently encountered in general practice.

**Table 2.1: Non death-related loss publications and methodologies**

<b>Loss</b>	<b>Author(s)</b>	<b>Methodology</b>
Downs Syndrome	Damrosch & Perry, 1989	Questionnaire
Removal of body parts by surgery	Maguire & Parkes, 1998	Clinical review
Infertility	Read, 1995	Clinical review
Alzheimer's disease	Liken & Collins, 1993	Case studies
Relinquishment of a baby for adoption	Condon, 1986	Task-specific questionnaire
Retirement	Mulley, 1995	Clinical review
Job loss	Archer & Rhodes, 1995	Task-specific questionnaires
Relationship breakdown	Kaczmarek & Backlund, 1991	Clinical review
Same sex relationships	Di Angi, 1982	Case study
Mental illness	Miller, Dworkin, Ward & Barone, 1990	Task-specific grief measure

In Australia, as in other countries of high immigration such as the United States and Israel, losses experienced by migrants, such as country, culture and family (Ben-Porath, 1991, Lerner, Mirsky & Barasch, 1994), are often overlooked. Similarly, losses of indigenous peoples, such as those associated with the stolen generation (Human Rights and Equal Opportunities Commission, 1997; Raphael, 2000) still need to be adequately acknowledged.

In fact the wide range of death and non-death related losses is now acknowledged under the distinct category of 'Loss and Grief' in the 'LIFE' document, the Australian national suicide prevention policy (Commonwealth Department of Health and Aged Care, 2000b).

Publications that now bear witness to the emergence of a new paradigm of loss and grief include a specific psychology text, *Perspectives on Loss* (Harvey, 1998); a medical text, *Coping with Loss: Helping Patients and their Families* (Parkes and Markus, 1998); a sociological and mental health perspective of loss and grief in Australian society (Raphael, 2000); a clinical tool (*Grief Map* (Clark, 2001)); journals, including the *Journal of Loss and Trauma*, and *Death Studies*; and peer support organisations such as the National Association for Loss and Grief in Australia. Although the study of bereavement has provided many more commonalities in terms of models of the effects and the processes of grief, frameworks for prevention complications, and therapeutic approaches for managing loss situations than did life events, caution is also needed in applying them across all losses until their applicability has been evaluated further.

## ***2.2 The present position***

The paradigm of loss and grief proposes fundamental concepts as a framework for understanding the effects and processes common to a wide variety of loss events (Bruce & Schultz, 2001; Harvey, 1996; Harvey, 1998; Murray, 2001; Neimeyer, 1996; Parkes, 1998; Parkes & Markus 1998).

Some basic concepts relating to the paradigm that will be employed in this thesis will be briefly described here.

### 2.2.1 Loss

#### **Definition**

Miller and Omarzu (1996) have produced one of the most appropriate definitions of loss:

‘Loss is produced by an event which is perceived to be negative by the individuals involved and results in long-term changes to one’s social situations, relationships or cognitions’.

This is suitable because the definition:

- applies to death-related as well as non-death related loss events;
- applies to recognised and disenfranchised losses; and
- applies to past, present and impending loss situations;
- specifies the requirement that the individual concerned interprets the event as loss.

However, the word “negative” is open to interpretation as, in addition to loss, it could imply an event or a situation that is difficult, such as an examination or a court hearing, and so does not distinguish sufficiently between a loss event and a life event. The missing qualifier in the definition is that the negative needs to be produced by the withdrawal of something from the life of the individual, whether this be a person, object, commodity (such as love or money), state or opportunity. Another problem is that Miller and Omarzu indicate that loss affects only three domains, rather than the six specified by Corr (1999). I shall therefore replace reference to the domains in the definition of loss by the term ‘grief’, and specify the domains under the

definition of grief. Therefore I propose the following modification to this definition of loss for use in this Thesis:

‘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.’

### **2.2.2 Features of loss**

A number of writers have sought to determine the important core features of a paradigm of loss and grief: Harvey, 1996; Murray, 2001; Neimeyer, 1998; Parkes, 1998. In reviewing these writings it becomes apparent that:

- loss causes grief;
- loss is recurrent and inevitable during the life span;
- loss affects people of all ages including young children;
- loss threatens or severs the bonds of attachment that maintain the individual’s homeostatic safety mechanism;
- loss rarely occurs singly and losses are commonly linked. For example, a primary loss, such as migration, may cause subsequent losses such as family, fatherland, culture, social position and home. Another example is when an initial loss, such as a bereavement, leads to depression (loss of mental health) which subsequently results in a yet another loss in the form of marital breakdown;
- loss events are a sub-group of life events. Not all life events involve loss (e.g. Christmas, getting married, taking an examination, appearing at a court hearing) or are interpreted as loss;
- loss can be categorised according to its aetiology of loss:
  - death loss, including stillbirth, abortion and miscarriage, death of a pet;

interpersonal loss, such as divorce, separation by migration, relinquishing a child for adoption, child leaving home, extramarital affair of partner;  
personal loss, such as job, health, finances, menopause; and

- loss events each have a set of unique features, so the application of research findings and theory from one loss to another needs to be approached with caution.

### **2.2.3 Grief**

#### **Definitions**

Grief has been defined in many different ways:

- as the reaction to loss (Parkes, 1986);
- as ‘keen mental suffering or distress over affliction or loss’ (Macquarie Dictionary: Delbridge Bernard, Blair, Butler, Peters, & Tardiff, 1990);
- as the working through of emotion (Worden, 1991);
- as an emotion in response to loss (Raphael, 1984; Stroebe, Stroebe & Hansson, 1993); and
- as the physical, emotional, behavioural, cognitive, social and spiritual reactions to loss (Corr, 1999).

These definitions are all problematic. Firstly, they do not agree about the extent of the effects of grief on the individual, that is, emotional versus other domains. Grief is now known to affect many aspects of the individual (Chapter 4.3.4) which leads me to prefer Corr’s (1999) definition<sup>1</sup>. Further, the definitions do not agree about whether the word ‘grief’ applies to the state or the process of grief. The state of grief is known to be continually changing within the course of the grieving process (Schuchter & Zisook, 1993) and therefore I propose the following two definitions:

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<sup>1</sup> Prior to Corr’s 1999 publication, this Thesis relied upon several references in the literature for citation of the six domains.

**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.

**Grief: the 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.

**2.2.4 Features of grief**

The features of grief have been theorised by a number of writers (Harvey, 1996; Murray, 2001; Neimeyer, 1998; Parkes, 1998, Brown & Harris, 1978, Parkes & Markus 1998) and include that:

- grief is a normal response to loss;
- grief occurs:
  - when the event is perceived by the individual to be a loss, either consciously or unconsciously;
  - in response to past, present or future losses;
  - in response to another's grief;
  - by reminders of the loss; and
- grief fluctuates by the hour, day and week in response to any given loss.



### **2.2.5 Definition of grief for this study**

In consideration of the above, the definition of grief that will be used in this study will be:

‘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; and
- losses caused indirectly through experiencing grief in sympathy with the grief of others.

### **2.2.6 Definition of the ‘extant state of grief’**

This leads me to be in a position to define the term the ‘extant state of grief’ which the instruments that will be constructed aim to measure (Introduction). The instruments need to measure the state of grief in subjects at the time that the instrument is being administered, and not the severity of the grief in the past. However, because one of the features of grief mentioned above is that it fluctuates, it is necessary to take into account more than just the instant at which the subject completes the instrument. Therefore a window period of two weeks was deemed an appropriate time over which to assess the state of grief. This is further explained in Chapter 4.3.5. The definition of the extant state of grief therefore becomes:

‘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.’

### **2.2.7 Features of the paradigm of loss and grief**

In contrast to the disparate variety of events that compose the group of life events, the paradigm of loss and grief consists of a number of unifying features. Firstly there are common features of loss and grief:

- all events have the common aetiology of loss;
- the resulting grief has common effects and complications; and
- there are common management strategies which can be applied to grief from any loss.

In addition to these common features, the paradigm also recognises that each loss has its own unique features. These include, the unique effects and specific issues of management relevant to each loss. For example, someone who has experienced sexual abuse will be likely to have feelings of loss of personal integrity, uncleanliness and of being violated, all of which all need to be addressed in counselling. Migrants by choice have different issues to deal with than refugees. Migrants’ losses are often disenfranchised because of the choice, whereas the pre-flight trauma may be a major issue for refugees. So the support needs to be different for both categories of migrants (Ben-Porath, 1991).

Further, the paradigm recognises the specific contribution to the outcome of the loss from the unique characteristics of the individuals and contexts concerned. These can be major determinants of the effects a particular loss will have on an individual. However, so far, these determinants have been researched only for life events and for bereavement, but not for loss events as a paradigm. The two groups of risk and protective factors concerned do not conflict

with each other, and it is current practice to apply either of these sets with circumspection to loss events.

### ***2.3 Loss and Grief: A new paradigm for general practice***

A common approach to diagnosis and management of loss events, such as the paradigm described above, could be of great benefit to the busy GP whose knowledge of different conditions is often stretched to capacity. By providing a simple diagnostic and management framework, such an approach may increase the doctor's confidence in dealing with a vast array of otherwise disparate issues. I therefore propose that the paradigm of loss and grief, employed by the paramedical professions, be introduced as a specific approach to patient care in general practice.

In the Kuhnian<sup>2</sup> sense, a paradigm is a specific set of ideas forming a distinct approach to a phenomenon that is accepted by the profession concerned and includes specific theories, models, frameworks and practices (Hoyningen-Huene, 1993). General practice has undergone numerous shifts of paradigm in the past to bring it to its present day state. An example of a sudden change of paradigm followed John Snow's theory of microbial contamination of well-water in London in the nineteenth century, which revolutionised the existing demonic beliefs about gastroenteritis and its associated practices. A more recent example of gradual change is the twentieth century shift away from general practice being merely reactionary medicine to encompassing planned, comprehensive and continuing care (Royal Australian College of General Practitioners, 1991).

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<sup>2</sup> Thomas Kuhn: Twentieth century scientific philosopher

## **2.4 The potential contribution of a loss and grief paradigm to general practice**

The various benefits that a paradigm of loss and grief may bring to general practice are outlined in the following section.

### **2.4.1 An improved classification for general practice problems**

The aetiologically-based classification of loss gives a pathway to diagnosis that may be more easily recognisable than other classifications. In fact, when inquiring into why the diagnostic rate of emotional disorders in general practice was so low, Goldberg (1984) reasoned:

‘We (psychiatrists) have failed to develop a taxonomy that is really of much use to our medical, surgical and GP colleagues.’

He goes on to say that by offering GPs a complicated variety of mutually exclusive categories, the psychiatric classification forces GPs sometimes to make an unrealistic single diagnosis. He cites the example of a patient who has symptoms of both depression and anxiety but who presents with physical symptoms. Should the diagnosis be depression, anxiety or somatiform disorder? Within the standard consultation time of 10-15 minutes the diagnosis may be all too difficult and be ignored.

Should it be established that the cause of a patient’s condition is a loss, the doctor can make the diagnosis grief from loss, thereby having a ready framework within which to manage the patient. In other words, GPs might be better served by creating their own aetiology-based taxonomy of loss and grief. This is echoed by Bowlby in the conclusion of his work *Loss, Sadness and Depression* (1980):

“ I have concentrated on problems of aetiology and psychopathology, believing that it will only be when we have a good grasp of what the causes are of psychiatric disorder and how they operate that we shall be in a position to develop effective measures either for their treatment or for their prevention”.

A biopsychosocial classification to psychiatric diagnosis has been proposed by Koopowitz (1999). Perhaps GPs, too, would be better served by returning to Engel’s (1977) original concept of the biopsychosocial model and establishing a multi-axial system of diagnosis which includes grief on a major axis.

#### **2.4.2 Improved patient care**

Apart from disguising the aetiology of loss, the symptomatic psychiatric classification system places emphasis on symptomatic treatment rather than treating the underlying cause. This is analogous to the inappropriate management by a GP in giving an analgesic to a patient, instead of first investigating whether the abdominal pain is gastrointestinal, obstetric, menstrual or urinary in origin.

The core concepts would assist doctors to gain a better understanding of the extent of their patient’s grief by:

- identifying not only primary losses, but also secondary and resurgent losses;
- assessing the patient through taking a history in the six domains;
- identifying risk and protective factors and thereby preventing complications; and
- initiating a plan of interventions based on current grief frameworks.

However, it would be important that the paradigm should supplement and not replace the standard diagnostic and management procedures for medical conditions. For example,

guidelines for the management of depression and anxiety in general practice should be followed; the additional application of the paradigm may provide a more appropriate pathway to treatment.

### **2.4.3 Destigmatisation of grief**

A further benefit of this paradigm for the patient is that it can provide a non-stigmatised label for their condition, rather than using psychiatric nomenclature, that, despite the current educational efforts of the Australian National Mental Health Strategy (Commonwealth Department of Health and Aged Care, 2001), may still cause embarrassment and humiliation.

## **2.5 The new vision**

“Though the world does not change with a change of paradigm, the scientist afterwards works in a different world....” (Kuhn, 1970)

It is envisaged that a new paradigm of loss and grief would contribute to better patient care and in particular, to better diagnosis and management of emotional problems. Just as GPs provide ante natal care for their patients that monitors the progress of the mother and baby, so they would provide after-loss care, watching how the patient accommodates the loss into their life and being available to give expert assistance if necessary (see Case 4: Appendix 1.1). Considering that most grieving people see their family and friends as their primary source of help (Caplan, 1990, Harrison Market Research Pty Ltd, 1994), this should not add greatly to the workload of the doctor, but rather render it more efficient and appropriate. The doctor can identify those most at risk of morbidity, use a death register (Khunti, 1996) to follow up at known times of intense grief, such as the three months' trough (Davidson, 1979) and the anniversary, and offer appropriate interventions. This does not mean that grief becomes

medicalised, as those in the allied health professions frequently fear, but rather that it is more appropriately dealt with in general practice rather than somatised or neglected altogether.

The benefits of post-loss care may not only be to reduce the mortality and morbidity associated with grief, but may also be beneficial economically. A Cochrane review demonstrated that patients receiving counselling by GPs for a variety of emotional issues benefited significantly psychologically from the interventions and were more satisfied with their treatment compared to patients receiving the usual GP care (Rowland, Bower, Mellor Clark, Heywood & Godfrey, 2001). No clear cost benefit was found, but long term outcomes still await evaluation. The benefits of bereavement interventions have been demonstrated by a systematic review of 20 controlled trials, which even allowing for some methodological concerns, demonstrated the bereaved benefited from the intervention on one or more measures compared to controls (Woof & Carter, 1997b). However, another review of four randomised controlled studies of bereavement counselling found methodological flaws that weakened the authors' claims of physical or psychological benefit from the intervention (Kato & Mann, 1999). Clearly, evaluation of the outcomes from the use of the paradigm must be part of that vision.

A profile of the paradigm for general practice will need to be established and future research will need to investigate:

- the prevalence of loss and grief among the general practice patient population;
- the common losses encountered;
- the extent and nature of the grief experienced; and
- the contribution of loss and grief to reasons for encounter, investigations performed, referrals to specialists and to health care costs.

It will also be essential to establish:

- in which aspects grieving individuals who choose to consult GPs are a different group from those who do not,
- whether the above are at greater risk of complications than the general grieving population; and
- evaluated therapies suitable for use in general practice;

The following will need to be developed:

- best practice guidelines for grief management (similar to those in the Manual of Mental Health Care in General Practice (Davies, 2000));
- risk assessment and prevention protocols (such as those in the Guidelines for Preventive Activities in General Practice (Royal Australian College of General Practitioners, 2001); and
- GP training programs in grief management.

Expected outcomes would be:

- better recognition of grief by GPs;
- improved identification and management of emotional problems in general practice;
- more appropriate use of medical resources, including referral for investigations, specialist consultations and interventions for those experiencing grief;
- a reduction of morbidity rates in grieving patients; and
- increased patient satisfaction with their consultations;

## ***2.6 Measurement of the paradigm***

So far the frameworks and concepts of the paradigm of loss and grief have been described and deemed suitable for general practice. This is therefore an appropriate starting point for investigating measures that would detect and measure grief from various types of loss. A



literature search failed to find any such instrument in the Medline, PsychLIT, PsycINFO, Sociofile and Pubmed electronic data-bases. However, a number of instruments were found for related paradigms but they were rejected because they were not sufficiently task-specific.

Instruments for life events were rejected because life events are not necessarily loss events.

They included:

- The Social Adjustment Rating Scale (Holmes & Rahe, 1967);
- Life Events Inventory (Tennant & Andrews, 1976);
- LEDS scale (Brown & Harris, 1978a);
- Impact of Event Scale (Horowitz, Wilner, Alvarez, 1979);
- Stress Response Rating Scale (Weiss, Horowitz, Wilner, 1984); and
- The Grief Map (Clark, 2001).

Instruments that measured bereavement were rejected because their applicability to grief following non-death loss was doubtful. They included:

- The Grief Experience Inventory (Sanders, Mauger & Strong, 1985);
- Measure of spousal grief (Jacobs, Kasl, Ostfeld, Berkman, Kosten & Charpentier, 1987);
- Grief Resolution Index (Remondet and Hannson, 1987);
- Texas Revised Inventory of Grief (Faschingbauer, Zisook & DeVaul, 1987);
- Perinatal Grief Scale (Toedter, Lasker & Alhadeff, 1988);
- Grief Experience Questionnaire (Barrett and Scott, 1989);
- Revised Grief Experience Inventory [RGEI] (Lev, Munro & McCorcle, 1993);
- Core Bereavement Items (Burnett, Middleton, Raphael, Martinek, 1997); and
- Bereavement Phenomenology Questionnaire (Burnett, Middleton et al, 1997).

As no instrument could be found that was applicable to detecting and measuring grief from all types of loss it therefore becomes necessary to develop and evaluate a new instrument. A research study to develop and evaluate such as instrument is described in detail, and forms the body of this Thesis.

## **2.7 Summary**

This chapter has described the human service provider's paradigm of loss and grief, and has argued its applicability to general practice. The present day concepts have been described that distinguish the paradigm from that of life events and from the science of bereavement. The lack of an appropriate tool within the paradigm to detect and measure grief has been demonstrated. The chapter concludes with the need to develop a new instrument for these purposes. The design of the study to develop such as instrument is described in the following chapter.

## Chapter 3: Study Design

This chapter describes the design of the study to develop an instrument to detect and measure grief in general practice patients and gives the rationale for creating a standardised interview in addition to the self-administered questionnaire. It describes the stages of the study through which both instruments evolved and explains how the objectives of the instruments are addressed.

### ***3.1 Rationale for the design***

Where there has been no existing validated and reliable instrument, the ultimate method of diagnosis in the disciplines of general practice and psychiatry has been a clinical interview conducted by experts (Goldberg, 1972; Goldberg, Cooper, Eastwood, Kedward, Shepherd, 1970). However, the problem of using interviews to measure prevalence, is that this is a cumbersome and impracticable method for accessing a large representative sample, so self-administered questionnaires are preferable. However, interviews have been valuable in providing the gold standard against which to develop new questionnaire-style instruments. Two notable instruments which were developed using this method are the General Health Questionnaire (Goldberg, 1972) and the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). This approach, of developing a questionnaire based on a gold standard interview, will be adopted in this study. The design of this study, therefore, includes the creation of a questionnaire, as well as of an interview as a gold standard against which the questionnaire will be compared.

### ***3.2 Stages of the study***

**Both instruments evolved through three stages: a development, a trial and finally an evaluation. There was also the additional step of the validation of the interview. These steps are all illustrated in Figure 3.1. The stages are described in the following paragraphs, which also detail how the objectives A to D for the instruments as described in the Introduction, have been addressed.**

### 3.2.1 Development

The pilot versions of both instruments were drafted, piloted and subsequently modified according to the results of the pilot. The format of the instruments are described in the paragraphs below.

The interview schedule was in four parts:

- an opening;
- a section to detect grief (Objectives A and B);
- a grief measure (Objective C); and
- a debrief and closure.

The questionnaire was in three sections;

- a demographic section: section A;
- a section to detect grief: section B (Objectives A and B); and
- a grief measure: section C (Objective C).

The development stages of the interview are more fully described in Chapter 5, and of the questionnaire in Chapter 7.

### 3.2.2 Trial

**The versions of the instruments, after the modifications from the pilot had been made became known as the trial versions. The trial interview schedule and the questionnaire were trialled on a representative sample of 100 general practice subjects. The results of the interview and questionnaire were analysed to:**

- Describe and compare the detection of grief by interview and questionnaire (Objectives A and B);
- Describe and compare the measurement of grief by questionnaire and interview (Objective C);

- Determine those items in the questionnaire that best measure grief (Objective C);
- Test the questionnaire for validity and reliability (Objective D); and
- Improve on the wording and format (Objectives A- D).

**The interview schedule and questionnaire were subsequently modified according to these results, to form the evaluation interview schedule and questionnaire. The trial method, results, and analysis and modifications are described in Chapters 8, 9 and 10 respectively.**

### *3.2.2.1 Sample size*

There were two considerations in estimating the number of subjects required for the trial:

- A minimum of 50 subjects is required for the frequency testing of measures (Streiner & Norman, 1995); and

**Due to the time and cost involved in interviewing, it was important to keep the number of subjects to a minimum.**

**Therefore a balance was struck between keeping the number of subjects to a minimum and yet having a sufficient sample size to yield data that would give significant results. In order to calculate the sample size of subjects needed for the study, an estimate of actual prevalence was made based on the pilot studies described in Chapter 1.2.1.**

**The prevalence of grief in a general practice sample was expected to be larger than the 27% found in the general practice pilot study (Clark, 1986) because the investigator then was not in a position to know all the patients' losses and because the study was restricted to a limited number of loss categories. The prevalence of grief would also be expected to be considerably greater than the 24% found in the South Australian Health Omnibus Survey (Harrison Market Research Pty Ltd., 1994) because of the self-selection of persons attending their GP. An estimate of 50% prevalence of grief was made for the present study.**

For testing of the grief measure:

Minimal number of subjects with grief =50

Assuming prevalence of grief of 50%:

Total number of subjects required in study =50 X 100/50  
=100

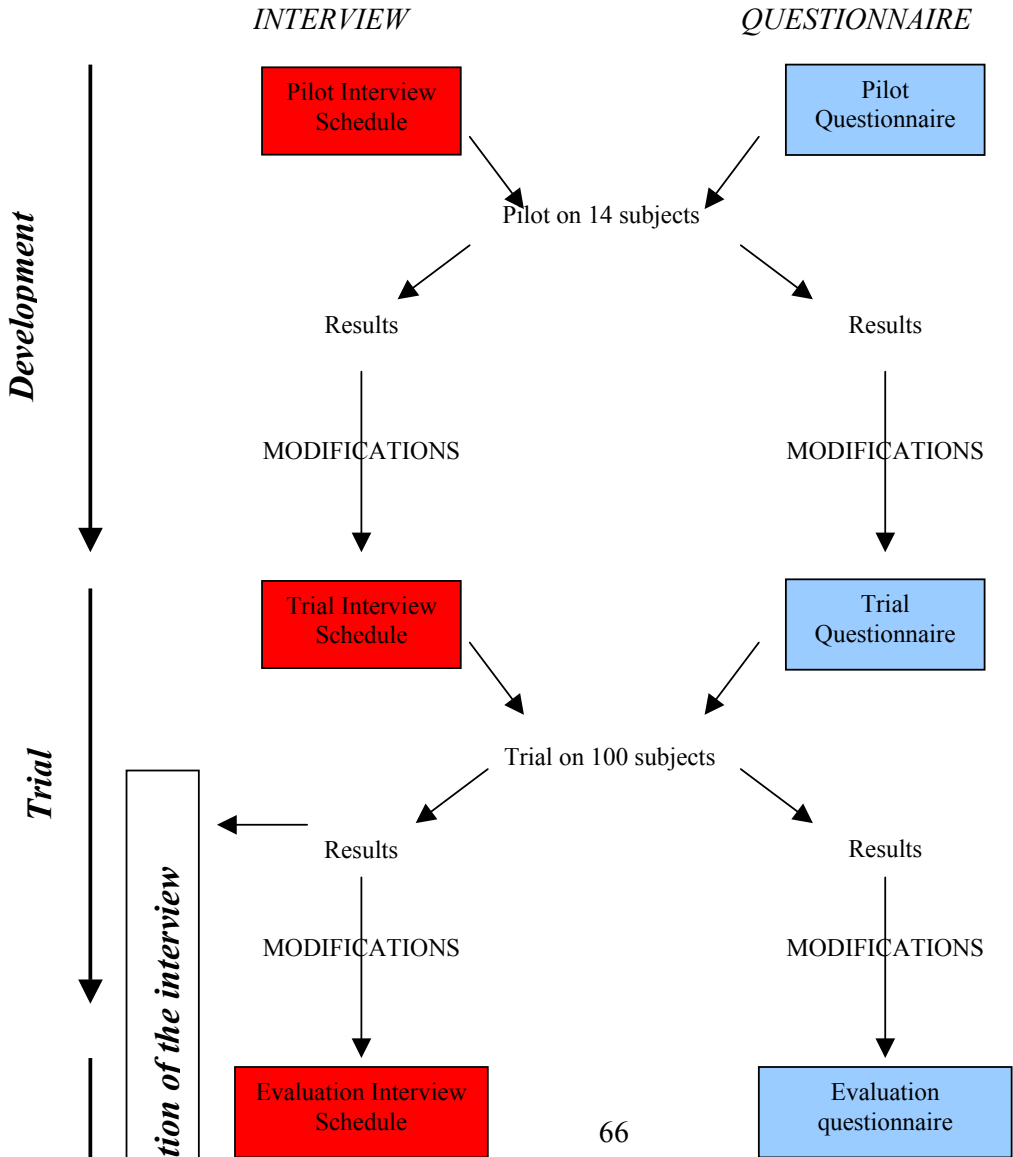
**3.2.3 Evaluation**

The evaluation questionnaire was evaluated against the interview using the same procedure as for the trial on a further sample of 63 subjects, and both instruments were modified to form the final questionnaire, the Grief Diagnostic Instrument, and the final interview schedule, the Grief Diagnostic Interview. The evaluation method, results, and analysis and modifications are described in Chapters 11, 12 and 13 respectively.

**3.2.4 Validation of the interview**

Interview data from the trial and evaluation were used to examine the inter-rater reliability, construct validity and internal consistency. This addressed Objective 4 for the interview and is described fully in Chapter 6.

**Figure 3.1: Study design**



### **3.3 Summary**

This chapter has outlined the design of the study 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. The methodological issues that follow from this design are addressed in the following chapter.

## Chapter 4: Methodological Issues

This chapter addresses a number of methodological issues that are fundamental to the design of the study, and to which frequent reference will be made throughout the Thesis. Issues include the ethics of conducting grief research, the nature of grief, and the context of general practice. The chapter describes the recent research findings about these issues, the consequent strategies and principles which were formed to guide the design of the instruments and the conduct of the study.

### **4.1 Ethical issues**

#### **4.1.1 Issues**

The Declaration of Helsinki (World Medical Association, 1964/1989) lays down the basic principles for conducting research on human subjects. However, the nature of grief and the general practice context in which the research for this study was carried out required some special considerations which are examined below.

##### **4.1.1.1 Non-maleficence and Beneficence**

The issues of emotional non-maleficence and beneficence are particularly well addressed in the Nuremberg Code of Conduct:

“The experiment should be so designed as to avoid all unnecessary physical and mental suffering and injury” (Nuremberg Code, 1946-49).”

In the present study it was possible that harm could have been caused to grieving subjects by increasing their distress over a current loss or by evoking past memories of grief. In support of this were some reports that generic counselling did not appear to benefit trauma victims (Bisson, Jenkins, Alexander & Bannister, 1997; Raphael, Meldrum & McFarlane, 1995) and



that the distress of some subgroups of bereaved persons increased with certain interventions (Murphy, Johnson, Cain, Gupta, Dimond, Lohan, & Baugher, 1998). However, research designed to evaluate possible distress caused to grieving subjects by participating in survey interviews found an overall benefit (Runeson & Beskow, 1991; Parkes & Weiss, 1983, page 26). Similar findings were obtained for mental health surveys of the general public (Henderson & Jorm, 1990). In addition, a review of the effectiveness of bereavement interventions suggested that overall, participants benefited on one or more outcome measures of the intervention (Woof and Carter, 1997b). Therefore the risks for subjects in considering whether to take part in this study were that, by doing so, they might increase their distress, or that by declining, they may miss out on a procedure that might ultimately have been beneficial. Parkes (1995) argues in relation to beneficence, that providing certain safeguards, such as informed consent, are put in place, these difficulties should not prevent research being carried out that may ultimately benefit grieving people as a whole.

#### ***4.1.1.2 Informed consent***

An ethical issue that has not previously been recognised is the effect of the cognitive deficit of grief on the competency of grieving individuals to make an informed choice. The cognitive deficit associated with grief has been shown to cause difficulties in absorbing information and in making decisions (see Chapter 4.3.4). Grieving individuals may therefore be disadvantaged in making an informed choice about whether or not to take part in a study. Competency in making informed consent relating to grief is not addressed in guidelines for making end-of-life decisions. However, the Statement on Human Experimentation and Supplementary Notes issued by the National Health and Medical Research Council of Australia (1992) makes mention of people who ‘merit special attention’ and cites examples such as elderly persons and those in doctor-patient relationships, but does not mention grieving people. This group should also be cited as meriting special attention. Therefore in this study, special procedures

were put in place, in gaining informed consent, to compensate for the deficit in cognitive abilities.

#### ***4.1.1.3 Autonomy and confidentiality***

Another issue that needed to be addressed was the freedom of individuals to decide whether or not to participate or to withdraw from the study at any time, without affecting their relationship with and treatment by their doctor. Subjects in whom competency is reduced and who are emotionally distressed may be particularly vulnerable to coercion. A further matter concerns maintaining the confidentiality of subjects' responses. These issues are addressed by the strategies below.

### **4.1.2 Strategies**

#### ***4.1.2.1 Ethics approval***

Approval for the study was obtained from the University of Adelaide Committee on the Ethics of Human Experimentation (Appendix 4.1).

#### ***4.1.2.2 Gaining informed consent***

Taub (1986) recommended that informing subjects on multiple occasions increased the validity of their consent and this strategy was adopted in this study. The following documents and processes were put in place to maximise the avenues of giving information to subjects.

#### **Poster**

A poster was prepared to be placed in the waiting rooms, to alert subjects that research into loss and grief was currently in progress in the practice and to prepare them for a request to participate in the study.

### Pre study Information sheet

An information sheet (Appendix 4.2) was prepared for participants to read and which they could take home with them after participating in the study. This informed participants:

- that the study was about grief;
- about the questionnaire and interview process;
- about the researchers and the Department of General Practice, which was auspicing the research;
- that participation was voluntary;
- that they were free to withdraw from the project at any time without affecting their relationship with or the treatment received from their doctor;
- that audiotaping of the interview would take place but was not essential and that the tape could be turned off at any time on request;
- of the confidentiality of their responses;
- that participation in the study may not benefit them but may help others in the future; and
- of the telephone number of their doctor whom they should contact in the event of queries or distress resulting from the project.

### Consent form

Subjects were required to sign a consent form (Appendix 4.3) indicating they had read and understood the study procedure and were willing to participate.

### Process

The poster explaining the study was displayed in the waiting room. In enrolling subjects the research assistant first explained verbally the nature of the study and the details on the information sheet and allowed them to read through the information sheet themselves. She asked if they had any questions before requesting their signed consent. In particular, the issues

of opting out without disadvantage and of maintaining confidentiality of responses, were included in the explanations.

#### ***4.1.2.3 Confidentiality safeguards***

No identifying information about the subject was recorded onto the interview schedules, questionnaires or audiotapes. All materials resulting from the study were kept locked away. Confidentiality issues were addressed in the training and debriefing of researchers (Appendix 8.4).

#### ***4.1.2.4 Care and support of the subjects***

Interviewers and research assistants were given training in supporting bereaved people, debriefing distressed subjects and in terminating the interview, if that was the wish of the interviewee. The chief investigator provided supervision. Training and supervision are described in detail in Appendix 8.4.

A post interview information sheet which listed the sources of further support subjects could access (Appendix 4.4) was handed to them after participating in the study.

## ***4.2 The detection of grief***

### **4.2.1 Difficulties in detection**

The difficulties in recognising and acknowledging the existence of grief are several:

- loss and grief is a relatively new paradigm within Western society (Chapter 2);
- the disenfranchisement of grief (Doka, 1989; Corr, 1999);
- cultural taboo among men (Golden, 1996) and in Australian society in general (Griffin, 2000); and

- cognitive deterioration in grief (Chapter 4.3.4), causing difficulties in the recognition of grief .

It was therefore anticipated that the effect on the study would be to cause:

- a considerable number of subjects to not participate in the study (non-responders); and
- a large number of negative responses to the loss reviews because subjects either would not recognise their grief or would choose not to disclose it (false negatives).

Selection attrition rates in a longitudinal bereavement study were found to lead to unrepresentative findings (Hayslip, McCoy-Roberts, & Pavur, 1998). It was acknowledged that a similar problem in this study could cause a non-response bias and unrepresentative patterns of loss category data and grief measurement.

These issues have implications for the method of detection adopted by the study, the education of subjects, the training and communication skills of the researchers and of the validity of the study results.

## **4.2.2 Strategies**

The following strategies were therefore adopted:

### ***4.2.2.1 Subject information***

The information given to subjects and the process by which this was given to them have already been addressed in Chapter 4.1.2.2.

#### ***4.2.2.2 Education and training of the researchers***

Grief education and training in communicating with grieving people was provided for the research assistant and interviewer and is described in Appendices 8.3I and 8.3II. The skills of legitimising feelings of shame were included.

#### ***4.2.2.3 Surroundings***

Privacy and confidentiality were necessary to provide the environment for honest self-revelation by the subject.

#### ***4.2.2.4 Design of the loss surveys***

Because grief itself is difficult to identify, the alternative method of identifying loss was adopted. Subjects were asked to respond to a list of easily recognisable loss situations. This list (Table 4.1) formed the basis of the loss reviews (see Glossary) for both the interview and questionnaire. The list was composed of a number of categories that aimed to be as mutually exclusive as possible. Examples were given within the categories to assist recognition. The list aimed to be as inclusive as possible of all known loss situations. The list of loss categories was drawn from the two pilot studies which had previously been conducted by the chief investigator (Clark, 1986; Harrison Market Research Pty Ltd, 1994) and her subsequent clinical experience. In addition, further loss situations were found by reviewing the loss and grief literature and the life event inventories mentioned in Chapter 2.

The criterion for including an example within a category was that the example represented a loss situation that was not suggested by existing examples. To illustrate this, 'disaster' is an example provided in the category 'Finance or property loss', and implies house fire, bush fire, flood, earthquake, drought, etc. It would have been unwieldy, considering the need for simplicity of the instruments, to have included all possible examples for every category in interview and questionnaire instruments and therefore umbrella examples only were included.

#### 4.2.2.5 Non-responder bias

Data about non-responders would be gathered to assess the extent of any possible bias. This is further addressed under validity issues in Chapter 4.5.6.

**Table 4.1: Loss review categories and examples**

<b>Category</b>	<b>Examples</b>
Death or impending death of someone close	In the past or future
Separation from someone close (other than by death)	Divorce, child leaving home
Fear of own death	-
Quality of life	Illness, disability, aging or injury
Employment	Retirement, redundancy, unemployment
Migration or moving house	-
Loss or lack of pregnancy	Infertility, miscarriage, abortion, sterilisation, stillbirth
Finance or property	Disaster, collapse of a financial company, burglary
Opportunity	Career choice
Serious illness or death of a pet	-
Personal integrity	Violence, such as rape, incest, domestic violence, war
Other (free response)	-

### **4.2.3 Seasonal variations**

Grief is known to recur with reminders of the loss, such as Christmas, when the absence of the deceased person may be particularly poignant (Chapter 2.2.4). Other dates include Easter, and Mother's and Father's days. Although seasonal variations would not be expected to affect the validity of the design of the questionnaire or the interview, they could have affected the prevalence results obtained from the trial and evaluation of these instruments on the patient population. For example, a trial of the instrument that included the Christmas period would be expected to give a higher prevalence of grief, than at other times of the year, for categories of loss such as death or expected death of a loved one and separation from someone close. The study was therefore conducted away from significant festivals as far as possible. It is however acknowledged that a number of non-Christian and secular festivals occurred during this period such as the Moslem festival of Ramadan.

## **4.3 Measurement of grief**

### **4.3.1 Principles**

The severity of psychiatric conditions is assessed by the number and severity of psychological, social and occupational symptoms (American Psychiatric Association, 1994).

However, grief is characterised by physical, emotional, social, behavioural, cognitive and spiritual phenomena (Corr, 1999). Therefore, the aim of this study was to measure grief in all these domains.

### **4.3.2 Recognised principles for measuring bereavement**

Important principles for validity have been discussed by several authors concerning the measurement of bereavement (Burnett, Middleton, Raphael & Martinek, 1997; Jacobs, 1987;



Middleton, 1995; Zisook, Devaul & Click, 1982). These are that the phenomena being measured;

- have high face validity of being core bereavement phenomena;
- be present throughout the grieving process;
- be quantifiable and not merely present or absent;
- change progressively and in the same direction over the course of the grieving process, that is, either decrease or increase with time;
- be common across all individual variations of the grieving response;
- be applicable across gender, age, social class and be culturally appropriate;
- measure the state of grief and not be dependent on the trait of the individual;
- be pertinent to the current state of grief and not retrospective; and
- be specific to grief, that is, distress caused by loss, and not measure other psychiatric conditions, such as depression and anxiety, which could act as confounders.

#### **4.3.3 Task-specific requirements**

For the purpose of this study, the following additional requirements were that the phenomena:

- be representative of grief from any loss; and
- be relevant to general practice patients. It was hypothesised that general practice patients, because they are a self-selected clinical population, are more likely than the general grieving population to present with physical symptoms, and to seek help for traumatic emotions including guilt and anger. The grief measures therefore included questions about physical symptoms and traumatic emotions.

#### **4.3.4 Grief phenomena**

The literature was studied for phenomena that best fulfilled the above conditions. These are described below under the six domains and listed in Table 4.2.

**Physical:** A wide variety of physical symptoms have been described related to the magnitude of stress in susceptible individuals. (Lindemann, 1944; Maddison & Viola, 1968, Maddison, Viola & Walker, 1969; Parkes, 1986; Raphael, 1984; Stroebe & Stroebe, 1987: Chapter 7).

**Emotional:** A diverse range of emotional phenomena may occur (Bowlby, 1980; Lindemann, 1944; Marris, 1958; Parkes, 1986; Parkes & Weiss, 1983; Raphael, 1984; Schuchter & Zisook, 1993; Stroebe & Stroebe, 1987: Chapter 2).

Core phenomena are related to detaching from the loved object and adjusting to life without them (Burnett P, Middleton W, Raphael B, Martinek N, 1997; Bowlby, 1980).

Fluctuations or swings in mood lasting between hours and days are normal (Shuchter & Zisook, 1993; Clark, 2001).

**Cognitive:** Deterioration in cognitive ability is a persistent phenomenon of grief independent of depression (Caplan, 1990; Corr, 1999; Seeman, Singer, Rowe, Horwitz, and McEwen, 1997; Stroebe & Stroebe, 1987). There is usually clarity of thinking in the first few days following a death, but as the emotional impact of the loss is felt, disorganisation in thinking processes may occur. Shuchter and Zisook (1993) found that difficulties in memory, concentration and decision-making were reported in 20% of bereaved spouses compared to 2% of a non-bereaved control group and that these features were still present 13 months after the death. Other cognitive symptoms described include difficulties in information gathering, evaluating information, making judgements and planning (Hansell, 1976). Disturbances of cognitive functioning may render individuals temporarily unable to work (Maddison & Viola, 1968). These phenomena are a result of pre-occupation with thoughts and feelings. Associated experiences may include hallucinatory-like images of the deceased (Raphael, 1984). An

additional cause of decreased cognitive functioning in bereavement is when the grief is complicated by depression.

**Social:** Two main trends in relationships, of withdrawal from and of increased connection with others, have been identified by Tudball (2001) in a critical review of the literature.

**Behavioural:** A number of general behaviours have been identified (Parkes, 1986, Raphael, 1984; Stroebe & Stroebe, 1987) as well as life-style behaviours (Parkes & Weiss, 1983).

**Spiritual:** Most grief experts either do not define the spiritual domain or when they do, cannot agree about the definition. The broad definition of pertaining to 'conscious life' taken from the Macquarie Dictionary (Delbridge Bernard, Blair, Butler, Peters, & Tardiff, 1990) will be used here in order to be as inclusive as possible. Phenomena listed are mainly restorative and come from the works of the following authors: Corr (1999) Gamino, Sewell & Easterling, (2000), Klass (1996), Neimeyer (2000), van der Val, (1989). Changes in this domain would be expected to increase with greater adaptation to the loss and at the pace of the individual.

**Table 4.2: Summary of main grief phenomena**

<b>Physical</b>		<b>Emotional</b>	
<b>Cardiovascular system:</b> Palpitations; Dizziness; Faints; Chest pain. <b>Respiratory system:</b> Shortness of breath. <b>Gastro-intestinal system:</b> Loss of appetite; Vomiting; Difficulty in swallowing.	<b>Pain:</b> Headache; Generalised aches and pains. <b>Miscellaneous:</b> Lethargy; Blurred vision; Skin rashes; Infections; Heavy periods.	<b>Core</b> Detachment from the lost object Mood fluctuations <b>Individual</b> Shock; Disbelief; Horror; Numbness; Anxiety; Sadness; Yearning ; Dread of the future;	Guilt; Anger; Rejection; Shame; Blame from others; Suicidal thoughts; Loneliness; Helplessness.
<b>Cognitive</b>		<b>Behavioural</b>	
Intrusive thoughts; Poor memory; Poor concentration; Difficulty making decisions; Reduced working capacity; Hallucinatory-like images.	Difficulty evaluating information, making judgements & planning; Loss of self-confidence.	<b>General:</b> Crying; Sleeplessness; Restlessness; Sighing; Searching; Reduced constructive activity; Expressions of sadness.	<b>Lifestyle behaviours:</b> Increased alcohol, tranquilliser, drug & tobacco consumption.
<b>Social</b>		<b>Spiritual</b>	
<b>Withdrawal:</b> Rejection of contact & support by others; Loss of trust in others Isolation.	<b>Associative:</b> Desire for support and comfort from others; Making help-seeking or help-giving contacts.	Closure with the lost person or object; Search for why; Search for something good or meaningful from the loss;	Change in values and beliefs about self and life; New inner relationship with the lost person or object.

#### 4.3.5 Window period

The existence of mood fluctuations in grief, noted in the previous section, has implications for the validity of items of the interview and questionnaire. It was possible that subjects'

responses to the questions could be dependent on how they felt at that moment in time, rather than be an accurate assessment of their overall current state.

The principle therefore was adopted of estimating the state of grief over the previous two weeks and not just at the precise instant in time at which the assessment was carried out. A one-week period was found to be the most accurate for measuring distress from trauma (Horowitz, Siegel, Holen, Bonanno, Milbrath, & Stinson, 1997). However, two weeks has been used for health assessment (Nelson, Landgraf, Hays, et. al., 1990). It was also felt a two week window period would be more appropriate for this study to allow for the normal fluctuations and resurgences of grief despite possible inaccuracies associated with the retrospective nature of the questions.

#### ***4.4 Design Issues***

Various features of the design of interviews and questionnaires can affect their validity. These are discussed below.

##### **4.4.1 The introduction**

Both the questionnaire and interview were preceded by an introduction informing subjects about the content. The reasons for this were:

- to assist subjects to recognise grief particularly as they may currently be experiencing some cognitive deficit; and
- to reduce the threat of the questions. Perceived threat of questions has been found to cause under-reporting of sensitive issues (Bradburn & Sudman, 1980).

#### **4.4.2 Questionnaire and question length**

The whole questionnaire and the questions themselves were made as short as possible to accommodate the cognitive deficit of grief (Chapter 4.3.4) and because brevity has been shown to maximise the validity of the item (Holden, Fekken & Jackson, 1985). However, Bradburn & Sudman (1980) demonstrated that for measures, questions needed to contain considerable detail of the phenomenon under investigation to provide the most accurate assessment, and therefore by necessity were longer. Therefore, for the questionnaire of this study, questions were made as brief as possible except for those of the grief measure which were a compromise between brevity and description.

#### **4.4.3 Question openness**

Open-ended questions were used as they have been recognised to provide more accurate responses for measures of a sensitive nature (Bradburn & Sudman, 1980).

#### **4.4.4 Question wording**

The wording of questions was made as simple as possible to enable them to be understood by persons of all levels of educational attainment and those affected by the cognitive impairment of grief. Questions were designed for a reading age of 12 years, and the wording was made as unambiguous as possible and without jargon.

#### **4.4.5 Use of the word ‘distress’**

The term ‘distress’ was used in the interview and questionnaire rather than use the word ‘grief’. One reason was because ‘grief’ is frequently misused in colloquial language. For example, ‘I fell downstairs and came to grief’. Secondly, it has already been established that grief itself is difficult to recognise (Chapter 4.2.1). Distress was

the preferred term as it is currently used in relation to loss (Delbridge, Bernard, Blair, Butler, Peters, & Tardiff, 1990) and can be applied to the other domains of the individual affected by grief and not imply merely the emotions. Further, the Australian Macquarie Dictionary (1990), defines grief as ‘distress over affliction or loss’.

#### **4.5 Validity Issues**

In the previous paragraphs, a number of characteristics of grief have been described that determined the validity of instruments for its detection and measurement. The manner in which these characteristics affect the validity will now be considered. (A summary is given in Table 4.3).

##### **4.5.1 Willingness to disclose**

Because of the private nature of grief and its disenfranchisement by society, subjects may have chosen not to disclose information about loss. Some quantitative methodologies for estimating the prevalence of sensitive health-related issues have demonstrated that there is lesser concealment using a less personal method, such as a questionnaire or telephone interview, rather than a face-to face interview (Abrahamson, 1990). However, a randomised controlled trial of data gathering techniques on 942 subjects found that face-to-face methods were better than a self-administered questionnaire in completion rates and that there was no difference in the under reporting of socially undesirable acts (Bradburn & Sudman, 1980). They also found no over-reporting of socially undesirable acts.

##### **4.5.2 Cognitive deficit**

Disturbances of cognitive functioning may reduce the subject’s competency to recognise grief and to understand and rate a questionnaire. This has implications for the validity of the study: completion of the questionnaire would have required higher levels of cognitive processing in

terms of reading, comprehension and decision-making than an interview. No reading skills were required for the interview and the interviewer assisted subjects to understand the questions. One could therefore assume that the information gained from subjects who had cognitive reduction would have been more accurate from the interview than from the questionnaire.

#### **4.5.3 Window period**

Emphasis on the two-week window period was facilitated by the flexibility of the interview process, in comparison to the statements relating to ‘the past two weeks’ in the questionnaire.

#### **4.5.4 Confounders**

The interviewers were trained to detect and allow for confounders, such as depression, or behaviours, such as exaggeration, defensiveness and dishonesty (Goldberg, 1972). The questionnaire made no allowance for these factors. Depression coexistent with grief may have caused subjects to view their grief as more severe and therefore to rate it higher than if they had been without depression. Depression may therefore have acted as a confounder in the questionnaire data and to a lesser extent in the interview data.

#### **4.5.5 Learning experience**

The first exposure of a subject to a grief instrument would be likely to provide them with a learning experience in recognising loss and in the acceptability of sensitive events. It would therefore be expected that a higher rate of endorsement of loss events would occur on a second exposure to such an instrument. In this study the questionnaire was administered before the interview, and therefore the interview would be expected to detect more losses than the questionnaire.



#### **4.5.6 Non-responders**

It could be supposed that those who would not wish to disclose would be those who would provide inaccurate information if they participated in the study. Further, these would be the most likely subjects to refuse to participate. It could therefore be supposed that those who would be likely to give inaccurate information would have eliminated themselves and that the accuracy of the information gathered in the study would thus be improved. This is supported by a study reported by Bradburn and Sudman (1980), of a random sample of over 2000 subjects which found that non-responders were more likely not to answer sensitive personal questions and that the data they provided was poorer in quality. They argued that the quality of information gathered is improved by eliminating non-responders, and that non-response is important for maximising the accuracy of the information gathered.

Another impact of non-responders is in relation to information that cannot be gathered from them. Non-responders may have deprived the study of certain particularly sensitive categories of loss and decreased the prevalence of grief found by the trial and evaluation. Therefore, the observable demographic data of the non-responders were analysed to determine possible non-response bias.

#### **4.5.7 Summary of validity**

A summary of the points described above is contained in Table 4.3 and indicates the interview as the more valid instrument and therefore its status as the gold standard for the questionnaire.

**Table 4.3: Summary of validity issues for the questionnaire and interview**

<b>Validity issue</b>	<b>Preferred measure</b>
Willingness to disclose socially undesirable event	No difference between interview & questionnaire
Completion rates	Interview better
Effect of cognitive deficit	Interview process less hindered
Window period	Interview process better
Allowance for confounders.	Interview process better
Learning experience of first exposure to instrument (questionnaire)	Interview better (second exposure)
Non-responders	Improve the quality of the information gathering of both questionnaire and interview.  Deprive the study of certain sensitive categories of loss

#### **4.6 General Practice Issues**

As the study was conducted on patients and relatives at the surgeries of their GPs there were several practical issues that required attention.

##### **4.6.1 Interruptions**

The research process had to be designed not to interfere with the doctors' schedules and to fit around the subjects' treatments. The strategy was adopted that, in the event of an individual's engagement in the study being interrupted by the consultation with the doctor, the process of the study would be resumed afterwards, at the stage at which it had been left off.

#### **4.6.2 Selection of surgeries**

As the research addressed personal issues, surgeries were selected that were large enough to provide two separate private rooms, one for the questionnaire process and the other for the interview. Surgeries were also selected that were staffed by several doctors and that had a high turnover of patients, so that the research assistant had a large pool of patients from which to draw, in the event that subjects refused to participate in the study.

#### **4.6.3 Medical issues**

As subjects could have had difficulty in participating and concentrating because of illness, this was another reason for making the questionnaire and interview as simple and as short as possible.

#### **4.7 Summary**

The various methodological issues described in this chapter provide the rationale for the design of the interview and the questionnaire, as well as for the methods employed in their trial and evaluation. The principles and strategies that follow from these issues have been detailed and reference will be made to these as appropriate in the chapters that follow.

## Chapter 5: Evolution of the interview

This chapter, together with Chapter 6, addresses the second aim of the study, that is, to devise a standardised interview, the Grief Diagnostic Interview, whose purpose is to detect and measure the extant state of grief in general practice patients. This chapter describes how the interview was designed in order to address the objectives stated in the Introduction:

**to detect the presence or absence of grief in patients attending general practices;  
to determine the categories of loss events causing grief; and  
to measure the extant state of grief in these patients;**

In the account that follows, the objectives for the interview and the method of designing it will be explained. The evolution of the interview through development, trial and evaluation stages of the study (Chapter 3) will be described. Descriptions of the interview schedule at the various stages of evolution will be given. The chapter concludes with the final version of the Grief Diagnostic Interview.

### ***5.1 Development stage***

#### **5.1.1 Recognised requirements**

The literature was searched to determine recommendations for the construction of screening and diagnostic interviews. Those of a psychiatric nature have been described by Goldberg, Cooper, Eastwood, Kedward & Shephard (1970), Cannell, Miller & Oksenberg (1982), and Fowler & Mangione (1990). The recommendations from these authors relevant to this study are:

1. the interview should be conducted by experienced and trained interviewers;
2. the setting should be a clinical setting or the subject's home;
3. the interview should discriminate clearly between subjects with and without the condition under investigation;

4. it should be economical with time so that many patients can be assessed;
5. to use a standardised interview procedure to maximise the validity;
6. to select the most appropriate wording for the target population;
7. to pilot the interview for appropriate structure, wording and timing;
8. to use rating scales to complement information gained in the interview;
9. to define the diagnostic standard, that is the definition of the condition;
10. to use a numerical scoring process of the severity;
11. to use interviewers who are trained and expert in the field. Both expert clinicians and trained non-medical interviewers have obtained similar reliability of results; and
12. to demonstrate the interview to be reliable by a series of raters.

### **5.1.2 Method of initial design**

The interview was designed by the chief investigator in conjunction with eight GPs who had an interest in mental health issues. Four of these were also expert tutors in the teaching of communication skills to medical students. Drafts were prepared by the chief investigator and were subsequently modified according to their suggestions.

### **5.1.3 Interview design**

The following description of the design of the interview is written to be read in conjunction with the draft interview schedule (Appendix 5.1). The interview was designed as a standard interview in four sections: an opening, a loss review, a grief measure (morbidity review) and a closure (debrief).

### ***5.1.3.1 Prompt sheet***

A prompt sheet (Appendix 5.2) was designed to be used in conjunction with the interview schedule. This gave standardised instructions and prompts to the interviewer. Its use will be described under the relevant sections of the interview. Some of the prompts are also given on the interview schedule where relevant.

The prompt sheet gave directions to the interviewer in the opening about establishing rapport, informing the subject that the purpose of the interview was to inquire about losses they might be experiencing, gaining their permission for the interview to be audio-taped and confirming confidentiality.

### ***5.1.3.2 Cover sheet***

The first page of the interview schedule recorded details such as the date, practice number, patient identification number and the audio-tape number, that enabled it to be paired with the corresponding questionnaire for each subject in the trial (Chapter 8). Below this was a statement to be read to the subject by the interviewer to inform them that the interview would be about their losses. At the bottom of the page were the four clinical score categories ('No grief', 'Mild grief', 'Moderate grief' and 'Severe grief'), one of which the interviewer would circle at the end of the interview to indicate the severity of the subject's grief.

The subsequent pages of the interview schedule were laid out so that the left-hand column contained the questions and the right-hand of the page contained columns for the interviewer to record information.

### ***5.1.3.3 The opening***

The purpose of the opening was to provide opportunity for the interviewer to build rapport, demonstrate empathy and sensitivity, and to put the subject at ease before the topic of loss

was raised. The opening consisted of a hierarchy of questions commencing with those of a non-threatening nature, for example, ‘What was the reason you have come to the doctor?’ and progressing to those of an increasingly sensitive nature to lead up to the subject of stress, with the question: ‘Have you been under any stress of any sort lately?’ This process enabled the interviewer to identify specific losses, such as those resulting from chronic illness, that might be revealed in discussing reasons for consultation with the doctor, as well as whether there were conditions, such as depression, that might confound the measurement of grief.

#### ***5.1.3.4 The loss review***

The following statement introduced the loss review: ‘I would now like to ask you a few questions about various losses’.

The purpose of the loss review was to address Objectives A and B. The principles for detecting grief by identifying losses that currently caused distress (Chapter 4.2.2.4) were followed. The list of loss categories given in Table 4.1 formed the basis of the loss review. In accordance with the definitions of loss and grief used in this study (see Glossary), questions about each category were framed to inquire about:

- past, present and future losses;
- death and non-death related losses ;
- losses occurring to the subject; and
- grief experienced in sympathy with the grief of others.

Questions were designed to be as short and simple as possible to maximise the attention span, and thereby the competency of the subjects, because of possible cognitive deficit (Chapter 4.4.2).

Where relevant, two questions were formed about each category: one relating to the subject's own experience and a second relating to the experience of significant others. An example is: 'Are you experiencing distress about your quality of life due to illness, disability, aging or injury?' and 'Are you experiencing distress about the quality of the life of someone close to you due to illness, disability, aging or injury?' A question that invited subjects to volunteer any other loss not already covered completed the loss review.

Prompt questions to be used with this section included: 'Do you regard this as a loss?' and: 'Does this situation..... (name the loss) cause you distress at present?' These were used to confirm that the identified events complied with the definitions of loss and grief used in this study, that is, that the subject perceived the event as a loss, and that the grief was current. These questions were also to be used to confirm that losses identified in the opening also complied with the definitions.

At the end of this series of questions there followed a flow chart where the interviewer was directed to choose one of two options depending on whether loss had been identified in any previous part of the interview. If no loss had been found, the schedule instructed the interviewer to inform the subject there would be no further questions and to thank them for participating. If loss had been recorded in the right hand column, the interviewer was directed to make a verbal summary of the losses and to request to explore these further.

#### ***5.1.3.5 The grief measure***

The purpose of the grief measure was to address Objective C, that is, to measure the extant state of grief resulting from the losses detected by the loss review. Consistent with the principles for measuring grief defined in Chapter 4.3, the grief measure consisted of items relating to the number and severity of symptoms in each of the six domains of functioning (physical, emotional, cognitive, social, behavioural and spiritual), and the spectrum between



disruption and adaptation as described in Chapter 4.3.4. The principles of using open questions, descriptive language and the term distress (Chapter 4.4.5) were followed.

As far as possible, open questions were used to gain information about a domain. However, specific questions were also necessary. For example, the behavioural domain could only be assessed by asking specific questions. Items were limited to those that were the most essential to avoid making the instrument too unwieldy. There was therefore a trade-off between asking many questions with the aim of increasing the validity, and brevity for economic and competency reasons. Questions for each domain are given below. In the interview schedule the physical and behavioural domains were combined under 'Physical symptoms'.

**Emotional domain:**

Tell me about .....[name the loss(es)]

How do you feel about.....[name the loss(es)] at present?

How is/are..... [name the loss(es)] affecting you emotionally?

**Physical domain:**

Are .....[name the loss(es)] causing you any physical symptoms?

If 'yes': Tell me about them.

If 'no': 'What about aches and pains, loss of energy, indigestion etc?'

**Behavioural domain:**

Is/are.....[name the loss(es)] keeping you awake at night?

Is/are.....[name the loss(es)] causing you to drink more?

Is/are.....[name the loss(es)] causing you to smoke more heavily?

Is are.....[name the loss(es)] causing you to take more medication or drugs of any sort?

**Cognitive domain:**

**Are you experiencing difficulty with memory as a result of.....[name the loss(es)]?**

If 'yes' Tell me about it.

Are you experiencing difficulty with concentration as a result of.....[name the loss(es)]?

If 'yes' Tell me about it.

Are you finding thoughts about the loss keep intruding into your mind?

If 'yes' Tell me about them.

**Social domain:**

Has/have.....[name the loss(es)] caused you to wish to withdraw from the company of others?

If 'yes' Tell me about it.

Do you feel .....[name the loss(es)] has/have caused you to feel a need for other people around you to give you comfort or support?- whether you have got that support or not?

If 'yes' Tell me about it.

**Spiritual domain:**

Has/have.....[name the loss(es)] changed your values?

If 'yes' Tell me about the changes.

Has/have.....[name the loss(es)] changed your beliefs?

If 'yes' Tell me about the changes.

The prompt sheet contained instructions for the interviewer to use open and confirmatory questions to determine the severity of each domain as they thought appropriate.

**5.1.3.6 Domain scores**

Included in the right hand column, corresponding to each of the domains of the grief measure, was a scale from zero to three, where zero represented no change or distress relating to the

loss, and three symbolised maximum change or distress. The interviewers would be required to circle a number on this scale corresponding to the degree of disruption and distress they perceived subjects to have experienced in this domain in relation to their loss.

#### ***5.1.3.7 Distress score***

The final item of the grief measure was a 10 centimetre Likert scale with zero at one end representing no distress and 10 symbolising the maximum distress the subject could imagine experiencing. Subjects would be asked to place a mark on this scale corresponding to the amount of distress they were currently experiencing in relation to the losses. This scale was used because it is a validated clinical method for estimating abstract phenomena such as pain, depression and anxiety (Andrews, Crino, Hunt, Lampe & Page, 1994)

#### ***5.1.3.8 The closure***

A debriefing of the subjects completed the interview. Instructions were given that, in the event of distress, expressions of support, legitimisation and empathy were to be made, consistent with current communication philosophy in medical education (Egan, 1990; Cohen-Cole, 1991; Novak, Goldsrein and Dube, 1994) and debriefing (Leon, Altholz and Dziegielewski, 1999). Instructions were given for all subjects to be handed the Post Interview Information Sheet (Appendix 4.4) listing the sources of further support they could access.

#### ***5.1.3.9 Recoding free responses***

After subjects had left the interview room, the interviewer was to code the losses found in the opening and under the free response item 'Are you experiencing distress from any other loss', into the existing categories. If no existing category was appropriate, they were to create a new category in conjunction with the chief investigator, which would be added to the interview schedule for subsequent use.

#### ***5.1.3.10 Allotting clinical grief score categories***

Finally, the interviewer was to categorise the severity of grief under the clinical score categories on the front of the interview schedule using subjects' domain scores of 0-3 and Likert distress scores as *aide memoires*.

#### ***5.1.3.11 Clinical score categories***

These were derived from the 'Severity and Course Specifiers' of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994).

The severity indicators were considered appropriate because:

- they are specifically designed to apply to the patient's current condition rather than previous states and they take into account the range and severity of the symptoms and signs; and
- these Specifiers have been found satisfactory for standardised interviews in developing previous questionnaire measures, for example the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961).

Definitions for each score category in relation to grief were drawn up corresponding to each of the definitions in the Manual.

#### **Mild grief**

The definition of mild disorder in the DSM-IV Manual is:

'Few, if any, symptoms in excess of those required to make the diagnosis are present, and symptoms result in no more than minor impairment in social or occupational functioning.' (Page 2).

This terminology was changed for the purpose of this study, in line with the definition of grief, to become:

Mild emotional response to perceived loss by an individual, or in sympathy to a loss sustained by a significant other, with few if any, disturbances within the other domains.

### **Moderate grief**

The DSM-IV definition of moderate grief is as follows:

‘Symptoms or functional impairment between mild and severe are present.’ (Page 2).

This terminology was adapted to grief to become:

Response to perceived loss by an individual, or in sympathy to a loss sustained by a significant other, between mild and severe.

### **Severe grief**

The DSM-IV definition of severe disorder is as follows:

**‘Many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in social and occupational functioning.’ (Page 2).**

This terminology was adapted to grief to become:

Severe emotional response to perceived loss by an individual, or in sympathy to a loss sustained by a significant other, with disturbances within many domains or several particularly severe symptoms within one or more domains.

## **5.1.4 The pilot**

### ***5.1.4.1 Method***

The interview was piloted on fourteen subjects consisting of patients and their accompanying relatives and friends selected at random from those in the waiting room of the general practice surgery of the chief investigator. There were three males and eleven females and their mean age was 56 years (range 27-73). The interview was conducted under the conditions described in Chapter 8. During the interview the interviewer completed the schedule described above and recorded queries and difficulties encountered by the subjects. At the end of the interview the interviewer asked for feedback about the content and process of the interview to see if it was acceptable and, after each subject had left, allotted the clinical score. Suggestions made by the interviewer to improve the interview were also recorded.

### ***5.1.4.2 Results***

Results of the pilot of the interview are shown in Table 5.1. The interview was satisfactory to all subjects and none had any comments to improve its content or format. The feedback given to the interviewer was that they had been pleased to participate and assist in researching this topic. However, the interviewer found several suggestions to improve the format.

**Table 5.1: results of the pilot of the interview**

<b>Comments by subjects</b>	<b>Suggestions for improving interview</b>
No problems with interview	-
Happy to participate in research	-
Interview not too intrusive	-
Glad doctors are interested in grief	-
Interview OK	-
<b>Comments by interviewer</b>	
Needed to be a complete question in the early part of the morbidity review about how a loss affected a person's life in any way whatsoever.	How is/are..... [name the loss(es) affecting your life?
Too wide a spectrum of grief experience contained in the 'mild' category	Introduce a lowest category of 'minimal' grief
-	Tick boxes would be easier than circling the clinical category

**5.1.4.3 Modifications**

The suggestions to improve the format were deemed reasonable by the chief investigator and the GPs. Hence the following three modifications were made:

- The question: How is/are..... [name the loss(es)] affecting your life? Was added to the emotional domain of the morbidity review;
- The interview schedule cover sheet was modified to include tick boxes;
- A fifth clinical score category of 'minimal grief' was introduced which was defined as:

‘Minimal emotional response to perceived loss by an individual, or in sympathy to a loss sustained by a significant other, with no disturbances within the other domains.’

The resultant five clinical score categories were as follows: ‘No grief’; ‘Minimal grief’; ‘Mild grief’; ‘Moderate grief’; and ‘Severe grief’.

#### ***5.1.4.4 The trial interview schedule***

With the modifications described above, this version of the interview became known as the trial interview schedule, and this was used in the trial stage of the study which is described in chapters 8-10. The trial interview schedule is shown in Appendix 5.3.

## ***5.2 Trial stage***

At this stage it was necessary to determine whether there were any categories of loss and significant examples within the categories that were missing from the loss review. This was achieved through using the trial interview schedule on a large number of subjects under standard conditions in the trial stage. The method of the trial is described in Chapter 8. The results of the trial, which included new categories and examples of loss, are described in Chapter 9. Chapter 10 describes the analysis of the results and the ensuing modifications that were made. A summary of the additions that were made to the interview schedule is given below:

- Category ‘adoption/fostering’ with example ‘being or caring for an adopted/fostered child’;

**Examples to existing ‘job’ category: ‘illness’ and ‘birth of a baby’; and An additional new category, ‘freedom’, found from the chief investigator’s concurrent clinical work in general practice, which was independent of the trial.**



Comparison of the detection of loss by questionnaire and interview during the trial determined that the questionnaire detected a higher proportion of subjects experiencing loss, higher multiples of loss categories per subject and more losses for each category, than did the questionnaire (Chapter 9.4). This is consistent with the expectations for the gold standard of identifying more losses than the questionnaire (Chapter 4.5.5).

### **5.2.1 The evaluation interview schedule**

The trial interview schedule was further modified by the additions described above to become the evaluation interview schedule. This was used in the evaluation stage of the study, which is described in chapters 11-13. The evaluation interview schedule is shown in Appendix 5.4.

### **5.3 Evaluation stage**

Further categories and examples were identified through the evaluation stage, in which the evaluation interview schedule was used on a further sample of 63 subjects. This stage is described in chapters 11-13. As a result, the following additions were made:

- New examples for ‘opportunity’ category: ‘promotion’ and ‘unfulfilled dream’; and
- New example for ‘adoption/fostering’ category: ‘giving up an adopted or fostered child’).

As in the trial, the interview identified more losses than the questionnaire (Chapter 12.4), thereby again fulfilling the expectations for the gold standard.

### **5.3.1 Final Grief Diagnostic Interview schedule**

The above changes were added to form the final Grief Diagnostic Interview Schedule, which is shown in Appendix 5.5.

## **5.4 Summary**

The Grief Diagnostic Interview schedule has been designed in four parts: an opening, a loss review, a grief measure and a closure, and is used in conjunction with a prompt sheet. Its design has been based on the principles of detecting and measuring grief and of constructing valid instruments, which were described in earlier chapters of this Thesis.

The opening provides opportunity for the development of rapport and trust between the interviewer and interviewee. The loss review identifies losses that are currently causing grief to the subject, and thereby addresses Objective A, that is, to detect the presence or absence of grief. It consists of questions designed to identify named categories of loss, thereby addressing Objective B, that is, to determine the categories of loss causing grief. The loss review also makes provision for recording losses that do not easily fall into existing categories, and so identifying new categories. The grief measure addresses Objective C, that is, to measure the extant state of grief by examining the effect of grief over the six domains of the emotions, and physical, social, cognitive, behavioural and spiritual functioning. The closure is designed to provide opportunity to debrief the subject and to provide information about sources of assistance in cases of distress. In both the trial and the evaluation the interview identified more losses than the questionnaire, thereby fulfilling the expectations for the gold standard. The validity of the interview will be the subject of the following chapter.

## Chapter 6: Validation of the interview

This chapter addresses objective D of the interview, that is, to demonstrate it to be valid and reliable in detecting and measuring grief. The method of validation and the results and the analysis of the results will be described. The chapter will conclude with a discussion about the validity of the interview as a standard against which the questionnaire can be compared.

### **6.1 Methods**

It was essential to establish the interview as a valid diagnostic instrument and measure of grief, if it was to provide the gold standard against which the questionnaire would be compared. As there was no other reliable criterion against which to measure validity, it was evaluated using the following three indirect means.

#### 1. Inter-rater reliability

The inter-rater reliability is the agreement between results obtained from the same structured interview used by pairs of interviewers when the interview is conducted blind on the same subjects. This is the standard means for assessing the validity of interviews, such as the interviews for validating the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and the General Health Questionnaire (Goldberg, 1972).

#### 2. Construct validity

It was important to establish that the interview measured grief and not another phenomenon. To investigate this, tests were performed to see whether the interview data were consistent with known constructs of the behaviour of grief. If the data supported these constructs it would be likely that the interview measured only grief.

#### 3. Internal consistency.

This investigated to what extent each individual domain of the interview grief measure performed the task of measuring its specific aspect of grief. Relationships between the domain scores and the clinical grief score would determine to what extent the domain scores contributed to the clinical grief score.

The loss review and the grief measure of the interview were evaluated using the methods described above. A plan is given in Table 6.1 and is described in the subsequent text.

**Table 6.1: Plan of the evaluation of the interview**

<b>Data</b>	<b>Analysis</b>	<b>Test</b>	
<b>Loss review</b>	Inter-rater reliability	Agreements between pairs of raters	Individual categories (Cohen's kappa)
			% complete agreements between categories
	Construct validity	Socio-economic cluster & multiples of loss	Table of results
			Kruskall-Wallis Test
<b>Grief measure</b>	Inter-rater reliability	Agreements of clinical scores between pairs of raters	Percentages
			Spearman's rho
			Tables
	Construct validity	Multiples of loss & clinical scores	Table of results
			Wilcoxon Two Sample Test
		Spearman's rho	
Gender & clinical scores		Table of results	
		Wilcoxon Two Sample Test	
Internal consistency	Correlations of domain scores & clinical grief score	Spearman's rho	

### **6.1.1 Inter-rater reliability**

#### **6.1.1.1 Issues**

The ideal method of testing for inter-rater reliability is for two raters to conduct the same interview, blind, on the same subject within a short time span (to avoid variation in the condition under study), and for the experience of the first interview to have no effect on the interviewee's responses to the second interview.

However, not all these conditions could be met in this study as there were several issues that determined the precise method used for obtaining paired observations of the same subject:

1. Interviewers for the trial and evaluation of this study were consecutive in time to each other and not concurrent, and therefore were not able to check their ratings against each other;
2. There were some potential problems of interviewing the same subject twice, once by each of two different interviewers. These were:
  - It was perceived that the educational effect of the first interview on the subject would result in different information being given at a second interview with the same subject. A similar problem was also identified by Beck et. al., (1961) in validating the gold standard interview used for the Beck Depression Inventory.
  - It was perceived that there would be a lack of sensitivity and increased distress to subjects by requiring them to divulge distressing material at a second interview. This would be counteractive to the ethical principles of doing harm;
3. Difficulties were anticipated should subjects be interviewed by a pair of raters at the same time, one acting as interviewer and the other as observer. The presence of an observer in the interview room could be insensitive and distressing to the subject and affect the rapport between the interviewer and subject as well as the quality of the information given by the subject. It is noted that Bradburn & Sudman (1980) found that the presence of a third party, who was unknown to the subject, made no effect on the quality of sensitive information given in an interview. However, the subjects in their study were not distressed. Therefore, in the present study, observers were not used for the validity testing.

### *6.1.1.2 Process*

The method adopted was as follows. Comparisons were made between data recorded at interviews during the trial and evaluation stages of the study, and ratings made by the chief investigator of the audio-taped recordings of these interviews. Audiotapes have been found to be a valid method of evaluating interviews (Goldberg, Cooper, Eastwood, Kedward, & Shepherd, (1970; Aday, 1996) and acceptable by patients (Runeson & Beskow, 1991).

This method had two disadvantages pertinent to the study. Firstly, the audio-tape rater would not be able to take into account the visual body language of the subject. Secondly, the audio-tape rater would be unable to carry out a totally blind assessment of the losses because the recording usually contained the summary of losses made by the original interviewer at the start of the grief measure section. To minimise this effect, the chief investigator, who rated the audio-tapes, recorded the losses she detected on the interview schedule while listening to the audio-tape. The summary of the losses made by the original interviewer at the end of the loss review was not taken into account. This problem did not apply to grief measurement ratings as these were not recorded verbally on the tape.

A total of 30 interviews were evaluated. Rater pairs consisted of the chief investigator (CI) and one of the three interviewers who took part in the study. Audio-taped recordings were used of interviews by interviewers 1 and 2 who undertook the trial, and of interviewer 3 who carried out the evaluation. Nine interviews of interviewer 1 were assessed, eleven of interviewer 2 and ten of interviewer 3 (Table 6.2). Two of the interviews rated for interviewer 3 were from a practice using the trial interview schedule.

**Table 6.2: Interviews evaluated by rater pairs**

<b>Raters pairs</b>	<b>CI/ interviewer 1</b>	<b>CI/ interviewer 2</b>	<b>CI/ interviewer 3</b>
<b>Interviews N=30</b>	9	11	10

The process whereby the interviews were selected for assessment is described as follows. An independent research assistant listed the subject identification numbers from all the interview schedules of the trial and evaluation in which positive clinical scores were recorded, that is, all subjects who gained clinical scores other than ‘no grief’. No record was made of the precise clinical score. From this list, the chief investigator randomly selected subject identification numbers and located the relevant interview by using the audio-tape register. Unfortunately, interviewer 1 failed to record many of the subjects’ identification numbers and only nine identifiable interviews could be found in which grief had been detected.

The results were coded and entered into the SAS data base (SAS Institute Inc., 1998). as described Chapter 8.8.2

### **6.1.1.3 Analysis**

#### **Loss data**

An analysis of the agreement between the loss data for each pair of raters was performed and expressed:

- as agreement between pairs of raters for individual categories using Cohen’s kappa (Cohen, 1968; Altman, 1991). Kappa is 1.0 where agreement is perfect and zero where the agreement is that of chance. Values of 0.81-1.00 indicate very good agreement, 0.61-0.80 indicate good agreement, 0.41-0.60 show moderate agreement, 0.21-0.40 show agreement is fair and below 0.2 is poor agreement (Landis and Koch, 1977). Kappa can only be calculated on a symmetric table where there are data in each of the cells. In instances



where a rater gave only a single alternative, such as only 'no' responses to a category, it was not possible to calculate kappa. In these instances, the number of congruent pairs is quoted;

- as a percentage of the complete agreements between categories.

#### *Clinical measure data*

Agreements between grief score data for each pair of raters were demonstrated by:

- Percentages;
- Spearman's rho correlation coefficients for interval data. Values range from 0 to +1, where 0 indicates no correlation and +1 indicates perfect correlation. Negative values down to -1 may similarly apply for inverse correlations (Armstrong, Calnan & Grace, 1990); and
- Tables demonstrating associations between the results.

### **6.1.2 Construct validity**

Loss review and grief measure data from the trial (Chapter 9) and evaluation interviews (Chapter 12) were combined. The data were analysed for constructs described in Chapter 8.9.2.6.2 and Chapter 8.9.2.6.5.

### **6.1.3 Internal consistency**

The combined grief measure data from the trial (Chapter 9) and the evaluation (Chapter 12) were examined for correlations between the domain scores (Chapter 5.1.3.6) and Likert distress scores (Chapter 5.1.3.7) of the interviews with the clinical scores (Chapter 5.1.3.11) using Spearman's rho.

#### **6.1.4 Investigation of discrepancies**

After the analysis, the chief investigator listened again to the audio-tape recordings in which there had been discrepancies between the raters to find out how they might have come about.

### **6.2 Results**

Results will be described in the order given in the plan of the evaluation set out in Table 6.1.

The results of the loss data will be described, followed by those of the grief measure.

#### **6.2.1 Loss data**

##### ***6.2.1.1 Inter-rater reliability***

Inter-rater reliability was demonstrated by agreements of the loss categories between pairs of raters using Cohen's kappa (Cohen, 1968) (Table 6.3). For every rater pair there was demonstrated to be moderate agreement or better for every category explored. Perfect agreement was demonstrated between raters for the categories where kappa was 1.000 and for categories where there were only congruent pairs. The dark shaded cells of the table indicate these results. Categories with kappa over 0.61, indicating good agreement, as well as a category with 8/9 congruent pairs, are shown by the light shaded squares. The unshaded cells all had the values of kappa between 0.41 and 0.61, indicating moderate agreement and included a category with 7/9 congruent pairs which was arbitrarily classed as moderate.

The results are similar for all three pairs of interviewers. 'Migration/moving' was the category with consistently lower agreements for all three interviewer pairs which may indicate this is a more difficult category to detect than others.

**Table 6.3: Agreements between pairs of raters on the loss data**

Category	Cohen's Kappa for pairs of raters (95% confidence limit)		
	CI & interviewer 1 N=9	CI & interviewer 2 N=11	CI & interviewer 3 N=10
Quality of life	1.00	1.00	1.00
Job	0.53	1.00	1.00
Death	1.00	1.00	1.00
Fear of death	All congruent pairs	1.00	1.00
Opportunity	1.00	1.00	0.74
Finance/property	8/9 congruent pairs	All congruent pairs	0.74
Migration/ Moving	0.73	0.56	0.52
Separation	-*	1.00	1.00
Pregnancy	All congruent pairs	All congruent pairs	1.00
Pet	All congruent pairs	1.00	All congruent pairs
Integrity	All congruent pairs	All congruent pairs	1.00
Adoption	-*	1.00**	1.00
Freedom	-*	-*	1.00***

\* No data - category not included in trial interview schedules

\*\* N=9 (category added during trial and not included in interview schedule for 2 interviews)

\*\*\* N=8 – trial schedule used for 2 interviews

Key (Classification system of Landis & Koch, 1977)

	Perfect agreement
	Very good agreement (k > 0.80)
	Good agreement (k=0.61-0.80)
	Moderate agreement (k=0.41-0.60)

The overall agreements between pairs of raters for all categories of the loss data, expressed as a percentage of the total, are given in Table 6.4. For all pairs of raters there was a total of 348 pairs of categories (90 pairs for interviewer 1, 130 for interviewer 2, and 128 pairs for

interviewer 3). These figures are less than the total number of categories for each subject (ie 30 subjects X 13 categories) because not all categories were present on all interview schedules: ‘adoption/fostering’ and ‘freedom’ were added during the course of the study; ‘separation’ was missing from the early trial schedules; and two interviews by rater 3 used the trial interview schedule as described under the method. There was a total of 338 agreements out of the possible 348 (97%).

**Table 6.4: The overall agreements between pairs of raters on the loss data (N=348)**

	N=	% agreement
<b>Perfect agreement between categories</b>	338	97%

#### **6.2.1.2 Construct validity**

##### **Effect of socio-economic cluster on multiples of loss**

Table 6.5 shows data for multiples of loss categories compared to socio-economic cluster (SEC) for the 153 subjects who nominated a postcode of residence. Examination of the median numbers of loss categories indicates no support of the construct of increasing multiples of loss with lower socio-economic cluster. Although the median for the ‘high’ cluster being greater than that for the ‘medium’ and ‘low’ clusters may disprove support for the construct, the very high median for the ‘very low’ category does suggest support. However, eight subjects is too small a number from which to draw such a conclusion, and this needs confirming on a larger number of subjects. A Kruskal-Wallis test found no significant difference between the clusters ( $P = 0.0852$ ), although, being only slightly over 0.05, suggested a trend.

**Table 6.5: Number of loss categories for socio-economic cluster (SEC)**

SEC	<i>N=153</i>	Numbers of loss categories (interview)		
		Median	Min	Max
<b>High</b>	64	1.50	0	9
<b>Medium</b>	27	1.00	0	6
<b>Low</b>	54	1.00	0	8
<b>Very low</b>	8	5.00	0	8

## 6.2.2 Grief measure data

### 6.2.2.1 Inter-rater reliability

When comparing the clinical score data between the pairs of raters, it is important to remember that the severity indicators of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994), from which the clinical grief scoring classification is derived, contains specific definitions for only two categories – ‘mild’ and ‘severe’. ‘Moderate’ is described as between ‘mild’ and ‘severe’. Later in the study a ‘minimal’ category was added for clarity of the severity, in response to feedback from the pilot study. As the boundaries of the clinical score categories were unclear, some overlap would be expected. Hence, the importance in assessing the agreement between the clinical scores of the raters was not merely the number of absolute agreements but their proximities to each other.

The degrees of agreement and Spearman’s correlation coefficients between the clinical grief scores for pairs of raters are shown in Table 6.6. Overall, perfect agreement between clinical scores was found for 53% of interviews, there was one degree of disparity between a further 43% and two degrees of disparity between 3%. This meant there was 96% agreement (53 + 43%) within one degree of disparity over all the pairs. Interpretation of agreements between individual pairs requires caution because the small numbers of interviews magnified any

minor variation. The example of note is that the 11% agreement for two degrees of disparity was caused by the results of only one interview between the chief investigator and rater 1.

The closest set of scores was obtained between the chief investigator and interviewer 3, as shown by the high percentage of perfect agreements and the correlation coefficient of 0.90. Greater differences were demonstrated between the chief investigator and interviewers 1 and 2. However all results were within one degree of discrepancy with the exception of the one pair of scores already discussed.

**Table 6.6: Relationships between the clinical grief scores for pairs of raters**

Agreement	Rater pairs			
	All N=30	CI & 1 N=9	CI & 2 N=11	CI & 3 N=10
<b>Perfect agreement</b>	53%	56%	36%	70%
<b>One degree of disparity</b>	43%	33%	64%	30%
<b>Two degrees of disparity</b>	3%*	11%*	0%	0%
<b>Within one degree of disparity</b>	96%	89%	100%	100%
<b>Correlations (Spearman's rho)</b>	0.57	0.39	0.40	0.90

\*caused by one outlier

Relationships between the data obtained for all rater pairs are shown in Table 6.7. Perfect agreements are highlighted in the dark squares. Agreements within one degree of disparity lie in the adjacent squares (lightly shaded). Apart from one outlier (starred), all paired data showed perfect agreement or agreement within one degree of disparity.

**Table 6.7: Agreements between the clinical scores for all pairs of raters**

CI	Interviewers 1, 2 and 3				Total
	Minimal	Mild	Moderate	Severe	
Minimal	2	0	0	0	2
Mild	2	7	4	0	13
Moderate	0	4	3	2	9
Severe	0	1*	1	4	6
Total	4	12	8	6	30

Agreements between the chief investigator and each interviewer are shown separately in Tables 6.8-6.10.

**Table 6.8: Agreement between the clinical scores for CI and interviewer 1**

CI	Interviewer 1			Total
	Mild	Moderate	Severe	
Mild	2	2	0	4
Moderate	1	1	0	2
Severe	1*	0	2	3
Total	4	3	2	9

**Table 6.9: Agreements between the clinical scores for CI and interviewer 2**

CI	Interviewer 2				Total
	Minimal	Mild	Moderate	Severe	
Mild	1	3	2	0	6
Moderate	0	2	1	1	4
Severe	0	0	1	0	1
Total	1	5	4	1	11

**Table 6.10: Agreements between the clinical scores for CI and interviewer 3**

CI	Interviewer 3				Total
	Minimal	Mild	Moderate	Severe	
Minimal	2	0	0	0	2
Mild	1	2	0	0	3
Moderate	0	1	1	1	3
Severe	0	0	0	2	2
Total	3	3	1	3	10

**6.2.2.2 Construct validity****Effect of multiples of loss on clinical scores**

Table 6.11 shows the clinical scores for multiples of loss for the 92 subjects who identified loss. As there were small numbers of subjects for each multiple of loss, levels of multiples were collapsed to form two groups, one consisting of one and two losses, and a second group of three or more. The median clinical grief score appears considerably higher for those with with three or more losses compared to those with one or two. A Wilcoxon Two-Sample Test



(Gravetter & Wallnau, 1996) gave a value of  $P=0.0001$  which confirmed significant difference between the median scores.

**Table 6.11: Clinical grief scores for multiples of loss**

<b>Multiples of loss</b>	<b>N</b>	<i>Clinical scores</i>		
		<b>Median</b>	<b>Min</b>	<b>Max</b>
<b>1-2</b>	40	13	0	58
<b>3 +</b>	52	21	8	72
<b>Total</b>	92	19	0	72

A Spearman's correlation coefficient value of 0.65 was obtained for the correlation between the clinical scores and multiples of loss indicating moderately good correlation.

#### Effect of gender on Section C scores

Table 6.12 shows losses and clinical scores for the 157 males and females who nominated their gender. The median number of losses for males and females is 1.00. However, the median clinical score for females is higher than that for males. A Wilcoxon Two-sample test gives a p value of 0.0631, which, being just greater above 0.05, is marginally significant. Assuming other variables to be equivalent for both genders, such as the types of loss and time since loss, these data support the construct that females score more highly than males.

**Table 6.12: Clinical scores for gender.**

<b>SES status/ gender</b>	<b>N=157</b>	<b>Median number of losses</b>	<b>Clinical score</b>		
			<b>Median</b>	<b>Min</b>	<b>Max</b>
<b>Male</b>	47	1.00	2.00	0.00	5.00
<b>Female</b>	110	1.00	3.00	0.00	5.00

### 6.2.2.3 Internal consistency

Correlation coefficients between the domain scores of the interviews and the clinical grief scores demonstrated moderate to good correlation, except for the spiritual domain, which showed a low correlation with the clinical score (Table 6.13). These figures demonstrate that the domain scores and Likert distress scores of the interview are all related to the clinical score.

**Table 6.13: Correlations between the interview domains and clinical scores (Spearman's correlation coefficient)**

	<b>Emotions</b>	<b>Physical symptoms</b>	<b>Cognitive functioning</b>	<b>Social</b>	<b>Spiritual</b>	<b>Distress scale</b>
<b>Clinical score</b>	0.71	0.71	0.70	0.61	0.30	0.83

All correlations are significant to the value of  $p < .0001$

### 6.2.3 Sources of discrepancies

#### 6.2.3.1 Loss categories

Discrepancies in the detection of loss categories between the raters were found to occur for two main reasons. The first reason was because there was lack of clarity about the precise category into which the loss should go. One example that arose in the reliability testing was the case of a subject who had a painful shoulder and was unable to work. The interviewer categorised this as 'loss of quality of life' and the chief investigator also included 'job'. Another example was of a female subject who identified the loss of her husband's job as a loss of opportunity. The interviewer categorised this as only 'job loss' whereas the chief investigator rater also identified 'loss of opportunity'.

The second reason was when a second, unrecognised loss was mentioned by the subject in the context of a recognised loss, and this second loss was detected by only one of the raters. An

example was when a subject described her grief about the terminal illness of a relative overseas and the distress caused by being so far away. The interviewer detected ‘future death of a loved one’ but the chief investigator also detected ‘migration’.

#### **6.2.3.2 Clinical score**

The single interview for which there were two degrees of disparity between raters’ results was investigated. The chief investigator re-rated the grief measure for this interview by listening again to the audio-tape and checked the original interview schedule scored by interviewer 1. Both the original results were confirmed and no explanation could be found for the disparity.

### **6.3 Analysis of results**

The results were analysed according to the plan set out in Table 6.1 and will be described in the order in which the analyses are listed in that table. The results are summarised in Table 6.14.

#### **6.3.1 Loss data**

Agreements for categories between pairs of raters indicated nearly all agreements were good to perfect, which points towards the loss review as being a reliable diagnostic instrument. As kappa takes chance into account it provides a reliable index for agreements when, as in this instance, a relatively small number of subjects is used.

A less reliable index but one which was used to make direct comparisons with other instruments was the percentage agreement. The high percentage of agreements (97) between categories for pairs of raters also indicated the loss review to be a reliable instrument for detecting loss. These results compare well with the validity of the gold standard interview used in validating the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, &

Erbaugh, 1961) in which agreements between two raters for diagnostic categories was 73%. However, it would be expected that there would be higher agreement when there is a choice between only two categories ('yes' and 'no') of the loss review than between the multiple categories of the Beck interview.

The trend in the relationship between socio-economic cluster (SEC) and multiples of loss is consistent with loss and grief constructs. The construct is not disproved.

### **6.3.2 Clinical score data**

The high percentage agreement (96%) of scores for pairs of raters within one degree of disparity indicated the grief measure to be reliable. This compares favourably with the validity of the Beck Depression Inventory interview in which a figure of 97% was found (Beck, Ward, Mendelson, Mock & Erbaugh 1961). This is further supported by the moderate correlation between raters' scores.

Both the grief constructs were supported by the data, which gives support to the supposition that the grief measure is specific to grief. All domain scores were demonstrated to contribute to the clinical score, further substantiating the validity of the interview.

**Table 6.14: Analysis of the evaluation results of the interview**

	Analysis	Test		Result	Conclusions
Loss review	Inter-rater reliability	Agreements between pairs of raters	Individual categories (Cohen's kappa)	Most good to perfect agreements. Migration lowest agreement.	Loss review is a reliable instrument for detecting loss. Migration disenfranchised.
			% complete agreements between categories	97% perfect agreement overall	
	Construct validity	SEC & multiples of loss	Table of results	Inconclusive	Inconclusive
			Kruskall-Wallis Test	Trend suggested	
Grief measure	Inter-rater reliability	Agreements	Percentages	96% agreement within one degree of disparity	Grief measure is a reliable instrument for measuring grief
			Spearman's rho	0.57 (moderate correlation)	
			Tables	1 outlier (N=30)	
	Construct validity	Multiples of loss & clinical scores	Table of results	Supported	Data consistent with grief constructs
			Wilcoxon Two Sample Test	Significant support for construct	
			Spearman's rho	0.65	
		Gender & clinical score	Table of results	Trend	
			Wilcoxon Two Sample Test	Support for construct marginally significant	
	Internal consistency	Correlations of domain scores & clinical score	Spearman's rho	High (4 categories) Moderate (1 category) Low (1 category)	All domains of the interview are valid

## 6.4 Discussion

There are a number of issues that require further discussion regarding the validation process.

### 6.4.1 Validity of the methods

Of all the possible methods to determine the inter-rater reliability discussed at the beginning of this chapter, none is free of methodological and ethical dilemmas. The method selected was believed to cause the least distress to the subjects and avoided some of the problems in reinterviewing the same subject. A criticism of the method chosen was that the inclusion of

the loss summary on the audio-tapes could have biased the loss ratings of the chief investigator.

The number of subjects (30) for which the inter-rater reliability was determined was 25% smaller than the sample of 40 used in the reliability study of the Goldberg's standardised psychiatric interview (Goldberg, Cooper, Eastwood, Kedward, & Shepherd, 1970). Further evaluation on larger samples is desirable to substantiate these results. It will also be important to investigate the relevance of the interview to other cultures and to indigenous peoples.

#### **6.4.2 Validity of the loss review**

The fact that only a trend in the relationship between socio-economic cluster and multiples of loss was demonstrated deserves comment. One reason may be that the method of assessing socio-economic status by the postcode in this study is only a rough approximation of the subject's socio-economic status. Another reason may be the difference between life events and loss events. If loss events were the same as life events, it would be expected that the same strong association between socio-economic cluster and life events found by Lima, Beria, Tomasi, Conceicao and Mari (1996) would also be demonstrated between socio-economic cluster and loss events. That no strong association was demonstrated, supports the principle that loss events are not the same as life events, as explained in Chapter 2. However the trend towards an association does suggest they are related. Another reason for there being no strong relationship is that the number of subjects was too few especially in the 'very low' socio-economic cluster. Further research on larger numbers of subjects in which the socio-economic status is clearly defined is necessary to clarify this.

The question therefore arises as to whether it was indeed loss that was detected by the interview or whether some other phenomenon is being found. This question can be answered indirectly: the measurement of grief is dependent on the loss review being specific for loss.

There is strong support for the grief constructs, and therefore this supports the specificity of the loss review.

In order to detect all losses, the interview was designed using numerous methodological and communication strategies for grief and a comprehensive list of loss categories. The supposition has been made that the interview is the gold standard for detecting grief.

However, it is still possible loss and grief may remain undetected by the interview for the following reasons: secrecy on part of the subject, the subject did not recognise the loss, the interviewer failed to identify it, or the loss review was not sufficiently exhaustive to identify all types of loss experience for all subjects. Further evaluation of the interview is necessary with larger numbers of subjects, and involving other cultures and indigenous peoples.

Additionally, it is possible that such research may further expand the concepts of loss and develop wider understandings of the phenomenon.

#### **6.4.3 Validity of the grief measure**

The definitions of the clinical grief score categories may have had an effect on the reliability of the grief measure. If all categories had been precisely defined and not merely the ‘mild’ and ‘severe’ categories, the inter-rater reliability may have been improved. Although this was not described as an issue by Beck et. al. (1961) who used the same mild, moderate and severe definitions as are now contained in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association, 1994), it is recommended that this be done in future studies.

It has been noted that the ratings of the chief investigator with interviewer 3 were more congruent than those with interviewers 1 and 2. One explanation for this is that increasing life experience with age provided more insight into the measurement of grief. The chief

investigator and interviewer 3 were similar in age (50s and 40s) whereas interviewers 1 and 2 were considerably younger (20s and 30s).

#### **6.4.4 Ethical issues**

The concern that taking part in an interview about personal grief issues might disturb subjects, does not seem to have been substantiated. Although the interview process had to be terminated for one distressed subject (who, as a result, was given information about further help available), most of the subjects seemed to have benefited. Evidence for this comes from the subjects' comments given at the team's debriefings (Appendix 9.3). Further, there were no adverse comments relating to the process or the nature of the study on the audio-taped interviews which the chief investigator rated: rather the comments were complimentary. This supports the claims by Runeson & Beskow (1991) that grief research may benefit subjects.

#### **6.5 Conclusions**

Objective D for the interview, (to be valid and reliable in detecting and measuring grief) has been met. Degrees of reliability for detecting and measuring grief similar to those of other validated psychiatric measures were demonstrated. The data from the interview conformed with known loss and grief constructs, indicating the interview is specific for detecting and measuring grief. Internal consistency indicated all parts of the interview are valid for measuring grief. As the interview met with these required criteria, it was considered a valid standard against which to compare the questionnaire in its evolution through the trial and evaluation.

It has been suggested that precise definitions of all categories in a measure, rather than of only some, may lead to more accurate application of the measure.



The difference between loss events and life events has been upheld by the finding of only a trend in support of the loss construct.

‘Migration/moving’ appears to be a loss category that is more difficult to recognise than the other loss categories and may be more disenfranchised than other categories. Further exploration is required for confirmation.

## **6.6 Summary**

This chapter has addressed objective D for the interview by demonstrating that it is a valid and reliable instrument for detecting and measuring grief in general practice patients. The interview therefore is a valid standard against which to compare the questionnaire in the trial and evaluation stages of the study. These stages are described in chapters 7-13 of this Thesis. Several methodological, ethical and validity issues raised in this validation process, have been discussed, and suggestions have been made for improving the accuracy of grief measurement using interval categories. Further discussion of the interview is included with the discussion of the whole study in the final chapter of this Thesis.

## Chapter 7: Development of questionnaire

This chapter describes the development of the questionnaire up to the stage at which it was ready to use in the trial. The aim in the development of the questionnaire was to design a self-administered tool to detect and measure the extant state of grief in general practice patients.

The definition of the extant state of grief in Chapter 2.2.5 will be used. This chapter addresses objectives A, B and C for the questionnaire, which are:

**A: to detect the presence or absence of grief in patients attending general practices;**  
**B: to determine the categories of loss events causing grief; and**  
**C: to measure the extant state of grief in these patients;**

The questionnaire was composed of three sections to address the objectives thus:

- a demographic section, section A (for purposes of analysis of the loss review and grief measure)
- a loss review, section B (Objectives A and B); and
- a grief measure, section C (Objective C)

Drafts were drawn up by the chief investigator in conjunction with a team, consisting of interviewer 1 and research assistant 1 (Appendix 8.2) and eight GPs who had an interest in mental health issues. The methodological principles from Chapter 2 that underpin the design will be referenced throughout this Chapter.

### ***7.1 Development of section A (demographic section)***

#### **7.1.1 Aim**

The aim of section A was to determine the demographic profile of subjects.

### **7.1.2 Pilot version**

A pilot version of section A (Appendix 7.1) was drafted as follows. The section commenced with the same identification items used in the interview: date, practice number and the subject's identification number

An introductory paragraph followed which informed the subjects about the purpose of the questionnaire (Chapter 4.4.1).

Demographic questions were taken from the South Australian Health Omnibus Survey (Harrison Market Research Pty Ltd, 1995). This instrument was selected as it was a validated instrument in current use for population studies in South Australia and had been trialled successfully in a previous prevalence study of loss and grief (Harrison Market Research Pty Ltd, 1994). The South Australian Health Omnibus Survey is a door-knock survey in which a trained researcher asks and records responses to a number of health-related questions. The topics addressed and their respective response options, are shown in Table 7.1.

**Table 7.1: Demographic items of the South Australian Health Omnibus Survey 1993**

<b>Question</b>	<b>Response options</b>
1. Your age	Free response
2. Your gender	Male Female
3. In which country were you born?	Free response
4. What is your marital status?	Married De facto Never married Separated/divorced Widowed
5. Level of highest educational attainment	Still at school Left school at 15 years or less Left school after aged 15 Left school after aged 15 but still studying Trade qualification/apprenticeship Certificate/diploma – one year full time or less Certificate/ diploma – more than one year full time Bachelor degree or higher
6. Household income	Up to \$12,000 \$12,000 - \$20,000 \$20,000 - \$30,000 \$30,000 - \$40,000 \$40,000 - \$50,000 \$50,000 - \$60,000 \$60,000 - \$80,000 Over \$80,000 Not stated

The items in Table 7.1 were converted to questions for use as a self-administered questionnaire. Closed questions were used, as they were easier for coding and recording data. A question about main occupation, which was missing from the Health Omnibus Survey, was added. This version of section A was piloted as described below.

### **7.1.3 Pilot**

#### ***7.1.3.1 Method***

The pilot was conducted on all three sections of the questionnaire together. It was also conducted concurrently with the pilot of the interview on the same subjects (Chapter 5.1.4.1).

Details of the method of the conditions under which the questionnaire was conducted are described in Chapter 8.

Subjects were asked to complete the whole questionnaire in a private room in the presence of a trained research assistant. The research assistant noted subjects' remarks as follows:

- suggestions for improving the wording and format;
- time taken to complete the questionnaire;
- comments about the acceptability of the content of the questionnaire;
- reactions to the questionnaire; and
- any other comments.

#### ***7.1.3.2 Results***

The results for sections A, B and C of the questionnaire are shown together in the left hand column of Table 7.2.

**Table 7.2: Pilot: results and modifications**

<u>RESULTS</u>	<u>SUBJECTS</u> (N=14) /TEAM	<u>MODIFICATIONS</u>
<b>General</b>		
Questionnaire too long.	Most subjects	
<b>Section A</b>		
Reduce instructions at beginning of Section A.	3	Deleted.
5. Confusion over lengths of certificates and diplomas (item 5).	2	The two items about certificates and diplomas were condensed into one: Certificate /diploma.
6. No <i>retired</i> category (item 6).	1	Item added.
6. No separate student category (item 6).	1	No change made (Contained in category Education or training).
7. Level of income is a confronting question in the personal context of general practice (item 7).	2	Use post code to assess social status instead of level of income.
<b>Section B</b>		
Fewer losses detected by questionnaire than by interview.	Research assistant	More explanatory introduction (version 2) constructed with a general stress question.
Introduction (version 2) too complex.	2	Shortened.
General question (version 2) too complex & detected fewer losses than the categorical inventory.	Team	Deleted.
Example is too complex and non contributory.	2	Deleted.
Questions too long and complex.	Most subjects	Questions changed to a stem 'In the past TWO WEEKS have you been experiencing distress about...'
Meaning of heading of time column not clear.	Team	Changed to Time since you knew about the loss.
Poor compliance with the time columns.	Most subjects	No suggestions.
Decision tree at end of section too complex.	2	Replaced by a statement.
<b>Section C</b>		
Questions repetitive.	Most	Selected items deleted.
Delete 'Loss situation' from items.	1	Deleted.
11*: Change '...have you found yourself yearning for the loss or that the loss will not occur' to '...have you found yourself longing for what is or will be lost'.	1	Changed.
13* : Change '...have you felt distress/ pain if for any reason you are confronted with the reality that the loss has occurred/will occur' to '...have you felt distress by the reality of the loss'.	1	Changed.
25*: Change '...of the loss...' to '...what is or will be lost...'	1	Changed.
31*: Change '...have you been reminded by people or familiar objects (...) of the loss...' to '...have people or familiar objects reminded you of the loss'.	1	Changed.
Add a thank you to the end of the questionnaire.	1	Added.
<b>Observations by researcher</b>		
No subjects became distressed by the content of the questionnaire.		
The length of time (mean=12 minutes 30 seconds; range 5-20) taken to answer the questionnaire was too long and prevented many patients from staying for the interview.		

\* Numbers for section C items refer to pilot version numbers

### ***7.1.3.3 Modifications***

The results obtained were discussed between the research team which consisted of the chief investigator, interviewer 1 and research assistant 1. Decisions were made regarding appropriate modifications.. These modifications are shown in the right hand column of Table 7.2.

One major change to section A was to withdraw question 7 relating to household income because this appeared to antagonise subjects who might otherwise take part in the study, and to substitute an item asking for the subject's postcode. Postcodes in South Australia can be matched for socio-economic status, calculated on cluster analyses of a number of known economic variables and indices in the Social Health Atlas of South Australia (Glover, Shand, Forster & Wollacot, 1996). The given socio-economic clusters were: high, medium, low and very low. According to the Atlas, most postcodes contain a heterogeneous mixture within the clusters, and therefore the postcode is only a rough estimate of the socio-economic status of any subject.

### **7.1.4 Trial version**

The modified pilot version became the trial version of section A and was used in the trial (Chapter 8). This is shown as section A of the trial questionnaire in Appendix 7.3.

## **7.2 Development of Section B (loss survey)**

### **7.2.1 Aim**

**The aim of the loss review was to address Objectives A and B of the questionnaire stated in the Introduction: to detect the presence or absence of grief in patients attending general practices, and to determine the categories of loss events causing grief.**

### **7.2.2 Pilot version**

A pilot version of Section B (Appendix 7.1) was drafted as follows. The section commenced with an explanatory statement showing the link between loss and grief, instructions for completing section B and an example.

This was followed by the loss survey, which consisted of questions relating to each of the categories of loss in Table 4.1. A question was constructed for each category asking subjects whether they were experiencing distress (Chapter 4.4.5) about loss in relation to that category, and requiring them to consider

- experiences of the past two weeks;
- losses to themselves;
- losses to others close to them; and
- past, present and impending losses.

Subjects were asked to respond by ticking either a 'Yes' or 'No' box for each category. For each 'Yes' box ticked, subjects were further required to indicate the number of years, months and weeks since the loss had happened, or until the loss would occur. Provision was made for subjects to record information for up to three separate losses in a single category.



The Section concluded with a flow chart asking those who had ticked any of the ‘Yes’ boxes to proceed to Section C. Those who had not, were informed there were no further questions and were thanked for completing the questionnaire.

### **7.2.3 Pilot**

#### ***7.2.3.1 Method***

The pilot version of Section B was piloted as described in Chapter 5.1.4. During the course of the pilot, subjects’ suggestions were discussed among the research team and section B was progressively updated with the agreed suggestions.

#### ***7.2.3.2 Results***

The results are shown in the ‘Results’ column of Table 7.2.

#### ***7.2.3.3 Modifications***

The modifications made are shown in the ‘Modifications’ column of Table 7.2.

1. During the course of the pilot some significant changes were made to the pilot version, which resulted in pilot version 2 of section B (Appendix 7.2). Although this version was abandoned later in the pilot, it included:
  - a fuller introduction to the section. This was formed in response to observations by the team that the questionnaire detected fewer losses than the interview. The new introduction attempted to provide a more complete explanation about loss and grief. This was found to be too complicated and was subsequently deleted; and
  - a general question about loss, to investigate whether this would be as accurate at identifying losses as the subsequent categorical inventory. This was found to identify far fewer losses than the categorical inventory and was also abandoned.

2. The heading of the time columns ‘Time since event occurred or until it will occur’ was replaced by ‘Time since you knew about the loss’. This was because the time interval since first receiving knowledge of the loss is the factor affecting grief rather than the timing of the event itself.
3. The example was deleted, being too complicated.

#### **7.2.4 Trial version**

The modified pilot version became the trial version of section B and was used in the trial (Chapter 8). This is shown as section B of the trial questionnaire in Appendix 7.3.

The trial version addressed the objectives for this section by using an inventory of death and non-death related loss categories, thereby detecting loss categories that were causing the subjects’ grief, and determining the individual categories of loss. It further addressed the definition of the extant state of grief by:

- using a window period of two weeks to allow for fluctuations of grief;
- asking subjects to consider past, present and impending loss;
- referring to self and significant others; and
- adhering to the design principles (Chapter 4.4).

### **7.3 Development of Section C (Grief Measure)**

#### **7.3.1 Aim**

The aim of section C of the questionnaire was to address Objective C for the instrument stated in the Introduction, that is, to measure the extant state of grief in patients, by measuring the grief resulting from the losses detected by Section B.

#### **7.3.2 Pilot version**

A pilot version of section C was drafted as follows and is shown in Appendix 7.1.

##### ***7.3.2.1 Sources of items***

The list of instruments in Chapter 2.6, which was found in the search for measures was revisited to find existing instruments that measure grief and its related paradigms, which could be adapted to quantify grief from both death and non death-related losses. These are listed in Table 7.3. The 28-item General Health Questionnaire was included, as this was an example of a psychiatric measure. The Grief Map (Clark, 2001) was also included, although it was acknowledged this was not a validated measure, because it represented a variety of phenomena common to a number of different types of loss.

**Table 7.3: Possible grief measures**

	<b>Instrument</b>	<b>Selection/ rejection</b>	<b>Reasons</b>
<b>Bereavement measures</b>	Core Bereavement Items [CBI](Burnett, Middleton, Raphael, Martinek, 1997);	Selected	Measures core grief phenomena
	Bereavement Phenomenology Questionnaire [BPQ] (Burnett, Middleton et al, 1997);	Non-resolution set selected	Measures core grief phenomena additional to above
	Revised Grief Experience Inventory [RGEI] (Lev, Munro & McCorcle, 1993);	Certain items selected	Measure core grief phenomena additional to above
	Grief Experience Inventory (Sanders, Mauger & Strong, 1985)	Rejected	In favour of RGEI
	Texas Revised Inventory of Grief (Faschingbauer, Zisook & DeVaul, 1987)	Rejected	No relevant additional phenomena / part retrospective
	Measure of spousal grief (Jacobs, Kasl, Ostfeld, Berkman, Kosten & Charpentier, 1987)	Rejected	No relevant additional phenomena/ part specific to anticipatory grief
	Grief Experience Questionnaire (Barrett and Scott, 1989)	Rejected	Specific to suicide
	Perinatal Grief Scale (Toedter, Lasker & Alhadeff, 1988)	Rejected	Specific to perinatal loss
	Grief Resolution Index (Remondet and Hannson, 1987)	Rejected	Specific to grief resolution
	Grief Map (Clark, 2001)	Certain items selected	Measure core grief phenomena additional to above
<b>Measures of related paradigms</b>	28-item General Health [28-item GHQ]Questionnaire (Goldberg and Hillier, 1979)	Certain items selected	Measure core grief phenomena additional to above
	Stress Response Rating Scale (Weiss, Horowitz, Wilner, 1984)	Rejected	Phenomena measured are not core grief phenomena
	Impact of event scale (Horwitz, Wilner, Alvarez, 1979)	Rejected	Phenomena measured are not core grief phenomena
	Social Adjustment Rating Scale (Holmes & Rahe, 1967)	Rejected	Phenomena measured are not core grief phenomena
	Life Events Inventory (Tennant & Andrews, 1976)	Rejected	Phenomena measured are not core grief phenomena
	LEDS scale (Brown & Harris, 1978a)	Rejected	Phenomena measured are not core grief phenomena

### **7.3.2.2 Item selection**

Selection of items from these instruments for the pilot version of the questionnaire was based on the requirements that they:

- complied with the principles for measuring grief (Chapter 4.3.2) and the task-specific requirements (Chapter 4.3.3);
- represented phenomena from the six domains (Chapter 4.3.4); and
- could reasonably be adapted to relate specifically to grief.

Selection or rejection of the instruments with the reasons are shown in the middle and right hand columns of Table 7.3.

#### **7.3.2.2.1 Core Bereavement Items**

The 17 items from the Core Bereavement Items (CBI) were selected, which were three sets of items representing the emotional domain:

- images and thoughts about the dead person;
- acute separation from the person; and
- reminders of the person.

The set relating to images and thoughts asks respondents about the severity of distress in relation to thoughts and images of the deceased person and about the frequency of thoughts about them.

The acute separation set investigates the phenomena of missing, yearning and pining for the deceased, reactions to reminders and searching for the deceased person.

The grief set describes a variety of feelings and behaviours that may occur in response to reminders of the dead person.

Reasons for selection:

- specifically designed to meet the requirements for bereavement measures (Burnet, Middleton, Raphael, Martinek, 1997); and
- validated as grief measures (Middleton, Burnett, Raphael & Martinek, 1996; Kissane, Bloch & McKenzie, 1997).

#### 7.3.2.2.2 Non resolution set (Bereavement Phenomenology Questionnaire)

These items measure traumatic emotional issues, such as guilt and anger.

Reasons for selection:

- validated on a general sample of subjects bereaved through cancer (Kissane, Bloch, McKenzie, 1997); and
- appropriate to a clinical sample.

#### 7.3.2.2.3 The Revised Grief Experience Inventory

Selected items:

Emotional domain

- I feel lost and helpless;

Social domain

- I tend to be more irritable with others since the death of my loved one;

Cognitive domain

- Concentrating on things is difficult;
- I seem to have lost my self-confidence;

Spiritual domain

- Life has lost its meaning for me; and
- Life seems empty and barren.

Reasons for selection:

- investigated phenomena not included in previous instruments; and
- validated items.

#### 7.3.2.2.4 The 28-Item General Health Questionnaire

Selected items:

Physical domain

- Felt that you are ill?;
- Lost much sleep over worry?;

Emotional domain

- Been getting scared or panicky for no good reason?;
- Been thinking of yourself as a worthless person?;
- Felt that life isn't worth living?;
- Found yourself wishing you were dead and away from it all?

Cognitive domain

Been taking longer over the things you do?; and

Felt capable about making decisions about things?.

Reasons for selection:

- appropriate to a clinical sample;
- investigated phenomena not included in previous instruments; and
- validated items.

#### 7.3.2.2.5 The Grief Map

The Grief Map (Clark, 2001) contained a range of additional phenomena that had been validated across a wide range of death and non death-related losses. The additional items included were:

##### Emotional domain

- Questioning why?;
- Horror and fantasies;
- Rejection;
- Loss of trust;
- Shame; and
- Blame from others.

##### Phenomena of reorganisation

- Quest for the positives;
- New life;
- Rebuilding self; and
- Creating purpose.

#### 7.3.2.2.6 General items

Two items to gauge the general level of distress experienced by subjects were included:

- How would you rate your overall feelings about your loss or losses?; and
- Overall how much have thoughts and feelings about your loss or losses distressed you?



### *7.3.2.3 Code number*

Each item was allotted a code number, which remained constant throughout the study. This enabled the item to be tracked throughout the evolution of the section.

### *7.3.2.4 Permission to use*

Letters seeking permission to adapt parts of the selected three instruments for use in this study were sent to the authors (Appendix 7.4). Responses are in Appendix 7.4.

### *7.3.2.5 Modifications*

Appendix 7.5 demonstrates the series of modifications made to the items throughout the evolution of section C over the course of this study, and should be viewed in conjunction with the following description.

Items were modified to render their meaning appropriate to past, present and impending death and non death-related losses. The original items with the item number from their respective instruments of origin are shown in column 1 of Appendix 7.5. The code numbers allotted to each item for this study are shown in the column 'Item code number' in this table.

The original items from the CBI, which were designed to measure grief following bereavement, referred to the person who had died as 'X'. The words 'X or X's death', were replaced by the phrase 'loss or loss situation'. The term 'loss situation' was used to refer to conditions and circumstances of loss such as infertility, career choice and unemployment.

The items adapted from non-bereavement measures were redesigned to be specific to grief. For example, item A4 of the 28-item GHQ 'Felt that you are ill' became 'Have thoughts or reminders of the loss caused you to feel sick or ill in any way?'

Those items were deleted where the original meaning was lost (code numbers 9 and 10) or duplicated in the adaptation to include non-death losses (code number 8).

Two new general questions (code numbers 1 and 2) were also designed to provide global measurements of grief.

The items selected represented all domains (see Appendix 7.6, which shows the spread of item code numbers over the domains).

#### *7.3.2.6 Stem*

The stem for the items was ‘Over the past TWO WEEKS...’.

#### *7.3.2.7 Measurement scale*

**Items were given a four-point interval measure adapted from the validated CBI scale. This scale was chosen as it had been previously validated and had been found to give a spread of endorsement across response options (Burnett, Middleton, Raphael, Martinek, 1997). The advantages of this scale were that it appeared to cover adequately the range of possible morbidity options required for this study, and could easily be coded for data entry, and subsequently be treated as interval data for data analysis.**

**The responses of the interval measures were placed in descending order of severity or frequency, starting from the left hand margin. A box was placed against each response for the subject to tick. Responses relevant to the items are shown by code number in Table 7.4.**

**Table 7.4: Item response options**

<b>Code number</b>	<b>Response options</b>			
<b>1</b>	<b>Exceedingly distressful</b>	<b>Quite distressful</b>	<b>Slightly distressful</b>	<b>No distress</b>
<b>3, 4, 6</b>	<b>Continuously</b>	<b>Quite a bit of the time</b>	<b>A little bit of the time</b>	<b>Never</b>
<b>5</b>	<b>Always</b>	<b>Quite a bit of the time</b>	<b>A little bit of the time</b>	<b>Never</b>
<b>2, 7-54</b>	<b>A lot of the time</b>	<b>Quite a bit of the time</b>	<b>A little bit of the time</b>	<b>Never</b>

**7.3.2.8 Instructions for subjects**

The following brief statement headed the list of items: ‘Please complete every question and tick one box for each question’.

**7.3.3 Pilot**

**7.3.3.1 Method**

This pilot version of section C (Appendix 7.1) was piloted as described under the development of section A. The wording of individual items was modified continuously between subjects.

**7.3.3.2 Results**

The suggestions for changes are shown in the ‘Results’ column of Table 7.2.

**7.3.3.3 Modifications**

The modifications made are shown in the ‘Modifications’ column of Table 7.2. After considering the results, a decision was made by the team to delete half the number of items based on the following:

- Brevity and simplicity were principles for the design of the questionnaire (Chapter 4.4.2 and 4.4.4);
- Subjects' comments that the questionnaire was too long (Table 7.2);
- Subjects' comments that the questions were repetitive (Table 7.2);
- The average time to complete the questionnaire was 12 minutes 30 seconds (Table 7.2);
- Observations of the research assistant that the length of time needed to complete the questionnaire deterred subjects from staying for the interview (Table 7.2).

#### 7.3.3.3.1 Items selected

Items were selected that complied most fully with the requirements for the design of section C (Chapter 4.3.2 and Chapter 4.3.3)

The CBI items and non resolution set from the Bereavement Phenomenology Questionnaire were retained because these were:

- previously validated as core bereavement phenomena; and
- appropriate to death and non death-related loss.

Items coded 26, 28, 34, 36 from other measures were retained because these:

- measured phenomena and domains not investigated by previously selected items;
- were relevant to a clinical sample;
- were appropriate to death and non death related loss; and
- decreased in intensity in parallel with accommodation to the loss.

#### 7.3.3.3.2 Items deleted

Items were deleted because they did not meet the principles for the design of the grief measure. Deleted items and the reasons for deletion are described below:

*Item coded 27*

- describes trait as well as state; and
- sleeplessness is not a constant feature and does not change progressively over the course of the grieving process.

*Item coded 29*

- not core.

*Items coded 31-33, 35 and 37-39*

- not specific to grief. These items measure depression and may confound the measurement of grief; and
- not constant features of the grieving process.

*Items coded 40-47 and 49-50*

- not previously validated as measures of grief.

*Items coded 53-56*

- not previously validated as measures of grief; and
- not constant features of the grieving process.

*Items combined*

Items 30, 36 and 48 were all items relating to cognitive erosion and were combined to make a single new item C10 of the trial questionnaire.

Items 51 and 52 were combined with item coded 26 to form a new single item C6 of the trial questionnaire.

### **7.3.4 Trial version**

#### *7.3.4.1 Sets*

The remaining twenty-six items fell into five sets which are shown in Table 7.5. Three sets remained unchanged from the adaptations of the original instruments: CBI images and thoughts; CBI acute separation; and CBI grief. The non-resolution set received an additional item coded 28 from the 28-Item GHQ. A set of general effects of grief was constituted from the two ‘general’ items, an item coded 26 tapping the physical effects of grief from the 28-Item GHQ, and two items, 35 and 36 from the RGEI, tapping social irritability and the cognitive effects of grief. These five sets comprised the form of the instrument that was used in the trial (Chapter 8) and collectively will be referred to as section C of the trial questionnaire.

**Table 7.5: Section C trial version (26 items)**

**General distress**

- 1 *how would you rate your overall feelings about your loss or losses*
- 2 *overall how much have thoughts and feelings about your loss or losses distressed you*
- 26 *have thoughts or reminders of what is or will be lost caused you to feel sick or ill in any way (eg generally unwell, loss of energy, headaches, dizziness etc)*
- 35 *have thoughts of your loss caused you to be more irritable with others*
- 36 *have thoughts of your loss made it difficult for you to concentrate, remember things or make decisions*

**CBI images and thoughts**

- 3 *have you experienced images of the events surrounding the loss*
- 4 *have thoughts of the loss come into your mind whether you wish it or not?*
- 5 *have thoughts of the loss made you feel distressed*
- 6 *have you thought about the loss*
- 7 *have images of the loss made you feel distressed*

**CBI acute separation**

- 11 *have people or familiar objects (photos, possessions, rooms etc) reminded you of the loss*
- 12 *have you found yourself longing for what is or will be lost*
- 13 *have you found yourself imagining that the loss has/will not occur*
- 14 *have you felt distress by the reality of the loss*

**CBI grief**

- 15 *have reminders of the loss such as people, photos, situations, music, places etc caused you to feel longing for what is or will be lost*
- 16 *have reminders of the loss such as people, photos, situations, music, places etc caused you to feel loneliness*
- 17 *have reminders of the loss such as people, photos, situations, music, places etc caused you to cry*
- 18 *have reminders of the loss such as people, photos, situations, music, places etc caused you to feel sadness*
- 19 *have reminders of the loss such as people, photos, situations, music, places etc caused you to feel loss of enjoyment*

**Non resolution**

- 20 *have thoughts or reminders of the loss caused you to feel dread*
- 21 *have thoughts or reminders of the loss caused you to feel disbelief about the loss*
- 22 *have thoughts or reminders of the loss caused you to feel anxious, nervous or strung up*
- 23 *have thoughts or reminders of the loss caused you to feel numb*
- 24 *have thoughts or reminders of the loss caused you to feel guilt*
- 25 *have thoughts or reminders of the loss caused you to feel anger*
- 28 *have thoughts or reminders of the loss caused you to feel scared or panicky*

Section C of the trial questionnaire was formed by randomly ordering the items. Items were then each allocated a section C item number. Section C numbers ran consecutively. The section C item numbers are distinguished from the code and pilot numbers in that they commence with the letter C.

All the above changes are shown in the 'Trial' column in the appendix showing the evolution of section C (Appendix 7.5). The remaining items represented all domains except the spiritual domain as shown in Appendix 7.6. Section C of the trial questionnaire appears in the full trial questionnaire (Appendix 7.3)

#### **7.3.4.2 Scoring**

##### **7.3.4.2.1 Item scores**

The response options to the items were allotted scores as follows:

- No distress/ never: score = 0
- Slightly distressful/ a little bit of the time: score = 1
- Quite distressful/ quite a bit of the time: score = 2
- Exceedingly distressful/ continuously/ A lot of the time: score = 3

The range of scores for an single item was 0-3.

##### **7.3.4.2.2 Set scores**

Set scores were generated to enable comparisons between sets to be made. As the numbers of items within sets differed, the average score for each set was used. The set score was defined as the average of the sum of the scores for the items of that set:

Set score = sum of scores of items for that set ÷ number of items in the set.

The range of set scores = 0-3.

##### **7.3.4.2.3 Section C score**

A score for the whole of section C was obtained by summing the scores for all the items.

The maximum score for Section C = (number of items in section C) X 3

For the trial questionnaire which comprised 26 items:



Section C score =  $26 \times 3 = 78$ .

For the evaluation questionnaire which comprised 16 items:

Section C score =  $16 \times 3 = 48$ .

#### ***7.3.4.3 Fulfillment of requirements***

Section C fulfilled the requirements for measuring grief in that:

- section C items tap all the domains except the spiritual domain (see Appendix 7.6). This appendix shows items 1-56 under the domains they represent. All the numbers represent the item code number and all items were represented in the pilot version. Starred items were included in the trial version. The underlined items were those that were selected for the evaluation version. For example, item 8 represented the cognitive domain in the pilot version but was not selected for the trial version. Item 11 from the pilot version was selected for the trial version and progressed further to be included in the evaluation and final versions.
- section C items are consistent with the recognised requirements for measuring grief (Chapter 4.3.2 and 4.3.3);
- section C items have been rendered specific to both death and non-death-related loss;
- the window period allows for fluctuations of the severity of grief (Chapter 4.3.5).

#### ***7.4 Summary***

The trial questionnaire contains a demographic section, loss review and a grief measure which address objectives A, B and C for the questionnaire. Additionally it addresses the criteria included in the definition of grief. Further, each section fulfils the stated requirements for validity for the section. The trial questionnaire will be explored in the trial stage of the study, which is described in the following chapter.

## Chapter 8: Trial: Method

This chapter describes the method used in the trial stage of the study. In this stage, the trial versions of the questionnaire and interview schedule were explored on the same set of subjects as described in Chapter 3. The principles of the methodological issues described in Chapter 4, which have been incorporated into the method, are noted where appropriate. The objectives and the plan of the data analysis of the results for both the trial and evaluation stages is described. The aims of the trial were to:

- determine to what extent the trial questionnaire fulfilled the objectives A to D described in the Introduction; and
- to determine ways in which it could be improved.

### ***8.1 Ethics approval***

In relation to the ethical issues described in Chapter 4, ethics approval was obtained from the University of Adelaide Human Research Ethics Committee (Appendix 4.1). Yearly applications for renewal were approved and no adverse ethical effects or events required reporting to the Committee.

### ***8.2 General practices***

#### **8.2.1 General considerations**

**The aim in selecting practices was to obtain a representative sample of general practice patients in South Australia on whom to carry out the study. However, for economic and practical reasons, it was decided to carry out the study entirely within metropolitan areas of Adelaide.**

#### **8.2.2 Selection criteria**

**The inclusion criteria for practices were that they: represented different geographical areas to include subjects from different age, gender, socio-economic, cultural, educational and occupational groups;**

provided two vacant rooms for privacy, one for subjects to complete the questionnaire and a second for interviews;  
 were sufficiently busy to provide adequate numbers of patients;  
 were known to have an interest in mental health issues. The reason for this was to ensure the doctors were sufficiently skilled to provide appropriate on-going support for subjects, if required; and  
 were sympathetic to research being conducted on their premises.

### 8.2.3 Enrolment into the study

A data base of practices involved in undergraduate teaching held by the Department of General Practice, University of Adelaide, as well as the Adelaide yellow pages telephone listing of GPs were searched for possible practices. All single doctor practices were eliminated because they were unlikely to be able to fulfil the room and patient number requirements. Possible practices were selected from different geographical and socio-economic areas and contacted by telephone to ascertain their willingness to participate and whether they could fulfil the criteria.

Interested doctors were sent a letter, formally inviting the practice to participate in the study and outlining what they would be required to provide. An outline of the study and a copy of the ethics approval accompanied the letter. Practices were required to confirm, in writing, their willingness to participate. Following the study, practices were sent a letter expressing appreciation for their involvement. Examples of all these items of correspondence are included in Appendix 8.1.

The room requirements eliminated many further practices from taking part in the study and no suitable practice could be found in the western suburbs. No 'very low' socio-economic cluster as defined by the Social Health Atlas of South Australia (Glover, Shand, Forster & Wollacot, 1996) was included in the metropolitan areas of Adelaide: all 'very low' clusters were in rural areas.

### 8.2.4 Practices

Details of the practices are summarised in Table 8.1.

**Table 8.1: Demographic data of the general practices**

Practice number	Geographical location	Socio-economic cluster*	Number of subjects recruited from each practice
1	North east Adelaide suburbs	High	42
2	North east Adelaide suburbs	Low	15
3	North Adelaide suburbs	Low	30
4	East Adelaide suburbs	Medium	7
5	South Adelaide suburbs	High	6
			<b>Total = 100</b>

\* as defined by the Social Health Atlas of South Australia (Glover, Shand, Forster & Wollacot, 1996)

## **8.3 Interviewers**

### **8.3.1 General considerations**

The original intention was to engage a single GP interviewer (Interviewer 1) for the whole study. This doctor was engaged in a Special Skills attachment of the Training Program of the Royal Australian College of General Practitioners at the Department of General Practice, University of Adelaide, and had a special interest in mental health issues. However, her contract expired before the study was completed and it was not possible to find another GP to take her place. A second interviewer (Interviewer 2) was therefore selected who conformed to the selection criteria below.

Interviewers were selected by interview with the chief investigator, in which they were asked about their interest in loss and grief and were assessed on their communication skills.

### **8.3.2 Selection criteria**

The selection criteria were:

- professional qualifications and experience in a mental health related discipline;
- previous experience in interviewing patients;
- interest in the area of loss and grief; and
- excellent ability to communicate and empathise with grieving people.

### **8.3.3 Background of interviewers**

The backgrounds of the interviewers 1 and 2 are shown in Appendix 8.2.

### **8.3.4 Training in clinical skills**

Training in empathy, objectivity, sensitivity and sincerity and the appropriate management of behaviours have all been cited as contributing to the validity of the interview (Dworkin, 1992; Rubin & Rubin, 1995). The interviewers were therefore trained as described in Appendix 8.2.

#### **Training in the process and scoring of the clinical interview**

The chief investigator also trained the interviewers in the process of the interview, the use of the interview schedule (Appendix 5.3), prompt sheet (Appendix 5.2) and scoring of the interview (Chapter 5.1.3.10). Before the start of the trial, the chief investigator observed interviews to monitor the process and scoring. Observations continued until three consecutive interviews gave identical results for the interviewer and the chief investigator for the categories of loss found by the loss review and for the clinical score.

## **8.4 Research assistants**

In addition to interviewers, research assistants were required to enrol subjects into the study and to supervise the completion of the questionnaire by subjects.

### **8.4.1 Selection criteria**

Selection criteria were:

- previous experience in conducting questionnaire research;
- excellent ability to communicate and empathise with grieving people;
- interest in the area of loss and grief.

### **8.4.2 Background and previous experience**

The original intention was to engage a single research assistant for the study (Research Assistant 1, Appendix 8.2). When she replaced the interviewer who departed, a science graduate (Research Assistant 2: Appendix 8.2) was selected.

### **8.4.3 Training**

Training for research assistants is described in Appendix 8.3.

## **8.5 Information pack**

Interviewers and research assistants were provided with an information and procedure pack about the study, and information about loss and grief (Appendix 8.4).

## **8.6 Method**

### **8.6.1 Period of trial**

The trial was carried out between April and August 1997. Mother's Day, which occurred in May may have artificially inflated the numbers of losses detected close to this date.

Otherwise the period conformed with the seasonal variation requirements mentioned in Chapter 4.2.3.

### **8.6.2 Enrolment into the study**

The research assistant approached individuals to enrol in the study, as they waited in the waiting room, after registering their attendance at the practice registration desk. Only sufficient numbers were approached that could be comfortably accommodated to avoid subjects having to wait. While waiting, subjects may have been alerted to the study first

through the poster (Chapter 4.1.2.2) on display. The research assistant informed each individual about the study and asked if they would be willing to participate. She then read them the information on the Patient Information Sheet (Appendix 4.2) and asked them to read it. This contained the following information:

- a) the nature of the study;
- b) the requirements of their participation, including optional audiotaping of the interview;
- c) that they may not benefit personally from participation in the study;
- d) that a decision not to participate would affect neither their relationship with their doctor nor their treatment;
- e) that participation was completely voluntary;
- f) that they were free to withdraw at any time without prejudicing their future treatment;
- g) that their responses would be kept confidential, and their name would not be used on the audiotape;
- h) that information from the tapes may be used in publications resulting from the study; and
- i) the contact telephone number of their doctor, should distress arise from the study.

If individuals agreed to participate they were requested to sign the Consent Form (Appendix 4.3) indicating they had understood the nature of the study and consented to take part in it. The Consent Form was countersigned by the research assistant to indicate that, in her opinion, the patient had understood the explanations. The Consent Form was retained by the study. The subject kept the Information Sheet for further reference.

If individuals declined to enrol in the study or decided to withdraw from it, the research assistant recorded, on a record sheet, their reasons for doing so, and their gender, and estimated age.

### **8.6.3 Conduct of the questionnaire**

After giving consent, and while waiting to see the doctor, documentation for the study was completed. The research assistant allotted subjects an identification and practice number. These were recorded, with the date, at the top of the questionnaire and interview schedules.

The research assistant then took subjects individually into a private room and asked them to complete the questionnaire themselves. She assisted with difficulties and prompted them to complete unfinished items and noted their suggestions for improving the questionnaire design. Afterwards, the research assistant recorded in a record book subjects' feelings about the content of the questionnaire in order to ascertain its acceptability to general practice patients.

The research assistant gave subjects the blank interview schedule to take to the interviewer to complete, and ushered them to the waiting area for the interview. There was no communication between the research assistant and the interviewer to ensure interviews were conducted blind.

### **8.6.4 Conduct of the interview**

#### ***8.6.4.1 The opening***

Using the Prompt Sheet (Appendix 5.2), the interviewer greeted subjects and spent a few minutes building rapport with them using verbal and non-verbal communication techniques.



Subjects were informed of the purpose of the interview and permission for audio-taping was obtained. The interviewer confirmed confidentiality, including that subjects' names would not appear on the audio-tapes. When consent was given, the interviewer recorded the subjects' identification numbers and the audio-tape identification on an audio-tape register so that interviews could be traced in the future. If permission was not given the tape recorder was not turned on.

The interviewer then led subjects through the series of opening questions in the Trial Interview Schedule (Appendix 5.3) using the Prompt Sheet questions to confirm events identified were consistent with the definitions of loss and grief used in this study. Losses identified as causing distress at the time of the interview were recorded in the right-hand column of the schedule against the relevant question.

#### ***8.6.4.2 Loss review***

The interviewer introduced the loss review with the statement from the Trial Interview Schedule 'I would now like to ask you a few questions about various losses'. She then took subjects through the list of questions relating to the categories of loss and the specific examples for each category. Prompt Sheet questions again were used and losses identified were recorded in the appropriate right-hand column of the schedule. Losses detected under the free response item 'Any other loss' were recorded against this question.

After the loss review, the interviewer followed the flow chart: if no loss had been found, she informed subjects there would be no further questions and thanked them for participating. If loss had been recorded, she made a verbal summary of the losses and asked subjects' permission to explore these further.

#### ***8.6.4.3 Grief measure***

The interviewer then took subjects through the questions of the morbidity review using the open and probing questions of the prompt sheet to ascertain the severity of the grief in cases where subjects gave positive responses. Subjects were closely observed for non-verbal cues as well as for verbal responses. As the interviewer completed inquiry about each domain, she allotted a domain score of zero to three against each as described in Chapter 5.1.3.6.

Finally, the interviewer explained the Likert distress scale (Chapter 5.1.3.7) asking subjects to place a mark through the scale to indicate their level of grief.

Afterwards, the interviewer debriefed the subjects according to the prompt sheet. If a subject was particularly distressed, the interviewer followed the 'For distressed subjects' debriefing format on the Prompt Sheet. All subjects were given the 'Post Interview Information Sheet' (Appendix 4.4) that listed telephone numbers of sources of help should they require further assistance. Any adverse outcomes were recorded in a record book.

#### ***8.6.4.4 Re-coding***

After subjects had left the room the interviewer re-coded losses documented in the Opening section of the Trial Interview Schedule and the free item 'Any other loss?' into existing appropriate loss categories.

#### ***8.6.4.5 Allotting the clinical score***

Finally the interviewer allotted a clinical score (Chapter 5.1.3.10)

#### ***8.6.4.6 Acceptability of the interview***

Subjects comments about the acceptability or not of the interview were recorded after they had left the interview room.

#### ***8.6.4.7 Interruptions***

If subjects were called for consultation with the doctor during any of these procedures, they were requested to continue with the research process afterwards.

#### ***8.6.4.8 Reporting***

Interviewers and research assistant reported regularly to the chief investigator with wording and format recommendations for the questionnaire, and comments from and observations of subjects relating to their participation in the study.

#### ***8.6.4.9 Creating a new category***

If no appropriate category already existed for losses recorded for the free response question on the interview schedule, the chief investigator was informed, and a new category was created on the master copies of the interview schedule and questionnaire for subsequent use. New examples within categories were also recorded and incorporated into the questionnaire and interview schedules by the same procedure.

#### ***8.6.4.10 Debrief***

Team meetings and debriefs have been recommended to preserve the objectivity of the interviewers throughout emotion-related qualitative studies, thereby maintaining validity (Dworkin, 1992).

After each session the interviewer and research assistant debriefed each other about their feelings as to avoid emotional burnout (Leon, Altholz & Dziegielewski, 1999).

The interviewers and research assistants were debriefed by the chief investigator at regular intervals during the project and at the termination of their attachments. Note was made of:

- their written records of subjects' experiences of participating in the study;

- their personal experiences of carrying out grief research on patients.

## **8.7 Subjects**

The selection and exclusion criteria for the 100 subjects were as follows:

### **8.7.1 Selection criteria**

Patients, their relatives and other companions, aged sixteen and over, who were in the waiting room of the general practice surgeries were selected for the study.

### **8.7.2 Exclusion criteria**

**Potential subjects who were not proficient in oral or written English language, or who had an intellectual disability were excluded.**

### **8.7.3 Demographics**

One hundred subjects completed the trial. The number of subjects enrolled from each practice is shown in Table 8.1. It had been intended originally that there should be an equal number enrolled from each practice. However, enrolments from practices 2, 4 and 5 were much too slow so a decision was made by the chief investigator to withdraw from these practices and to return to practices 1 and 3 to complete the sample. Table 8.1 shows that the spread of practices across the three metropolitan clusters of 'high', 'medium' and 'low' is uneven. The demographic data of the subjects is shown in Tables 8.2 -8.4.

#### **8.7.3.1 Age**

Ages for subjects are shown in the stem and leaf table (Table 8.2) where the tens and units columns represent the ages of subjects. For example, there are three subjects in their eighties who are aged 81, 81 and 83. There are more young subjects, so the data are skewed to the young population.

**Table 8.2: Ages of subjects**

<b>Tens</b>	<b>Units</b>	<b>Numbers of subjects</b>
8		0
8	113	3
7	66888	5
7	022334	6
6	55678999	8
6	1223	4
5	56789	5
5	0122344	7
4	5666677778	10
4	00112222223333344	17
3	5555668888999	13
3	01133344	8
2	5556667889	10
2	00	2
1	79	2

Total=100

Descriptive statistics for the age variable are shown in Table 8.3.

**Table 8.3: Descriptive statistics for age of subjects**

<b>N</b>	<b>Mean</b>	<b>Median</b>	<b>SD</b>	<b>Range</b>	<b>25% Quartile</b>	<b>75% Quartile</b>	<b>Distribution (Skewness)</b>
100	47.7	43.5	16.8	17-83	35.0	61.5	0.4

Descriptive statistics for other variables are shown in Table 8.4 and are described below.

### **8.7.3.2 Gender**

There were 35 males and 62 females (n = 97).

#### ***8.7.3.3 Socio-economic cluster***

There was an uneven representation of the socio-economic clusters. The 'high' category had the greatest (43% of subjects), followed by the 'low' cluster (38% subjects). the 'medium' cluster (17% of subjects) and the 'very low' cluster (2% of subjects).

#### ***8.7.3.4 Highest level of educational attainment***

The highest level of educational attainment for nearly one third of subjects was 'school over the age of 15 with no further study', a quarter had left school aged 15 or under, and nearly another quarter had obtained a certificate or diploma. Others held a tertiary degree, had a trade qualification or apprenticeship, or were still studying.

#### ***8.7.3.5 Occupation***

Forty-five percent of subjects were employed full or part-time, 27% were engaged in home duties, 19% were retired, and the remainder were either unemployed or students.

#### ***8.7.3.6 Country of birth***

Approximately two thirds were born in Australia, with the remaining third from the UK and Ireland, Europe, Asia and Africa.

#### ***8.7.3.7 Marital status***

Two thirds were in marital or defacto relationships, and the remaining one third were never married, separated/divorced, or widowed.

**Table 8.4: Frequencies (F) and percentages for subjects' demographic variables.**

Variable (Subjects N=)	Level	F	Per Cent*	Variable (Subjects N=)	Level	F	Per Cent*
<b>Sex (97)</b>	Male	35	36	<b>Age (100)</b>	17-24	4	4
	Female	62	64		25-34	18	18
<b>SES (95)</b>	High	41	43		35-44	30	30
	Medium	16	17		45-54	17	17
	Low	36	38		55-64	9	9
	Very low	2	2		65-74	14	14
<b>Education (99)</b>	At school	1	1		75-84	8	8
	Left school <=15	25	25	<b>Birth country (100)</b>	Australia	68	68
	Left school > 15	31	31		New Zealand	0	0
	Left school/study	5	5		UK & Ireland	21	21
	Trade qualification	6	6		Europe	8	8
	Certificate/dip	22	22		Asia	2	2
	Degree	9	9		Africa	1	1
<b>Occupation (99)</b>	Home duties	27	27		America	0	0
	Retired	19	19	<b>Marital status (99)</b>	Married/defacto	66	67
	Student	3	3		Never married	13	13
	Unemployed	5	5		Sep/Divorced	11	11
	Employed	45	45		Widowed	9	9

## **8.8 Data management**

### **8.8.1 Qualitative data**

Four categories of qualitative data were collected during the trial:

- Non-responders (process described in Chapter 8.6.2);
- Questionnaire (process described in Chapter 8.6.3);
- Interview (process described in Chapter 8.6.4.6); and
- Team debriefs (process described in Chapter 8.6.4.10).

Table 8.5 summarises the qualitative data collected during the trial and by whom. Information was recorded onto a separate paper record for each category and from there entered into Word format tables.

**Table 8.5: Qualitative data collected during Trial**

Category of qualitative data	Recorder	Information recorded	Location of record in Thesis
Non-responders	Research assistant	i. Gender; ii. Estimated age.	Appendix 9.4 Appendix 12.3
Questionnaire	Research assistant	iii. New categories of loss	Chapter 9.3
		iv. New examples within categories	Chapter 12.3
		v. Comments about the questionnaire; vi. Difficulties in understanding the questions; vii. Suggestions for improving wording and format of questionnaire; viii. Subjects' feelings about the content and acceptability of questionnaire.	Appendix 9.1 Appendix 12.1
Interview	Interviewer	ix. New categories of loss;	Chapter 9.3
		x. New examples within categories;	Chapter 12.3
		xi. Subjects reactions to interview.	Appendix 9.2
		xii. Comments of the interview process; xiii. Observations of subjects.	
Team debrief	Chief investigator	xiv. Team members experiences	Appendix 9.3

## 8.8.2 Statistical data

### 8.8.2.1 Data coder

The data were managed by a single trained coder throughout the trial. This was the Honours psychology graduate who acted as Interviewer 2 and Research Assistant 1 (Appendix 8.3).

### 8.8.2.2 Data collection

#### Interview

Loss review and grief measure responses were recorded by the interviewers directly onto the interview schedules.

#### Questionnaire

Responses were recorded directly by the subjects onto the questionnaires. Free items were recoded by the data coder into existing categories.



### ***8.8.2.3 Data entry***

Data were entered by the coder into the data management system ACCESS. A code book was developed to record instructions about the coding process and the allotted codes. Categories were created corresponding to the questions of the interview and the questionnaire. The numbers of each question were recorded at the head of the data field that contained the responses to the respective question. Where appropriate, labels were also placed at the head of the data field column to indicate the category to which the data field related in order to make it easier to relate the data to the source question. This was particularly important where more than one question related to a single category, as, for example, in the loss surveys.

### ***8.8.2.4 Coding of data***

#### **Questionnaire**

#### ***Section A (Demographic section)***

In the demographic section open data were entered directly. Closed data were allotted numerical codes of 1 through to 7 for the various response options.

#### ***Section B (Loss review)***

Because for some questions in the loss survey, more than one question related to a single category, each question was entered in a separate data field and identified at its head by name of category and subcategory. Data were coded as follows: 1=loss, 2=no loss and 0=missing data. The length of time since the loss was entered under separate fields for years, weeks and months. A field was designated for comments about incomplete interviews. Free entries recorded on the questionnaire were recoded into the relevant category in the database. New categories were created in discussion with the chief investigator for free entries that did not fit into existing categories.

For purposes of simplification of data management for this study, loss was recorded as category endorsed (1=loss) or category not endorsed (2=no loss). The numbers of losses per category were not recorded. The loss data in this study therefore refer to the numbers of loss categories and not to the absolute numbers of losses. Subjects were provided with the means to record up to three losses per category. This feature of the instrument may be useful for future studies where actual numbers of losses are counted.

### *Section C (Grief measure)*

Numerical codes were entered for each item and were allotted as follows: 1=continuously/a lot of the time; 2=quite a bit of the time; 3=a little bit of the time; and 4=never.

#### **Interview**

##### **Loss review**

Similar to the coding for the questionnaire loss review, each question was entered in a separate data field and identified at its head by name of category and subcategory. Data were coded as for the interview: 1=loss, 2=no loss and 0=missing data. Second and third losses in a single category were not recorded on the data base.

##### **Grief measure**

Clinical scores were represented by numerical codes as follows: 0=no grief; 1=minimal grief; 2=mild grief; 3=moderate grief; and 4=severe grief. The given numerical scores for the sections of the interview (emotions, physical symptoms, and cognitive, social and spiritual functioning) were also entered. Finally, subjects' records on the distress scale were entered.

#### ***8.8.2.5 Data checking and cleaning***

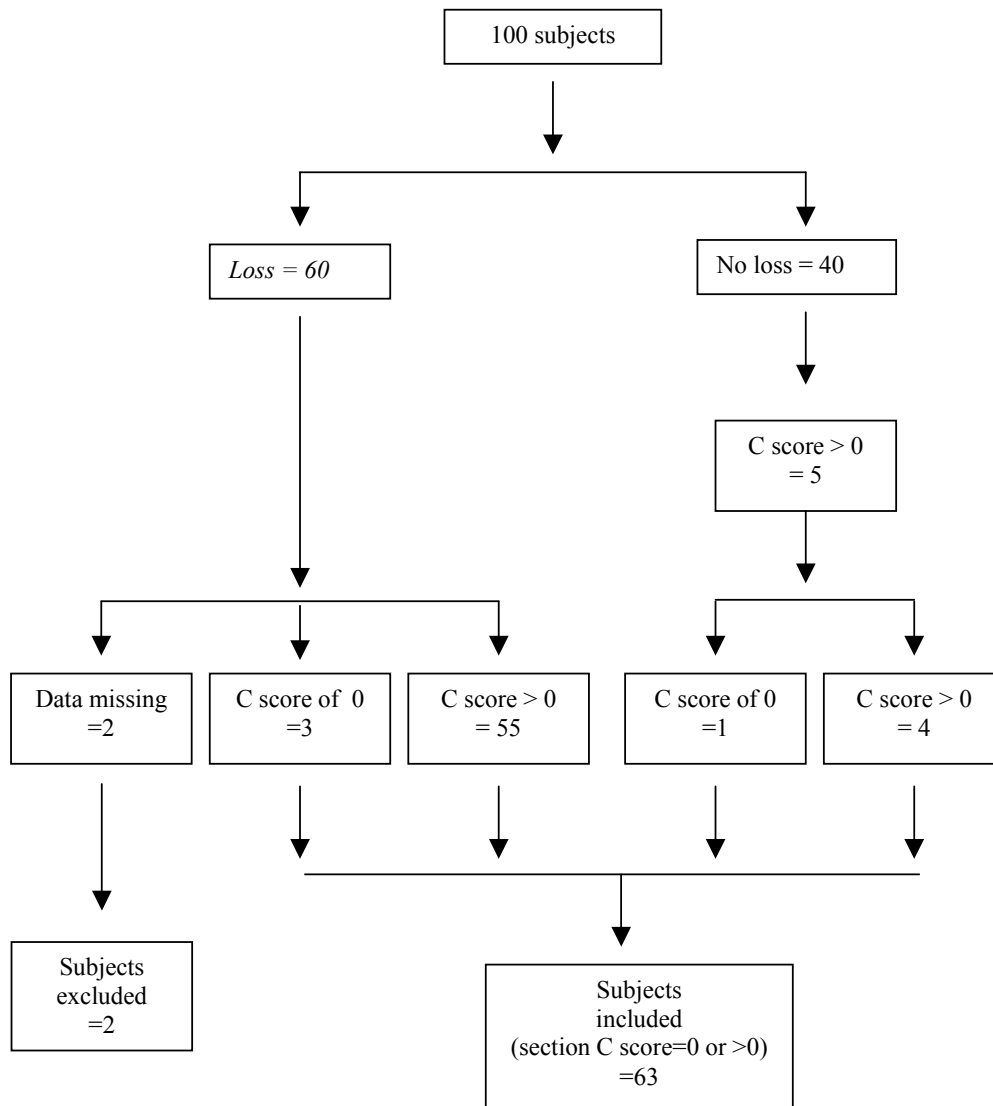
Data were checked by examining the range of codes for each data field to look for anomalies. All anomalies were checked against the original questionnaires or interview schedules. Data

from a random sample of 20 interview schedules and questionnaires were checked against the entered data by the chief investigator. In addition, contingency checking was carried out to determine the relationship between responses from the loss surveys and the grief measures of both questionnaire and interview. No inaccurate data entry was detected.

#### ***8.8.2.6 Section C data***

Several anomalies were detected in contingency checking of the questionnaire that determined which data were included in the analysis of section C (Figure 8.1). Sixty subjects recorded loss and would have been expected to complete the grief measure (section C). Of these, data were missing for two subjects. A section C score of zero was recorded for three and the remaining 55 had a section C score over zero. Data from these 58 subjects who recorded a section C score of zero and above were included in the analysis.

Of the 40 subjects who recorded no loss, five had completed the grief measure. One of these gained a grief score of zero and the other four had a score greater than zero. Checking the original questionnaires of these subjects confirmed the anomalies and no reason could be found. However, the interview loss reviews for the same subjects all detected losses so it was presumed that the interview record was the true record. The Section C scores for these five subjects were therefore also regarded as true and were included with the other 58 who recorded a loss, making a total of 63.



**Figure 8.1: Anomalies in data checking: questionnaire**

#### **8.8.2.7 Missing data**

Data missing from the data base were checked against the original questionnaire and interview schedules. Much of the data relating to the time since the loss were missing and a decision was made not to use these data fields in the analysis. Data relating to the ‘separation’ category were found missing from 60 interviews on the interview data base. On checking the original interview schedules, it was found that this category had been omitted. However, notes

made about other loss categories in the schedule, enabled deductions to be made for four subjects that a separation loss was a current issue for the subject and the appropriate changes were made on the data base. Apart from this omission, there were very few other missing data and, where they did occur, they occurred singly.

## **8.9 Data analysis**

The plan of the analysis of both the trial and evaluation data is shown in Table 8.6. The objectives of the analysis and the methods, tests and indicators are described in the rest of this chapter. The results of these tests are given in Chapter 9 for the trial and in Chapter 12 for the evaluation. The analyses of the results using the indicators listed in the table are given in Chapter 10 for the trial and Chapter 13 for the evaluation.

A few of the analyses noted in the table were performed on the evaluation data results only but are described here for completeness.

### **8.9.1 Objectives of the analysis**

The objectives of the data analysis follow from the objectives for the instruments (Introduction). The objectives of the analysis are described below.

**Objective 1: To examine and optimise the wording, format and acceptability of the interview and questionnaire**

The purpose of this was to improve the acceptability and validity of the interview and questionnaire (Objectives A –D for the instruments).

**Objective 2: To describe the demographic characteristics**

Demographic characteristics were produced to quantify the variables for the analyses for objectives 3, 4 and 5 below.

**Objective 3i: To determine new categories of loss and examples within categories**

The purpose was to improve the comprehensiveness of the loss reviews (Objectives A and B for the instruments).

**Objective 3ii: To describe and compare the detection of loss and loss categories between questionnaire and interview**

The purpose was to examine the ability of the questionnaire to detect grief compared to the interview as a gold standard (Objectives A and B).

**Objective 4: To examine the validity of the components of section C of the questionnaire to determine those items that best measure grief**

The purpose was to examine the items of Section C for which best measured grief, and whether withdrawal of any would increase the validity (Objective C).

**Objective 5: To examine the questionnaire for validity and reliability**

The loss review and grief measure of the questionnaire were examined for their validity and reliability (Objective D). Validity was defined as the ability of the instrument to measure what is was intended to detect and measure (Bowling, 1995), that is, loss and grief. The reliability was defined as the ability to produce consistent results on different occasions where there is no evidence of change (Bowling, 1995).

### **8.9.2 Methods used**

The methods used in the analysis are described in the following discussion and follow the order of Table 8.6.

**Table 8.6: Plan of analysis of data (part 1)**

Objectives of the instrument	Objectives of the analysis	Methods	Data collected/ tests	Indicator
A-D below	1. To examine and optimise the wording, format and acceptability of the questionnaire and interview.	Qualitative data collection and analysis	<p><b>Questionnaire:</b>  Comments about the questionnaire;  Difficulties in understanding the questions;  Suggestions for improving wording and format;  <b>Subjects' feelings about the content and acceptability.</b></p> <p><b>Interview:</b>  Subjects reactions to interview;  Comments of the interview process;  Observations of subjects.</p> <p><b>Team debriefs</b></p>	Common themes
	2. To describe the demographic characteristics to: i. Compare population studied with the Australian general practice population ii. Use in objectives 3ii-5.	Descriptive statistics	Age; Gender; Socio-economic cluster; Country of birth; Marital status; Educational attainment; Main occupation.	Population similar to the Australian general practice population



**Table 8.6: Plan of analysis of data (part 2)**

A. To detect the presence or absence of grief in general practice patients;	3. i To examine the loss data to determine new categories of loss and examples within categories	Qualitative data collection and analysis	New categories of loss New examples within categories	) ) from interview ) and ) questionnaire )	New data	
	and B. To determine the categories of loss causing grief	ii To examine the loss data to describe and compare the detection of loss and loss categories between interview and questionnaire	Descriptive statistics	i. The detection of loss	Numbers of subjects endorsing loss/ not endorsing loss	Comparison of questionnaire with interview data
ii. Multiples of loss				Mean number of loss categories per subject	Comparison between interview & questionnaire	
				Maximum number of loss categories		
iii. Loss categories by frequency				Types of loss categories detected	Non endorsement of a category would indicate the category not to be valid	
				Frequencies and rates of endorsement of categories Rankings of categories by rate of detection	Comparison of questionnaire with interview data	
iv. Loss by demographic grouping	Loss by age Multiples of loss by gender					

**Table 8.6: Plan of analysis of data (part 3)**

C. Measure the extant state of grief on these patients	4. Examine the validity of the components of Section C to determine those items that best measure grief	i. Face validity	% Frequency of zero endorsement	Proportion (p) of zero endorsement of option < 80%
		ii. Discriminatory validity	i. % Frequency of endorsement across options	Spread of endorsements across options Proportion (p) of endorsement of option <80%
			ii. Section C scores Set scores Item scores	) Range of scores ) demonstrated ) Significant median ) scores
		iii. Internal consistency	i. Section C sets	Cronbach's alpha 0.70-0.90
			ii. Sets with items withdrawn	(Cronbach's alpha – item) = or < alpha for set
			iii. Item to total score correlation	)
			iv. Correlation between sets	) Spearman's rho>0.70 )
		v. Factor analysis	Factors demonstrated	

**Table 8.6: Plan of analysis of data (part 4)**

D. Demonstrated validity and reliability	5. Examine the questionnaire for validity and reliability	Loss review	Criterion validity	i. Graphical representation of relationships between loss data sets	
				ii. Correlation between loss data sets	Spearman's rho>0.70
				iii. Agreements between loss data sets	Cohen's kappa
				iv. Sensitivities, specificities and predictive values	
			Construct validity	SEC & multiples of loss	Increasing multiples of loss with lower SEC
			Reliability- Test-retest (Evaluation only)	ii. Direct comparison	Absolute numbers
				iii. Correlation of the numbers of losses	Spearman's rho
				iv. Agreements between categories of loss.	Cohen's kappa
		Grief measure		Criterion validity with clinical score	Section C score Set scores Item scores
			Construct validity	i. Multiples of loss and section C scores	Higher section C scores with increasing multiples of loss
				ii. Gender & section C scores	Grief scores in females to be higher or equal to those of males.
			Test-retest reliability (Evaluation only)	Section C scores Set scores Item scores	) ) Spearman's rho>0.70 )
		Item validity (Evaluation only)	Correlations of repeated item	Spearman's rho>0.70	
		Overall	Bias	Demographic data of non-responders	Wilcoxon two-sample test

SEC = Socio-economic cluster

**8.9.2.1 Objective 1: To examine the wording, format and acceptability of the interview and questionnaire**

The following qualitative data (listed in Table 8.5) were examined for common themes:

**Questionnaire:**

- v. Comments about the questionnaire;
- vi. Difficulties in understanding the questions;
- vii. Suggestions for improving wording and format; and
- viii. Feelings about the content and acceptability;

**Interview:**

- xi. Subjects' reactions to interview;
- xii. Comments about the interview process; and
- xiii. Observations of subjects;

**General comments:**

- xiv. Team members' experiences.

**8.9.2.2 Objective 2: To describe the demographic characteristics**

Descriptive statistics were produced for the following demographic characteristics:

- Age;
- Gender;
- Country of birth;
- Socio-economic cluster;
- Marital status;
- Highest level of educational attainment; and
- Main occupation.

These data were used:

- to compare the study population with the Australian general practice population as found in the 1990-91 nation-wide audit of 113, 468 patient encounters (Bridges-Webb, Britt, Miles, Neary, Charles, & Traynor, 1992). This was used for comparison because it was one of the largest and most representative audits conducted in Australia prior to this present study;
- to compare the study population with the Adelaide metropolitan population as given in the Social Health Atlas of South Australia (Glover, Shand, Forster & Wollacot, 1996; Glover & Tennant, 1999); and
- for testing analysis objectives 3ii-5.

Median, minimum and maximum values were used to summarise the data because the data were not continuous and not normally distributed. Ordinal data were treated as interval data (Aday, 1996).

#### ***8.9.2.3 Objective 3i: To determine new categories of loss and examples within categories***

The following qualitative data listed in Table 8.5 were noted

from the questionnaire:

- iii. New categories of loss; and
- iv. New examples within categories;

and from the interview:

- ix. New categories of loss; and
- x. New examples within categories;

#### ***8.9.2.4 Objective 3ii: Describe and compare the detection of loss and loss categories between interview and questionnaire***

Descriptive statistics were produced for the following for the questionnaire and interview:

- i. Numbers of subjects endorsing/not endorsing loss;

- ii. Multiples of loss: Subjects endorsing more than one loss category:
  - Mean number of loss categories per subject;
  - Maximum number of loss categories per subject; and
  - Multiples of loss by interview and questionnaire.
- iii. Frequency of detection of categories:
  - Types of loss categories detected – non endorsement of a category would indicate the category not to be valid;
  - Frequencies and rates of endorsement of categories; and
  - Rankings of categories by rates of detection.
- iv. Percentage of each age group which endorsed each loss category.

Frequencies (F) were used to describe categorical data. Loss data described the number of loss categories, not the total number of losses (Chapter 8.8.2.4). Results of questionnaire data were compared with the interview. The results of the interview were regarded as the gold standard for reasons given in Chapter 6.3.

***8.9.2.5 Objective 4: To determine the validity of the components of Section C and to determine those items that best measure grief***

Components of section C of the questionnaire were examined for face validity, discriminatory validity and internal consistency. Each of these will now be described in turn. Their inclusion in the analysis arose from the principles of measurement of bereavement listed in Chapter 4.3.

**8.9.2.5.1 Face validity**

Face validity of a component determines whether the phenomenon it measures is central to the construct of grief (Streiner and Norman, 1995) and thereby fulfils the requirement of high face validity given in Chapter 4.3.2.

Such phenomena would be expected to be highly endorsed by subjects. High zero endorsement (i.e. endorsement of the response 0=never) would indicate the item is not relevant to the measurement of grief (Streiner & Norman, 1995). The frequencies of zero endorsement (i.e. endorsement of the response never=0) compared to positive endorsement (i.e. endorsements of the responses a little bit of the time=1, quite a bit of the time=2, a lot of the time=3) were examined. Items which had a zero endorsement of <80% were retained (Streiner & Norman, 1995).

#### 8.9.2.5.2 Discriminatory validity

Discriminatory validity of an instrument and its components determines whether these are able to distinguish across the whole spectrum of the severity of grief (Streiner & Norman, 1995) and thereby fulfils the requirements of the measure that the phenomena tapped by each item are measurable and change progressively over the course of the grieving process (Chapter 4.3). The two tests which generated information about the discriminatory validity of the measure are described below.

- i. The frequencies of endorsement of items for each alternative response (a little bit of the time=1, quite a bit of the time=2, a lot of the time=3) were examined to determine the spread of endorsements across the various options. The proportions (p) of subjects who endorsed each alternative response were examined to determine whether any one of these options were endorsed by the majority. This would indicate the item to be a poor discriminator in the measure. Items with endorsements of over 80% would indicate low discriminatory ability and would be withdrawn (Streiner & Norman, 1995).
- ii. A spread of scores over the possible range and significant median scores for section C, sets and items would indicate good discrimination of severity of grief (Streiner and Norman, 1995).

### 8.9.2.5.3 Internal consistency

Internal consistency demonstrates the degree to which components of a measure are related to each other (Streiner & Norman, 1995). If the internal consistency is high, the components are tapping aspects of the same condition rather than a different occurrence. This is another method of determining whether phenomena are core as well as determining compliance with some other requirements of measures, namely that phenomena tapped are present throughout the grieving process and are common across individual variations (Chapter 4.3). Four tests were performed to assess the internal consistency.

- i. Cronbach's alpha (Cronbach, 1951) was used to examine internal consistency of section C and its component sets. The following standards were used (Nunnally, 1978):

0.70-0.90 = optimal correlation

< 0.70 = less good correlation

>0.90 indicates items in the scale measure the same attribute and that some are redundant.

- ii. Alpha was also calculated for sets with each component item withdrawn in turn. This enabled the identification of items whose deletion would increase the correlation of the set and thereby increase its homogeneity. Alpha was calculated between each item and the total of the remaining items in its set. If the standardised alpha increased after removing the item, then deletion of that item would make the scale more reliable (Streiner & Norman, 1995).

- iii. Correlations were produced between item to total scores, that is, the correlation between an item and the section C score minus the score for that item;



Correlations were shown using Spearman's Rho because the data were interval in type and skewed, using the following standards (Weiten, 1998).

> 0.7 = high

0.3-0.7 = moderate

< 0.3 = low

iv. An exploratory varimax rotation analysis was used to investigate the inter-relationships of the items and to compare them with the given sets. The number of subjects required for a varimax analysis is 5-10 times the number of factors. The lower end of the range can be used only if there are a large number of variables for each factor and the communalities are high (Norman & Streiner, 2000). The number of subjects used in the present study is only 2.46 times the number of items, whereas over 200 subjects (8+ times the number of items) is optimal because of the low number of items in each set.

Thus, factor analysis was performed to explore the principal sets without drawing strong conclusions. Items were loaded onto a factor if they had a value above 0.3 and if this value was greater by 0.2 of their loading onto other factors (Tabachnick & Fidell, 2000).

#### ***8.9.2.6 Objective 5: Examine the questionnaire for validity and reliability***

The loss review (section B) and grief measure (section C) of the questionnaire will be described separately.

#### **LOSS REVIEW**

The loss review was examined for criterion validity, construct validity and reliability. Each of these will now be described in turn.

#### 8.9.2.6.1 Criterion validity

Criterion validity is a measure of the instrument under investigation to perform its task compared with another validated standard (Streiner and Norman, 1995). The interview was used as the standard in this study.

The loss data sets of the questionnaire and interview were compared by:

- i. graphical representation;
- ii. correlation using Spearman's Rho;
- iii. agreement using the kappa statistic.

Cohen's kappa (Cohen, 1968; Altman, 1991) was used to look for agreement between paired data. Kappa is 1.0 where agreement is perfect and zero where the agreement is that of chance. Values of 0.81-1.00 indicate very good agreement, 0.61-0.80 indicate good agreement, 0.41-0.60 show moderate agreement, 0.21-0.40 show agreement is fair and below 0.2 is poor agreement (Landis and Koch, 1977); and

- iv. sensitivities, specificities and predictive values.

As the interview was the gold standard against which the questionnaire was compared, it was assumed the interview correctly identified subjects experiencing loss and those not experiencing loss. Subjects found by the questionnaire and interview to be experiencing loss were true positives and those found not to be experiencing loss by both methods were true negatives. Subjects found by the questionnaire but not by the interview as endorsing loss were false positives. Subjects not identified by the questionnaire but identified by the interview were false negatives. Table 8.7 was used for the calculations (Abrahamson, 1990).

**Table 8.7: Table for calculating sensitivity and specificity**

<i>Questionnaire (test)</i>	<b>Interview (gold standard)</b>	
	<b>Loss</b>	<b>No loss</b>
<b>Loss</b>	TP	FP
<b>No loss</b>	FN	TN

Where TP = true positive  
 FP = false positive  
 TN = true negative  
 FN = false negative

The sensitivity of the questionnaire is a measure of its ability to correctly detect all subjects experiencing loss in a population with an assumed prevalence of loss. That is, it is the proportion of the population who are truly experiencing loss (as found by the gold standard interview) that is detected by the questionnaire, ie =  $TP/(TP+FN)$ .

The specificity of the questionnaire is a measure of its ability to correctly identify negative results. That is, it is the proportion of subjects who are truly not experiencing loss (as found by the gold standard interview) that was correctly identified by the questionnaire, ie =  $TN/(FP + TN)$ .

The predictive value of the questionnaire is a measure of its ability to correctly detect loss among a population with assumed prevalence of loss. That is, it is the proportion of all those detected by the questionnaire to be experiencing loss who truly were (as found by the gold standard interview), ie =  $TP / (TP + FP)$ .

#### 8.9.2.6.2 Construct validity

Construct validity was tested by examining demographic variables known to affect loss. It would be expected that there would be increasing multiples of loss with lower socio-

economic cluster because a higher number of adverse life events is associated with lower socio-economic status (Lima, Beria, Tomasi, Conceicao and Mari,1996). It could be conceived that loss, as a particular type of life event, would demonstrate an association.

The mean number of losses for each socio-economic cluster (SEC) was calculated to look for associations between them. The Kruskal-Wallis Test was used because there were more than two groups to be compared and the data were not normally distributed. A value  $p \leq 0.05$  indicated significant differences between multiple data (TexaSoft, 1996-2001).

#### 8.9.2.6.3 Reliability

The reliability of an instrument is a measure of the amount of error inherent in its quantification (Streiner and Norman, 1995). One method of determining the reliability is the test-retest method. This is used to make comparisons between results of the same test on the same sets of subjects at different intervals in time. The intervals should be large enough to prevent memory of the first test confounding the second, and small enough to assume constancy in the phenomena under investigation.

Reliability testing was conducted only for the evaluation questionnaire. The questionnaire was completed by the same subjects on two occasions (T1 and T2) one week apart. The interval of one week was chosen as this fell within the window period but provided a sufficient time interval for an assessment independent of memories of the first occasion. T1 was at the time of engaging in the study in the doctor's surgery. T2 was at home one week later (see Chapter 11.1.6 for details of the method). Analyses of the paired T1 and T2 loss data sets were carried out for each subject as follows:

- i. Direct comparison by absolute numbers;
- ii. Correlation between the numbers of losses using Spearman's rho;
- iii. Agreements between categories of loss using Cohen's kappa.

## GRIEF MEASURE

The grief measure was examined for criterion validity, construct validity, reliability and item validity. Each of these will now be described in turn.

### 8.9.2.6.4 Criterion validity

Criterion validity, was investigated by comparing the section C data set with results from the interview grief measure. Spearman's rho correlation coefficient was used to quantify the comparison using Weiten's (1998) standards given previously.

For each subject the following from the questionnaire were compared with the clinical scores obtained by interview.

- section C scores;
- set scores; and
- item scores.

### 8.9.2.6.5 Construct validity

Construct validity was tested by examining demographic variables known to affect the severity of grief:

- multiples of loss ;
- gender.

The following associations would be expected:

- i. higher grief scores with increasing multiples of loss as an established association between higher multiples of death losses and higher levels of grief (Parkes, 1998; Sanders, 1993) would also be expected to apply to non death losses.

ii. grief scores in females to be higher or equal to those of males as higher scores on bereavement grief scales have been found for females than males (Cleiren, 1993; Farberow, Gallagher-Thompson, Gilewski, Thompson, 1992a; Murphy, Johnson, Cain, Gupta, Dimond, Lohan & Baugher, 1998). However, Burnett, Middleton, Raphael & Martineck (1997) found no gender differences using the Core Bereavement Items which form a major contribution to the current measure under investigation. It would therefore hold that grief scores in females would be expected to be higher or equal to those of males, and not less. Being core to the construct of grief from any loss, this would also be expected to apply to non-death losses. However, this would only be true if other variables were equivalent for both genders, such as the multiples of loss, types of loss and time since loss.

The Wilcoxon Two Sample Test was used to compare two groups for data that were not normally distributed. The Wilcoxon null hypothesis is that there is no difference between paired data. When the Wilcoxon T value  $\leq 0.05$  the null hypothesis is rejected indicating significant difference between pairs (Gravetter & Wallnau, 1996).

The Kruskal-Wallis Test was used to compare three or more groups for data that were not normally distributed (where  $\leq 0.05$  indicates significant difference between multiple data (TexaSoft, 1996-2001).

#### 8.9.2.6.6 Reliability

Correlations were produced using for the various grief scores generated at T1 and T2 in the test-retest reliability study described above. Spearman's rho correlation coefficient were produced for the following:

- section C scores;
- set scores; and

- item scores

#### 8.9.2.6.7 Item validity

Item validity was determined for the evaluation questionnaire. The validity of Section C items was estimated by determining the Spearman's correlation coefficient value between two identical items of the evaluation questionnaire (C4 and C9) spaced apart in the questionnaire. Ideally the correlation between two identical items would be perfect (Spearman's  $\rho=1.00$ ). However, allowing for human variation in mood and memory, correlation may be less than perfect but would be expected to be the higher between two identical items than between any other two items of the instrument.

#### 8.9.2.6.8 Testing for bias

Possible non-response bias was tested by comparing demographic data of non-responders with subjects.

### 8.9.3 Preparation for analysis of the quantitative data

A measurement matrix (Table 8.8) was drawn up to demonstrate how each section of the interview and questionnaire addressed the objectives of the analysis shown in Table 8.6 above and to show the levels of measurement.

**Table 8.8: Measurement matrix**

Section of questionnaire/ interview	Questionnaire section	Level of measurement	Interview section	Level of measurement	Objectives of the analysis (Table 8.6)
<b>Demographics</b>	Demographic section (section A)	Nominal	-	-	2
<b>Loss survey</b>	Loss survey (section B)	Nominal	Loss survey	Nominal	3ii, 5
<b>Grief measure</b>	Grief measure (section C)	Ordinal	Grief measure	Ordinal	4, 5

Mock tables were created to display the information that would be required from the analysis, and how that information would be presented in writing up the results. The relevant fields on the ACCESS database were exported to the statistical package SAS (SAS Institute Inc.,1998) for analysis. For purposes of data analysis, categories that had been expanded into more than one question in the interview schedule and questionnaire were collapsed back into one category. Numerical scales that were reversed were modified so they appeared in order of magnitude consistent with the meaning of the response options. Similarly, scales were altered to commence at zero where the meaning of the first item implied a null value. Ordinal data were treated as interval data in the analysis as described by Aday (1996). Section C scores, set scores and item scores, as defined in Chapter 7.3.4.2 were produced. Clinical scores for the categories defined in Chapter 5.1.3.11 were generated as described in Chapter 8.8.2.4.

### ***8.10 Summary***

The methods used in the trial stage of the questionnaire and interview, incorporating the principles from the methodological issues given in Chapter 4, have been described. In particular, this chapter has given the plan for the data analysis which forms the basis of the presentation of results and of the analyses of these results for the trial and evaluation. The results of the trial are presented in the next chapter.



## Chapter 9: Trial: Results

This chapter gives the results from the trial of the questionnaire and interview, the method of which is described in the previous chapter. The results are presented in order of the plan of analysis given in Table 8.6 and described in Chapter 8.9.2.

### ***9.1 Wording, format and acceptability of the questionnaire and interview***

#### ***(Objective 1)***

##### **9.1.1 Questionnaire**

**The qualitative data for the questionnaire are shown in Appendix 9.1.**

##### **9.1.2 Interview**

**The qualitative data for the interview are shown in Appendix 9.2.**

##### **9.1.3 Team debriefs**

**Qualitative data from team debriefs are shown in Appendix 9.3.**

### ***9.2 Demographic characteristics (Objective 2)***

**These are presented in Chapter 8.7.3.**

### ***9.3 New categories of loss and examples within categories (Objective 3i)***

Table 9.1 shows the one new category and the examples identified during the trial of the interview.

**Table 9.1: New categories of loss and examples within categories: trial**

	<b>Questionnaire</b>	<b>Interview</b>
<b>New category of loss</b>	-	‘adoption/fostering’. Example: ‘being or caring for an adopted/fostered child’.
<b>New examples of loss</b>	-	‘illness’ ) in ‘job’ ‘birth of a ) category. baby’

#### **9.4 Descriptive statistics for the loss data (Objective 3ii)**

**Questionnaire and interview results will be presented consecutively for each analysis of the loss data. As much of the data relating to the time since the loss was missing from the evaluation questionnaires, this field was not analysed (Chapter 8.8.2.7).**

##### **9.4.1 The detection of loss**

**Loss surveys counted the number of loss categories endorsed by subjects and not the number of losses (Chapter 8.8.2.4). The questionnaire identified 60 (60%; N=100) subjects who endorsed one or more loss categories. Forty (40%) subjects did not endorse any loss category. The interview identified 74 (74%) subjects who endorsed one or more loss categories and 26 (26%) subjects who did not endorse any loss category.**

##### **9.4.2 Multiples of loss**

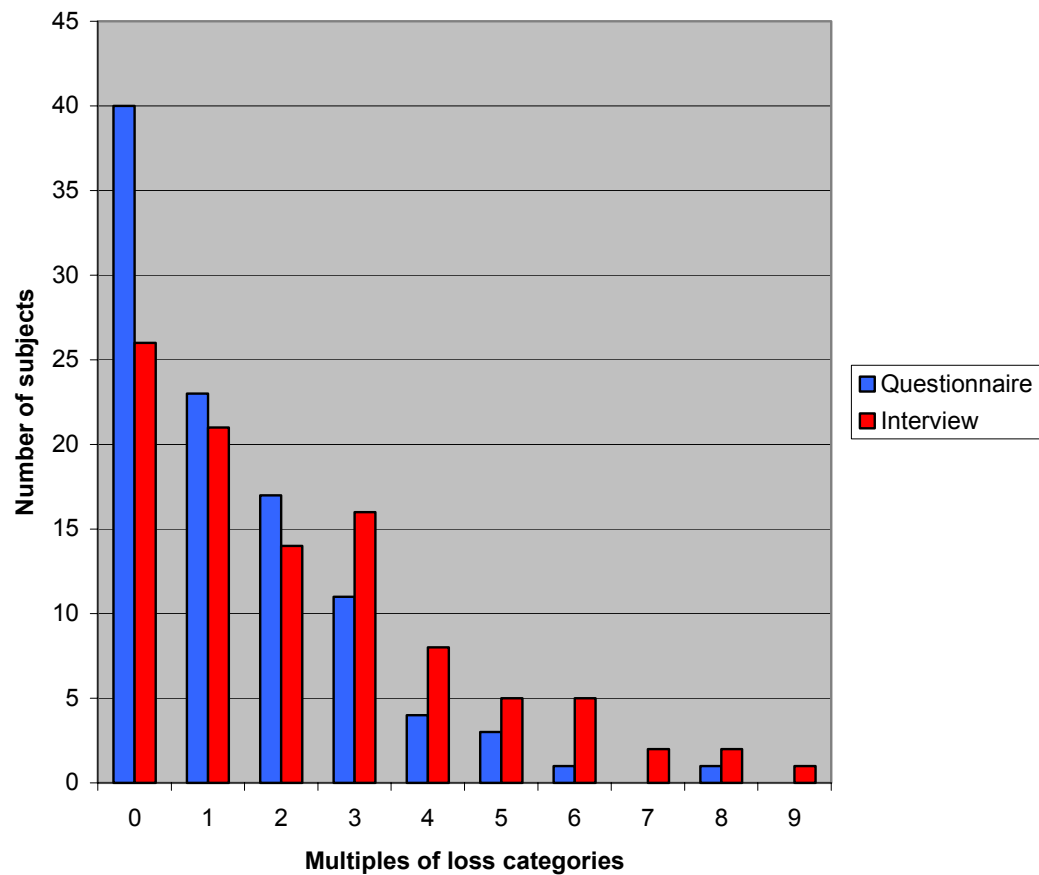
Table 9.2 shows the numbers of loss categories endorsed by subjects in both the questionnaire and interview. The 60 subjects, identified by the questionnaire to be experiencing loss, endorsed a total of 135 loss categories between them (mean loss categories per grieving subject = 2.25). Twenty-three of the 60 subjects indicated one loss category, seventeen indicated two categories, eleven indicated three and a decreasing number indicated up to eight categories.

The 74 subjects found by the interview to be experiencing loss identified a total of 223 loss categories between them (mean losses per grieving subject = 3.0). The interview identified

more subjects grieving a higher number of loss categories than did the questionnaire (Table 9.2 and Figure 9.1).

**Table 9.2: Numbers of loss categories endorsed by the 100 subjects by interview and questionnaire**

<b>Multiples of loss categories</b>	<b>Questionnaire</b>		<b>Interview</b>	
	<b>Subjects N=</b>	<b>Losses per category</b>	<b>Subjects N=</b>	<b>Losses per category</b>
<b>0</b>	40	0	26	0
<b>1</b>	23	23	21	21
<b>2</b>	17	34	14	28
<b>3</b>	11	33	16	48
<b>4</b>	4	16	8	32
<b>5</b>	3	15	5	25
<b>6</b>	1	6	5	30
<b>7</b>	0	0	2	14
<b>8</b>	1	8	2	16
<b>9</b>	0	0	1	9
<b>Mean</b>		2.25		3.0
<b>Total</b>	100	135	100	223



**Figure 9.1: Multiples of loss categories by questionnaire and interview**

### 9.4.3 Loss categories by frequency

#### 9.4.3.1 Types of loss

All of the twelve categories of loss were endorsed by both the questionnaire and interview (Table 9.3). Therefore all categories were valid.

#### 9.4.3.2 Frequencies and rates of endorsement of categories

The frequencies (F) and rates of endorsement of categories are shown in Table 9.3. All categories had a higher or equal rate of endorsement by interview than by questionnaire. No categories were more highly endorsed by the questionnaire. The differences in the rates of detection of 'separation' by questionnaire and interview may be distorted because of the low

numbers of subjects (N=44) for this category in the interview (see notes below table). The differences in detection of loss by questionnaire and interview are demonstrated in Figure 9.2. Low frequencies in many categories require that the results be interpreted with caution. However it is notable that a five-fold increase was found in the detection of ‘migration’ by interview than by questionnaire.

Only 13% of all losses identified by questionnaire and 11% of all losses identified by interview were ‘death’ losses (death of a significant other). A further 6% of losses identified by questionnaire and 5% of losses identified by interview were ‘fear of own death’. Therefore a total of 19% of losses identified by questionnaire and 16% identified by interview concerned death-related loss. The remaining losses concerned non-death related loss. These figures are only approximate because of incomplete data in the ‘separation’ and ‘adoption/fostering categories (as explained under Table 9.3).

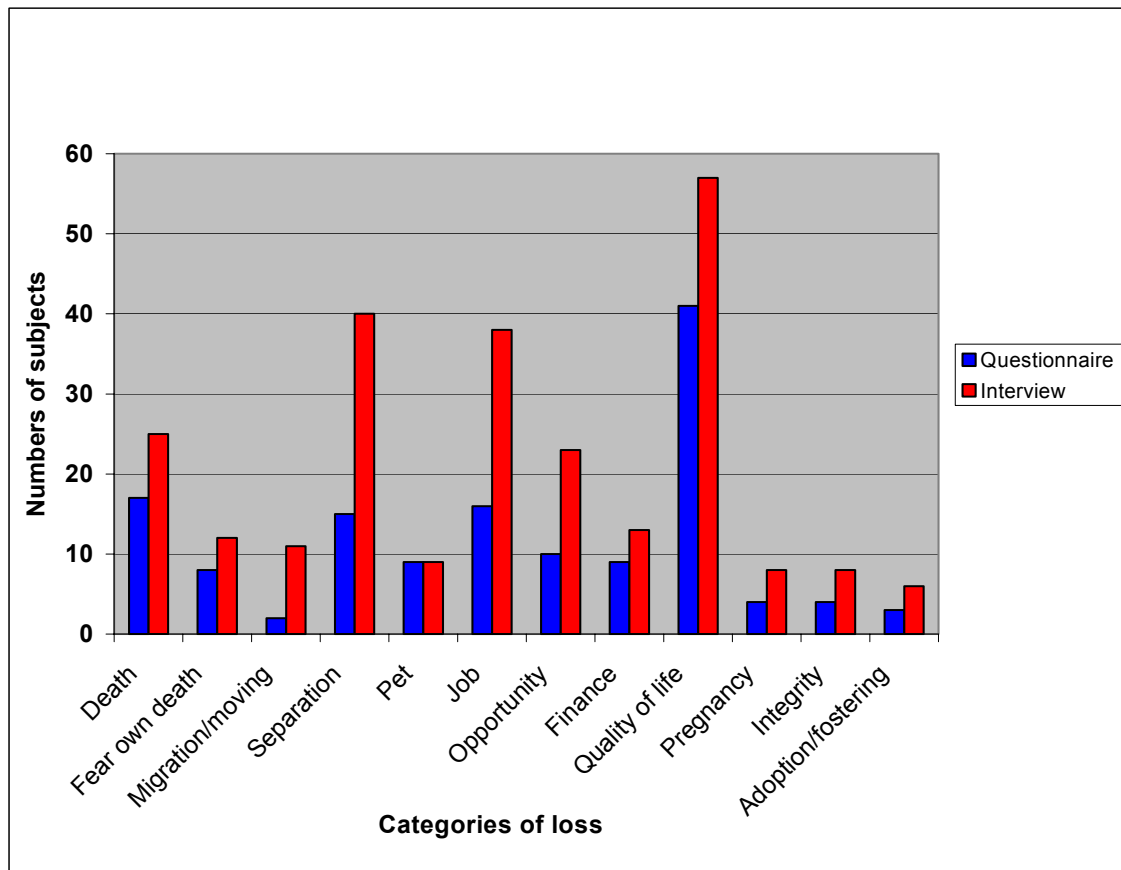
**Table 9.3: Frequencies (F) and rates endorsement of loss categories by questionnaire and interview**

Loss category (type)	Questionnaire*		Interview**	
	F	Rate (% subjects)	F	Rate (% subjects)
<b>Death</b>	17	17	25	25
<b>Fear own death</b>	8	8	12	12
<b>Migration/ moving house</b>	2	2	11	11
<b>Separation</b>	15	15	17	40
<b>Pet</b>	9	9	9	9
<b>Job</b>	16	16	38	38
<b>Opportunity</b>	10	10	23	23
<b>Finance/property</b>	9	9	13	13
<b>Quality of life</b>	40	41	57	57
<b>Pregnancy</b>	4	4	8	8
<b>Integrity</b>	4	4	8	8
<b>Adoption/ fostering</b>	1	3	2	6
<b>Total number of losses</b>	135		223	

*Frequencies and rates are corrected to nearest whole numbers.*

*\* Number of subjects (N) = 98 for all loss categories except for opportunity (N = 97) and adoption/fostering (N = 34; category added during the trial).*

*\*\* N = 100 except for integrity (N = 99), separation (N = 44; questionnaire error – Chapter 8.8.2.7) and adoption/fostering (N = 35; category added during trial).*



**Figure 9.2: Rates of endorsement of loss categories by questionnaire and interview**

#### *9.4.3.3 Rankings of detection of categories*

The order of rates of detection of categories differed little between questionnaire and interview (Table 9.4). The same loss categories, ‘quality of life’, ‘death’, ‘separation’ and ‘job’, had a high rate of endorsement by both methods. Similarly, ‘opportunity’ ‘finance/property’, ‘pet’ and ‘fear of own death’ were in the middle range of endorsement by both questionnaire and interview. With the exception of ‘migration/moving house’, the same categories were in the lower range of endorsement: ‘integrity’, ‘pregnancy’ and ‘adoption/fostering’.

**Table 9.4: Loss categories in descending order of rate of endorsement by questionnaire and by interview**

	Questionnaire		Interview	
	Loss category in rank order	% subjects	Loss category in rank order	% subjects
<b>High</b>	<b>1. Quality of life</b>	41	<b>1. Quality of life</b>	57
	<b>2. Death</b>	17	<b>2. Separation</b>	39
	<b>3. Job</b>	16	<b>3. Job</b>	38
	<b>4. Separation</b>	15	<b>4. Death</b>	25
<b>Middle</b>	<b>5. Opportunity</b>	10	<b>5. Opportunity</b>	23
	<b>6. Finance/property</b>	9	<b>6. Finance/property</b>	13
	<b>7. Pet</b>	9	<b>7. Fear own death</b>	12
	<b>8. Fear own death</b>	8	<b>8. Migration/moving house</b>	11
<b>Low</b>	<b>9. Pregnancy</b>	4	<b>9. Pet</b>	9
	<b>10. Integrity</b>	4	<b>10. Integrity</b>	8
	<b>11. Adoption/fostering</b>	3	<b>11. Pregnancy</b>	8
	<b>12. Migration/moving house</b>	2	<b>12. Adoption/fostering</b>	6

**9.4.3.4 Loss by demographic grouping**

Loss endorsement by each age group is shown in Table 9.5. Although all age groups were affected by loss, no general conclusions can be drawn because of the small numbers of subjects. The same median number of losses was experienced by males and females (Table 9.6).

**Table 9.5: Loss by age (questionnaire)**

Age	Loss	No loss	Total
16-24	3	1	4
25-34	8	10	18
35-44	20	10	30
45-54	11	6	17
55-64	5	4	9
65-74	10	4	14
75-84	3	5	8
Total	60	40	100

**Table 9.6: Multiples of loss by gender**

<b>Gender</b>	<b>N=97</b>	<b>Median</b>	<b>Mean</b>	<b>SD</b>	<b>Min</b>	<b>Max</b>
Male	35	1	1	1	0	5
Female	62	1	1	2	0	8

The associations between numbers of loss categories and socio-economic cluster are given later in this section under construct validity (Chapter 9.6.2.1).

### ***9.5 Validity of the components of Section C (Objective 4)***

The results are given below for the 63 subjects who gained a section C score of 0 or >0 as explained in Figure 8.1 (Chapter 8.8.2.6).

Section C, set and item scores are defined in Chapter 7.3.4.2.

Item numbers refer to the item number in the trial questionnaire (Appendix 7.3) and not the item code number.

#### **9.5.1 Face validity**

##### ***9.5.1.1 Zero endorsement of items***

The percent frequencies of endorsement of each alternative response for items, that is, the proportions of subjects (p) who endorsed the responses never=0, a little bit of the time=1, quite a bit of the time=2, a lot of the time=3, are shown in Table 9.7. No item has a proportion of zero endorsement, that is, endorsement of the response never=0 greater than the recommended 80%. Therefore all items are relevant to the measure. The frequency of zero endorsement is highest for items C16 (72%) and C25 (71%) indicating the phenomena they were tapping were less frequently experienced than phenomena measured by other items. Error is magnified in percenting the frequencies because of the small number of subjects (63).



## **9.5.2 Discriminatory validity**

### *9.5.2.1 Percent frequencies of endorsement across options*

**Table 9.7 shows that the proportions (p) of endorsement of each alternative response is less than the recommended 80%. There is a decrease in the frequency of scoring across options 1, 2 and 3 as would be expected.**

**Table 9.7: Percent frequencies of endorsement of alternative responses of section C items (N=63)**

Section C item  (number refers to order in trial questionnaire)	Proportion (p) of subjects who endorsed alternative responses			
	Never= 0	A little bit of the time=1	Quite a bit of the time=2	A lot of the time=3
C1	18	50	20	12
C2	25	50	20	5
C3	17	48	25	10
C4	53	30	8	8
C5	12	65	18	5
C6	10	58	22	10
C7	8	55	28	8
C8	25	43	20	12
C9	22	48	22	8
C10	48	29	13	11
C11	23	56	14	7
C12	30	46	19	5
C13	40	42	12	5
C14	43	41	12	4
C15	55	25	14	5
C16	72	18	5	5
C17	30	51	11	9
C18	23	53	16	9
C19	48	37	7	8
C20	58	27	7	8
C21	41	44	8	7
C22	39	40	15	7
C23	44	40	8	8
C24	40	43	10	8
C25	71	18	12	0
C26	28	50	12	10

**9.5.2.2 Section C scores**

Section C scores for subjects are shown in Table 9.8 where the tens and units columns represent the scores of subjects. For example, five subjects gained scores in the range 30-39: 30, 31, 32, 36, and 39. Section C scores were spread over almost the whole range of possible

scores, with most in the mid and lower ranges. The highest score of 72 was just below the maximum of 78.

**Table 9.8: Section C scores (N=63)**

Sections C scores		Numbers of subjects
Tens	Units	
7		0
7	2	1
6		0
6	24	2
5	568	3
5		0
4	59	2
4	223	3
3	69	2
3	012	3
2	6778	4
2	001122334444	12
1	566667899	9
1	001333444	9
0	5567779	7
0	000014	6
		Total=63

The median, mean, standard deviation (SD), range and percent frequency of scores for section C are given in Table 9.9. The skewness of 1.0 confirms the tail of higher scores demonstrated in Table 9.8 above. The median and quartile scores confirm that most scores are in the lower range.

**Table 9.9: Descriptive statistics for section C scores**

N	Mean	Median	SD	Range	25% Quartile	75% Quartile	Distributi on
63	22.97	20.00	17.12	0-72	11.00	30.00	Skewness = 1.00

### 9.5.2.3 Set scores

Descriptive statistics for set scores (average of the scores for the component items: Chapter 7.3.4.2) are shown in Table 9.10. Out of a possible total maximum of 3.00, the median for the sets varied between 0.57 for 'non-resolution' and 1.00 for 'images and thoughts'. These figures are consistent with the lower and middle range scores demonstrated in Table 9.8. Maximum scores were attained for all sets except for non-resolution and acute separation.

**Table 9.10: Descriptive statistics for set average scores**

<b>Sets</b>	<b>N</b>	<b>Median</b>	<b>Mean</b>	<b>SD</b>	<b>Min</b>	<b>Max</b>
<b>General distress</b>	62	0.70	0.94	0.74	0	3.00
<b>Images &amp; thoughts</b>	61	1.00	1.08	0.69	0	3.00
<b>Non-resolution</b>	63	0.57	0.70	0.68	0	2.57
<b>Acute separation</b>	62	0.75	0.89	0.71	0	2.75
<b>Grief</b>	62	0.80	0.88	0.70	0	3.00

### 9.5.2.4 Item scores

Descriptive statistics for section C items are given in Table 9.11. All items recorded a spread of scores over the possible range of 0 to 3.00 except one item (C25: imagining that the loss has not or will not occur), which recorded a maximum of 2.00. This indicated that C 25 was less discriminatory over the whole range of intensities of grief. Additionally, the median for all items was 1.00 except for the following four items: feelings of guilt (C4), numbness (C16), physical symptoms (C20) and C25, which all had medians of 1.00. The standard deviations demonstrated the wide spread of scores across the options.

**Table 9.11: Descriptive statistics for section C items**

	<b>N</b>	<b>Median</b>	<b>SD</b>	<b>Min</b>	<b>Max</b>
C1	60	1.00	0.89	0.00	3.00
C2	60	1.00	0.81	0.00	3.00
C3	60	1.00	0.87	0.00	3.00
C4	60	0.00	0.94	0.00	3.00
C5	60	1.00	0.69	0.00	3.00
C6	60	1.00	0.79	0.00	3.00
C7	60	1.00	0.76	0.00	3.00
C8	60	1.00	0.95	0.00	3.00
C9	60	1.00	0.87	0.00	3.00
C10	56	1.00	1.02	0.00	3.00
C11	57	1.00	0.81	0.00	3.00
C12	57	1.00	0.85	0.00	3.00
C13	57	1.00	0.85	0.00	3.00
C14	58	1.00	0.80	0.00	3.00
C15	56	1.00	0.91	0.00	3.00
C16	57	0.00	0.82	0.00	3.00
C17	57	1.00	0.88	0.00	3.00
C18	57	1.00	0.86	0.00	3.00
C19	60	1.00	0.91	0.00	3.00
C20	60	0.00	0.94	0.00	3.00
C21	61	1.00	0.85	0.00	3.00
C22	62	1.00	0.89	0.00	3.00
C23	62	1.00	0.90	0.00	3.00
C24	61	1.00	0.90	0.00	3.00
C25	61	0.00	0.69	0.00	2.00
C26	60	1.00	0.90	0.00	3.00

### **9.5.3 Internal consistency**

#### **9.5.3.1 Section C**

Cronbach's alpha (Cronbach, 1951) of 0.97, indicated very high internal consistency.

#### **9.5.3.2 Sets**

Cronbach's alphas for sets were high. All were within the acceptable range of 0.70-0.90

(Table 9.12), except for the 'Non resolution' set with an alpha of 0.91, which is marginally

above the recommended maximum but is regarded as acceptable.

**Table 9.12: Cronbach's alpha for sets**

<b>Set</b>	<b>Cronbach's alpha</b>
<b>General</b>	0.89
<b>Images and thoughts</b>	0.90
<b>Non-resolution</b>	0.91
<b>Acute separation</b>	0.82
<b>Grief</b>	0.89

**9.5.3.3 Sets with items withdrawn**

Cronbach's alpha was calculated between each item and the total of the remaining items in its set in order to identify items to be deleted. Table 9.13 shows the alpha for the set when each item is deleted in turn. Comparison with the alpha for the whole set in Table 9.12, shows that in general the alpha is decreased or remains the same by deletion of the item, indicating consistency of the set. In three cases the alpha increases: by removing C5 from 'images and thoughts' set, C25 from the 'acute separation', and C21 from the 'grief' set. These are starred in the table.

**Table 9.13: Cronbach's alpha for sets with items deleted**

**General set**

<b>Deleted item</b>	<b>Alpha</b>
<b>C1</b>	0.89
<b>C6</b>	0.89
<b>C10</b>	0.84
<b>C20</b>	0.85
<b>C23</b>	0.84

**Images and thoughts set**

<b>Deleted item</b>	<b>Alpha</b>
<b>C2</b>	0.89
<b>C3</b>	0.90
<b>C5</b>	0.91*
<b>C7</b>	0.90
<b>C26</b>	0.90

#### Non-resolution set

Deleted item	Alpha
C4	0.89
C12	0.89
C14	0.89
C15	0.89
C16	0.88
C17	0.90
C19	0.89

#### Acute separation set

Deleted item	Alpha
C8	0.74
C9	0.73
C22	0.81
C25	0.88*

#### Grief set

Deleted item	Alpha
C11	0.86
C24	0.84
C13	0.86
C18	0.85
C21	0.91*

\* indicates deletion of this item would raise the alpha for the set

#### 9.5.3.4 Item to total score correlation

The relationships of each item with the sum of the remaining items in section C (section C score minus the score for that item) are shown using Spearman's rho and Cronbach's alpha (Table 9.14). High values of Cronbach's alpha were obtained for all items. High values of Spearman's rho ( $=$  or  $>0.70$ ) were obtained for 21 items indicating close association between them and the whole instrument. A further four items (C1, C17, C19 and C21) showed moderately high correlation ( $\rho=0.66-0.69$ ). C25 showed moderate correlation (0.49)

**Table 9.14: Relationships between section C items and the rest of section C (p<0.0001)**

<b>Deleted item</b>	<b>Spearman's rho</b>	<b>Cronbach's alpha</b>
C1	0.66	0.97
C2	0.83	0.97
C3	0.82	0.97
C4	0.71	0.97
C5	0.75	0.97
C6	0.77	0.97
C7	0.75	0.97
C8	0.82	0.97
C9	0.84	0.97
C10	0.80	0.97
C11	0.78	0.97
C12	0.75	0.97
C13	0.74	0.97
C14	0.70	0.97
C15	0.75	0.97
C16	0.81	0.97
C17	0.69	0.97
C18	0.77	0.97
C19	0.66	0.97
C20	0.77	0.97
C21	0.66	0.97
C22	0.77	0.97
C23	0.83	0.97
C24	0.85	0.97
C25	0.49	0.97
C26	0.86	0.97

**9.5.3.5 Correlation between the sets**

Correlations between the sets using Spearman's rho are shown in Table 9.15. All sets correlate highly with each other, ranging from 0.87 to 0.68 signifying they are measuring phenomena that are inter-related.



**Table 9.15: Spearman’s Rho correlations between sets (p<0.0001)**

	<b>General distress</b>	<b>Images &amp; thoughts</b>	<b>Non-resolution</b>	<b>Acute separation</b>
<b>General distress</b>				
<b>Images &amp; thoughts</b>	0.83			
<b>Non-resolution</b>	0.78	0.84		
<b>Acute separation</b>	0.77	0.87	0.74	
<b>Grief</b>	0.68	0.81	0.82	0.78

**9.5.3.6 Factor analysis**

An exploratory varimax rotation analysis was used to investigate the inter-relationships of the items and to compare them with the given sets.

Table 9.16 shows the items fall into four factors. Items that loaded onto a factor are shown by shaded cells. Thirteen items load onto one of the factors. All remaining items load onto two or more factors, so it was not clear to which factor they were most related. For example, C6 loads onto factors one and three. There is support for a ‘Grief’ set (two items loaded onto factor 1), a ‘Non-resolution’ set (three items loaded onto factor 2 and an ‘Images and thoughts’ set (two items loaded onto factor 3). No strong conclusions can be drawn because of the small sample size (N=63). The analysis needs to be repeated on a minimum sample of 8 X 26 = 208 subjects with loss, as described in Chapter 8.9.2.5.3iv.

**Table 9.16: Factor analysis of section C items (N=63)**

<i>Set</i>	<b>Item number</b>	<b>Factor 1</b>	<b>Factor 2</b>	<b>Factor 3</b>	<b>Factor 4</b>
<b>General</b>	<b>C1</b>	0.00	0.26	0.77	0.42
	<b>C6</b>	0.60	0.17	0.61	0.07
	<b>C10</b>	0.54	0.45	0.10	0.58
	<b>C20</b>	0.44	0.64	0.15	0.29
	<b>C23</b>	0.49	0.58	0.14	0.50
<b>Images &amp; thoughts</b>	<b>C2</b>	0.56	0.18	0.45	0.48
	<b>C3</b>	0.41	0.40	0.42	0.44
	<b>C5</b>	0.31	0.28	0.77	0.11
	<b>C7</b>	0.49	0.04	0.77	0.24
	<b>C26</b>	0.59	0.48	0.32	0.25
<b>Non-resolution</b>	<i>C4</i>	0.22	0.75	0.28	0.11
	<b>C12</b>	0.63	0.44	0.25	0.16
	<b>C14</b>	0.19	0.71	0.30	0.28
	<b>C15</b>	0.46	0.50	0.19	0.45
	<b>C16</b>	0.58	0.60	0.11	0.34
	<b>C17</b>	0.27	0.38	0.59	0.16
	<b>C19</b>	0.20	0.70	0.21	0.22
<b>Acute separation</b>	<b>C8</b>	0.46	0.25	0.51	0.50
	<b>C9</b>	0.50	0.33	0.59	0.28
	<b>C22</b>	0.81	0.25	0.28	0.09
	<b>C25</b>	0.09	0.19	0.18	0.69
<b>Grief</b>	<b>11</b>	0.77	0.19	0.35	0.22
	<b>13</b>	0.56	0.39	0.30	0.28
	<b>18</b>	0.61	0.31	0.54	0.05
	<b>21</b>	0.30	0.53	0.55	-0.22
	<b>24</b>	0.77	0.38	0.29	0.19

## **9.6 Validity and reliability of the questionnaire (Objective 5)**

**Results will be given for the loss review followed by those for the grief measure and finally, those for the questionnaire as a whole.**

### **LOSS REVIEW**

#### **9.6.1 Criterion validity**

##### ***9.6.1.1 Graphical representation of relationships between loss data***

Figure 9.3 shows the relationships between the numbers of loss categories found by questionnaire and interview for subjects. Absolute agreements between subjects' questionnaire and interview loss data lie on the line that bisects the axes (31 subjects). Increasing distance from the line indicates increasingly lower agreement. There are 18 subjects above the bisector indicating these subjects scored more losses by questionnaire than by interview. Compared to this, there are 51 subjects below the bisector, indicating these subjects scored more losses by interview than by questionnaire. In particular, the wide scatter of many of these subjects from the bisector indicates the greater ability of the interview to detect higher multiples of loss than the questionnaire.

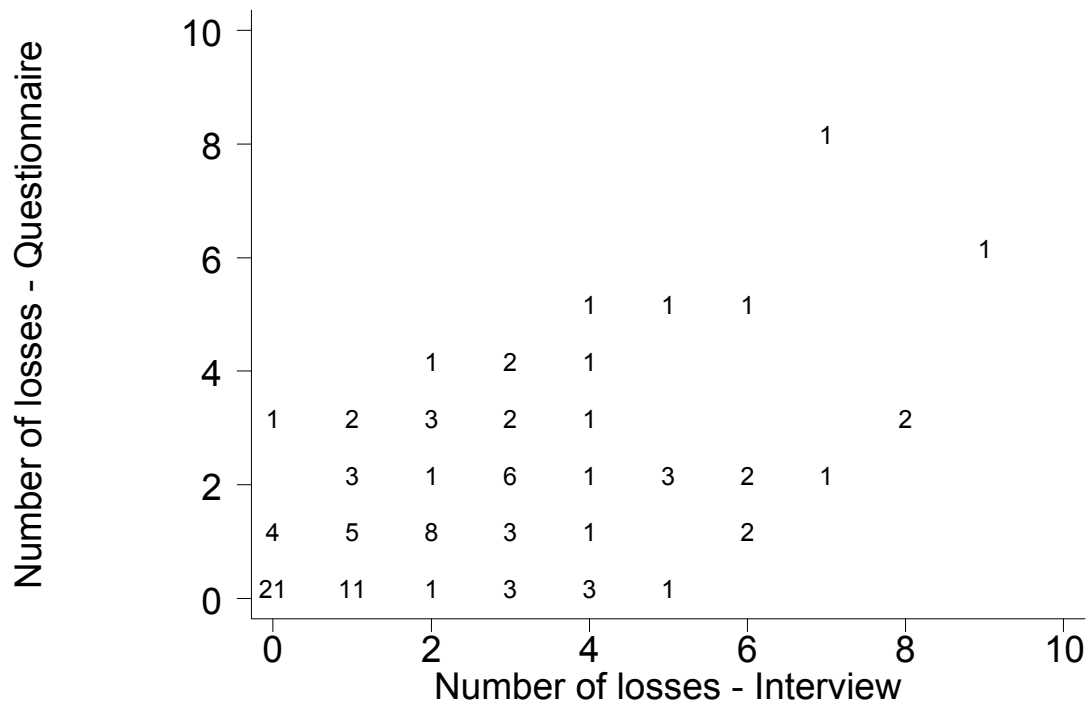


Figure 9.3: Subjects' responses by questionnaire and interview (N=100)

#### 9.6.1.2 Correlation between loss data sets

Spearman's rho was 0.59 ( $p=0.0001$ ) between all questionnaire and interview loss data for all 100 subjects, indicating moderate correlation.

#### 9.6.1.3 Agreements between loss data sets

The kappa statistic was used to test agreement between the paired questionnaire and interview data for the whole loss data sets and for each category of loss (Table 9.17). Using the gradings of Landis and Koch (1977) (Chapter 8.9.2.6.1), agreement for the whole data set was moderate (0.47). For individual categories there was:

- good agreement for 'pregnancy', 'pet' and 'adoption/fostering';
- moderate agreement for 'quality of life', 'job', 'fear of own death', and 'opportunity';
- fair agreement for 'death', 'finance' and 'integrity'; and
- agreement was found for the 'moving/migration' and 'separation' to be less than zero.

The lack of agreement for the 'migration/moving' category is consistent with the wide

separation for these categories in the rankings of detection by questionnaire and interview (Table 9.4).

**Table 9.17: Loss data: Agreements between questionnaire and interview (Cohen's kappa).**

Loss category	N	Kappa	95% confidence limits
All categories	100	0.47*	0.30-0.64
Quality of life	98	0.42*	0.25-0.59
Separation	43	0.18	-0.11-0.47
Job	98	0.44*	0.27-0.61
Death	98	0.34*	0.12-0.56
Fear own death	98	0.56*	0.28-0.83
Opportunity	97	0.44*	0.21-0.67
Finance	98	0.39*	0.11-0.67
Migration/ moving	98	0.28	-0.03-0.59
Pregnancy	98	0.65*	0.33-0.96
Pet	99	0.63*	0.36-0.90
Integrity	97	0.30*	0.06-0.64
Adoption	33	0.65*	0.02-1.28

\* indicates significant agreement between questionnaire and interview data

#### **9.6.1.4 Sensitivities, specificities and predictive values**

Table 9.18 shows sensitivities, specificities and predictive values for section B of the questionnaire (loss review) relative to the interview data.

**The sensitivity of section B was 74% indicating that it correctly identified 74% of cases of loss determined by the interview and missed 26% of cases. This is consistent with the recognised difficulties in detecting loss (Chapter 4.2.1). The specificity for section B was 80% indicating it correctly identified 80% of subjects who did not experience grief as determined by the interview. The predictive value of section B was 92% indicating it was accurate in identifying true loss.**

**When examining the individual categories, the small numbers of subjects imply that no strong conclusions can be drawn. Sensitivities for the separate categories demonstrate a wide range (18-67%) and are shown in descending order of sensitivity in the table. The specificities for the separate categories of section B were high (range 85-100%), which indicated that endorsement of a category may be highly specific for loss relating to that category. Predictive values vary widely between 50-100%.**

**Table 9.18: Sensitivities, specificities and predictive values for loss categories**

Section B/ Category	Subjects N=	Sensitivity (%)	Specificity (%)	Predictive value (%)
<b>Section B</b>	100	74	80	92
<b>Pet</b>	9	67	97	67
<b>Opportunity</b>	10	61	97	80
<b>Quality of life</b>	40	60	84	83
<b>Pregnancy</b>	4	50	100	100
<b>Fear of own death</b>	8	50	98	75
<b>Adoption</b>	1	50	100	100
<b>Job</b>	16	41	98	94
<b>Death</b>	17	40	90	59
<b>Finance/property</b>	9	39	95	56
<b>Separation</b>	15	31	85	56
<b>Integrity</b>	4	25	98	50
<b>Migration/moving</b>	2	18	100	100

## 9.6.2 Construct validity

### 9.6.2.1 Effect of socio-economic cluster on numbers of loss categories

Table 9.19 shows the numbers of loss categories by socio-economic cluster. The median numbers of losses are identical for the high, medium and low socio-economic clusters. Although the median is higher for the very low cluster, the numbers of subjects within that cluster are too small for any conclusions to be drawn. The Kruskal-Wallis test (Chapter 8.9.2.6.2) was used to investigate differences between the clusters and confirmed no significant difference between them ( $p = 0.1594$ ). However the data suggest a trend of increasing numbers of loss categories being associated with decreasing socio-economic cluster, but this needs to be confirmed with a larger sample.

**Table 9.19: Numbers of loss categories for SES cluster**

SES cluster	Subjects (N)	Numbers of loss categories (questionnaire)		
		Median	Min	Max
<b>High</b>	41	1.0	0	6
<b>Medium</b>	16	1.0	0	5
<b>Low</b>	36	1.0	0	8
<b>Very low</b>	2	3.5	3	4

## GRIEF MEASURE

### 9.6.3 Criterion validity

#### 9.6.3.1 Interview clinical scores

The frequencies of clinical scores for the whole sample are shown in Table 9.20. There was a spread of subjects across the categories.

**Table 9.20: Frequency of clinical scores**

Clinical score	% Frequency	% all subjects	% subjects with grief score
No grief	29	29	
Minimal	24	48	68
Mild	24		
Moderate	14	23	32
Severe	9		
<b>Total</b>	100		

#### 9.6.3.2 Correlation of Section C scores, sets and items with the clinical score

Correlation of individual subjects' section C and item scores with their corresponding clinical scores as expressed by Spearman's correlation coefficient are shown in Table 9.21. Using Weiten's (1998) standards (Chapter 8.9.2.5.3), section C scores showed a moderately high correlation of 0.64 with the clinical scores. Set and item scores were all moderately correlated with the clinical scores.

**Table 9.21: Correlations between section C, set and item scores with the clinical scores**

Section C /set/ item number	Correlation with clinical score (Spearman's rho)
Section C scores	0.64
General distress	0.58
Images & thoughts	0.61
Non-resolution	0.65
Acute separation	0.50
Grief	0.53
C1	0.48
C2	0.46

C3	0.58
C4	0.49
C5	0.58
C6	0.50
C7	0.58
C8	0.47
C9	0.50
C10	0.45
C11	0.42
C12	0.46
C13	0.38
C14	0.50
C15	0.56
C16	0.52
C17	0.62
C18	0.51
C19	0.54
C20	0.51
C21	0.49
C22	0.43
C23	0.58
C24	0.47
C25	0.31
C26	0.42

#### 9.6.4 Construct validity

##### 9.6.4.1 Effect of multiples of loss categories on Section C scores

Table 9.22 shows the section C scores for numbers of loss categories. As there were small numbers, levels of multiples were collapsed to form a group of two losses and less and a second group of three or more loss categories. The median section C score for subjects with three or more loss categories was considerably higher than that for those with two or less loss categories. A Wilcoxon Two-Sample Test (Chapter 8.9.2.6.5) indicated the section C score for 3 or more losses was significantly greater than for the 0 to 2 loss categories group ( $T=0.0025$ ). These support construct validity of the questionnaire.

**Table 9.22: Section C scores for numbers of loss categories**

Numbers of loss categories	N	Section C score		
		Median	Min	Max
<b>Two or less</b>	43	16.0	0.0	62.0
<b>3 or more</b>	20	27.0	7.0	72.0
<b>Total</b>	63	20.0	0.0	72.0



#### **9.6.4.2 Effect of gender on Section C scores**

The median grief scores for females were almost twice that of the males (Table 9.23). A Wilcoxon Two-sample test confirmed the difference between the genders is significant ( $p = 0.0023$ ), which supports the construct validity of the questionnaire.

**Table 9.23: Section C scores for gender.**

<b>Gender</b>	<b>N</b>	<b>Section C score</b>		
		<b>Median</b>	<b>Min</b>	<b>Max</b>
<b>Male</b>	24	12.00	0	62
<b>Female</b>	37	23.00	5	72
<b>Total</b>	61			

#### **9.6.5 Testing for bias**

Gender and approximate ages of non-responders are given in Appendix 9.4. A number of subjects withdrew from the study after their appointment with their doctor and before they had completed the study. No record was kept of these subjects.

#### **9.7 Summary**

This chapter has presented the results of the trial of the questionnaire and interview. This has included the qualitative and statistical data from the loss reviews and grief measures of both instruments. The analysis of these results is described in the following chapter together with the consequent modifications of the trial instruments to form the new evaluation instruments.

## Chapter 10: Analysis of trial results

This chapter analyses the results of the data from the trial of the questionnaire and interview which were presented in the previous chapter. The analysis follows the order of objectives for the analysis given in Table 8.6 and described in Chapter 8.9.2. For each objective the description is in the following order:

- Analysis;
- Conclusions;
- Further tests (here the conclusions are indeterminate in fulfilling the objectives of the analysis); and
- Modifications made to the instruments as a result of the analysis.

The evaluation questionnaire and interview schedule that evolved from this process are shown in Appendices 10.1 and 5.4 respectively.

### ***10.1 Wording, format and acceptability of questionnaire and interview (Objective 1)***

#### **10.1.1 Analysis**

##### ***10.1.1.1 Questionnaire***

The themes from the data presented in Appendix 9.1 are summarised in Table 10.1.

**Table 10.1: Qualitative data results from questionnaire**

<b>Section A: Demographic section</b>	
Comments	Suggestions
<b>No adverse comments</b>	<b>None</b>
<b>Section B: Loss review</b>	
Comments	Suggestions
All subjects felt questions were acceptable.	
Some subjects had difficulty remembering to include losses to significant others;	Format selected instructions in upper case;
Some subjects had difficulty remembering to include past and impending losses;	<b>Reduce number of words by creating longer</b> stem and shorter items
Some subjects misunderstood separation loss to include loss by death;	Place 'death' first;
Many subjects commented that the following categories were stigmatised, 'financial', 'job' and 'personal integrity';	Move 'job' and 'financial' losses down the list and retain 'personal integrity' near the end;
Many subjects did not complete items relating to time even when prompted;	Reduce number of time columns from 3 to 1;
Too long and complicated	Replace original decision tree at end of section
<b>Questionnaire: Section C: Grief measure</b>	
Comments	Suggestions
All subjects felt questions were acceptable;	
Many subjects felt there were too many questions and that the questions were repetitive;	) ) )
Some subjects irritated by the repetitiveness of items;	) Eliminate similar questions; ) )
Too long for some subjects who lost concentration, became tired and needed coaxing to finish;	) ) )
Some subjects confused between existing physical symptoms and those caused by grief in C20;	Add: 'other than existing illness or disability' to C20;

### *10.1.1.2 Interview*

**A summary of the comments about the wording, format and acceptability of the interview presented in Appendix 9.2 are given below:  
all questions were understood by subjects;  
interview was acceptable to all subjects except one subject who was too distressed to continue. In this case the interview was terminated prematurely as described under the training of interviewers (Appendix 8.3); and  
grieving subjects were generally pleased to have the opportunity to talk about their grief, even though it appeared distressing at the time to some of them.**

### **10.1.2 Conclusions**

All themes and suggestions regarding the questionnaire presented in Table 10.1 were deemed reasonable by the research team and the appropriate modifications described below were made.

### **10.1.3 Modifications**

#### *10.1.3.1 Questionnaire*

The following modifications were made:

#### Section B

- selected instructions formatted in upper case;
- items were shortened and the stem lengthened correspondingly
- ‘death’ category placed first;
- ‘job’ and ‘financial’ categories moved further down the list and ‘personal integrity’ retained near the end; and
- number of time columns reduced from 3 to 1.

#### Section C

- selected items eliminated (see objective 4 for process);
- ‘other existing illness or disability’ added to C20 to become new evaluation item C6.

### ***10.1.3.2 Interview***

As the interview wording and format were acceptable, no changes were made to it.

## ***10.2 Demographic characteristics (Objective 2)***

### **10.2.1 Analysis**

The demographic characteristics of the trial population given in Chapter 8.7.3 were compared with demographics of the Australian general practice population and of the Adelaide metropolitan area.

#### ***10.2.1.1 Comparison with the Australian general practice population***

The third national general practice survey (Bridges-Webb, Britt, Miles, Neary, Charles, & Traynor, 1992) provided age and gender data with which to compare the trial population. This surveyed patients of all ages whereas the trial population consisted of people 16 years and over. Therefore data for only the age groups of 15-75+ of the population of the national general practice survey were used for comparison and were expressed as a percentage of this population and not of the whole population included in their study. It is also to be noted that the age category of 15-24 of the national general practice survey differed from the 16-24 year-old category of the present study.

The comparison is seen in Table 10.2. Gender ratios are similar for the national general practice survey and the trial population. There are also similarities between the age demographics of the national general practice survey and the trial population: the main differences are a higher proportion of 25-44 year olds and a lower proportion of 16-24 year olds in the trial population than of the national general practice survey.

**Table 10.2: Comparison of the trial population with the national general practice survey**

DEMOGRAPHIC		Third national general practice survey (% of 15-75+ population)	Trial (%)
Gender	Male	40.0	36.0
	Female	60.0	64.0
	<b>Total</b>	100.0	100.0
Age	<b>16-24</b>	*13.1	**4.0
	<b>25-44</b>	30.8	48.0
	<b>45-64</b>	26.7	26.0
	<b>65-74</b>	16.1	14.0
	<b>&gt;75</b>	13.3	8.0
	<b>Total</b>	100.0	100.0

\* age category 15-24

\*\* age category 16-24

#### *10.2.1.2 Comparison of the demographics of the evaluation population with those for the population of the Adelaide metropolitan area*

Data from the Social Health Atlas of South Australia (Glover, Shand, Forster & Wollacot, 1996; Glover & Tennant, 1999) were used to compare the demographics of metropolitan Adelaide with the trial population. The 1999 edition contained statistics from the 1996 national Census and was therefore the preferred comparison, being closest in date to this study. However it lacked specific relevant information to the distribution of socio-economic clusters and therefore the 1996 edition, which contained socio-economic cluster data from the 1991 national Census, was used for this comparison.

Data for socio-economic clusters and the proportions of people born overseas, unemployed and aged 65 and over are shown in Table 10.3. The Atlas gives socio-economic cluster by the number of metropolitan areas (of which there are 121) and not by the percentage of population. In the table the clusters are therefore expressed as a percentage of the total number of clusters rather than as a percentage of the population. There was a higher proportion of subjects from the 'low' socio-economic cluster, and a lower proportion from the 'medium' cluster than generally among the metropolitan population. Proportions from the 'high' cluster of the trial were similar to metropolitan Adelaide.. The two percent of the trial population who were in the 'very low' represented two subjects from 'very low' clusters in

rural South Australia. However the table also shows that the proportion of people born overseas was more highly represented in the trial population and the unemployed were under-represented. There was a greater proportion of those aged 65 and over in the trial population which is consistent with expectations for general practice because of the greater need of the elderly for medical attention.

**Table 10.3: Comparison of the evaluation population with the population of metropolitan Adelaide**

<b>Demographic</b>		<b>Adelaide metropolitan population %</b> (Social Health Atlas of South Australia)	<b>Trial %</b>
<b>Socio-economic cluster*</b>	<b>High</b>	50	41
	<b>Medium</b>	30	16
	<b>Low</b>	20	36
	<b>Very low</b>	0	2
<b>Born overseas**</b>		13	32
<b>Unemployed**</b>		11	5
<b>People aged 65+**</b>		14	22

\*1996 edition of the Social Health Atlas for South Australia

\*\*1999 edition of the Social Health Atlas for South Australia

### 10.2.2 Conclusions

In comparison with the Australian general practice population, the trial subjects did not differ significantly in age and gender, apart from the youth being under-represented. Differences were demonstrated between the trial population and that of metropolitan Adelaide in terms of their socio-economic cluster, unemployed, elderly and their proportion born overseas,.

### 10.3 New categories of loss and examples within categories (Objective 3i)

From the results stated in Chapter 9.3, the following additions were made to the loss reviews of the questionnaire and interview:

- category ‘adoption/fostering’ with example ‘being or caring for an adopted/fostered child’; and

- examples to existing 'job' category: 'illness' and 'birth of a baby'.

**In addition, another new category (freedom) was found as a result of the chief investigator's concurrent clinical work which was independent of the trial.**

#### ***10.4 Descriptive statistics for the loss data (Objective 3ii)***

##### **10.4.1 Analysis**

**A comparison of the results of the descriptive statistics for the questionnaire and interview loss data given in Chapter 9.4 is made in Table 10.4.**

**The descriptive statistics for the questionnaire and interview data were similar. However, the interview identified more losses than the questionnaire. Losses that were not endorsed by subjects at their first encounter with one of these instruments (the questionnaire) were endorsed subsequently by either the subject or the interviewer in agreement with the subject, at the second encounter (the interview). It follows that losses that were endorsed only on the second encounter were either not recognised or were not seen as acceptable initially, and therefore comply with Doka's (1989) definition of disenfranchised grief (Chapter 2.1.2.4).**

**All categories of loss were endorsed, indicating they were all valid. Death-related losses accounted for 20% of losses and non-death related losses accounted for the remaining 80% of losses detected. Rates of endorsement for individual categories were higher by interview than by questionnaire. Migration/ moving loss was five fold more frequently detected by interview than by questionnaire suggesting this category was disenfranchised. Moreover the findings are consistent with expectations in general practice in that categories with the highest rankings, such as 'quality of life', 'death', 'separation' and 'job' would all be expected to be frequent problems encountered in general practice (Bridges-Webb, Britt, Miles, Neary, Charles & Traynor, 1992), either because they are reasons for encounter or because they are common events among the general population. The lowest ranking category, 'adoption/ fostering' would be expected to be low because it is neither a common reason for encounter, nor is it common among the general population. Loss was experienced across the age range of subjects (16-83) and by both genders.**

**Further tests to determine the validity of the questionnaire loss data are addressed in the analysis of Objective 5 (Chapter 10.6).**





## 10.4.2 Conclusions

### 1. The validity of section B is indicted by:

- Similar results obtained by questionnaire and interview;
- All categories endorsed; and
- Findings consistent with expectations of general practice.

2. 2/3 of all subjects were experiencing loss;

3. The most frequently encountered loss categories were 'quality of life', 'death', 'separation' and 'job';

4. The concept of disenfranchised grief was confirmed, particularly losses associated with migration and moving home; and

5. Further validity testing of section B is required. This is addressed in Chapter 10.6.

## 10.5 Validity of the components of section C (Objective 4)

### 10.5.1 Analysis

The results investigating the validity of the components of sections C and the items that best measure grief that were given in Chapter 9.5 are summarised in Table 10.5.

The face validity was demonstrated by:

**- zero endorsement of all items being <80%. Therefore all items were core phenomena and relevant to the measure.**

**Discriminatory validity was demonstrated in that:**

- endorsement of all options for all items <80%;
- the scores for section C were spread over almost the whole possible range and section C median scores were significant. This indicted that the section C score discriminated between subjects with less severe and those with more severe grief;
- set scores were spread over the whole possible range for all except the 'Non-resolution' and 'Acute separation' sets, which just failed to reach their maximum indicating these

were the least discriminatory sets. Significant median set scores were generated by all sets with 'Non-resolution' generating the lowest; and  
- all items, except C25, achieved a maximal score indicating they were discriminatory. Twenty-two of the 26 items generated a significant median score. C4, C16, C20 & C25 were the exceptions, indicating these were the least discriminatory.

The internal consistency of section C was demonstrated by:

- the high Cronbach's alpha for the whole measure. The value obtained exceeded the desirable range of 0.70-0.90, indicating redundancy of items; and
- Cronbach's alpha in the acceptable range (0.70-0.90) for all sets.

The high Spearman's rho coefficients (0.66-0.86) between items and the remaining Section C items demonstrated that the phenomena they measured were related to the instrument. C25 demonstrated the lowest (moderate) correlation.

The internal consistency of the sets could be improved by

- Withdrawing C5 from the 'Images and thoughts' set (marginal improvement); and
- Withdrawing C21 from the "Grief set" (marginal improvement); and
- Withdrawing C25 from the 'Acute separation' (considerable improvement).

**Table 10.5: Validity of components of Section C**

Objective	Purpose	Test	Result & (source)	Conclusion
Face validity	Centrality to the construct of grief	Frequency of zero endorsement	Zero endorsement of all items <80%. (Table 9.7)	All items measured core grief phenomena
Discrimin-atory validity	Discrimination over the range of severity	Frequency of endorsement across options	Endorsement of all options for all items <80% (Table 9.7)	All items discriminatory
		Section C scores	Range of scores demonstrated (Table 9.8) Median score=20. (Table 9.9)	Whole measure discriminatory
		Set scores	Maximum range of scores demonstrated by all except 'Non-resolution' and 'Acute separation' (Table 9.10) Significant median scores by all sets; 'Non-resolution' set lowest. (Table 9.10)	All sets discriminatory.
		Section C item scores	Maximum scores by all items except C25. Significant median scores by all items except C4, C16, C20 & C25. (Table 9.11)	All items discriminatory.  Least discriminatory items: C4, C16, C20 & C25.
Internal consistency	Relevance to the rest of the measure	Internal consistency of section C	Cronbach's alpha=0.97 (Chapter 9.5.3.1)	All items measure similar phenomena. Redundancy of items.
		Internal consistency of sets	Cronbach's alpha for all sets=0.82-0.91 (Table 9.12)	All items related to their set
		Internal consistency of sets with items withdrawn	Cronbach's alpha with item withdrawn= or < alpha for set for all sets except for C5, C21 and C25. (Table 9.13)	Internal consistency of sets improved by removal of items C5, C21 & C25
		Correlations between section C items & rest of section C	All Spearman's rho coefficients high (0.66-0.86) except for C25. (Table 9.14)	All items highly related to each other except C25.
		Factor analysis	4 factors loaded. Support for 'Grief', 'Non-resolution' & 'Images & thoughts' sets.( Table 9.16)	Inconclusive. Needs repeating on a larger sample

## 10.5.2 Conclusions

1. Validity of the components of section C has been demonstrated by

- face validity;
- discriminatory validity; and
- internal consistency.

**2. The number of items in section C required reducing. This was indicated by:**

- the high Cronbach's alpha of 0.97 for the whole measure indicated some items were so closely related as to be measuring very similar phenomena and therefore that some were redundant; and
- conclusions from the qualitative data Chapter 10.1.1.1.

## 10.5.3 Further tests

**In considering the conclusions above, three further tests were performed to determine which items to eliminate:**

1. Analysis of the relative merits of the items found to be least valid (C4, C5, C16, C20, C21 and C25);
2. Analysis of the items with the principles of measuring grief; and
3. A modified Q sort.

These tests are described in the following paragraphs.

### *10.5.3.1 Analysis of least valid items*

Items that were least discriminatory and least relevant to the measure (Chapter 10.5.3) were:

C4: Have thoughts or reminders of the loss caused you to feel guilt;

C16: Have thoughts or reminders of the loss cause you to feel numb;

C20: Have thoughts or reminders of what is or will be lost caused you to feel sick or ill in any way (eg generally unwell, loss of energy, headaches, dizziness etc);

C25 Have you found yourself imagining that the loss has not/will not occur;

C 5: Have thoughts of the loss made you feel distressed; and

C 21 Have reminders of the loss such as people, photos, situations, music, places etc cause you to cry.

#### Rationale

- C4, C16 and C20 were originally included in the measure specifically because they pertained to a clinical sample. This benefit was seen to outweigh the disadvantages outlined above and therefore they were retained.
- C5, C21 and C25 all tapped distinct grief phenomena that provided different perspectives to the measure. This was seen as contributing more to the measure than the increased validity created by their removal. Therefore these items were also retained.

#### Conclusion

Those items that were least valid in Section C were found to be contributory to the measure and therefore none of these was removed.

#### *10.5.3.2 Analysis of items using the principles of measuring grief*

Each item in Section C was compared to the original principles for measuring grief in Chapters 4.3.2 and 4.3.3. The following items were deleted for reasons given following.

<b>Item</b>	<b>REASON:</b>
C12 Have thoughts or reminders of the loss caused you to feel anxious, nervous or	Trait not state

strung up

C15	Have thoughts or reminders of the loss caused you to feel disbelief about the loss	Non-conformity with requirements
C19	Have thoughts or reminders of the loss caused you to feel scared or panicky	Trait not state
C21	Have reminders of the loss such as people, photos, situations, music, places etc caused you to cry	Trait not state
C24	Have reminders of the loss such as people, photos, situations, music, places etc caused you to feel loneliness	Non-conformity with requirements

#### Trait v state

Item C12 and C19 were eliminated because they both measured aspects of anxiety. This is a trait in some people (Andrews, Crino, Hunt, Lampe, Page, 1994) and therefore could act as confounder.

Item C21 was eliminated because of reports that tears are not necessarily an indicator of the level of distress, and that males in many Western cultures are conditioned not to cry (Golden, 1996).

#### Non-conformity with requirements

Item C15 was eliminated because disbelief is not present throughout the grieving process.

Studies of bereavement have found that disbelief and feelings of unreality that the dead person is never coming back, occur in the early months after the death (Bowlby, 1980; Parkes, 1986; Raphael, 1984; Worden, 1991). It would be expected that a similar situation would apply to other losses.

Item 24 was deleted because it did not measure a phenomenon that changed in the same direction over the course of the grieving process. Feelings of loneliness are usually felt more

severely around three months after a death, when the reality of the loss is sinking in and social support is dropping off (Clark, 2001; Farberow, Gallagher-Thompson, Gilewski, Thompson, 1992b). Feelings of loneliness are also greater when there is a low level of social support and this may happen sporadically in the grieving process. The relationship between social support and the severity of grief therefore does not appear to comply with the requirements to be present and to change progressively in the same direction throughout the grieving process. Another reason for deleting C24 was that loneliness has been reported to be more specific to spousal bereavement than from other kinship deaths (Raphael, 1984), and is therefore not regarded as a core phenomenon.

This process deleted only 5 items which was not considered a sufficient number to remedy the problems of the repetition and the length of section C. The further process of a modified Q sort was therefore used to identify items that were similar to each other.

#### ***10.5.3.3 Modified Q sort***

A modified Q sort procedure (Anastasi, 1976) was used to determine which paired items had similar meanings so that one of the pair could be eliminated.

The questions were written in random order on a sheet of paper and copies were given to seven GPs who had an interest in mental health issues and two postgraduate students who were taking the Graduate Certificate in Bereavement and Palliative Care Counselling of the University of Adelaide. They were asked, independently of each other, to link together those items that had similar meanings and to return the sheet in a sealed envelope to the chief investigator.

Seven responses were returned complete. The linked pairs of items on the returned lists were rated by the chief investigator for frequency of endorsement. Pairs were selected that were



endorsed by the majority (four or more) of raters (Table 10.6). Items C5 and C6 were agreed unanimously to be of similar face value. Four other pairs were all endorsed as having similar face value by four sorters and are shown on the table. Not shown are three more pairs which were endorsed by three sorters, eight further pairs by two sorters and 14 pairs by one sorter.

**Table 10.6: Q sort pair endorsements**

<b>Items with similar meanings</b>	<b>Endorsements (n=7)</b>	<b>Item with lower correlation</b>	<b>Action taken</b>
C5 Have thoughts of the loss made you feel distressed & C6 Overall how much have thoughts and feelings about your loss or losses distressed you	7	C6	C6 retained (common to both pairs); C1 & C5 deleted
C1 How would you rate your overall feelings about your loss or losses & C6 Overall how much have thoughts and feelings about your loss or losses distressed you	4	C1	
<b>C3 Have thoughts of the loss come into your mind whether you wish it or not?</b> & C7 Have you thought about the loss	4	C3=C7	C7 deleted
C13 Have reminders of the loss such as people, photos, situations, music, places etc caused you to feel loss of enjoyment & C18 Have reminders of the loss such as people, photos, situations, music, places etc cause you to feel sadness	4	C13	C13 deleted
C26 Have images of the loss made you feel distressed & C5 Have thoughts of the loss made you feel distressed	4	C26	C26 deleted

Of the items endorsed by four or more of the sorters, those that had the lower correlation of the pair (Table 9.22) with the clinical score were deleted. The clinical score was taken as the criterion because this was the gold standard for this study.

#### 10.5.4 Modifications to section C

Sixteen items remained in section C. This number was felt to be a satisfactory compromise between reducing the measure to a manageable number of items without losing core phenomena from the questionnaire. These items are shown in Table 10.7 grouped according to their original sets. The items tap the phenomena of feelings of acute separation from the lost object or situation, images and thoughts about the loss, reminders about the loss, items relating to phenomena associated with non-resolution and traumatic grief, and a general set taps emotional, physical, social and cognitive features associated with the grieving process.

Section C thereby fulfils the criteria stated in Chapter 7.3.2.2, that they:

- complied with the principles for measuring grief;
- complied with the task-specific requirements; and
- represented various domains. However Appendix 7.6, which shows the items by domain, demonstrates that not all the domains were represented and there was not equal representation over all the represented domains. There are 11 items in the emotional domain and 5 remaining items in the following domains:

##### *Physical domain*

Have thoughts or reminders of what is or will be lost caused you to feel sick or ill in any way (eg generally unwell, loss of energy, headaches, dizziness etc).

##### *Social domain*

Have thoughts of your loss caused you to be more irritable with others.

##### *Cognitive domain*

Have thoughts of your loss made it difficult for you to concentrate, remember things or make decisions.

Have you experienced images of the events surrounding the loss.

Have thoughts of the loss come into your mind whether you wish it or not.

**Table 10.7: Section C evaluation version (16 items)**

**General**

Overall how much have thoughts and feelings about your loss or losses distressed you

Have thoughts or reminders of what is or will be lost caused you to feel sick or ill in any way (eg generally unwell, loss of energy, headaches, dizziness etc)

Have thoughts of your loss caused you to be more irritable with others

Have thoughts of your loss made it difficult for you to concentrate, remember things or make decisions

**Images and thoughts**

Have you experienced images of the events surrounding the loss

Have thoughts of the loss come into your mind whether you wish it or not?

**Acute separation**

Have people or familiar objects (photos, possessions, rooms etc) reminded you of the loss

Have you found yourself longing for what is or will be lost

Have you found yourself imagining that the loss has not/will not occur

Have you felt distress by the reality of the loss

**Grief**

Have reminders of the loss such as people, photos, situations, music, places etc caused you to feel longing for what is or will be lost

Have reminders of the loss such as people, photos, situations, music, places etc cause you to feel sadness

**Non-resolution**

Have thoughts or reminders of the loss caused you to feel dread

Have thoughts or reminders of the loss caused you to feel numb

Have thoughts or reminders of the loss caused you to feel guilt

Have thoughts or reminders of the loss caused you to feel anger

## **10.6 Validity of the questionnaire (Objective 5)**

**The results of the tests that examined the validity of the questionnaire that are given in Chapter 9.6 were summarised for section B in Table 10.8 and for section C in Table 10.9.**

### **10.6.1 Analysis of loss review**

Relationships were demonstrated between questionnaire and interview data sets graphically, by correlations using Spearman's rho, by absolute agreements using Cohen's kappa, and there were also significant agreements between most corresponding categories. Although no strong conclusion can be drawn from values obtained for the individual categories because of the small numbers of subjects, the very low agreements between 'finance/property', 'migration/moving' and 'integrity' are consistent with these being disenfranchised losses.

The sensitivity of 74% indicates the questionnaire successfully screens the majority of losses. The fact that the sensitivity is not higher confirms the concept of disenfranchised grief. The specificity of 80% confirms the questionnaire is successful in identifying subjects who do not have grief. Although the sensitivity of 74% and the specificity of 80% fall short of the ideal 100%, these values are similar to other validated mental health instruments: the range of sensitivities for the 30-item General Health Questionnaire (Goldberg & Williams, 1988) has been found to be 55-92% and of specificities to be 80-99% (Vieweg & Hedlund, 1983). Such values of sensitivity and specificity combined with the high predictive value obtained, indicate validity of the instrument (Abrahamson, 1990).

**Further, validity of Section B is indicated by the loose association between multiples of loss and socio-economic cluster.**

**Table 10.8 Analysis of results from validity tests of section B**

	<b>Test</b>	<b>Trial result</b>	<b>Conclusion</b>
<b>Criterion validity</b>	Graphical representation	Wide scatter around bisector of axes	Relationship demonstrated between questionnaire and interview data
	Correlations between loss data sets	Moderate correlation (Spearman's rho=0.59)	
	Agreements between loss data sets	Moderate agreement (Cohen's kappa=0.47)	
	Agreements for individual categories	Significant agreement for 10/12 categories	
	Categories with lowest agreements	'finance/property', 'migration/moving' 'integrity'	
	Sensitivities Specificities Predictive values	74% 80% 92%	High validity
<b>Construct validity</b>	SES & multiples of loss	Trend (Table 9.20)	Construct not disproved

### 10.6.2 Conclusions

The validity of section B of the questionnaire is indicated by:

- Demonstrated criterion validity; and
- Construct validity not disproved.

The disenfranchisement of grief identified earlier in the analysis of the descriptive statistics for the loss data in Chapter 10.4.1 is further confirmed.

### 10.6.3 Analysis of grief measure

Table 10.9 demonstrates the criterion validity of the questionnaire by the moderate correlations between section C scores, and set and item scores with the clinical scores. One

quarter of all subjects were experiencing moderate to severe grief. The measurement of grief by the questionnaire conformed to the two known constructs which further supports the validity of section C.

**Table 10.9: Validity and reliability tests for Section C**

Test		Trial result (source)	Conclusion
Criterion validity	Section C scores with clinical scores	Moderate correlation: Spearman's rho=0.64 (Table 9.21)	Criterion validity supported
	Set scores	Moderate correlation: Spearman's rho=0.50-0.65 (Table 9.21)	
	Section C item scores with clinical scores	Moderate correlations for all items (Table 9.21)	1/3 subjects with loss had moderate or severe grief
Construct validity	Multiples of loss & section C score	Significant support (Table 9.22)	Construct validity supported
	Gender & section C score	Significant support (Table 9.23)	

#### 10.6.4 Conclusions

1. The validity of section C of the questionnaire is indicated by:

- demonstrated criterion validity; and
- demonstrated construct validity.

2. 1/3 of those subjects experiencing loss (1/4 of all subjects) were experiencing moderate or severe grief.

#### 10.6.5 Analysis of whole questionnaire

**Analysis of the genders of non-responders and subjects, shown in Appendix 9.4, suggested there was a higher proportion of females among the non-responders (75%) than among subjects (64%) (Table 10.10). However, a Wilcoxon two-sample test showed there was no significant difference between the two groups (T=0.227). No gender bias was therefore demonstrated. Ages were too non-specific for analysis.**

**Table 10.10: Responders compared with non-responders**

	<b>Number</b>	<b>Male</b>	<b>Female</b>
<b>Subjects</b>	97*	35 (36%)	62 (64%)
<b>Non-responders</b>	36**	9 (25%)	27 (75%)

\*Gender not recorded N=3

\*\* Gender not recorded N=3

### **10.6.6 Conclusion**

No gender bias was demonstrated.

### **10.7 Summary**

This chapter has analysed the results from the trial of the questionnaire and interview and described the subsequent modifications of the instruments as a consequence. The evaluation questionnaire and interview schedule that resulted are shown in Appendices 10.1 and 5.4. The objectives of the analysis (Chapter 8.9.2) have been fulfilled as follows as pertains to the questionnaire:

#### **Objective 1**

- The questionnaire was modified to optimise wording and format;
- The questionnaire demonstrated content acceptability; and
- The grief measure was abbreviated to an appropriate length.

#### **Objective 2**

- Demographic characteristics of the population studied were defined and were compatible with those of the Australian general practice population.

#### **Objective 3i**

- New categories and examples of loss were detected and added to the loss survey.

#### Objective 3ii

- The validity of section B of the questionnaire was demonstrated by:
  - questionnaire loss data findings are consistent with those obtained by interview;
  - loss data findings are consistent with expectations of general practice; and
  - all categories of loss were endorsed.

#### Objective 4

- 16 items were retained in Section C that most complied with the principles of measuring grief.

#### Objective 5

- The validity of section B was demonstrated by:
  - criterion validity, including acceptable sensitivities, specificities and predictive values;
  - construct validity.
- The validity of section C was demonstrated by:
  - criterion validity; and
  - construct validity.
- The validity of the whole questionnaire is demonstrated by:
  - no non-responder bias was demonstrated.

#### Initial results from the trial indicate:

- 2/3 of all subjects to be experiencing loss
- 1/3 of those subjects experiencing loss (1/4 of all subjects) were suffering moderate or severe grief;



- most frequently encountered loss categories were ‘quality of life’, ‘death’, ‘separation’ and ‘job’;
- death-related losses accounted for 20% of losses and non-death related losses accounted for the remaining 80% of losses detected; and
- disenfranchisement of grief was demonstrated, particularly grief from migration losses.

The first part of Objective D for the questionnaire has therefore been met, that is, it has been demonstrated to have acceptable levels of validity. Its reliability will be addressed, along with further validity testing, in the evaluation stage which is the subject of the following three chapters.

## Chapter 11: Evaluation: Method

This chapter describes the method used in the evaluation phase of the study. In this stage, the evaluation questionnaire (Appendix 10.1) and evaluation interview schedule (Appendix 5.4) were evaluated on a second set of 63 subjects, which was a different set from those of the trial. The aims of the evaluation were to:

- determine to what extent the evaluation questionnaire fulfilled the objectives A to D described in the Introduction; and
- to determine ways in which it could be further improved.

This chapter focuses particularly on the differences of method compared to the trial. In this chapter, all the numbers quoted for the items of section C refer to their order in the evaluation questionnaire.

### ***11.1 Variations on the trial method***

The method was identical to that used in the trial (Chapter 8) except where stated below.

#### **11.1.1 Ethical approval**

This was included with the approval for the trial. No adverse ethical effects or events occurred.

#### **11.1.2 Sample selection and size**

Ideally, a sample of 50 subjects experiencing grief was required to provide sufficient data to evaluate the items in the grief measure of the questionnaire. As limited funds remained in the grant, a decision was made to save time and expense by eliminating practices from the evaluation in which the enrolment of subjects during the trial had been slow. The busiest practices were therefore used in the evaluation and these are shown in Table 11.1. Although

this further reduced the geographical representation, there was still a spread across the socio-economic clusters with practices in both the high and low cluster being included.

A sample size of only 63 subjects was obtained with the funds available for the study which resulted in data from 34 subjects being generated for purposes of evaluation of the grief measure. Although this was less than the number desired, it was considered adequate for purposes of evaluation.

**Table 11.1: Demographic data of the general practices**

<b>Practice number*</b>	<b>Geographical location</b>	<b>Socio-economic status**</b>	<b>Number of subjects recruited from each practice</b>
<b>1</b>	<b>North east Adelaide suburbs</b>	<b>High</b>	<b>23</b>
<b>2</b>	<b>North east Adelaide suburbs</b>	<b>Low</b>	<b>20</b>
<b>3</b>	<b>North Adelaide suburbs</b>	<b>Low</b>	<b>20</b>
			<b>Total=63</b>

\* Practice numbers correspond to those in the trial (Table 8.1)

\*\*as defined by the Social Health Atlas of South Australia (Glover, Shand, Forster & Wollacot, 1996)

### **11.1.3 Interviewer**

No GP was available to assist with the study and therefore a general practice nurse was engaged through the same process used in the trial and who fulfilled the selection criteria described in Chapter 8.3.2. Her details are given in Appendix 11.1

### **11.1.4 Research assistant**

A new research assistant was engaged using the process used in the trial and who fulfilled the selection criteria described in Chapter 8.4.1. Her background is given in Appendix 11.1.

### **11.1.5 Conduct of questionnaire and interview**

The trial was carried out between June and mid November 1998. Father's Day occurred in September and may have artificially inflated the numbers of losses detected close to this date. Otherwise, the period conformed with the seasonal variation requirements mentioned in Chapter 4.2.3. The same method of enrolling subjects into the study was used as for the trial.

**The conduct of the questionnaire differed from the trial in that no prompting was given by the research assistant. However, she did note difficulties that subjects had in completing the questionnaire and the effects of the questionnaire on them. The conduct of the interview and the process of reporting back to the chief investigator remained unchanged.**

### **11.1.6 Reliability testing**

The first 25 subjects who completed the questionnaire and interview were given a second questionnaire in a stamped addressed envelope, with the instructions to complete it in a week and to return it by mail.

## **11.2 Subjects**

Selection and exclusion criteria were the same as for the trial. Of the 63 subjects who enrolled in the study, two had recorded on their questionnaires that they were under the age of 16, and as this was outside the inclusion criteria, their data were not used in the study. The demographic data for the remaining 61 subjects included in the analysis are given in Tables 11.2-11.4. Variables were generally similar to those found for the trial population.

### **11.2.1 Age**

Ages for subjects are shown in the stem and leaf table (Table 11.2) where the tens and units columns represent the ages of subjects. Ages show a normal distribution with a median of 50 years (see also Table 11.3).

**Table 11.2: Ages of subjects**

<b>Tens</b>	<b>Units</b>	<b>Numbers of subjects</b>
7	68	2
7	00234	5
6	579	3
6	00234	5
5	5567899	7
5	000133334	9
4	56778888999	11
4	01123	5
3	799	3
3	0	1
2	5577899	7
2	23	2
1	6	1
		Total=61

**Table 11.3: Descriptive statistics for age of subjects**

<b>N</b>	<b>Mean</b>	<b>Median</b>	<b>SD</b>	<b>Range</b>	<b>25% Quartile</b>	<b>75% Quartile</b>	<b>Distribution</b>
61	49.4	50.0	15.0	16-78	41	59	Normal

Descriptive statistics for other variables are shown in Table 11.4 and are described as follows.

### 11.2.2 Gender

Males formed only 20% of the evaluation population, compared to 36% in the trial.

### 11.2.3 Socio-economic cluster

The same uneven spread across the socio-economic clusters that was found in the trial was replicated in the evaluation. There was an uneven representation of the socio-economic clusters. The ‘high’ category was most highly represented (40% of subjects), followed by the

'low' category (31% subjects), 'medium' category (19% of subjects) and the 'very low' category (10% of subjects).

#### **11.2.4 Highest level of educational attainment**

Educational attainment for the evaluation population was similar to the trial population. The highest level of educational attainment for nearly one third of subjects was 'school over the age of 15 with no further study', a quarter had attained a certificate or diploma and 20% had left school aged 15 or under. Others held a tertiary degree, had a trade qualification or apprenticeship, or were still studying.

#### **11.2.5 Occupation**

The occupations of the evaluation and trial populations were similar. 40% of subjects were employed full or part-time, 36% were engaged in home duties, 13% were retired, and the remainder were either unemployed or students.

#### **11.2.6 Country of birth**

As for the trial population, approximately two thirds of the evaluation population were born in Australia, with the remaining third from the UK and Ireland, Europe and one from Asia.

#### **11.2.7 Marital status**

As for the trial population, two thirds of the evaluation population were in marital or defacto relationships, and the remaining one third were never married, separated/divorced, or widowed.

**Table 11.4: Frequencies (F) and percentages for demographic variables.**

Variable (Subjects N=)	Level	F	Per Cent*	Variable Subjects (N=)	Level	F	Per Cent*	
<b>Sex (60)</b>	Male	12	20	<b>Age (61)</b>	17-24	3	5	
	Female	48	80		25-34	8	13	
<b>SES (58)</b>	High	23	40		35-44	8	13	
	Medium	11	19		45-54	20	33	
	Low	18	31		55-64	12	20	
	Very low	6	10		65-74	8	13	
<b>Education (60)</b>					75-84	2	3	
	At school	1	2		<b>Birth country (61)</b>	Australia	42	69
	Left school <=15	13	22			New Zealand	0	0
	Left school > 15	18	30			UK & Ireland	14	23
	Left school/study	2	3	Europe		4	7	
	Trade qualification	7	12	Asia		1	2	
	Certificate/dip	16	27	Africa		0	0	
Degree	3	5	America	0		0		
<b>Occupation (61)</b>				<b>Marital status (61)</b>	Married/defacto	41	67	
	Home duties	22	36		Never married	7	11	
	Retired	8	13		Separated/divorced	9	15	
	Student	3	5		Widowed	4	7	
	Unemployed	3	5					
Employed	25	41						

### **11.3 Data management**

#### **11.3.1 Qualitative data**

Data collection, recording and entry were as described in Chapter 8.8.1.

#### **11.3.2 Statistical data management**

##### **11.3.2.1 Method**

The same research assistant coded the data as for the trial. The same processes of data collection, entry, coding, checking, cleaning and management of missing data were used as previously, as described in Chapter 8.8.2.

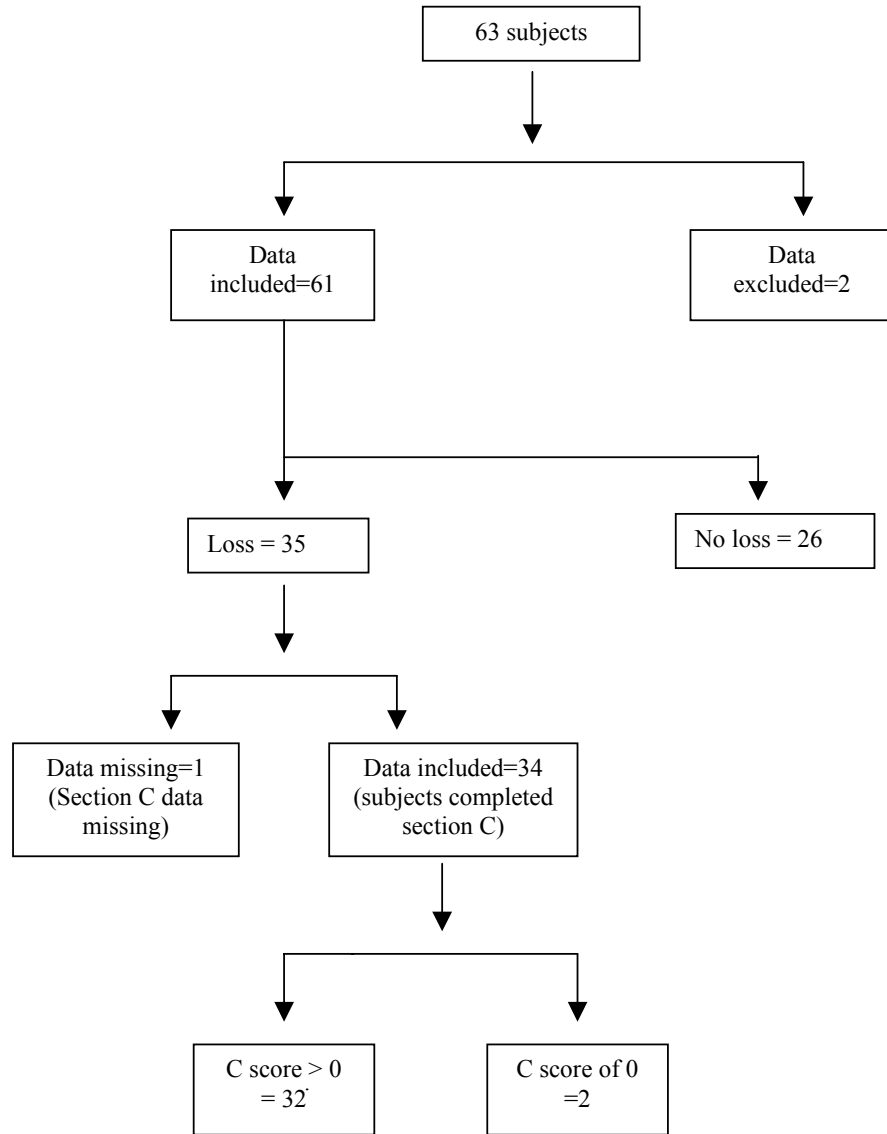
### Data checking

No inaccurate data were found on checking. Much of the data relating to the time since the loss were missing on the questionnaires as in the trial. No other consistent omissions of data were found.

The anomaly, of subjects completing Section C without endorsing a Section B loss, which was found in the trial (Chapter 8.8.2.6), did not occur. However, there were other anomalies which are shown diagrammatically in Figure 11.1 and are described below.

There were 63 subjects who completed the evaluation. Of these, two were not included, as mentioned previously, as their recorded ages were under 16 years. From the 61 subjects remaining, 35 endorsed loss in the questionnaire and 26 did not endorse any loss. Of the 35 who endorsed loss, one subject did not complete section C so no section C score could be obtained. Two of the subjects who completed section C gained a section C score of zero.





**Figure 11.1: Anomalies in data checking: questionnaire**

### *11.3.2.2 Data analysis*

The data analysis followed the same plan as given in Table 8.6 and which is described in Chapter 8.9. The exception was that no analysis was performed on sets because their original configuration was changed by the process of deleting items, as described in Chapter 10.5.3. The analysis included an additional two tests to those performed in the trial. These were test-retest reliability and item validity. Descriptions of these tests were included in Chapter 8.9.2 and Table 8.6 for the sake of completeness.

#### **11.4 Summary**

This chapter has focused on the methods used for the evaluation phase of the study that differ from those used in the trial in Chapter 8. The results for the evaluation are presented in the following chapter.

## Chapter 12 Evaluation: Results

This chapter gives the results from the evaluation of the questionnaire and interview, the method of which is described in Chapter 11. The results are presented in order of the plan of analysis given in Table 8.6 and described in Chapter 8.9.2.

### ***12.1 Wording, format and acceptability of the questionnaire and interview***

#### ***(Objective 1)***

##### **12.1.1 Questionnaire**

**The qualitative data for the questionnaire are shown in Appendix 12.1.**

##### **12.1.2 Interview**

**No qualitative data were collected for the interview, as it appeared satisfactory at the trial stage.**

##### **12.1.3 Team debriefs**

**Qualitative data from team debriefs are shown in Appendix 9.3.**

### ***12.2 Demographic characteristics (Objective 2)***

The demographic characteristics are presented in Chapter 11.2

### 12.3 New categories of loss and examples within categories (Objective 3i)

No new categories were identified either by questionnaire or interview (Table 12.1). Three new examples were found during the evaluation of the interview.

**Table 12.1: New categories of loss and examples within categories**

	Questionnaire	Interview
<b>New categories of loss</b>	-	-
<b>New examples of loss</b>	-	'promotion'; ) 'Opportunity' 'an unfulfilled ) category <b>dream</b> '. )  'giving up a ) 'adoption/ <b>child for</b> ) fostering' <b>adoption or</b> ) category <b>fostering</b> '

### 12.4 Descriptive statistics for the loss data (Objective 3ii)

Questionnaire and interview results will be presented consecutively for each analysis of the loss data. Data from the 61 subjects who came within the inclusion criteria (Chapter 11.2) were analysed. As much of the data relating to the time since the loss was missing from the evaluation questionnaires, this field was not analysed.

#### 12.4.1 The detection of loss

The questionnaire identified 35 (57%, N=61) subjects who endorsed one or more loss categories. Twenty six (43%) subjects did not endorse any loss category. The interview identified 44 (72%) subjects who endorsed one or more loss categories and 17 (28%) subjects who did not endorse any category.

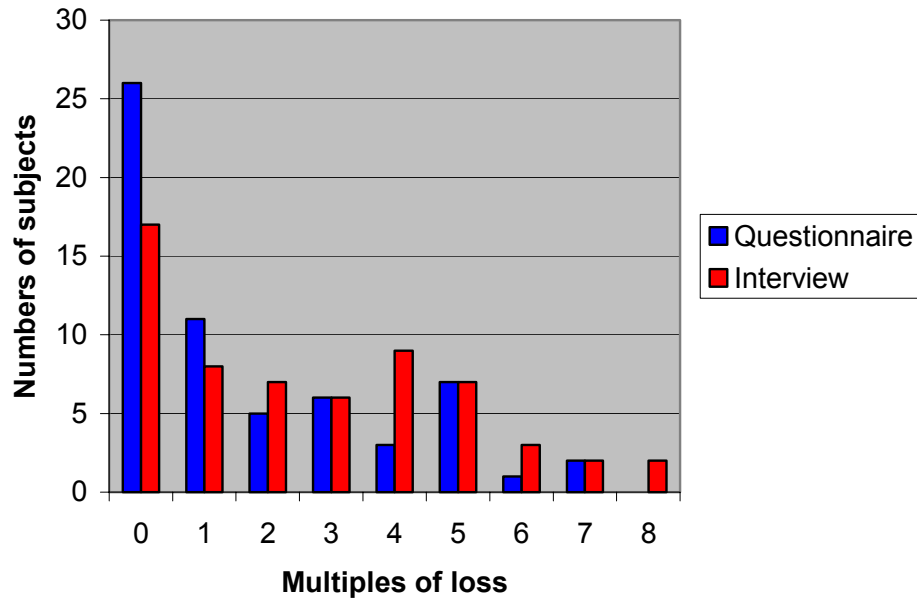
### 12.4.2 Multiples of loss

Table 12.2 shows the number of loss categories endorsed by subjects in both the questionnaire and the interview. The 35 subjects, identified by the questionnaire to be experiencing loss, endorsed a total of 106 loss categories between them (mean loss categories per grieving subject = 3.0). Eleven of the 35 subjects (18%) indicated one loss category, five (8%) indicated two, six (10%) indicated three and a decreasing number indicated up to eight categories.

The 44 subjects found by the interview to be experiencing loss identified a total of 159 losses between them (mean loss categories per grieving subject = 3.6). The interview also identified more subjects grieving a higher number of loss categories than did the questionnaire (Table 12.2 and Figure 12.1).

**Table 12.2: Numbers of loss categories endorsed by the 61 subjects by interview and questionnaire**

Multiples of loss categories	Questionnaire		Interview			
	Subjects		Losses per category	Subjects		Losses per category
	N=	(%*)		N=	(%*)	
<b>0</b>	26	(43%)	0	17	(28%)	0
<b>1</b>	11	(18%)	11	8	(13%)	8
<b>2</b>	5	(8%)	10	7	(11%)	14
<b>3</b>	6	(10%)	18	6	(10%)	18
<b>4</b>	3	(5%)	12	9	(15%)	36
<b>5</b>	7	(11%)	35	7	(11%)	35
<b>6</b>	1	(2%)	6	3	(5%)	18
<b>7</b>	2	(3%)	14	2	(3%)	14
<b>8</b>	0	(0%)	0	2	(3%)	16
<b>Mean</b>			3.0			3.6
<b>Total no</b>	61	(100)	106	61	(99)	159



**Figure 12.1: Multiples of loss by questionnaire and interview**

### **12.4.3 Loss categories by frequency**

#### *12.4.3.1 Types of loss*

All of the thirteen categories of loss were endorsed by both the questionnaire and interview (Table 12.3). All categories, including the category ‘freedom’ which was added after the trial, were therefore valid.

#### *12.4.3.2 Frequencies and rates of endorsement of categories*

The frequencies (F) and rates of endorsement of each category are shown in Table 12.3. With the exception of ‘pet’ loss, all categories were more highly endorsed by interview than by questionnaire. The differences between the detection of loss by questionnaire and interview are shown in Figure 12.2. Although the small frequencies caution interpretation of the findings, some of the greatest differentials in rates of detection are worth noting. The category with the greatest difference was ‘migration’ as was found in the trial. However the difference was only 2.5 fold in the evaluation compared to 5 fold in the trial. The other category with a

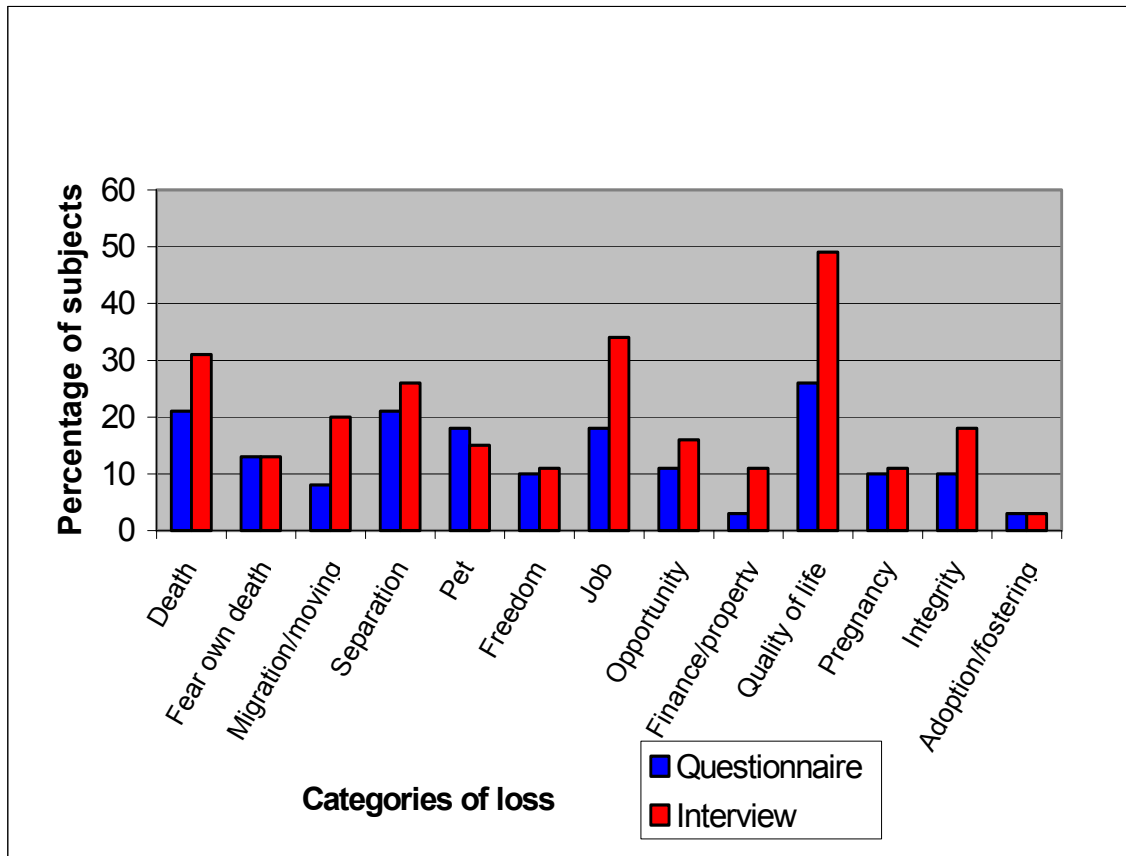
large differential in rates of detection was ‘quality of life’: the detection rate by interview was twice that by questionnaire.

Only 12% of all losses identified by questionnaire and interview were ‘death’ losses (death of a significant other). A further 8% of losses identified by questionnaire and 5% of losses identified by interview were ‘fear of own death’. The total percentages of death related losses identified were 20% by questionnaire and 17% by interview. The remaining 80% of losses concerned non-death related loss.

**Table 12.3: Frequencies (F) and rates of endorsement of loss categories by questionnaire and interview**

Loss category (type)	Questionnaire			Interview		
	F	Rate (%* subjects)	%* of all losses	F	Rate (%* subjects)	%* of all losses
<b>Death</b>	13	21	12	19	31	12
<b>Fear own death</b>	8	13	8	8	13	5
<b>Migration/ moving house</b>	5	8	5	12	20	8
<b>Separation</b>	13	21	12	16	26	10
<b>Pet</b>	11	18	10	9	15	6
<b>Freedom</b>	6	10	6	7	11	4
<b>Job</b>	11	18	10	21	34	13
<b>Opportunity</b>	7	11	7	10	16	6
<b>Finance/property</b>	2	3	2	7	11	4
<b>Quality of life</b>	16	26	15	30	49	19
<b>Pregnancy</b>	6	10	6	7	11	4
<b>Integrity</b>	6	10	6	11	18	7
<b>Adoption/ fostering</b>	2	3	2	2	3	1
<b>Total number of losses</b>	106		101	159		99

Number of subjects=61 for all categories



**Figure 12.2: Rate of endorsement of loss category by questionnaire and interview**

#### *12.4.3.3 Rankings of detection of categories*

The order of frequency of the detection of loss categories by questionnaire and interview is shown in Table 12.4. The same loss categories, ‘quality of life’, ‘death’, ‘separation’ and ‘job’, had a high frequency of endorsement by both methods. The middle and lower orders did not follow similar patterns for the questionnaire and interview except that ‘adoption/fostering’ came at the bottom of the rankings. ‘Migration/moving house’ was widely separated in the order of rankings between questionnaire and interview, consistent with the differential in the previous Figure.



**Table 12.4: Loss categories in descending order of frequency of endorsement by questionnaire and by interview**

	Questionnaire		Interview	
	Loss category in rank order	%* subjects	Loss category in rank order	%* subjects
<b>High</b>	1. Quality of life	26	1. Quality of life	49
	2. Death	21	2. Job	34
	3. Separation	21	3. Death	31
	4. Job	18	4. Separation	26
<b>Middle and Low</b>	5. Pet	18	5. Migration/ moving house	20
	6. Fear own death	13	6. Integrity	18
	7. Opportunity	10	7. Opportunity	16
	8. Pregnancy	10	8. Pet	15
	9. Integrity	10	9. Fear own death	13
	10. Freedom	10	10. Finance/property	11
	11. Migration/ moving house	8	11. Pregnancy	11
	12. Finance/property	3	12. Freedom	11
	13. Adoption/fostering	3	13. Adoption /fostering	3

**12.4.3.4 Loss by demographic grouping**

Loss endorsement by each age group expressed as a percentage of the total number of subjects are shown in Table 12.5. Although all age groups were affected by loss, no general conclusions can be drawn because of the small numbers of subjects. Females experienced a higher numbers of losses than males (Table 12.6).

**Table 12.5: Loss by age (questionnaire)**

Age	Loss	No loss	Total
16-24	1	2	3
25-34	5	3	8
35-44	6	2	8
45-54	12	8	20
55-64	7	5	12
65-74	3	5	8
75-84	1	1	2
Total	35	26	61

**Table 12.6: Multiples of loss by gender**

Gender	N	Median	Mean	SD	Min	Max
Male	12	0	1	1	0	4
Female	48	1	2	2	0	7
Total	*60	1	2	2	0	7

*\*Gender missing for 1 subject*

The associations between numbers of loss categories and socio-economic cluster are given later in this section under construct validity (Chapter 12.6.2.1).

### **12.5 Validity of the components of Section C (Objective 4)**

The results are given below for the 34 subjects who gained a section C score. Section C and item scores are defined in Chapter 7.3.4.2. No analyses were performed on sets because factor analysis in the trial was indeterminate and was unable to confirm the formulation of the sets for the evaluation questionnaire. Item numbers refer to the item number in the evaluation questionnaire (Appendix 10.1) and not the item code number. Item 4 was eliminated from all analyses, except the item validity test, as this was identical with item 9.

#### **12.5.1 Face validity**

##### **12.5.1.1 Zero endorsement of items**

The percent frequencies of endorsement of each alternative response for items, that is, the proportion of subjects (p) who endorsed the responses never=0, a little bit of the time=1, quite

a bit of the time=2, a lot of the time=3, is also shown in Table 12.7. No item has a proportion of zero endorsement, that is, endorsement of the response never=0 greater than the recommended 80%. Therefore all items are relevant to the measure. Error is magnified in percenting the frequencies because of the small number of subjects (34).

## **12.5.2 Discriminatory validity**

### ***12.5.2.1 Percent frequencies of endorsement across options***

Table 12.7 shows that the proportions (p) of endorsement of each alternative response is less than the recommended 80%. This shows there is a spread of scores over the alternatives for all items except C5, C11, C14 and C15 which all had zero endorsement of option 3. The last item, C15 is the same as C25 in the trial that also failed to endorse option 3. There was a decreasing frequency of scoring across options 1, 2 and 3 as would be expected.

**Table 12.7: Percent frequencies of endorsement of alternative responses for section C items (N=34)**

SECTION C ITEM (EVALUATION QUESTIONNAIRE)	Frequency of endorsement (%*) for alternative responses of 0-3			
	Never=0	A little bit of the time=1	Quite a bit of the time=2	A lot of the time=3
C1	21	50	21	9
C2	29	41	27	3
C3	18	59	12	12
C4**	32	41	18	9
C5	50	44	6	0
C6	47	29	21	3
C7	12	59	21	9
C8	18	47	29	6
C9**	21	53	18	9
C10	47	41	9	3
C11	35	53	11	0
C12	18	53	24	6
C13	27	50	15	9
C14	65	24	12	0
C15	50	41	9	0
C16	15	41	29	15
C17	27	53	15	6

\*correct to nearest whole number

\*\*identical items

#### 12.5.2.2 Section C scores

Section C scores for subjects are shown in Table 12.8. Section C scores were spread over almost the whole range of possible scores, with most in the mid and lower ranges as were found in the trial. The highest score of 39 was somewhat below the maximum of 48 (Chapter 7.3.4.2) indicating that most of the score range was utilised by this sample.

**Table 12.8: Section C scores (N=34)**

<b>Tens</b>	<b>Units</b>	<b>Numbers of subjects</b>
4		0
4		0
3	89	2
3	24	2
2	9	1
2	01111	5
1	6667799999	10
1	0112223	7
0	889	3
0	0014	4
		Total=34

The median, mean, range and quartiles of scores for section C summed scores are given in Table 12.9. The skewness of 0.5 confirms the tail of higher scores demonstrated in Table 12.8 above. The median and quartile scores confirm that most scores are in the lower range of the scale.

**Table 12.9: Descriptive statistics for summed C scores**

<b>N</b>	<b>Mean</b>	<b>Median</b>	<b>SD</b>	<b>Range</b>	<b>25% Quartile</b>	<b>75% Quartile</b>	<b>Distribution (Skewness)</b>
34	16.6	16.5	9.7	0-39	11.0	21.0	0.5

### **12.5.2.3 Item scores**

Descriptive statistics for section C items are given in Table 12.10. All except four items recorded scores spread over the possible range of 0 to 3.00. The four exceptions were items C5 (guilt), C11 (irritability with others), C14 (numbness) and C15 (imagining that the loss has not or will not occur). These all recorded a maximum of 2 indicating that these items may be

less good at discriminating over the whole range of intensities of grief. Additionally, the median for all items was 1.00 except for items C5 and C15 that recorded a median of 0.05 and item C14, which recorded a median of 0.00. This indicated these items were not as highly scored as the other items and which is consistent with them failing to gain endorsement of option 3 (Table 12.7). The standard deviations confirmed the wide spread of scores across the options.

**Table 12.10: Descriptive statistics for section C items**

	<b>N</b>	<b>Median</b>	<b>SD</b>	<b>Min</b>	<b>Max</b>
C1	34	1.00	0.87	0	3
C2	34	1.00	0.83	0	3
C3	34	1.00	0.87	0	3
C4*	34	1.00	0.94	0	3
C5	34	0.50	0.61	0	2
C6	34	1.00	0.88	0	3
C7	34	1.00	0.79	0	3
C8	34	1.00	0.82	0	3
C9*	34	1.00	0.86	0	3
C10	34	1.00	1.07	0	3
C11	34	1.00	0.65	0	2
C12	34	1.00	0.80	0	3
C13	34	1.00	0.88	0	3
C14	34	0.00	0.71	0	2
C15	34	0.50	0.66	0	2
C16	34	1.00	0.93	0	3
C17	34	1.00	0.82	0	3

\*identical items

### 12.5.3 Internal consistency

#### 12.5.3.1 Section C

Cronbach's alpha for section C was 0.93. This is lower than the value of 0.97 obtained for the trial indicating that many redundant items have been eliminated.

### 12.5.3.2 Item to total score correlation

The relationships of each item with the sum of the remaining items in section C, that is, the section C score minus the score for that item, are shown using Spearman's rho and Cronbach's alpha (Table 12.11). High values of Cronbach's alpha were obtained for all items. High values of Spearman's rho coefficients ( $\geq 0.70$ ) were obtained for nine items indicating close association between the phenomena tapped by the items and the whole instrument, and that the items are relevant to the measure. Moderate correlation (0.30-0.69) was demonstrated between a further six items (C2, C6, C11, C14, C15 and C17) and the rest of the instrument. One item, C5, showed a low correlation at the evaluation, which differed from its high correlation (0.71) as C4 at the trial.

**Table 12.11: Relationships between section C items and the rest of section C ( $p < 0.0001$ )**

Deleted item	Spearman's rho	Cronbach's alpha
C1	0.75	0.92
C2	0.68	0.92
C3	0.75	0.92
C5	0.21	0.93
C6	0.66	0.92
C7	0.71	0.92
C8	0.80	0.92
C9	0.76	0.92
C10	0.74	0.92
C11	0.51	0.92
C12	0.82	0.92
C13	0.73	0.92
C14	0.63	0.92
C15	0.30	0.93
C16	0.76	0.92
C17	0.38	0.92

### 12.5.3.3 Factor analysis

Only 34 subjects fully completed section C and, as in the trial, this fell short of the number required for a meaningful varimax rotation analysis (Chapter 8.9.2.5). Nevertheless, an

exploratory analysis was performed to look at factor loadings. Item C4 was not included as this was identical with item 9.

The factors loading through this analysis, shown by the shaded cells, indicate a heterogeneous mixture of items from the original sets (Table 12.12). Factor 1 loads three ‘General’ items, two items from the ‘Images and thoughts’ set, two from ‘Non-resolution’, and one from the ‘Acute separation’ set. Factor 3 loads an item from the ‘Acute separation’ set and an item about anger from the ‘Non-resolution’ set. Factor 4 loads a single item about guilt from ‘Non-resolution’. Many of the remaining factors load on to two factors. Further analysis is required with a minimum number of  $8 \times 16 = 128$  subjects with loss as mentioned in Chapter 8.9.2.5.3.

**Table 12.12: Factor analysis of section C items**

<b>Original set</b>	<b>Item number</b>	<b>Factor 1</b>	<b>Factor 2</b>	<b>Factor 3</b>	<b>Factor 4</b>
<b>General</b>	<b>C12</b>	0.79936	0.29975	-0.02705	0.27001
	<b>C1</b>	0.83624	0.02093	-0.01752	0.21421
	<b>C6</b>	0.78153	-0.22962	0.25125	0.08827
	<b>C11</b>	0.55876	-0.08068	0.56079	0.16346
<b>Images &amp; thoughts</b>	<b>C2</b>	0.83255	-0.15904	0.12621	-0.22480
	<b>C7</b>	0.60329	0.47070	0.43588	-0.18726
<b>Non-resolution</b>	<b>C5</b>	0.25015	-0.02566	-0.01128	0.89148
	<b>C10</b>	0.83457	0.07425	-0.20868	0.04717
	<b>C14</b>	0.74010	0.08589	-0.20164	-0.34903
	<b>C17</b>	0.32322	0.22391	0.70470	-0.2887
<b>Acute separation</b>	<b>C3</b>	0.60360	0.61987	0.23619	-0.02091
	<b>C8</b>	0.86486	0.05196	-0.00459	0.12888
	<b>C13</b>	0.59084	0.69843	-0.05178	-0.12250
	<b>C15</b>	0.44054	0.04797	-0.61424	-0.16123
<b>Grief</b>	<b>C9</b>	0.60669	0.68890	0.10806	0.09751
	<b>C16</b>	0.64411	0.63946	-0.07123	0.04114

### **12.6 Validity and reliability of the questionnaire (Objective 5)**

**Results will be given in the following order:**

**loss review;**

**grief measure; and**

**the whole questionnaire.**

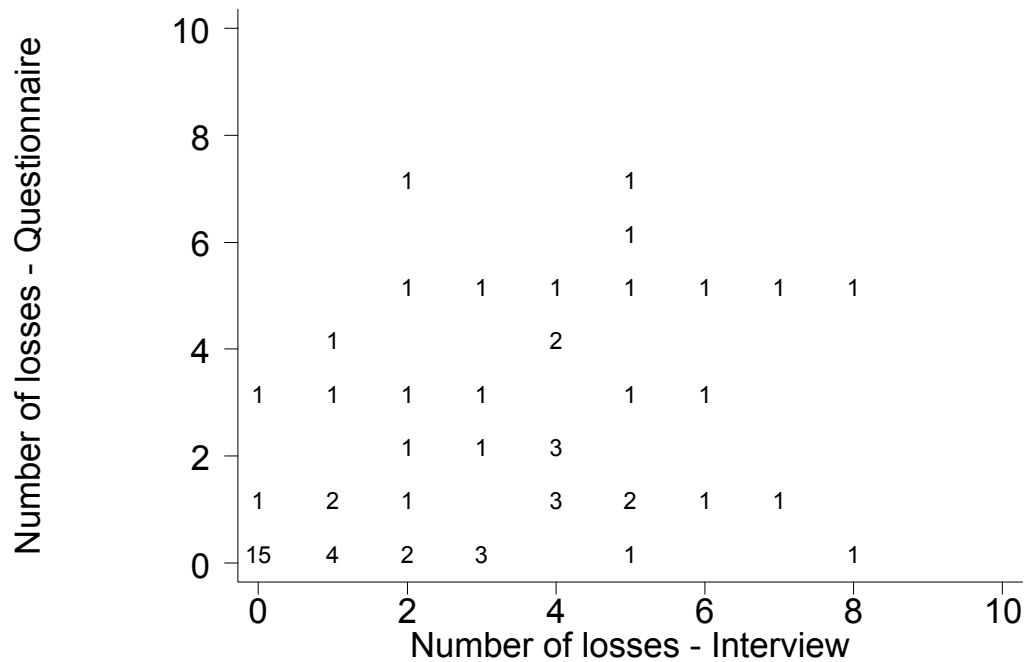


## LOSS REVIEW

### 12.6.1 Criterion validity

#### *12.6.1.1 Graphical representation of relationships between loss data*

Figure 12.3 shows the relationships between the numbers of loss categories found by questionnaire and interview for subjects. Each number on the graph represents the number of subjects whose losses detected by questionnaire and interview are represented by their position on the graph. Absolute agreements between subjects' questionnaire and interview loss data lie on the line that bisects the axes (22 subjects). Increasing distance from the line indicates increasingly lower agreement. There are 11 subjects above the bisector indicating these subjects scored more losses by questionnaire than by interview. Compared to this, there are 28 subjects below the bisector, indicating these subjects scored more losses by interview than by questionnaire. In particular, the wide scatter of many of these subjects from the bisector indicates the greater ability of the interview to detect higher multiples of loss than the questionnaire.



**Figure 12.3: Subjects' responses by questionnaire and interview (N=61)**

#### *12.6.1.2 Correlation between loss data sets*

The correlation between the loss data resulting from the questionnaire and interview for all the 61 subjects was found to be 0.58 ( $p=0.0001$ ) using Spearman's rho which indicates moderate correlation.

#### *12.6.1.3 Agreements between loss data sets*

Agreement was also demonstrated between the paired questionnaire and interview data using the kappa statistic (Altman, 1991) (Table 12.13). Using the gradings of Landis and Koch (1977) (Chapter 8.9.2.6.1), the agreement for the whole data set was moderate (0.54). For individual categories there was:

- perfect correlation for 'adoption';
- moderate correlation for 'quality of life', 'separation', 'death', 'fear of own death' and 'pregnancy';
- fair correlation for 'job', 'opportunity' and 'freedom'; and

- no correlation for ‘finance’, ‘migration/moving’, pet’ and ‘integrity’.

**Table 12.13 Loss data: Comparison between questionnaire and interview using the kappa statistic (N=61). Shaded cells indicate significant agreement**

Loss category	Kappa ( $\kappa$ )	95% confidence limits of $\kappa$
<i>All categories</i>	0.54	0.34-0.75
<i>Quality of life</i>	0.41	0.20-0.61
Separation	0.50	0.25-0.76
Job	0.35	0.10-0.59
Death	0.50	0.26-0.74
Fear own death	0.57	0.26-0.88
Opportunity	0.39	0.07-0.71
Finance	0.18	-0.18-0.54
Migration/ moving	0.27	-0.03-0.57
Pregnancy	0.57	0.23-0.91
Pet	0.28	-0.02-0.59
Integrity	0.26	-0.05-0.57
Adoption	1.00	1.00-1.00
Freedom	0.40	0.04-0.76

#### 12.6.1.4 Sensitivities, specificities and predictive values

Table 12.14 shows sensitivities, specificities and predictive values for Section B relative to the interview..

**The sensitivity of section B was 75%, indicating that it correctly identified 75% of cases of loss determined by the interview. The specificity for section B was 94% indicating it correctly identified 94% of subjects in whom there was no grief as determined by the interview. The predictive value of section B was 88%, indicating it was accurate in identifying true loss.**

**When examining the individual categories, the small numbers of subjects who endorsed each category imply that no strong conclusions can be drawn from these figures. Sensitivities for the separate categories demonstrate a wide range (14 -100% ) and are shown in descending order of sensitivity in the table. The specificities for the separate categories of section B were high (range 87-100%), which indicated that endorsement of a category may be highly specific for loss relating to that category. Predictive values vary widely between 50-100%.**

**Table 12.14: Sensitivities, specificities and predictive values for the loss categories**

<b>Section B/ Category</b>	<b>Subjects N=</b>	<b>Sensitivity (%)</b>	<b>Specificity (%)</b>	<b>Predictive value (%)</b>
<b>Section B</b>	61	75	94	88
<b>Adoption</b>	2	100	100	100
<b>Fear of own death</b>	8	63	94	63
<b>Pregnancy</b>	6	57	96	67
<b>Separation</b>	13	56	91	69
<b>Death</b>	13	53	93	77
<b>Quality of life</b>	16	46	93	88
<b>Pet</b>	11	44	87	36
<b>Freedom</b>	6	43	94	50
<b>Opportunity</b>	7	40	94	57
<b>Job</b>	11	38	93	73
<b>Integrity</b>	6	27	94	50
<b>Migration/moving</b>	5	25	96	60
<b>Finance</b>	2	14	98	50

## **12.6.2 Construct validity**

### *12.6.2.1 Effect of socio-economic status on numbers of loss categories*

Table 12.15 shows the numbers of loss categories by socio-economic cluster. In considering the ‘high’, ‘medium’ and ‘low’ clusters, there appears no demonstrable increase in the number of loss categories with lower socio-economic status. However, the higher median number of loss categories endorsed by the ‘very low’ group suggests a trend towards an association between an increase in the number of loss categories with lower socio-economic cluster. However, the numbers of subjects are too small to make an objective assessment. This is confirmed by the Kruskal-Wallis Test for comparing multiple data. The p value of 0.1275 exceeds the required value of 0.05 to show significance.

**Table 12.15: Multiples of loss categories for socio-economic cluster**

SES cluster	Subjects (N=60*)	Multiples of loss categories (questionnaire)				
		Median	Mean	SD	Min	Max
<b>High</b>	23	1	2	1.9	0	6
<b>Medium</b>	11	0	1	1.8	0	5
<b>Low</b>	18	1	2	1.9	0	5
<b>Very low</b>	6	5	4	3.0	0	7

\*Socio-economic cluster not recorded by 1 subject

### 12.6.3 Test-retest reliability

The loss data and grief scores were analysed for reliability by comparing the results of two questionnaires completed by the same subjects one week apart, as described in Chapter 11.1.6.

#### 12.6.3.1 Loss data

The response rate for the follow-up questionnaire was 92%. Only two of the 25 subjects who were asked to complete a questionnaire at Time 2 did not return the second questionnaire. Three further questionnaires were returned incomplete. The data of the remaining 20 subjects were analysed by direct comparisons, Spearman's rho and the kappa statistic.

Of the 20 subjects, 11 endorsed one or more loss categories at T1 and T2, and nine did not endorse loss on either occasion.

Table 12.16 compares the number of loss categories (0,1 and more categories) endorsed at Time 1 and Time 2. Time 2 data compared to Time 1 showed three subjects recorded fewer loss categories, eleven recorded the same number and six recorded more. Of the six who recorded more losses, three did not record a loss at the first occasion. It is not possible to know whether the greater numbers of losses recorded by the six subjects at Time 2 were due

to new losses occurring in the week that elapsed or because completing the questionnaire and interview at Time 1 may have been a learning experience about grief, which helped subjects to recognise existing loss.

**Table 12.16: Comparison of numbers of losses endorsed at Times 1 and 2**

<b>Numbers of loss categories at T1 compared with T2</b>	<b>Subjects (N=20)</b>	<b>% of subjects</b>
<b>Fewer</b>	3	15
<b>Same</b>	11	55
<b>More</b>	6	30
<b>Total</b>	20	100

The correlation between the numbers of losses for the whole loss data sets endorsed at Time 1 and Time 2 gave a value for Spearman's rho coefficient of 0.52, which indicated moderate correlation.

Agreement between the paired T1 and T2 data for the categories of loss was investigated using Cohen's kappa (Altman, 1991) and the results are shown in Table 12.17. For some categories, the paired data provided only one alternative response at either time 1 or time 2. A kappa statistic could not be calculated for these categories and therefore the number of congruent pairs are indicated. For congruent pairs, an arbitrary proportion of 17/20 was taken as significant.

**Table 12.17: Loss data: Comparison between loss data at times 1 and 2 using the kappa statistic (N=20 except pregnancy & freedom=19). Shaded cells indicate significance**

Loss category	Kappa ( $\kappa$ )	95% confidence limits of $\kappa$
Quality of life	0.49	-0.02-0.98
Separation	0.61	0.11-1.10
Job	0.77	0.35-1.20
Death	0.38	-0.12-0.87
Fear own death	0.77	0.35-1.20
Opportunity	0.46	-0.14-1.06
Finance	18/20 congruent pairs	
Migration/ moving	All congruent pairs	
Pregnancy	1.00	1.00-1.00
Pet	0.64	0.01-1.28
Integrity	17/20 congruent pairs	
Adoption	19/20 congruent pairs	
Freedom	17/20 congruent pairs	

Significant agreement was demonstrated for 10 of the 13 categories. ‘Migration/moving’ and ‘pregnancy’ showed perfect agreement. In addition, ‘finance/property’, ‘integrity’, ‘adoption/fostering’ and ‘freedom’ showed a high number of congruent pairs. The kappa statistic indicated close agreement for ‘separation’, ‘job’ and ‘fear of own death’. However, three categories failed to show agreement: ‘quality of life’, ‘death’ and ‘opportunity’.

## GRIEF MEASURE

### 12.6.4 Criterion validity

#### 12.6.4.1 Interview clinical scores

The frequencies of clinical scores for the whole sample are shown in Table 12.18. There was a spread of subjects across the categories.

**Table 12.18: Frequencies of clinical scores**

<b>Clinical score</b>	<b>Frequency</b>	<b>%*</b>	<b>% all subjects</b>	<b>% subjects with grief score</b>
<b>No grief</b>	**18	30	30	
<b>Minimal</b>	9	15	31	44
<b>Mild</b>	10	16		
<b>Moderate</b>	15	25	39	56
<b>Severe</b>	9	15		
<b>Total</b>	61	101		

\*\*17 subjects with no loss in section B (Chapter 12.4.1) + 1 subject with section B loss but gained 'No grief' clinical score =18

*12.6.4.2 Correlation of section C scores and items with the clinical scores*

Correlation of individual subjects' section C and item scores with their corresponding clinical scores as expressed by Spearman's correlation coefficient are shown in Table 12.19.

Moderate correlation (Spearman's rho=0.59) was demonstrated between section C and clinical scores. The highest value of 0.78 for C6 indicates a high correlation of this item with the interview (Weiten, 1998). Eleven other items have values slightly lower indicating moderate correlation. Four items have low correlations: C5, C13, C15 and C17. Identical items 4 and 9 have moderate correlations of 0.42 and 0.35 respectively.



**Table 12.19: Correlations between Section C, items and the clinical score**

<b>SECTION C/ ITEM NUMBER</b>	<b>Correlation with clinical score (Spearman's rho)</b>
Section C	0.59
C1	0.65
C2	0.68
C3	0.31
C4=9	0.42
C5	0.24
C6	0.78
C7	0.60
C8	0.59
C9=4	0.35
C10	0.49
C11	0.61
C12	0.50
C13	0.32
C14	0.41
C15	0.20
C16	0.38
C17	0.28

Table 12.20 and Figure 12.4 investigate the relationships between clinical score categories of minimal, mild, moderate and severe grief with the section C scores for the 32 subjects who gained a section C score >0. Table 12.20 shows that the median, 25%ile and 75%ile section C scores for each clinical category increase with increasing severity in the clinical score indicating an association between the section C scores and the clinical scores.

**Table 12.20: Relationship between clinical categories and section C score**

<b>Clinical score</b>	<b>Section C score</b>					
	<b>N Total=32</b>	<b>Median</b>	<b>25% quartile</b>	<b>75% quartile</b>	<b>Min</b>	<b>Max</b>
<b>Minimal</b>	6	10	1	13	0	21
<b>Mild</b>	9	16	11	19	9	21
<b>Moderate</b>	9	19	16	21	4	29
<b>Severe</b>	8	26	18	36	12	39

Figure 12.4 demonstrates the relationships between section C and clinical scores. The box plot demonstrates that, despite some overlap of clinical categories, those subjects who gained low clinical scores also gained low section C scores, as would be expected. Similarly, those who gained higher clinical scores gained correspondingly higher section C scores.

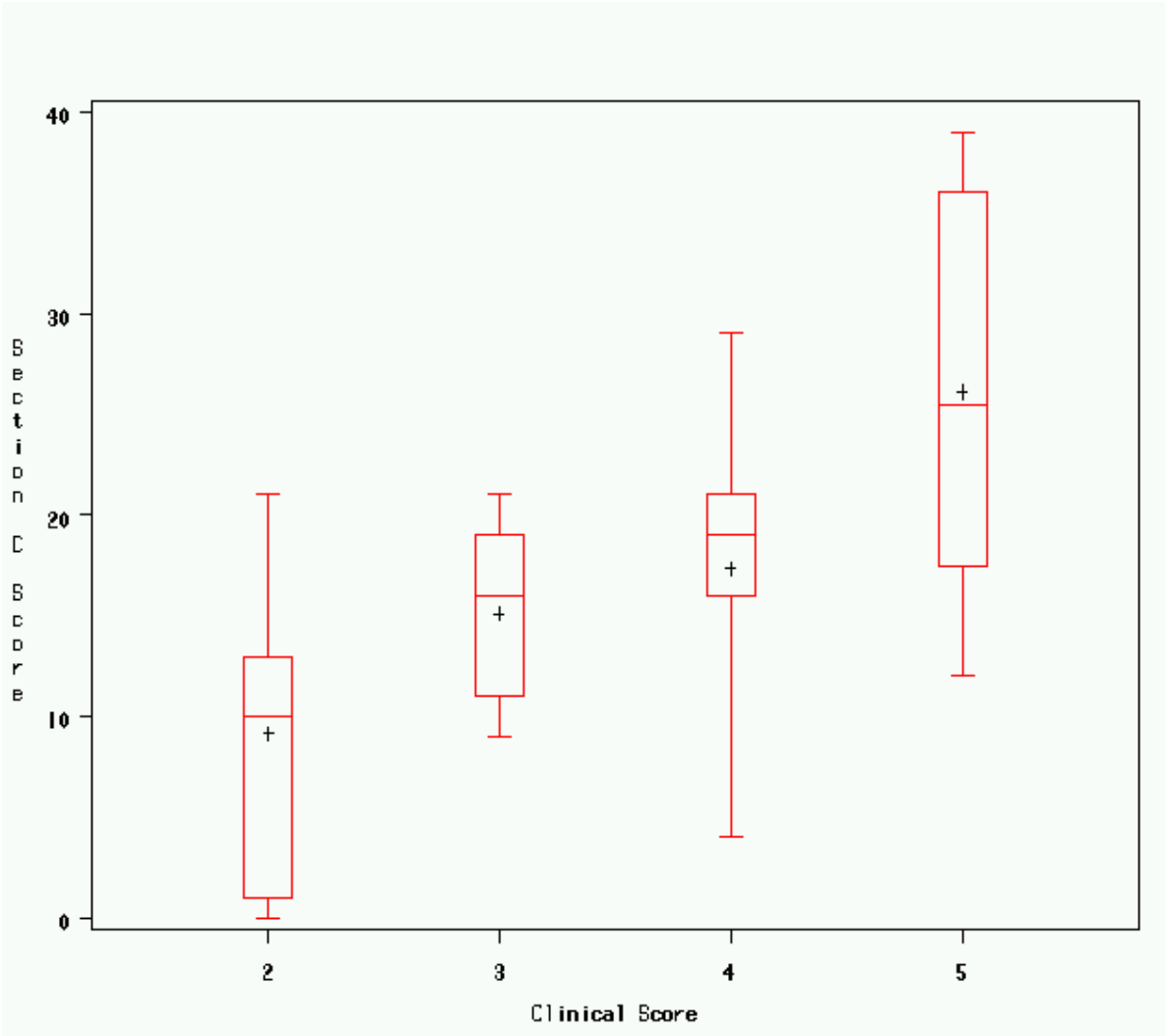


Figure 12.4: Relationships between section C scores and clinical score categories (N=32)

## 12.6.5 Construct validity

### 12.6.5.1 Effect of multiples of loss on Section C scores

Table 12.21 shows section C scores for multiples of loss categories. As in the trial, multiples of loss categories were collapsed to form a group of one and two loss categories, and a second group of three or more. Median section C scores for 3 or more loss categories were higher than for two or less. A Wilcoxon Two-Sample Test gave a T value of 0.1487 indicating the difference between the two groups was not significant but it was sufficiently low to support a trend in the construct of the mean grief scores increasing with increasing multiples of loss.

**Table 12.21: Section C score for multiples of loss**

Multiples of loss	Subjects (N)	Section C score				
		Median	Mean	SD	Min	Max
1 or 2	15	12	15	12.9	0	39
3 or more	19	17	18	6.3	8	34
Total	34	17	17	9.7	0	39

### 12.6.5.2 Effect of gender on Section C scores

Table 12.22 shows the median, mean and maximum grief scores are considerably greater for females than for males. However, the median number of losses for females is 1.00 compared to 0.00 for males, so higher grief scores would be expected for the females. Another difficulty in interpreting these results is that the number of males is too small to make an objective assessment. The suggestion from the table that the data supports the common finding in grief measure, that females score equally or more highly than males, therefore cannot be concluded.

**Table 12.22: Data for the grief scores compared to gender.**

Gender	Subjects (N=34)	Section C score				
		Median	Mean	SD	Min	Max
Male	5	12	10	7.3	1	19
Female	29	17	18	9.7	0	39

### **12.6.6 Test-retest reliability**

Correlation between the section C scores obtained at T1 and T2 were investigated using Spearman's rho coefficient for the eleven subjects who completed section C. A value of 0.97 was obtained indicating a very high correlation between the data.

When the three subjects who gained a grief score at time 2 but not at time 1 were added, Spearman's rho for the 14 subjects was 0.71 which still indicated high correlation.

### **12.6.7 Item validity**

Spearman's rho between C4 and C9 was 0.79, indicating high correlation between these identical items. This is just below the highest correlation of between items: a value of 0.80 was obtained between C16 and C9 in the Corr Procedure (Appendix 12.2).

An exploration of the relationships between C4 with C9 is given in Table 12.23, which shows how individual responses for C4 and C9 relate to each other:

- 25 absolute agreements in the shaded cells;
- 8 outliers next to the shaded cells indicate that the difference in scoring of these items is slight; and
- 1 outlier (starred) in the cell once removed from the shaded cells, indicates greater difference in scoring. This contributes significantly to the lower value of rho.

**Table 12.23: Correlations between items C4 and C9**

<i>Response options to C4</i>	<b>Response options to C9</b>				Total
	0	1	2	3	
<b>0</b>	6	5	0	0	11
<b>1</b>	1	12	0	1*	14
<b>2</b>	0	1	5	0	6
<b>3</b>	0	0	1	2	3
<b>Total</b>	7	18	6	3	34

#### **12.6.8 Testing for bias**

Gender and approximate ages of non-responders are given in Appendix 12.3. As in the trial, a number of subjects withdrew from the study after their appointment with their doctor and before they had completed the study. No record was kept of these subjects.

#### **12.7 Summary**

**This chapter has presented the results of the evaluation of the questionnaire and interview. This has included the qualitative and statistical data from the loss reviews and grief measures of both instruments. The analysis of these results is described in the following chapter together with the consequent modifications of the evaluation instruments to form the final Grief Diagnostic Instrument and the Grief Diagnostic Interview.**

## Chapter 13: Analysis of evaluation results

This chapter analyses the results of the data from the evaluation of the questionnaire and interview, which are presented in the previous chapter. The analysis follows the order of objectives for the analysis given in Table 8.6 and described in Chapter 8.9.2. Following the analysis the main conclusions will be drawn for each objective. The modifications made to the instruments as a result of the analysis will be explained. The Grief Diagnostic Instrument and the Grief Diagnostic Interview Schedule that evolved from this process are shown in Appendices 13.1 and 5.5 respectively.

### ***13.1 Wording, format and acceptability of questionnaire and interview***

#### ***(Objective 1)***

#### **13.1.1 Analysis**

##### ***13.1.1.1 Questionnaire***

The themes from the data presented in Appendix 12.1 are summarised in Table 13.1.

**Table 13.1: Qualitative data results from questionnaire**

<b>Section A: Demographic section</b>	
<b>Comments</b>	<b>Suggestions</b>
No adverse comments	There should be a demographic question to identify people of aboriginal and Torres Strait island origin
<b>Questionnaire: Section B</b>	
<b>Comments</b>	<b>Suggestions</b>
All subjects felt the questions were acceptable.	<p><b>‘This section determines whether you are experiencing grief at the moment.</b> You may be feeling grief now from losses you are currently experiencing as well as from past losses or losses you know will happen in the future.</p> <p><b>In the last TWO WEEKS have you been distressed about any of the following losses to you or someone close to you.’</b></p> <p>Change headings to ‘Date you knew about the loss’ and ‘Month’ and ‘Year’.</p>
The introduction to Section B was difficult to understand.	
Most subjects did not complete items relating to time.	
<b>Questionnaire: Section C</b>	
<b>Comments</b>	<b>Suggestions</b>
All subjects felt the questions were acceptable.	<p><b>Now consider ALL the losses you ticked</b></p> <p><b>In the past 2 weeks:</b></p> <p>Delete repetitive items</p> <p>‘dread of the future’ ‘emotions to feel numb’</p>
The introduction to Section C could state more clearly that it applies to all losses	
Several respondents commented on the similarity of the questions	
Difficulties in understanding ‘dread’ (C 10) Difficulties in understanding ‘numb’ (C14)	
<b>General Comments</b>	<b>Suggestions</b>
Respondents needed no help in completing the questionnaire	<p>‘This questionnaire is about grief. Grief is the distress we feel when we lose anything of value in our lives. It can follow the death of someone we love, the breakdown of a relationship, or loss of something or some situation that is precious to us. We may also experience grief knowing that someone we love or care for is grieving. Grief results from losses we are currently experiencing as well as from past or future losses.’</p>
Questionnaire did not appear to be too long for sick patients to complete	
Questionnaire needs an introduction to replace that given by the research assistant	

### *13.1.1.2 Interview*

No adverse comments about the interview occurred.

## **13.1.2 Conclusions**

### *13.1.2.1 Questionnaire*

The following were deemed reasonable by the research team:

- Although there was some comment about the similarity of items, a decision was made not to delete further items from section C because:
  - the length of the questionnaire appeared satisfactory
  - deletion of further items would reduce the number of phenomena tapped and thereby reduce the validity of the questionnaire
- All other themes and suggestions regarding the questionnaire are presented in Table 13.1;

### *13.1.2.2 Interview*

No modifications were necessary to the interview.

## **13.1.3 Modifications**

The following word and bold format modifications were made to the questionnaire:

### **Introduction**

- ‘This questionnaire is about grief. Grief is the distress we feel when we lose anything of value in our lives. It can follow the death of someone we love, the breakdown of a relationship, or the loss of something or some circumstance that is precious to us. We may also experience grief knowing that someone we love or care for is grieving themselves. Grief results from losses we are currently experiencing as well as from past or future losses.’



## Section A

- If ‘yes’ (Australian), are you of Aboriginal or Torres Strait Islander origin?’

## Section B

- **Introduction:** ‘This section determines whether you are experiencing grief at the moment. You may be feeling grief now from losses you are currently experiencing as well as from past losses or losses you know will happen in the future. In the last TWO WEEKS have you been distressed about any of the following losses to you or someone close to you.’
- Time column headings changed.

## Section C

- Introduction: ‘**Now consider all the losses you ticked. In the past 2 weeks:**’
- C9 removed (duplicate of C4). Numbering altered of the subsequent items;
- C10 changed to C9 ‘Have thoughts or reminders of the loss caused you to feel dread of the future’; and
- C14 changed to C13 ‘Have thoughts or reminders of the loss caused your emotions to feel numb’;
- 

### **13.2 Demographic characteristics (Objective 2)**

The demographic characteristics of the evaluation population given in Chapter 12.2 were compared with demographics of the Australian general practice population, of the Adelaide metropolitan population, and with the trial population.

### 13.2.1 Analysis

The comparison between the evaluation population and national general practice demographics, as determined by the third national general practice survey (Bridges-Webb, Britt, Miles, Neary, Charles, & Traynor, 1992) is seen in Table 13.2. The evaluation population contains a greater proportion of females than do either the national general practice survey or the trial populations. There are similarities between the age demographics of the national general practice survey and the evaluation population: the main differences are a higher proportion of 45-64 year-olds and lower proportions of 16-24 and over 75 year-olds in the evaluation population. Comparisons between the evaluation and trial populations are similar except that the bulge in the 25-44 year-old group in the trial population has shifted to the older age group of 45-64 year olds in the evaluation, and there is a lower proportion of those over 75 in the evaluation.

**13.2: Comparison of the demographics of the evaluation population with those for the Australian general practice population**

DEMOGRAPHIC		Bridges-Webb % of the 15- 75+ population	Evaluation %	Trial %
<b>Gender</b>	<b>Male</b>	41	20	36
	<b>Female</b>	59	80	64
	<b>Total</b>	100	100	100
<b>Age</b>	<b>16-24</b>	13.1	4.9	4.0
	<b>25-44</b>	30.8	26.2	48.0
	<b>45-64</b>	26.7	52.5	26.0
	<b>65-74</b>	16.1	13.1	14.0
	<b>&gt;75</b>	13.3	3.2	8.0
	<b>Total</b>	100.0	99.9	100.0

Comparisons of the evaluation population with the Adelaide metropolitan population, as given in the Social Health Atlas of South Australia (Glover, Shand, Forster & Wollacot, 1996; Glover & Tennant, 1999), and with the trial population are given in Table 13.3.

The socio-economic clusters for the evaluation are similar to the trial and, except for the ‘very low’ cluster, to metropolitan Adelaide. The ten percent of the evaluation population who were in the ‘very low’ cluster represented six subjects from rural South Australia. The table shows that the evaluation population did not differ greatly from the trial population in the proportions of subjects born overseas or in the unemployed. There was however a slight decline in the proportion of persons over 65 years of age.

**Table 13.3: Comparison of the evaluation population with the population of metropolitan Adelaide**

<i>Demographic</i>	<b>Adelaide metropolitan population</b>	<b>Evaluation</b>	<b>Trial</b>
<b>SOCIO-ECONOMIC CLUSTER*</b>			
<b>High</b>	50	40	41
<b>Medium</b>	30	19	16
<b>Low</b>	20	31	36
<b>Very low</b>	0	10	2
<b>Born overseas**</b>	12.5	31	32
<b>Unemployed**</b>	10.6	5	5
<b>People aged 65+**</b>	14.1	16	22

### 13.2.2 Conclusions

Similarities were demonstrated between the evaluation and trial populations, between the evaluation population and the national Australian general practice population, and between the evaluation population the Adelaide metropolitan population. The main differences of the evaluation population compared with the national Australian general practice population were that males, youth and the elderly were under-represented. Compared to the Adelaide metropolitan population, the unemployed were under-represented and those born overseas were more highly represented.

### ***13.3 New categories of loss and examples within categories (Objective 3i)***

#### **13.3.1 Conclusions**

That no new categories were found during the evaluation may indicate that, for this population, section B identifies all appropriate categories. However considering the limited cultural and socio-economic demographics of the populations studied in the trial (Chapter 8.7.3) and evaluation (Chapter 11.2), the questionnaire needs further evaluation on a more diverse population including indigenous peoples, migrants from Asia, Africa and the Americas and those within the ‘very low’ socio-economic cluster.

#### **13.3.2 Modifications**

From the results stated in Chapter 12.3, the following additions were made to the loss reviews of the questionnaire and interview:

- New examples for ‘opportunity’ category:

‘promotion’,

‘unfulfilled dream’

- New example for ‘adoption/fostering category:

‘giving up a child’.

### ***13.4 Descriptive statistics for the loss data (Objective 3ii)***

#### **13.4.1 Analysis**

The analysis of the results of the descriptive statistics for the loss data given in Chapter 12.4 is presented in Table 13.4. This table also compares the results for the evaluation with those for the trial (Chapter 9.4). Results of the evaluation were similar to those of the trial in almost all respects. Descriptive statistics for the questionnaire were again similar to the interview. As

was found at the trial, the interview identified more losses than the questionnaire, confirming the concept of disenfranchised grief. Similar percentages of subjects endorsed loss by questionnaire (60%: trial and 57%: evaluation) and interview (74%: trial and 72%: evaluation). A maximum of 9 loss categories per subject was found at the trial compared to 8 loss categories at the evaluation. On both occasions the interview identified a higher mean number of losses per subject and higher multiples of loss than did the questionnaire.

All categories of loss were endorsed at the evaluation as in the trial, indicating all categories were valid. As in the trial, death-related losses accounted for 20% of losses and non-death related losses accounted for the remaining 80% of losses detected. There were similarities in the order of rankings of the detection of categories between the trial and evaluation. The higher order categories were consistent with the expectations of the reasons for encounter in general practice, indicating face value of section B: patients consult their GP primarily about health related quality of life issues so this category would be expected to head the list.

Patients also seek the advice of their doctor in regard to symptoms and practical assistance relating to the death of someone close, separation and divorce, and health-related job loss and incapacitation (Bridges-Webb, Britt, Miles, Neary, Charles & Traynor, 1992). Migration was considerably better detected by interview, indicating this category was least well recognised by subjects, which is consistent with Doka's concept of disenfranchised grief. Loss was experienced across the age range of subjects (16-83) and by both genders.

**Table 13.4: Analysis of results from descriptive statistics of the loss data of the trial (Chapter 9.4) and evaluation (Chapter 12.4)**

Test	Trial result	Evaluation result	Conclusion
Loss	Questionnaire	60%	) Similar results )
	Interview	74%	
No loss	Questionnaire	40%	) Similar results )
	Interview	26%	
Mean number loss categories per subject	Questionnaire	2.25	) Similar results )
	Interview	3.0	
Maximum number loss categories per subject	9	8	Similar results
Multiples of loss	Interview identified higher multiples than questionnaire	Interview identified higher multiples than questionnaire	Same result
Types of loss category	All categories endorsed	All categories endorsed	All categories valid
Death related losses: non-death related losses	20%:80%	20%:80%	Same results
Rates of endorsement of categories (interview compared to questionnaire)	Higher by interview	Higher by interview	Same results
	Migration considerably better detected by interview	Migration considerably better detected by interview	Migration disenfranchised
Rankings of categories	Highest	'quality of life' 'death' 'separation' 'job'	High order is consistent with expectations in general practice indicating face value of section B.
	Middle	'opportunity' 'finance/property' 'fear of own death' 'pet'	
	Lowest	'integrity' 'pregnancy' 'adoption/fostering'	Similar rankings of higher, middle and lower order categories
Loss and age	All age groups and both genders affected by loss	All age groups and both genders affected by loss	Same result

### 13.4.2 Conclusions

1. The validity of section B is indicated by:

- similar results obtained by questionnaire and interview;
- all categories endorsed;
- findings consistent with expectations of general practice; and
- trial results replicated by the evaluation.

2. 2/3 of all subjects were experiencing loss;
3. The most frequently encountered loss categories were ‘quality of life’, ‘death’, ‘separation’ and ‘job’;
4. The concept of disenfranchised grief confirmed, particularly losses associated with migration and moving home; and
5. Further validity testing of section B is required (addressed in Chapter 13.6).

### ***13.5 Validity of the components of section C (Objective 4)***

#### **13.5.1 Analysis**

The results investigating the validity of the components of sections C and the items that best measure grief that were given in Chapter 12.5 are summarised in Table 13.5. These findings are similar in almost all respects to those of the trial as can be seen by comparing the trial and evaluation columns in this table.

The face validity was demonstrated by:

**zero endorsement of all items was <80%. Therefore all items were core phenomena and relevant to the measure.**

**Discriminatory validity was demonstrated by the: endorsement of all options for all items <80%; scores for section C were spread over almost the whole possible range and the median section C median score was significant. This indicated that the section C score discriminated between subjects with less severe and those with more severe grief; and scores for section C were spread over almost the whole possible range for 12 of the 16 items indicating these were discriminatory. The four exceptions, C5, C11, C14 and C15, failed to endorse option 3 (=a lot of the time) showing these were the least discriminatory items. All items except C14 generated significant median scores indicating C14 was less discriminatory than the rest.**

**Of the four items identified above as being least discriminatory, three performed similarly in the trial: C5 (C4 in the trial), about feelings of guilt; C14 (C16 in the trial), about feelings of numbness; and C15 (C25 in the trial), about imagining that the loss has not/will not occur. C 11 (C23 in the trial), about thoughts of the loss causing irritability with others, appeared less discriminatory in the evaluation only. The validity of items C5, C14, and C15 has already been established (Chapter 10.5.3.1) and deletion of these**

is therefore not appropriate. C11 was retained because its validity was established in the trial (Chapter 10.5.1).

Internal consistency of section C was demonstrated by the: high Cronbach's alpha for the whole measure. The alpha of 0.93 was lower than the alpha of 0.97 for the trial, indicating that most of the redundant items had been withdrawn. Although this still exceeds the recommended range of 0.70-0.90 and indicates there may still be redundant items, it is an acceptable value and consistent with the value of 0.91 found for the Core Bereavement Items (Burnett, Middleton, Raphael, Martinek, 1997), on which this measure is based; and the moderate to high Spearman's rho coefficients (0.30-0.80) between almost all items and the Section C scores demonstrated the phenomena they measured were related to the instrument.



**Table 13.5: Validity of components of Section C**

Objective	Purpose	Test	Trial results & (source)	Evaluation results & (source)	Conclusion
Face validity	Centrality to the construct of grief	Frequency of zero endorsement	Zero endorsement of all items <80%. (Table 9.7)	Zero endorsement of all items <80%. (Table 12.7)	All items measured core grief phenomena
Discriminatory validity	Discrimination over the range of severity	Frequency of endorsement across options	Endorsement of all options for all items <80% (Table 9.7)	Endorsement of all options for all items <80% (Table 12.7)	Whole of section C and all items were discriminatory.  Least discriminatory items: C5, C11, C14 and C15.
		Section C scores	Range of scores demonstrated (Table 9.8) Median score=20. (Table 9.9)	Almost whole range of scores demonstrated. (Table 12.8) Significant median section C score (Table 12.9)	
		Section C item scores	Maximum scores by all items except C25. Significant median scores by all items except C4, C16, C20 & C25 (Table 9.11).	Maximum scores by all items except C5, C11, C14, C15. Significant median scores attained by all items except C14. (Table 12.10)	
Internal consistency	Relevance to the rest of the measure	Internal consistency of section C	Cronbach's alpha=0.97 (Chapter 9.5.3.1)	Cronbach's alpha=0.93 (Chapter 12.5.3.1)	Alpha acceptable Lower alpha than in trial indicates most redundant items have been eliminated.
		Correlations between section C items & rest of section C	All Spearman's rho coefficients high (0.66-0.86) except for C25. (Table 9.14)	Moderate to high Spearman's rho correlations for 15/16 items: C5 exception (Table 12.11)	All items related moderately or strongly with each other, except C5.
		Factor analysis	4 factors loaded. Support for 'Grief', 'Non-resolution' & 'Images & thoughts' sets (Table 9.16).	Inconclusive (Table 12.12)	

### **13.5.2 Conclusions**

1. Validity of the components of section C has been demonstrated by
  - face validity;
  - discriminatory validity; and
  - internal consistency.
2. The number of items in section C is satisfactory and no deletions were indicated.
3. Findings of the evaluation replicated those of the trial.

### ***13.6 Validity and reliability of the questionnaire (Objective 5)***

**The results of the tests that examined the validity and reliability of the questionnaire that are given in Chapter 12.6 were summarised for section B in Table 13.4 and for section C in Table 13.5. Trial results are also given for comparison.**

#### **13.6.1 Analysis of loss review**

Results for the trial and evaluation were similar in almost all respects (Table 13.6). For both the trial and evaluation, relationships were demonstrated between questionnaire and interview data sets graphically, by correlations using Spearman's rho, by absolute agreements using Cohen's kappa and by significant agreements between most corresponding categories.

'Adoption/fostering' was the category with the highest agreement in both the trial and the evaluation. 'Finance/property', 'migration/moving' and 'integrity' are loss categories with the least agreement between questionnaire and interview, which is consistent with Doka's concept of disenfranchised grief.

The moderate sensitivities and high specificities and predictive values for section B at the evaluation confirm those found in the trial and indicate high validity of the instrument

(Abrahamson, 1990). The sensitivity of 75% indicates section B successfully screens for the majority of losses but misses around 25%, consistent with the concept of disenfranchised grief. This is obviously less than the ideal situation (sensitivity =100%) but is consistent with known difficulties in identifying loss. The specificity improves on that found at the trial.

However, the small evaluation sample (61) limits the certainty with which these conclusions can be drawn. These figures compare favourably with sensitivities of 0.55-0.92 and specificities of 0.80-0.99 found in various studies for the 30-Item General Health Questionnaire (Vieweg and Hedlund, 1983).

The trend supporting construct validity of section B is repeated in the evaluation. The finding of no strong association between the socio-economic clusters and multiples of loss is consistent with similar findings in the analysis of the interview data (Chapter 6.4.2), and supports the proposition there that loss events are not the same as life events. Clarification on a larger sample is desirable to establish the relationship between multiples of loss and socio-economic status.

Reliability is demonstrated for the whole data sets and individual categories. The correlation of 0.52 between T1 and T2 for the section B loss data is moderate and may be biased downwards by a learning effect of the first questionnaire. However, the value obtained lies within the lower range of 0.51-0.90 for coefficients test-retest reliability for psychiatric diagnoses found in various surveys for the 30 item General Health Questionnaire (Goldberg and Williams, 1988).

**Table 13.6 Analysis of results from validity tests of loss data of the evaluation**

Test	Trial result	Evaluation result	Conclusion	
Criterion validity	Graphical representation	Wide scatter around bisector of axes	Wide scatter around bisector of axes	
	Correlations between loss data sets	Moderate correlation (Spearman's rho=0.59)	Moderate correlation (Spearman's rho=0.58)	
	Agreements between loss data sets	Moderate agreement (Cohen's kappa=0.47)	Moderate agreement (Cohen's kappa=0.54)	
	Agreements for individual categories	Significant agreement for 10/12 categories	Significant agreement for 9/13 categories	
	Category with highest agreement	'adoption/fostering'	'adoption/fostering'	
	Categories with lowest agreements	'finance/property', 'migration/moving', 'integrity'	'finance/property', 'migration/moving', 'integrity'	
	Sensitivities Specificities Predictive values	74% 80% 92%	75% 94% 88%	Comparable with 30-item GHQ: Sensitivity 0.55-0.92 Specificity 0.80-0.99
Construct validity	SES & multiples of loss	Trend (Table 9.19)	Trend (Chapter 12.6.2.1)	Construct not disproved
Test-retest reliability	Correlation (whole loss data sets)	–	Moderate correlation (Spearman's rho=0.52)	Comparable with 30-item GHQ: rho=0.51-0.90
	Correlations between individual loss categories	–	Significant agreement for 10/13 categories (Chapter 12.6.3.1)	Reliability of section B supported

30-Item GHQ = General Health Questionnaire (Goldberg and Williams, 1988)

### 13.6.2 Conclusions

The validity of section B of the questionnaire is indicated by:

- demonstrated criterion validity;
- construct validity not disproved;
- demonstrated test-retest reliability; and
- results obtained in the trial were repeated at the evaluation.

The disenfranchisement of grief is confirmed;

The dissimilarity of loss events and life events is supported.

### 13.6.3 Analysis of grief measure

A comparison of the tests showing the validity and reliability of fro section C is given in Table 13.7. Comparing the clinical scores, as the gold standard, with section C and item scores, moderate correlations were found at both the trial and evaluation. The correlation coefficients for section C scores of 0.64 and 0.59 for the trial and evaluation correspond favourably with those for the Beck Depression Index. Beck collapsed his four clinical categories of none, mild, moderate and severe into two (none/mild and moderate/severe): correlations of Beck Depression Index scores with these two interview categories gave coefficients of 0.65-0.67 (Beck et al, 1961). A higher correlation would be expected for the Beck Depression Index because of the smaller number of clinical categories (2) compared with the four of section C (minimal, mild, moderate, severe).

Graphical representation comparing clinical and section C grief scores for the evaluation, demonstrated that increments in section C scores corresponded with increasing severity of the clinical scores. There is therefore support for the validity of the section C score as a measure and, additionally, for the interpretation of section C scores in terms of severity of grief as defined by this study (minimal, mild, moderate, severe: Chapter 5.1.3.11). Section C scores corresponded with clinical scores as follows:

- around 10 - minimal grief;
- around 16 - mild grief;
- around 19 - moderate grief; and
- around 25 - severe grief.

Only 32% of the subjects experiencing loss in the trial gained a moderate or severe clinical score whereas the figure was 58% for the evaluation. There may be several reasons for the discrepancy between these figures:

smaller number of subjects in the evaluation would magnify any error;  
a genuine difference in the levels of grief between the two populations; and  
differences between the clinical scores allotted by the interviewers.

As described in Chapter 4, no comparisons were made directly between the interviewer in the evaluation and those in the trial, rather comparisons were made between each interviewer (rater) and the chief investigator (CI). Although little difference was demonstrated between the raters in how they compared with the CI within one degree of disparity, rater 3 had a significantly greater proportion of perfect agreements with the CI (70%) than did the other raters (56% and 36%). These differences may accounted for error across the mild / moderate divide, so that raters 1 and 2 may have scored subjects as mild whereas rater 3 may have scored them as moderate. The main conclusion to be drawn is that a considerable proportion of all subjects at both the trial (1/4) with loss and evaluation (1/3) were suffering moderate or severe grief.

One of the constructs, the relationship between multiples of loss and section C scores, is supported at both the trial and evaluation. A trend between socio-economic cluster and section C scores was suggested at the trial but no relationship was found at the evaluation. There is no clear reason why this should be except that the sample may was too small. Significant support was given for the association of higher grief scores for females at the trial. However, no deductions could be made at the evaluation because females had twice the median numbers of losses than males and this would have contributed to the result.

**High item validity was demonstrated. Similar test-retest section C scores indicate that this is a reliable measure of grief.**

**Table 13.7: Validity and reliability tests for Section C**

Test	Trial result (source)	Evaluation result (source)	Conclusion	
Criterion validity	Section C scores with clinical scores	Moderate correlation: Spearman's rho=0.64 (Table 9.22)	Moderate correlation: Spearman's rho=0.59 (Table 12.19)	Correlations correspond with 0.65-0.67 for BDI  Criterion validity supported
	Graphical representation	32% subjects with loss gained moderate or severe clinical score	58% subjects with loss gained moderate or severe clinical score	
		–	Relationship between section C and clinical scores (Figure 12.4)	
	Section C item scores with clinical scores	Moderate correlations for all items (Table 9.22)	Moderate correlations for 13/16 items Low correlations for 3/16 items: C5, C15, C17 (Table 12.19)	
Construct validity	Multiples of loss & section C score	Significant support (Table 9.23)	Strong trend (Chapter 12.6.5.1)	Construct validity supported
	Gender & section C score	Significant support (Table 9.24)	Conclusions cannot be made (Chapter 12.6.5.2)	
Item validity (C4 & C9 identical)	–	High correlation: Spearman's rho=0.79 (Chapter 12.6.7)	High item validity	
Reliability	Correlation between T1 & T2 section C scores	–	High correlation: Spearman's rho = 0.97 (Chapter 12.6.6)	Very high reliability

**BDI = Beck Depression Inventory (Beck et al, 1961)**

### 13.6.4 Conclusions

The validity of section C of the questionnaire is indicated by:

- Demonstrated criterion validity;
- Support for construct validity;
- Demonstrated item validity;
- Demonstrated test-retest reliability; and
- The results of the trial were reproduced at the evaluation.

1/2 of subjects experiencing loss (1/3 of all subjects) were suffering moderate or severe grief.

### 13.6.5 Analysis of whole questionnaire

Data of the genders of non-responders and subjects (Appendix 12.3) suggested there was a higher proportion of females among subjects (80%) than among non-responders (67%). However, a Wilcoxon two-sample test (Table 13.8) showed there was no significant difference between the two groups ( $p = 0.308$ ). No gender bias was therefore demonstrated. Ages were too non-specific for analysis.

**Table 13.8: Subjects compared with non-responders**

Number	Subjects		Number	Non-responders	
	Gender			Gender	
	M	F		M	F
60	12 (20%)	48 (80%)	15	5 (33%)	10 (66%)

### 13.6.6 Conclusions

No non-responder gender bias was found at either the trial or the evaluation. Other biases, such as age, could not be estimated because the data were too non-specific.

## 13.7 The Grief Diagnostic Instrument

The Grief Diagnostic Instrument (Appendix 13.1) was formed as a result of the modifications made to the evaluation questionnaire which are described in the preceding sections of this chapter. There is support for validity and reliability of section B as a screening instrument and of section C as a measure of grief.

The known difficulties in detecting loss were demonstrated throughout the study and are reflected in the sensitivity of the instrument.



### **13.8 Summary**

This chapter has analysed the results from the evaluation of the questionnaire and interview and described the conclusions and modifications of the instruments as a consequence. The objectives of the analysis (Chapter 8.9.1) have been fulfilled as pertains to the questionnaire as follows.

The wording, format and acceptability of the questionnaire have been examined (Objective 1).

The wording changes made to trial questionnaire appeared satisfactory in the evaluation.

Further modifications were made to the evaluation questionnaire to optimise the wording and format. Subjects comments demonstrated that the format and content were acceptable, including that section C was an appropriate length.

The demographic characteristics of the evaluation population were defined (Objective 2) and were found compatible with those of the trial population and the Australian general practice. Some expected differences were demonstrated between the evaluation population and the Adelaide metropolitan population.

Loss data from the evaluation were examined to determine new categories of loss and examples within categories (Objective 3i). No new categories of loss were found, indicating the evaluation loss inventory may be complete for this population. Two new examples of loss were added to the loss survey, thereby improving the comprehensiveness of the loss reviews.

The detection of loss was described and compared for the questionnaire and interview (Objective 3ii). The validity of section B of the questionnaire was demonstrated in that similar results were obtained by questionnaire and interview, but that the interview identified loss better than the questionnaire. In addition, all categories of loss were endorsed, the loss data

findings were consistent with expectations of general practice, and the trial results were replicated by the evaluation.

The validity of the components of section C of the questionnaire was examined to determine those items that best measured grief (Objective 4). The validity of the items included in the evaluation questionnaire was replicated in the evaluation. In addition, the number of items in section C was demonstrated to be satisfactory, and no further deletions were indicated. The 16 retained items were demonstrated to be appropriate.

The questionnaire was examined for validity and reliability. Section B was deemed valid in that the results found in the trial were replicated in the evaluation, criterion validity, construct validity and test-retest reliability were demonstrated. Sensitivities and specificities were similar to values for the 30-item General Health Questionnaire (Goldberg and Williams, 1988). The validity of section C of the questionnaire is demonstrated in that the results of the trial were reproduced at the evaluation, and criterion, construct and item validity were demonstrated, as well as test-retest reliability. Further, the criterion validity was similar to that demonstrated for the Beck Depression Index (Beck et. al., 1961). No non-responder bias was demonstrated.

Initial results from the instruments demonstrated:

- 2/3 of all subjects to be experiencing loss;
- 1/2 of those experiencing loss (1/3 of all subjects) were suffering moderate or severe grief;
- the most frequently encountered loss categories were 'quality of life', 'death', 'separation' and 'job';
- death-related losses accounted for 20% of losses and non-death related losses accounted for the remaining 80% of losses detected;

- 1/4 to 1/3 of all subjects were experiencing moderate or severe grief;
- the disenfranchisement of grief found in the trial was confirmed in the evaluation and again, particularly, grief from migration losses; and
- the dissimilarity of loss events and life events.

## Chapter 14: Discussion

This thesis addresses two aims, the first of which was to design and evaluate a questionnaire, the Grief Diagnostic Instrument, to detect and measure the extant state of grief in general practice patients. This instrument investigates grief from past, present and future death and non-death related losses occurring directly to the subject, as well as caused indirectly through experiencing grief in sympathy with that of others. The purpose was to provide a means of measuring the prevalence of loss and grief in general practice patients in order to test the hypothesis that loss and grief are under diagnosed and under treated in patients attending their GP. In order to provide the criterion against which to evaluate the questionnaire, a second aim is addressed: to devise a standardised interview, the Grief Diagnostic Interview, in order to detect and measure the extant state of grief in general practice patients.

This chapter will summarise the main findings that arise from the study and discuss validity issues concerning the methodology. Finally, the contributions of this study to grief research and to clinical practice will be discussed .

### ***14.1 Summary of main findings***

#### **14.1.1 The Grief Diagnostic Instrument (GDI)**

The GDI is in three parts: a demographic section (section A); a section to detect grief (section B); and a grief measure (section C). All three parts were demonstrated to provide valid measures.

The loss review (section B) detects the presence or absence of grief in patients attending general practice, and determined the categories of loss events causing grief. Thirteen valid categories of loss, with subcategory examples, have been established for the population studied. These are:

- death (of another);
- fear of own death;
- (health-related) quality of life;
- job;
- separation (from a significant other);
- opportunity;
- finance/property;
- pet (death or serious illness);
- pregnancy;
- integrity;
- migration/moving;
- freedom; and
- adoption/fostering.

Subjects may record additional losses that do not fit into existing categories, thereby providing a means of identifying further categories. Provision is made for subjects to record up to three losses for each category.

The grief measure (Section C) measures the extant state of grief resulting from the losses detected by Section B. It contains 16 items that measure grief phenomena on a four point Likert scale. The items fulfil the requirements for measuring grief: they comply with the recognised principles for grief measurement (Chapter 4.3.2), with the task-specific

requirements (Chapter 4.3.3) of being core phenomena of grief from any loss and relevant to general practice patients, and tap the emotional, physical, social and cognitive domains affected by grief. The questionnaire was improved and evaluated through a two-stage process of a trial and subsequent evaluation. Validity of all three sections of the questionnaire was demonstrated in that all five objectives of the validity analysis were satisfied. Further, these validity tests produced values similar to those of accepted mental health measures.

The Grief Diagnostic Instrument therefore fulfils the objectives stated in the Introduction:

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

#### **14.1.2 The Grief Diagnostic Interview**

The Grief Diagnostic Interview is in four parts: an opening, a loss review, a grief measure and a closure, and is used in conjunction with a prompt sheet. The opening is designed to provide opportunity for the development of rapport and trust between the interviewer and interviewee. The loss review consists of questions designed to identify losses associated with the same 13 categories of loss as the questionnaire, as well as making provision for recording losses that do not easily fall into existing categories, thereby identifying new categories. The loss review therefore detects the presence or absence of grief in patients attending general practices, and determines the categories of loss events causing grief. The grief measure examines the affect of grief over the six domains of emotions, physical symptoms, and the social, cognitive, behavioural and spiritual functioning thereby measuring the extant state of grief. The closure is designed to provide opportunity to debrief the subject and to provide information about sources of assistance in cases of distress.

The interview detected a higher proportion of subjects experiencing loss, higher multiples of loss categories per subject and more losses for each category, than did the questionnaire. The

loss review of the interview therefore fulfils the expectations for the gold standard of detecting more losses than the questionnaire. The validity of the interview was demonstrated by high inter-rater reliability, construct validity and internal consistency. Additionally, the results of the loss data of the trial and the evaluation of the interview were consistent with expectations of findings in general practice, and the interview was found to be acceptable to general practice patients. The Grief Diagnostic Interview therefore also fulfils the objectives stated in the Introduction.

### **14.1.3 The prevalence of loss and grief in general practice**

Initial results from the trial and evaluation identify 2/3 of all subjects to be experiencing loss. Of these, more than 1/3 (that is, over 1/4 of all subjects) were suffering moderate or severe grief. These findings support the hypothesis that loss and grief are under-recognised and under-treated in general practice. The loss categories most frequently endorsed were 'quality of life', 'death', 'separation' and 'job'. Death related losses accounted for only 20% of the losses detected, whereas non-death related losses accounted for the remaining 80%. Grief was experienced across the age range investigated (16-80+) and by both genders.

It is important to recognise that although the instruments make provision for recording more than one loss per category, this study determined the number of loss categories and not the number of losses endorsed by subjects. Examination of the original questionnaires showed that some respondents identified more than one loss for some categories. The actual number of losses experienced by this study is therefore an underestimate.

### **14.2 Validity issues of the study**

There are a number of validity issues concerning the design of the study that need comment, which are described in the following paragraphs.

### **14.2.1 How 'gold' is the gold standard?**

Although it has been claimed that the interview is the gold standard for detecting grief in this study, it is not known how many cases of grief still remained undetected in the sample. Cases of true grief could have remained undetected because the subject did not want to mention them, or because the subject or the interviewer did not recognise them. The validity of the interview relies on the diagnostic ability of interviewers and their empathy with the client to put them at sufficient ease for them to reveal their loss.

### **14.2.2 The process as a learning experience**

Throughout this study it has been maintained that the higher detection rate of loss by the interview over the questionnaire is due not only to the innate qualities and methodology of the interview, but also to the learning provided by the first experience of a grief instrument (Chapter 4.5.5). The results of the test-retest reliability testing substantiate this: more losses were detected at T2 (subjects' second experience with the questionnaire and third exposure to a loss and grief instrument) compared to T1 (subjects first experience with the questionnaire and with any study instrument). Further research on larger samples is required. For example, a study in which only one instrument is presented on two occasions to the same set of subjects would explore the learning effect of the instrument. Further, a study in which the questionnaire and interview were completed in different orders would eliminate the learning effect and explore the merit of the interview as the gold standard.

### **14.2.3 Effects of non-responders**

Non-responders may have deprived the study of certain particularly sensitive categories of loss so it is possible that these categories are not included in the loss reviews of the



instruments. Additionally, some categories may themselves be under-represented in prevalence, which, in turn, may contribute to a lower overall prevalence of grief.

#### **14.2.4 Demographic considerations**

**Another issue concerns how representative was the study population compared to the Australian general practice population. Another concern is the effects of the sample on the development of the instruments. The study omitted the rural community for reasons of convenience and thereby excluded the ‘very low’ socio-economic cluster. Although included in the final instrument, there was no response option for indigenous peoples in the demographic section (A) of the study questionnaire, so the numbers of Aboriginal subjects in the study are unknown. Although people born overseas are over-represented in both the trial and evaluation sample, the actual numbers of subjects is small (32 in the trial and 19 in the evaluation). It is questionable whether the loss events and situations particular to these groups are adequately represented by the existing categories or whether there are some categories still to be identified. Similarly, grief phenomena in these groups may differ from those in the population studied. The applicability of the grief measure items of the questionnaire (section C) therefore also remains uncertain.**

As the study has been carried out on a limited population, caution is required in using the instruments on the ‘very low’ socio-economic cluster, indigenous peoples, certain groups of migrants, in settings other than general practice and in other countries.

#### **14.2.5 Effects of the interviewer**

The possible effects of the interviewer on the validity of the interview require comment.

Observer error may have been caused by the interviewer wrongly detecting what she wanted to detect and creating false positives of the interview loss data. However the question ‘Do you regard this as a loss?’ on the prompt sheet provided a check that subjects perceived an event or situation they were experiencing as loss. Additionally, error may have been caused by the subject stating what he or she thought the interviewer wanted stated.

#### **14.2.6 Effect of depression**

Although efforts were made in the interview to allow for the effects that subjects’ depression may have had on their self disclosure about the numbers of losses and the severity of their

grief, feedback from the interviewers established this was very difficult to do. In the questionnaire, inclusion of items to measure aspects of depression and anxiety was deliberately avoided. The effect these conditions may have had on subjects' responses to the questionnaire and interview remains unknown. It is possible that depression, whether pre-existing or as a complication of the grief under measurement, may have predisposed subjects to view their grief more negatively and to rate their responses higher. Therefore depression remains a possible confounder of this study. The concurrent use of the Grief Diagnostic Instrument with standard measures for depression and anxiety on the same set of grieving subjects would be valuable in determining relationships between these.

### ***14.3 Issues arising from the study***

#### **14.3.1 The disenfranchisement of grief**

There are several findings from this study that support the concept of disenfranchised grief. The fact that the interview consistently detected more losses than the questionnaire indicates the learning experience about loss and grief that has already been discussed. This is further supported by the sensitivities of the questionnaire of 60-70%.

The findings that 2/3 of the sample population were experiencing grief and that for over 1/3 of these the grief was moderate or severe, demonstrate the previously unrecognised high level of grief in general practice patients.

The fact that 80% of the losses detected were non-death related losses is also significant. The appropriateness of applying the results of bereavement research to non-death related loss must therefore be questioned. It follows that more emphasis be placed on non-death related loss and on the paradigm of loss and grief as an entity. It also begs the question as to the adequacy of the number of support services in Australia for non-death related loss compared to death-

related loss. Although certain non-death related losses, such as sexual abuse, have relevant support services, many others, such as redundancy, have no recognisable support. On the other hand, grief from death related loss is recognised and supported by bereavement support groups and palliative care programs. Similarly, in relation to research, the number of studies undertaken into bereavement far outweighs the number carried out about non-death related losses. Therefore non-death related loss appears to be disenfranchised not only by society, but also by research. ‘Migration /moving’ appeared the most disenfranchised category throughout the study, which is remarkable in a country formed by migrants.

### **14.3.2 A paradigm of loss and grief for general practice**

The high level of grief among the study subjects indicates that grief is a major issue in general practice patients. Evidence presented in Chapter 1 indicates that there is little or no recognition of loss and grief by GPs. The initial results from the use of the GDI and Interview therefore indicate that loss and its subsequent grief is under recognised by GPs. The proposal discussed in Chapter 2.3 for a separate paradigm of loss and grief for general practice with a separate diagnostic category, and diagnostic and management protocols supported by researched evidence, therefore seems reasonable.

### **14.3.3 Grieving subjects as a ‘special’ group as defined by the NH&MRC ethics guidelines**

This study has identified references in the literature to the existence of a cognitive deficit in grief. This study has postulated that this may affect the competency of grieving individuals to undertake informed consent. Further research is necessary to establish whether this is so. If a deficit is substantiated, grieving individuals may need to be regarded as one of the groups that ‘merit special attention’ in the Statement on Human Experimentation and Supplementary Notes issued by the National Health and Medical Research Council of Australia (1992).

#### **14.3.4 Acceptability of the exploration of grief by subjects**

Partaking in research on personal grief issues was acceptable to subjects. Although the interview was terminated for one subject who became very distressed, many others commented that they appreciated the opportunity to discuss their grief. It is not possible to know what the later effects were on the subjects, but neither the practices nor the researchers received any reports of undue distress arising from the study. As far as can be determined, the questionnaire and interview conformed to the ethical requirement of doing no harm, consistent with evaluations of other grief studies (Runeson & Beckow, 1991; Parkes & Weiss, 1983).

#### **14.3.5 Dissimilarity of loss events and life events**

The lack of strong correlation between socio-economic cluster and multiples of loss, compared to the strong correlations found between socio-economic status and life events previously discussed (Lima, Beria, Tomasi, Conceicao, & Mari, 1996), may indicate the dissimilarity between loss events and life events. However, the method of assessing socio-economic status by the postcode in this study can only give a rough approximation.

### ***14.4 Current research context***

#### **14.4.1 Development of grief measures**

This study has taken place at a time when a number of new grief measures have appeared in the literature. These have been created because the validity of existing grief measures has been questioned and developing new, more valid ones has become important in the bereavement research agenda (Hansson, Carpenter & Fairchild, 1993; Neimeyer & Hogan, 2001). The issue of validity is fundamental to grief research as valid and standardised

measures are vital to the conduct of controlled comparative studies to identify determinants of morbidity and recovery, and to support evidence-based practice. Some new bereavement measures have attempted to be more focussed on finding the most valid phenomena of grief, such as the Core Bereavement Items (Burnett et. al., 1997) on which the Grief Diagnostic Instrument was based. A different initiative has been to measure grief across a number of domains, such as the measure of the Loss Response List (Wheeler & Austin, 2000). The GDI, like the Loss Response List, addresses the physical, social, cognitive and emotional domains of functioning.

Other instruments have followed a different path in order to address the fundamental problem of the lack of definition of the end point of grief. Whereas traditionally, the end point of grief was regarded as the cessation of grief symptoms (Cleiren, 1993; Farberow, Gallagher-Thompson, Gilewski & Thompson., 1992a; Zisook, Devaul, & Click, 1982), more recently, reorganisation and adaptation have been recognised as integral parts of the grieving process. Consequently, new instruments include a wider range of grief phenomena, such as coping and recovery. Among those with a broader focus is the Hogan Grief Reaction Checklist (Hogan, Greenfield & Schmidt, 2001) which includes the sub-scale of personal growth, which is new to grief measures.

Another focus of grief measures has been to create instruments for specific groups of bereaved individuals. An example of this is the Grief Experiences Scale, reported by Murphy, Johnson, Cain et. al. (1998) which pertains to parents whose young adult children had died violent deaths. Another measure, the Loss Response List (Wheeler & Austin, 2000), is specific to adolescents.

A further spotlight of attention has been in measuring specific aspects of grief. A case in point is the Inventory of Traumatic Grief (Prigerson, Machiejewski, Reynolds et. al., 1995) which

differs from previous scales in that it measures symptoms of complicated grief that predict long-term functional impairment.

Grief resulting from non-death losses has also become another focus of grief measurement. The Perinatal Grief Scale (Toedter, Lasker & Alhadeff, 1988) has been used to address not only grief from perinatal death but also from induced abortion and the adoption of a baby. The Mental Illness version of the Texas Inventory of Grief, was devised to measure grief of family members whose relative develops a serious mental illness (Miller, Dworkin, Ward & Barone, 1990). A structured interview and a standardised questionnaire have been designed to assess the severity of the grief following job loss (Archer & Rhodes, 1995). More recently, the Loss Response List (Wheeler & Austin, 2000), like the present study, aims to measure grief from a number of losses in adolescents including bereavement, abortion and miscarriage.

One of the major problems with all of these instruments is that they measure grief only from individual pre-determined losses, and do not attempt to detect other coexisting losses that may compound a subject's grief. Another major problem is that the use of different instruments makes it difficult to compare the severities of grief caused by different losses, such as loss of a job with the loss of a spouse. The GDI addresses both of these issues. It provides for the identification of a wide range of losses and for the grief of individual losses to be compared because the same measurement scale is used. It also enables a number of other variables to be identified and standardised when used on large numbers of subjects (see 14.5.2.2 and 14.5.2.4).

#### **14.4.2 Grief literacy**

This study has also taken place in the context of concern for health and mental health literacy (Goldney, Fisher & Wilson, 2001; Jorm, Jacomb, Christensen, Rodgers & Pollitt, 1997; Nutbeam, Wise, Bauman et.al., 1993). In this context, literacy means:

‘the ability to recognise specific disorders; knowing how to seek .... health information; knowledge of risk factors and causes, of self-treatments, and of professional help available; and attitudes that promote recognition and appropriate help-seeking’ (Jorm, Korten, Jacomb, Christensen, Rodgers & Pollitt, 1997).

I propose extending the use of the term ‘literacy’ to grief, so as to encourage knowledge of grief as a positive attribute. Improved grief literacy would enable the general public and professionals to identify grief more readily, to seek out relevant information and to adopt appropriate supports, and thereby be pro-active in avoiding complications from the grieving process such as depression.

#### ***14.5 Implications for future research***

##### **14.5.1 Further evaluation of the Grief Diagnostic Instrument**

The instrument needs further evaluation in regards to a number of aspects not already addressed. Using the grief measure on a large number of subjects (200 minimum) will help to confirm the relevance of the present items of Section C to the measure of grief. The population selected for the development of the instrument was necessarily limited by the method employed of comparing it with the interview. It will therefore be important to establish the appropriateness of the questionnaire to a more diverse range of subjects. In particular, the ‘very low’ socio-economic group, rural residents, migrants from different cultural backgrounds and indigenous peoples. Preliminary investigation of losses by focus groups may be appropriate. Losses incurred by these groups may be very different from those detected in the current study. It is conceivable the instrument is also applicable to other clinical populations, such as to social work, psychiatry and psychology practices as well as the general population. Trials among these populations would be worthwhile.

### **14.5.2 Contribution to grief research**

The GDI is suitable for epidemiological studies to determine the prevalence and severity of grief in patients attending their GP. By using it in conjunction with GPs' clinical audits, it would be possible to determine the detection rate of grief by GPs among their patients and to substantiate the hypothesis that loss and grief are under-diagnosed and under treated in general practice. Confirmation on a large scale of the findings of the present study would assist in raising awareness and destigmatising grief.

Another concern is how can we be sure that existing bereavement scales measure grief resulting from only the bereavement under consideration and not grief resulting from other losses? For example, a woman whose sister is killed in a motor vehicle accident may grieve more for the husband who died 10 years previously than for the sister, because the new situation she finds herself in reinforces her husband's absence at a time when his comfort is most needed. Measurements of her grief by a standard bereavement measure may demonstrate unexplainably severe and long lasting grief. If the same woman had lost her job instead of her sister, she may be perceived as grieving inappropriately by the job loss questionnaire (Archer & Rhodes, 1995) until the husband's death is identified. The likelihood of this phenomenon is supported by this study as of the 19 subjects who were found to be experiencing a death loss by the evaluation interview, only 5 identified death as the sole loss. The other 14 subjects identified up to 6 other losses. The Grief Diagnostic Instrument and Interview improve on former instruments by detecting a broad range of losses and measuring their combined effect. Use of the GDI will therefore enable the variety of loss variables to be taken into account in grief, bereavement and mental health research.



The GDI is suitable to explore loss in specific populations, such as detained migrants, in order to understand the distress of detention. Similarly, investigating loss situations experienced by the elderly may lead to better care of this expanding group within western countries.

This instrument may also be used to identify differences as well as commonalities among populations affected by the same loss. For example, losses common to those who experience a specific disaster could be assessed. Losses particular to individuals, such as previous losses, could also be determined. Grief patterns could be monitored over the ensuing months and individuals at risk could be identified and targeted for particular interventions.

The Grief Diagnostic Instrument provides a means of measuring grief from different losses, thereby forming comparisons of severity and course over time between losses. A large-scale comparative study, standardising for other variables would enable migration to be compared with a particular kinship bereavement, and so its severity in comparison to bereavement could be determined.

## ***14.6 Clinical uses of the Instruments***

### **14.6.1 The Grief Diagnostic Instrument**

The GDI is suitable as a screening tool for grief, to be given to patients to complete while they are waiting to see the doctor. Once loss has been identified and the grief measured, the instrument could then be used to assess the response of patients to therapy by measuring the change of the severity of grief over time. The GDI is therefore suitable as an assessment tool for the 3 Step Mental Health Process in the Australian Better Outcomes in Mental Health Care initiative (Australian Divisions of General Practice, 2002). The score will provide an indication of the severity of grief similar to the psychiatric severity descriptors of the

Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994). The finding of a score above the level expected for the loss will alert the doctor to the coexistence of undisclosed losses, intercurrent losses and give an early indication of conditions such as chronic grief (Middleton, Burnett, Raphael & Martinek, 1996) or depression. The instrument has the means to record up to three losses per category so the doctor may count the actual numbers of losses.

#### **14.6.2 The Grief Diagnostic Interview**

The Grief Diagnostic Interview would also be used as a clinical tool. By enabling the GP to diagnose and measure the severity of grief of his or patients, the interview will contribute significantly to the thorough investigation of patients presenting with psychological and physical symptoms. This will enable the doctor to investigate further the relationships between loss and symptoms and, if grief were diagnosed, to manage the grief appropriately and specifically. Additionally, it will be useful to clarify loss and grief situations arising from the use of the GDI.

#### ***14.7 Recommendations that arise from this study***

Recommendations are made that:

- further evaluation of the GDI and Interview be undertaken regarding the loss categories and grief measure items on a larger samples and on diverse populations;
- the GDI be used for a large scale prevalence study to confirm the high prevalence of loss and grief in general practice patients that was found in this study. There is also a need to explore to what extent GPs detect loss and grief in order to confirm the hypothesis that loss and grief are under-diagnosed and under-treated in general practice;

- the GDI be used to determine losses and the subsequent grief within and between specific populations; and
- the GDI and Interview be further evaluated for use as clinical tools for the assessment and monitoring of individual patients.

### **14.8 Conclusions**

1. A questionnaire, the Grief Diagnostic Instrument, and an interview, the Grief Diagnostic Interview, have been developed to detect and measure the extant state of grief in general practice patients. These instruments investigate grief from past, present and future death and non-death related losses occurring directly to the subject, as well as caused indirectly through experiencing grief in sympathy with the grief of others. The unique feature of these instruments is that they detect a wide variety of losses and measure grief from all these losses, rather than merely a single loss.
2. These instruments have demonstrated validity, reliability and sensitivity and are acceptable to patients.
3. Recommendations for further evaluation of the GDI have been proposed.
4. Uses of the instruments, both in research and as clinical tools have been made.
5. Initial results from the study have demonstrated that grief is a mental health issue in general practice patients that has been previously unrecognised. Further, patients themselves do not recognise grief. 80% of losses identified were non-death related losses compared to 20% that were death related. Migration and relocation proved to be the category least well recognised.

6. These findings support the case for a new paradigm of loss and grief in general practice and for educational programs about grief.

### **14.9 Summary**

This Thesis has addressed two research questions:

- the design and evaluation of a questionnaire, the GDI, to detect and measure the extant state of grief in general practice patients; and
- the design and evaluation of a gold standard interview, the Grief Diagnostic Interview.

The objectives for design of these instruments have been fulfilled, and methodological issues concerning grief have been incorporated into the design of the study.

The GDI has been demonstrated to be a concise, valid, reliable and sensitive measure, and acceptable to general practice patients. The Grief Diagnostic Interview also has demonstrated validity and sensitivity. A unique feature of these instruments is that they investigate and measure grief from all losses rather than just a single loss. Suggestions have been made for further validation studies on these instruments. Their contributions to future grief research and clinical practice have been described.

Initial results from the trial and evaluation of the instruments have shown grief to be a significant issue among 2/3 general practice patients. The lack of recognition of grief by subjects was demonstrated, particularly of grief resulting from migration. These results support the hypothesis of this Thesis that loss and grief are under-diagnosed and under-treated in general practice. A large-scale randomised study using the GDI into the prevalence of loss and grief in general practice patient populations and the diagnostic rate of loss and grief by GPs, is now required.