

A Stratified Model of Bereavement Care:

Risk assessment and effectiveness of
a nationwide intervention programme



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Een gestratificeerd model model van hulpverlening bij rouw:

Risicoassessment en effectiviteit van een
nationaal interventieprogramma (met een
samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de
Universiteit Utrecht op gezag van de rector
magnificus, prof. dr. G. J. van der Zwaan,
ingevolge het besluit van het college voor
promoties in het openbaar te verdedigen op
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uur door

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geboren op 29 juni 1975
te Torrance, Californië,
Verenigde Staten van Amerika

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Copromotor: Dr. H. A.W. Schut

In memory of my father, Rick Newsom (1943-1996), who may not have approved of the psychology part, but would have appreciated the rest of it; and in memory of my brother-in-law, Chris Kennaway (1976–2012), scientist and skipper.

“Though much is taken, much abides;”

—Alfred, Lord Tennyson; “Ulysses”

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Chapter 1

Introduction

*I did not know the work of mourning
Is like carrying a bag of cement
Up a mountain at night
The mountaintop is not in sight
Because there is no mountaintop
Poor Sisyphus Grief!*

—Edward Hirsch, “Gabriel: A Poem”

There is no getting around it: bereavement is one of the most difficult experiences in life, and nearly all of us will face it. Over time, the majority of bereaved people appear to adjust reasonably well, drawing on their own strength and personal resources, including the help of family and friends. A small proportion—estimated varyingly at 10% to 20% of bereaved people—will suffer to such an extent that their grief is debilitating to their health and functioning, and outside help is warranted (e.g. Bonanno, 2005; Prigerson et al., 1999; Zisook et al., 2010). In this context, bereavement can be understood both as a highly distressing, though inevitable, life experience; and also a condition that is associated with an increased risk of morbidity and mortality (Boyle, Feng, & Raab, 2011; Stroebe, Schut, & Stroebe, 2007; Zisook et al., 2014).

A number of grief intervention programmes have been developed across the world over the last half century with the objective of helping bereaved people in need. In the UK, as in other countries including Australia, Japan, the Netherlands and the USA, the majority of these interventions are delivered by non-profit or voluntary sector organisations, including palliative care programmes and hospices (see Breen, Aoun, O’Connor, & Rumbold, 2014). These programmes have generally been implemented without evidence of their effects on bereaved people. Only a limited number has been put to any sort of test at all. The most frequent way of testing such programmes has been simply to ask the clients themselves how satisfied they are with the programme in which they participated. While satisfaction is also important, it is generally a subjective measure that is reflective of change over a period of time immediately preceding the measure, and is not necessarily the result of the intervention.

The present project was developed in response to the lack of greater scientific scrutiny for bereavement intervention *in practice*. This project began with two main goals. The first was to answer the question of whether grief counselling for high distress and/or high risk bereaved people who requested help—and where the complexity of the intervention techniques was tailored to the problems of the client—was effective. The second aim of the project was to determine whether intervention was more effective for certain categories of bereaved people than for others.

The research in this dissertation was made possible by an opportunity in Scotland to conduct a nation-wide controlled intervention study of grief counselling—the first of its kind. In this study, people who had been bereaved for at least six months and had sought professional help were assigned to an intervention mode (differing in level of complexity of intervention technique), based on a systematic assessment of their levels of grief and risk factors present. Changes in psychological, social and medical functioning were compared with bereaved people who also sought help but who for logistical reasons could not receive it.

The following sections of this introduction begin by outlining the terms, context and research relating to this dissertation: The basic concepts are defined and a brief review of previous empirical work is included. This research led us to the selection of criteria and parameters for our intervention model. Then the model is described in more detail, as well as the setting and design of the study. Next, the four different studies that were conducted to test the effectiveness of the intervention model and its application are set out, which also form the basis for the empirical chapters of this dissertation. Finally, a summary and general discussion of the results of these investigations is provided.

Definitions: Grief-Related Terms

It is helpful to establish the definition of the terms in use and to consider the research context of this work before turning directly to the literature. *Bereavement* in this dissertation is used to indicate the state of having lost (through death) a significant person (Stroebe, Schut, Stroebe, 2007). *Grief*

denotes the emotional response, which may include functional, physical and psychological components, that bereaved people commonly experience after the death of someone important to them (Stroebe et al., 2007). Grief symptoms may include feelings of anger, anxiety, fatigue, guilt, loneliness, sadness, and intense yearning; cognitive impairments such as disbelief or preoccupation with or avoidance of reminders of the death and the deceased person; and physical and /or functional impairments, such as appetite and sleep disturbances, forgetfulness or restlessness (Worden, 1991, p. 18-30). Although the duration and severity of symptoms varies from individual to individual, the intensity of symptoms generally begins to subside over time, typically after three to six months have passed; Shear, 2015). The term *complicated grief* is used here in accordance with its definition as “[a] deviation from the normal (in cultural and societal terms) grief experience in either time course or intensity of specific or general / reactions or symptoms of grief” (Stroebe, Boerner, & Schut, 2017, p. 3). Research norms have been developed following widespread use of this construct and the assessment instruments developed to measure it (especially the Inventory of Complicated Grief Revised, ICG-R, Prigerson et al., 1999). It should be noted that several similar constructs have also been formulated (e.g., prolonged grief disorder; pathological grief; for a review see Doering & Eisma, 2016). An ongoing debate exists over the substantive and semantic differences between these constructs, as well as the prospect of including different variants into the diagnostic compendia of psychological conditions, including the DSM-V and the ICD-11 (Maciejewski, Maercker, Boelen, & Prigerson, 2016). It should also be noted that the term complicated grief is used in this dissertation to distinguish between duration and levels of symptom severity, and not as a diagnostic categorisation of a mental disorder, as it is sometimes used.

Risk factors are the characteristics—both interpersonal and bereavement-related—that have been associated with increased vulnerability to a range of difficulties coping with bereavement (Stroebe, Folkman, Hansson Schut, 2006). Table 1 provides a summary of widely-recognised risk factors that have been associated with greater difficulties.

Table 1.

Recognised risk factors for heightened distress and/or complicated grief (adapted with permission from Stroebe, Schut & Stroebe, 2007; with updates)

Risk factor	Conclusions <i>Greater difficulties coping with grief for:</i>	Study sample characteristics	Citation
I. Sociodemographic variables			
Age	Young people (more than elderly) “ “ Mixed ages (curvilinear pattern detected)	[Various] [Various] Adult bereaved family members (with non-bereaved cohort)	Hansson & Stroebe, 2006 Archer, 1999 Perkins & Harris, 1990
Financial status	Low income spousesly bereaved (potentially; when compared with married counterparts) People with low household income	Spousally bereaved (with married cohort) Online sample of parents bereaved of a (minor) child	Martikainen & Valkonen, 1996 Cacciatore et al, 2016
Gender	Men (more than women; among spousesly-bereaved) “ “ Women (among a general bereaved adult sample) Mothers (more than fathers; among parents bereaved of minor children)	Bereaved spouses Bereaved spouses (and non-bereaved cohort) Bereaved adults (general) Parents bereaved of children	van Grootheest, Beekman, Broese van Groenou, & Deeg, 1999 Lee, DeMaris, Bavin & Sullivan, 2001 Schaal, Richter & Elbert, 2014 Kempson, 2001
Personal health status	Bereaved caregivers (who neglected own physical and emotional health)	Bereaved caregivers	Schulz, Beach, Lind et al., 2001

Risk factor	Conclusions <i>Greater difficulties coping with grief for:</i>	Study sample characteristics	Citation
II. Bereavement-related variables			
Caregiving reponsibility	Primary family caregivers whose schedules were more disrupted through caregiving	Bereaved primary family caregivers of cancer patients	Thomas, Hudson, Trauer, Remedios & Clarke, 2014
Cause of death	Bereaved people where the death involved a chronic illness with high degree of suffering (witnessed by the bereaved person)	Bereaved family caregivers of hospice patients	Prigerson et al., 2003
	People bereaved through suicide	Bereaved family members (of suicide completers)	Agerbo, 2005
	People bereaved through a traumatic death	Bereaved spouses	Kaltman & Bonanno, 2003
	“ “	Bereaved adults	Raphael & Martinek, 1997
Multiple losses	People bereaved multiple times	Bereaved family members	Cleiren, 1993
Perceived unexpectedness of loss	People bereaved unexpectedly (as compared to expected losses)	Bereaved adults	Schaal, Richter & Elbert, 2014
III. Interpersonal variables			
Attachment patterns	<i>Bereaved people with:</i> Anxious attachment patterns Avoidant attachment patterns Lower emotional stability	Bereaved adults Spouslyly bereaved Spouslyly bereaved	Fraley & Bonanno, 2004 Mancini et al., 2015 Mancini et al., 2015
Kinship tie to deceased	Bereaved of an (adult) child (more than loss of spouse) “ “	Bereaved family members	Cleiren, 1993
Previous mental health complaints	Bereaved of spouse	Bereaved family members	Nolen-Hoeksema & Larson, 1999
Quality of relationship to the deceased person	Pre-bereavement depression Close emotional bond to the deceased person	Primary family caregivers of cancer patients Bereaved adults Bereaved adults	Thomas et al., 2014 Raphael, Minkov & Dobson, 2001 Schaal et al., 2014

Cause of death	Bereaved people where the death involved a chronic illness with high degree of suffering (witnessed by the bereaved person)	Bereaved family caregivers of hospice patients	Prigerson et al., 2003
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Multiple losses	People bereaved multiple times	Bereaved family members	Cleiren, 1993
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<i>Bereaved people with:</i>			
Attachment patterns	Anxious attachment patterns	Bereaved adults	Fraley & Bonanno, 2004
	Avoidant attachment patterns	Spousally bereaved	Mancini et al., 2015
	Lower emotional stability	Spousally bereaved	Mancini et al., 2015
Kinship tie to deceased	Bereaved of an (adult) child (more than loss of spouse)	Bereaved family members	Cleiren, 1993
	“ “	Bereaved family members	Nolen-Hoeksema & Larson, 1999
	Bereaved of spouse	Primary family caregivers of cancer patients	Thomas et al., 2014
Previous mental health complaints	Pre-bereavement depression	Bereaved adults	Raphael, Minkov, & Dobson, 2001
Quality of relationship to the deceased person	Close emotional bond to the deceased person	Bereaved adults	Schaal et al., 2014

Note. This table reports only selected major studies for each risk factor and should not be considered a comprehensive

While the risk factors in Table 1 have been demonstrated through a number of empirical studies, they have not always been well-confirmed, nor is the list a comprehensive list of potential risk factors (see Burke & Niemeyer, 2013). Moreover, as Table 1 shows, empirically-demonstrated risk factors can even appear contradictory (e.g., heightened risk for bereaved mothers, but for men among the spousally bereaved). As many have pointed out (e.g., Worden, 1991; Mancini & Bonanno, 2009), individuals' grief responses represent a complex interplay of personal and circumstantial factors that can influence their abilities to cope effectively. Screening for risk factors can help identify those people who may be in need of and might benefit from bereavement intervention—when other indications of need (such as elevated grief symptoms) are also present.

Definitions: Intervention Terms

Turning to interventions for bereavement-related grief, the term *bereavement intervention* is used here to refer to interventions that are designed to assist bereaved people in overcoming the emotional and practical problems encountered following the death of someone significant to them (Schut & Stroebe, 2005). While biomedicine offers its own interventions, psychological approaches have ranged from online journaling and behaviour modification exercises to in-person group activities, to private psychotherapeutic or cognitive behavioural sessions. Interventions may be offered to all bereaved people on a basis termed *primary intervention*; or they may only be available on request to certain bereaved people who are at higher risk of complicated grief due to the presence of risk factors, termed a *secondary intervention*, or on a treatment basis for people who are experiencing complicated grief, termed *tertiary intervention* (Schut, Stroebe, van den Bout et al., 2001). The bereavement intervention that will be examined in this dissertation is *grief counselling*. Worden (2008) defines the goals of grief counselling as helping the bereaved person adapt to the loss of the deceased person and adjust to the reality of living without that person. This can be achieved through loss-orientated activities (confronting

the reality of the loss, addressing emotional and behavioural pain) and restoration-orientated activities (overcoming barriers to readjustment, and re-engaging in daily life while maintaining a continuing bond to the deceased person) (Stroebe & Schut, 1999). Though grief counselling can take different forms and take place in a variety of settings (Worden, 2008), this dissertation will focus on a particular counselling intervention that is offered on a 1:1 basis and incorporates elements of the cognitive-behavioural, psychodynamic, and person-centred traditions.

Although grief counselling interventions are widely available, particularly in the voluntary sector, there has been little scientific investigation—though much analysis (e.g., Hoyt & Larson, 2010; Larson & Hoyt, 2009; Schut, 2010)—concerning the effectiveness of these specific interventions (Waller et al., 2015). By contrast, more studies have been conducted that demonstrate the effectiveness of psychotherapy and cognitive behavioural therapy (e.g. Litz et al., 2014; Papa et al., 2013; Pfoh, Kotoučová, & Hagl, 2014; Wagner, Knaevelsrud, & Maercker, 2006) for a review: Doering & Eisma, 2016). To date, there have been no controlled efficacy studies of grief counselling as offered by the third sector organisations (such as bereavement support charities, condition-specific support organisations, or hospices) that deliver the majority of the grief counselling support provided. Specific methodological challenges may account for this lack of (scientifically rigorous) research. While a longitudinal, randomised, controlled study design remains the gold standard in psychological research, achieving this to test grief counselling models presents a challenge due to the varied institutional settings and conditions in which grief counselling is delivered. It has been further argued that such ecological factors could affect research results, with real-life grief counselling outcomes differing from controlled research study results (Larson & Hoyt, 2009).

Research studies that have included grief counselling have shown a lack of effectiveness for primary interventions (e.g., Kato & Mann, 1999; Schut & Stroebe, 2005; Wittouck, Van Autreve, De Jaegere, Portzky,

& van Heeringen, 2011). In contrast, participants in bereavement intervention (again including counselling) offered on a secondary or a tertiary basis have demonstrated better outcomes (Schut, Stroebe, Van den Bout, & Terheggen, 2001). Additional criteria associated with effective, differentiated care included the following:

1. *How client-counsellor contact was established* (outreaching intervention being related to less positive effects than following help-seeking behaviour on the part of the bereaved person) (*see* Schut et al., 2001);
2. *Time since bereavement* (interventions early after bereavement appear to be ineffective, *see* Bonanno, 2005; Currier, Neimeyer, & Berman, 2008; Schut et al., 2001; Wittouck et al., 2011);
3. *Initial level of distress* of the bereaved person (higher distress correlates with better intervention results; *see* Prigerson & Jacobs, 2001; Shear, 2015; Zisook et al., 2014);
4. *Presence of risk factors* (higher risk is related to better intervention outcomes; *see* Burke & Neimeyer, 2013; Shear, 2015).

The first three points in the above list may be relatively straightforward to consider; all are important considerations for the design of the current investigation. Concerning Point 1, people who actively seek help are more likely to want, need and benefit from it: in the early days after a bereavement. On Point 2, it is largely impossible to distinguish maladaptive from successful coping responses at an early date, since a broad range of behaviours can be expected in those early days (Shear, 2015). With respect to Point 3, it can be understood that bereaved people who are not suffering from elevated distress levels are probably coping effectively and would not benefit from intervention. For Point 4, the presence of risk factors, it should be noted that the identification of specific risk factors for (or predictors of) complicated grief, has been the source of much investigation, and much debate.

Based on these results, it would be expected that an intervention model that incorporated the criteria described above would result in better outcomes for bereaved people seeking support. An empirical investigation of such a model would be needed, however, to test its effectiveness in practice.

Bridging Research and Grief Counselling in Practice

At a time of growing awareness of the importance of screening for risk factors and symptom levels to provide preventive secondary interventions and create successful outcomes, in 2006, the bereavement support charity Cruse Bereavement Care Scotland (CBCS) was taking steps to develop a new, evidence-based model for bereavement intervention. An independent Scottish charity since 2001, CBCS maintained operations in over 30 locations across Scotland, staffed by a small core of administrators and 600+ volunteers, providing approximately 55,000 service hours per year to support 12,000 people annually. From its inception, CBCS has made it a fundamental objective of its organisational development to integrate evidence-based scientific principles into the daily practice of bereavement counselling. The charity had implemented a new administrative arrangement, with a single, national phone line for people to request support, and CBCS local services that were spread across Scotland were reporting to a central headquarters (at the time located in Perth). Along with these changes, staff and trained volunteers expressed their willingness to take a new approach to delivering one-to-one support for bereaved adults. A committee was formed consisting of experienced CBCS and non-CBCS practitioners, along with a few academics specialised in the field of bereavement care. Together, they developed a bereavement intervention model that would deliver differentiated or *stepped care*: bereavement support that would be tailored to individuals' needs based on the severity of their grief-related symptoms and risk of developing complications. To implement this model with operational consistency across all CBCS locations and personnel, a uniform service structure was needed. In line

with CBCS's commitment to evidence-based practice, this model would also need to be evaluated for effectiveness—an objective that ultimately led to the current investigation.

A Stratified Model for Bereavement Intervention

Building on contemporary scientific thinking regarding effective and efficient grief counselling, as described above, the CBCS Service Model incorporated several innovative characteristics:

1. Systematic assessment of grief symptom severity and risk of developing complications
2. Systematic allocation to an intervention mode, based on assessment of initial levels of grief symptoms
3. A stratified intervention model, with three distinct modes of intervention corresponding to the client's case complexity, and the counsellor's experience level

For the first point, the service model required a systematic intake assessment process to measure clients' symptom severity and risk of complications. This process needed to be quick to administer and easy to use, to minimise any added stress for clients, and so as not to impede access to care. On the one hand, the instrument needed to allow for a certain degree of flexibility in the assessment of risk, in case of uniquely complicating factors in clients' lives that could not be foreseen. On the other hand, to make the best use of resources, it needed to be consistent for all adult clients who could participate in the standard care model (i.e. did not require additional tailoring of support due to cognitive processing challenges or special communication needs). This would be critical for CBCS to optimise the process of allocating clients to the most appropriate, available volunteers. Most important of all, the process needed to be valid and reliable.

In response to these competing needs, a new intake assessment instrument was developed: the Indicator of Bereavement Adaptation—Cruse Scotland (the IBACS; to be discussed at length in Chapters Two and Three). The IBACS is comprised of two sections: 1) a section on risk factors that are the basic determinants of complications in grieving, and 2) a symptom list consisting of an authorised selection of items from the Inventory for Complicated Grief (ICG, Prigerson et al., 1995). This selection was based on predictive power for assessing complicated grief (as established in personal CBCS correspondence with the ICG’s lead researcher, 2006).

Figure 1 illustrates the IBACS intake assessment process, including allocation to a volunteer. Following indications from experienced practitioners and subject matter experts, three service categories were established to accommodate clients based on the severity of their symptoms and their levels of risk. Clients with the most severe symptoms would be matched with volunteers with the most experience and training (the latter are largely also professional therapists and counsellors) while clients with moderate symptom levels would be matched with a skilled volunteer with fewer years of experience. For internal use, these categories were named Skilled Listener, Advanced Skills Listener, and Counsellor, reflecting the experience level (including hours of experience and extent of professional-grade training) of the volunteer practitioners providing support. Implicit in this model was a fourth, “watchful waiting” category for clients who contacted CBCS for one-to-one support, but for whom bereavement intervention was counter-indicated. These would include clients whose symptom levels and risk of complications were low enough not to warrant intervention (because they were already coping effectively); clients who presented with other conditions requiring immediate intervention, who would be referred onward to the appropriate external specialised resources; and clients who requested bereavement support during the acute phase of grief, shortly after the death and before it could be determined whether

or not they were coping effectively (currently understood by CBCS as within the first six months post-bereavement). Lastly, score norms were established (based on professional opinion) to correspond with each of those categories. As illustrated in Figure 1, the minimum IBACS-score was 0, and the maximum was 55.

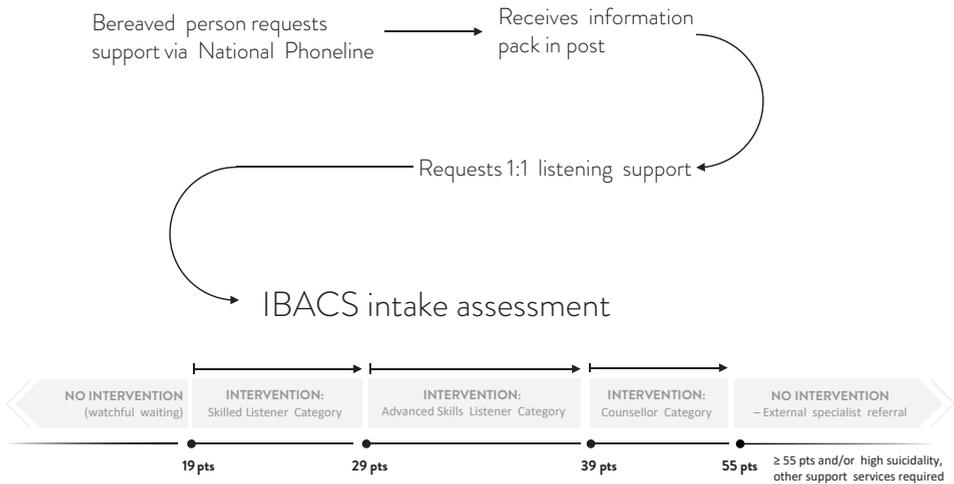


Figure 1. *The CBCS client intake process (including assessment and allocation to intervention categories)*

Guidelines were also developed with respect to the training, qualifications, experience and competencies required of the volunteers to operate in each of the three CBCS intervention modes. Every new CBCS volunteer started with a minimum training level equivalent to a counselling skills certification from COSCA, Scotland’s professional body for counselling and psychotherapy, and participated in a 64-hour module of bereavement-specific training. Volunteers who have completed 180 (professionally supervised) hours of client contact and CBCS’s annual minimum continuing professional development training requirement may apply to be accredited as advanced skills listeners. Volunteers who complete an additional 450 supervised hours of client contact may apply to be accredited as counsellor.

This model was well received by volunteers, and satisfied the organisation's operational needs. Clients continued to provide positive feedback—but satisfaction ratings can be misleading. Did it actually help?

The Intervention Efficacy Study

From the inception of CBCS's stratified model for bereavement intervention, evaluating the effectiveness of the model *in situ* was an expressed goal. A naturalistic study was therefore designed to assess its effectiveness among existing CBCS clients. Before this could be carried out, a critical step of enlisting the support of CBCS staff and volunteers was undertaken. Study committee members travelled to CBCS locations across Scotland to speak in person with staff and volunteers and discuss their concerns. It was particularly important for study organisers to reassure client-facing volunteers that the efficacy study was not an evaluation of individual practitioners' performances or individual clients' outcomes, but an analysis of aggregate results. Once support for the project had been gained (as indicated by volunteers in local town hall meetings), a more detailed study design process could begin.

This longitudinal investigation featured a quasi-randomised design with two overall conditions: an experimental condition (that received CBCS intervention) and a non-intervention control group. CBCS clients who had requested one-to-one listening support were invited to participate in the study. Clients received recruitment packs either in person from a CBCS office administrator when visiting CBCS or by post following an informational appointment either by telephone or in person. Special training sessions were held with CBCS telephone line and regional office staff to train them for distributing information packs. Information packs included a description of the study and an invitation to participate; two copies of a consent form to sign, one of which was to be returned to the study administrators by post; and the first questionnaire, sealed, to be opened if the client elected to participate. CBCS administrators and volunteers

were not informed of individual client's decisions to participate in research; only study administrators had access to study enrolment records, which were stored securely and separately from the CBCS database.

Both conditions would be comprised of adult clients of CBCS who had actively requested bereavement counselling. Participants who received one-to-one support were assigned to the experimental condition. Participants were assigned to the control category when they could not receive bereavement intervention for logistical reasons. These reasons were specific to the individual, but largely concerned the distance from a CBCS location, which some participants found was too great to travel regularly. It was originally anticipated that this would occur exclusively and extensively in rural settings, such as the mountainous Scottish Highlands and the Scottish Border regions, which have circuitous road connections and are underserved by public transportation. In reality, rural regions were better served than previously expected; however, difficulties travelling to a service location were also (unexpectedly) reported in urban settings such as Glasgow, where city topography and traffic could render a central CBCS location similarly remote. Other barriers cited for an inability to receive support included scheduling difficulties, and in a few instances, a waiting list for support. Study administrators regularly checked CBCS records to identify which study participants received or did not receive bereavement intervention, in order to maintain accurate records of intervention group assignment. CBCS records were also consulted to obtain participants' IBACS results, and ensure that participants in the intervention condition were assigned to the intervention category indicated by their IBACS results.

Figure 2 illustrates the study recruitment, enrolment and data collection process. Measures were taken uniformly across conditions at three points in time: a baseline measure at intake (T); a post measure (T+12 months), and a follow up measure (T+18). Although it would have been preferable to administer a post measure to each participant in the experimental condition immediately following completion of counselling sessions, there were considerations that made this a less favourable option. At the time

of study design, it was CBCS operational policy to leave the exact number of sessions each client received to be determined mutually by clients and their assigned volunteers based on need. The amount of time elapsed would therefore have potentially varied from participant to participant in the intervention condition, and would have been difficult to mirror in the control condition. Since the passage of time itself is known to have a strong effect on bereavement symptom severity, this would have compromised results. (In hindsight, we now see that participants received an average of six sessions in the study, and revised CBCS policy is to offer clients a standard six sessions). Instead, the passage of time was made standard in the study, and time since the completion of sessions was allowed to vary within the experimental condition.

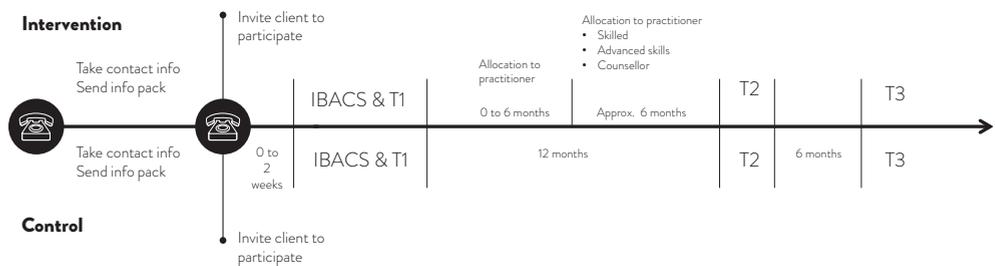


Figure 2. *Study recruitment, enrolment and data collection processes*

Measures were administered as postal questionnaires and were provided along with an addressed, stamped envelope for the participant's convenience to return them by post. Participants were also invited to write comments on the back of the questionnaire if they wished. Reminders were sent if no response was received after two weeks, and a final reminder was sent a week after that. If the participant did not respond to the second reminder, it was considered a non-response. Based on indications from other bereavement research studies, especially those using postal questionnaires, a high rate of non-response and attrition was anticipated (with complete data sets expected to be received from approximately 44% of baseline intervention condition participants and 25% of the baseline control condition).

Ethical review and approval was sought from the NHS East of Scotland Research Ethics Committee, which oversees activities in the region where CBCS was headquartered. (The research ethics committee associated with the sponsoring university, Utrecht University in the Netherlands, had no jurisdiction in Scotland.) Because the present study was not affiliated with the NHS, special permission was needed to receive a review. This was eventually granted due to the fact that our proposed study recruits were NHS clients. Approval of the study was granted in November 2010 (IRAS project ID 56758).

Each of the three questionnaires consisted of a bespoke set of demographic questions to assess background variables and a number of validated instruments. Background variables assessed at baseline included the participant's age, educational level, employment status, ethnic background, financial situation, living arrangements, marital and family status (including children—number, gender, age, living at home), (hours, reasons for not working), use of antidepressant or anti-anxiety medication, previous bereavement experiences, previous psychological diagnoses, and religious affiliation. Information regarding the deceased person was also requested, including that person's age, gender, and the nature and quality of that person's relationship to the participant, as well as the circumstances surrounding the death (cause and date, expectedness, funeral arrangements). Post-measure and follow-up questionnaires asked after any changes in personal circumstances, and any additional stressors.

The instruments administered in the questionnaires (and repeated at each time point to measure change) included a grief-specific assessment, the Inventory of Complicated Grief-Revised (Prigerson & Jacobs, 2001); general psychological health assessments, the Symptom Checklist 90 (Derogatis & Unger, 2010) and the CORE-Revised (Barkham, Mellor-Clark, Connell, & Cahill, 2006); and a measure of post-traumatic stress-related symptoms, the Impact of Events Scale-Revised (Weiss & Marmar, 1997). Each questionnaire took over an hour to complete.

Study Objectives

The objective of this dissertation is to examine the effectiveness of the stratified model for bereavement intervention as delivered by CBCS. The data collected in the course of this project have provided the opportunity to conduct a number of related analyses, which are presented in the subsequent chapters of this dissertation. In the next two chapters, the intake assessment component of the stratified model of bereavement intervention, the IBACS, is examined to determine whether it detected risk of complications and grief symptom severity consistently across modes of delivery. The following two chapters focus on intervention outcomes, and the investigation of whether the overall model is effective in reducing grief symptom levels among help-seeking bereaved adults in general, as well as a specific, under-served category of bereaved adults: people living in relative poverty. As this was a naturalistic study, requiring us to accommodate the existing operational realities of CBCS service delivery as we found them, we will present the analyses in the order in which they were conducted. This was determined in part by the availability of data at a given time.

Outline of the Chapters

In Chapter 2, we examine for differences in delivery methods for the IBACS, which had been designed for in person delivery, but in practice was also being offered over the telephone. It was essential to determine whether these two modes of administering the IBACS introduced differences in intake assessment results—and if so, how we could account for them. This exercise also raised important theoretical questions, however, concerning the potential for subjectivity in the IBACS risk assessment that might be amplified based on the immediate absence or presence of a participant.

In Chapter 3, an assessment exercise using ROC curve analysis is conducted to validate the IBACS, the intake process that underpins

the CBCS service model. Since the IBACS is used to assess existing grief symptom levels and risk of developing complications, it was essential to evaluate this instrument's ability to predict complicated grief. Validation would also indicate the usefulness of assessing not just grief symptom levels, but also the risk of developing complications.

Chapter 4 examines the main effects of the intervention study. In this section, we investigate the mission-critical question of whether the CBCS model of bereavement intervention makes a difference in reducing grief-related symptoms over time, compared to the passage of time alone. Since this tailored intervention matches the symptom complexity and risk level presented by participants at intake with an intervention mode, effectiveness demonstrated by this model would support the need for including risk assessment in intervention, as well as the benefits of secondary as well as tertiary interventions.

Chapter 5 examines the effects of intervention on a concrete level by taking an in-depth look at a specific risk group: participants with low (below poverty threshold) household incomes. As indicated in Table 1, low income is a critical risk factor that was largely overlooked until recently. The increased vulnerability to prolonged and elevated grief symptoms introduced by this socio-economic status is rendered even more problematic by its concomitant tendency to hinder access to support services. Chapter 5 provides an indication of the level of demand for support services that comes from low-income bereaved people, in addition to examining the effectiveness of support among this subgroup.

Lastly, in Chapter 6, the conclusions of this research will be discussed, along with recommendations for future research. Particular emphasis will also be placed on practice implications for voluntary sector bereavement support providers as well as recommendations for applied (naturalistic) research in these organisations.

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Chapter 2

Telephone versus in-person intake assessment for bereavement intervention: Does efficiency come at a cost?

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Abstract

Objectives: Results of a semistructured intake assessment for grief intervention, the IBACS, were examined for differences when conducted over the telephone or in-person. **Methods:** Participants ($N = 445$) were bereaved adults in Scotland who had requested counselling support. IBACS scores and resulting intervention category assignments were collected from IBACS sessions (330 in person; 115 telephone). Differences in scores and clinical implications were evaluated. **Results:** An independent samples t test detected a significant ($p = .003$) medium size effect difference for delivery method, with composite assessment scores approximately two points lower for the telephone condition ($M = 26.05$) than in-person ($M = 28.76$). However, chi square tests revealed no difference ($p = .096$) in assignment to counselling categories. When the semi-structured component of the IBACS was omitted, no difference was detected.

Conclusion: Though mean results were different based on IBACS delivery method, clinical implications were not. Further research is needed to investigate whether discretionary point allocation accounts for differences between delivery formats. Careful training and guidelines on discretionary point allocation are recommended to increase uniformity across delivery formats.

Research has indicated that bereaved people who—for various reasons—are considered to be at risk of experiencing complications in the grieving process are the ones professional bereavement interventions should focus on (Currier, Holland, & Neimeyer, 2006; Schut & Stroebe, 2005). This calls for valid assessment of grieving difficulties to identify such vulnerable people, since standardised, evidence-based risk assessment is an important component in the provision of effective bereavement care (Schut & Stroebe, 2005). Such assessment enables care providers to offer the right kind of help to those who need it, and, as importantly, avoid providing intervention to people who will probably not benefit from it. In addition,

psychotherapists and counsellors are increasingly under pressure to operate as efficiently as possible while minimising operating costs. In this context, in recent years, offering intake assessment over the telephone, by video conference call, or by means of other e-health technologies, has been considered a potential way of reducing costs for clients and practitioners, increasing availability to serve people needing help, and identifying which people stand a good chance of benefiting from intervention, and which people will most likely cope better on their own.

Drawing from the broader e-health literature, remotely-conducted intake assessment offers unique advantages and disadvantages (Crawford, 2003; Freir et al., 1999; O'Reilly et al., 2007). Potential advantages include cost savings, physical and social accessibility, and the extent of available intervention services (see Lee et al., 2010; Peñate, 2012). Another possible advantage is the reduction in fear of social stigma associated with accessing psychological or psychiatric services (see: Cukor et al., 1998; Kavanagh & Yellowlees, 1995; Peñate, 2012). Doubts about such assessment have to do with quality of the encounter (e.g., commitment regarding the keeping of appointments, and the active engagement of the client, see Mozer, Franklin, & Rose, 2008). Indeed, O'Reilly and colleagues (2007) observed that 10% of people approached to participate in a videoconferencing study declined to do so, citing their unwillingness to receive services remotely. Concerning the broader range of e-health modalities, access to and familiarity with technological platforms must also be considered. Modalities can range from a basic telephone call to low-cost internet telephony applications for audio and video conference calls to social media or virtual reality programs (see Peñate, 2012). At the time of writing, factors such as advanced age, lower education level and lower socio-economic status are liable to restrict access.

In-person assessment modalities have their own advantages and disadvantages. Advantages range from feasibility to preference for seeing a counsellor in person (see Cukor et al., 1998). Indeed, some people cannot

or do not wish to use telephones or other communications technology, while others may not have adequate privacy when they use them to answer personal questions. In their meta-study of remote assessments and interventions, García-Lizana and Muñoz-Mayorga (2010) concluded that a preference for in-person over remote assessment predominates among both clients and practitioners. Disadvantages to in-person assessment mirror some of the advantages of remote assessment, for example, the relatively higher costs of in-person services and potential physical and social (e.g., stigma) barriers to accessing care at a counselling location.

Given the range of potential advantages and disadvantages, the impact of integrating an e-health assessment procedure into a bereavement intervention programme needs careful consideration. There are various ways that evaluation of e-health initiatives can be approached. Guidelines recommended by The American National Institutes of Health for evaluating telehealth initiatives follow Hicks et al.'s (2011) transactional economics-based model, which stipulates concentrating on one of three foci of analysis: cost, quality, or access; and one of three levels of analysis: society, community, or individual. To date, no evaluations of e-health versus in-person assessments have been conducted for bereavement intervention programs. Although a great deal of research has been conducted recently on the efficacy of e-health interventions for a range of psychological health conditions and therapies among different populations, our focus will *assessment* in a telehealth context. Specifically, the present study is interested in the *quality* of an assessment for bereavement intervention (the similarity of results across conditions) at the *individual* level (the assessment of bereaved persons' grieving difficulties).

The study was designed, first, to compare the results of assessment for the two modes of intake: Is there a difference in evaluation of the client's difficulties in the grieving process (including level of grief symptomatology and risk of grief complications), when assessed remotely (telephone intake) or in-person? Second, the clinical implications

of employing one or other mode of assessment were explored, notably: Are there differences in assignment to specific types of bereavement intervention, depending on whether remote or in-person intake has been employed? In the present study, the telephone was selected as the means for delivering the remote assessment for several reasons, which are discussed further below.

In the next section, given that research on intake procedures specific to assessment for bereavement intervention is lacking, scientific literature from a wider range of telephone-based psychological and psychiatric assessment services is briefly reviewed. Then the rationale and design of the present study are outlined.

Telephone versus in-person assessment: review of empirical studies.

In general, it has been shown that remote and in-person assessments have produced similar results when it comes to practitioners' assessment of clients' mental health, particularly when structured interviews are used (for social anxiety disorder, see Crippa et al., 2008; Lyneham & Rapee, 2005; for depression, see Pinto-Meza et al., 2005; Simon, Revicki, & Von Korff, 1999; Spek, Nyklíček, Cuijpers, & Pop, 2008; for Axis I and II disorders see Brar et al., 2001; Rohde et al., 1997; for a meta-analysis of studies, see Hyler, Gangure, & Batchelder, 2005). Exceptions have also been reported, indicating the need for careful consideration, interviewer training, and clearly established and communicated guidelines before implementing a telephone-based assessment programme where questions may address sensitive personal matters. Although Rohde and colleagues (1997) reported generally quite equivalent results from telephone and in-person interviews, significant discrepancy was noted in the telephone condition's responses to substance abuse questions. The authors suggested this may have been attributable to lack of privacy, as several participants attended telephone interviews with their children or spouses in the room.

Investigations of the equivalence of semi-structured diagnostic assessments conducted over the telephone and in-person, however, have

produced mixed results. In a study using a test-retest design to examine the equivalence of telephone and in-person delivery of the Structured Clinical Interview for DSM-IV for axis I disorders (SCID I), Cacciola and colleagues (1999) reported a significantly higher number of diagnoses of lifetime major depression in the in-person interviews than in the telephone interviews. They also found poor agreement with social phobia. The authors suggested that the in-person bias in diagnosis of major depression may have been attributable to the opportunity, introduced by the semi-structured interview format, for the clinical interviewers to make use of their professional skills to gather information. Not specially trained for assessment via telephone, the interviewing clinicians in the study may have been better able to probe for further information in the in-person assessment format, to which they were accustomed, and were less adept at eliciting further information over the telephone. Crippa and colleagues (2008) repeated Cacciola's investigation using the SCID-I for social anxiety with results that demonstrated equivalence across telephone and in-person conditions. They attributed the difference in results with Cacciola and colleagues to the extensive training process that their interviewers went through to prepare for telephone delivery, including role-plays and simulations, discussions of potential responses and their ratings, and observation of interviews.

Based on the general findings reported above, there seem to be good reasons to expect that telephone-delivered and in-person assessment can yield equivalent results in terms of quality in a structured format, and possibly also in a semi-structured format when sufficient interviewer training is provided.

Telephone-versus in-person assessment for bereavement-related grief symptoms and risk. Reservations about the quality of telephone versus in-person assessment of the psychological services identified above also imply the need for specific quality assessment of these assessment modalities in the bereavement intervention area. In other words, we need to determine

whether it is appropriate to deliver an assessment of bereavement-related grief symptoms and risk remotely or in-person, and whether assessment results from the two delivery methods can be integrated into the same client intake system. Furthermore, it is necessary to understand whether—and if so, how precisely—the assessment results differ.

For that purpose, a naturalistic quasi-experimental study was conducted, first, to compare the results of assessment for the two modes of intake: are there differences in evaluation of the client's grief complications risks when assessed over the telephone or in-person? Second, if the previous question were to be confirmed, the clinical implications of employing the one or other mode of assessment needs be explored, notably: Are there differences in assignment to specific types of bereavement intervention, depending on whether telephone or in-person intake has been employed? Given the lack of grief-specific evidence in the reviewed literature, the current study was exploratory in nature.

Methods

The opportunity to conduct this naturalistic investigation was presented in the context of a larger study of the efficacy of the national bereavement care service implemented by Cruse Bereavement Care Scotland (CBCS), a charity that provides over 12,000 hours of one-to-one bereavement support and serves over 3,000 bereaved people each year. Because of long waiting lists for bereavement intervention services, and the organisation's broad geographical remit, CBCS introduced telephone-based assessment in 2011 to expand their overall capacity for assessment. CBCS considers evaluation of this extension to the care programme an important step in its implementation. The telephone was selected as the means of remote assessment delivery (rather than video conferencing and other web-based technologies) by the service-providing organisation because it remains the most accessible means of telecommunication for most of the UK population. As of May 2013, 14% of the UK population aged 75 and over have never used the Internet. Scotland also continues

to struggle with good quality Internet connections across its regions, though the government has set an objective to develop a high-quality Internet infrastructure across Scotland by 2020 (Scottish Government, 2013).

Participants

Potential participants were identified (with client consent) via the CBCS database. All participants had initiated contact with the bereavement support organisation themselves and had actively requested support. All were adults (age 18 and over) who had been bereaved for at least six months prior to the intake assessment. For inclusion in the study no distinction was made with respect to the participants' relationship to the deceased, which nevertheless followed a similar pattern in both conditions and was representative of general CBCS client demographics. A description of participants' details can be seen in Table 1.

Table 1

Study participant details by condition

	In-person		Telehealth		Total
	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Total	330	100%	115	100%	445
Relationship to the deceased—participant was:					
Parent of an adult child	43	13%	16	14%	59
Parent of a child under 18	10	3%	3	3%	13
Partner	88	26%	43	37%	132
Adult child of a parent	126	38%	41	36%	170
Sibling	35	11%	7	6%	42
Other	30	9%	5	4%	35
Cause of death					
Health problem	189	59%	62	57%	251
Accident	23	7%	11	10%	34
Other (homicide/suicide; drug/ alcohol-related)	109	34%	36	33%	145
Missing / not available	189	59%	62	57%	251
Time since bereavement					
Between 6 months and 1 year	148	45%	59	51%	207
Between 1 and 2 years	83	25%	29	25%	112
Between 2 and 3 years	33	10%	8	7%	41
Between 3 and 5 years	23	7%	10	9%	33
Over 5 years	42	13%	9	8%	51
Not available/Missing	1	1%	0	0%	1

A priori power analysis was conducted using G*Power version 3.1.9 to determine the optimal sample size required with a desired level of power set at .95, an α -level at .05. Given the heterogeneity of effect sizes reported in the literature (cf. Hyler, Gangure, & Batchelder, 2005), as well as the lack of data specific to grief assessment, a standard, moderate effect size of $d = .50$ was expected. Based on this, it was determined that 210 participants (105 per group) were required to ensure adequate power for the independent samples t-test. Our study reached this criterion. In total, data from 445 participants were selected for the study, with 115 in the telephone condition, and 330 in the in-person condition (eight participants had to be excluded from the study for various reasons, e.g., a few clients presented with substance abuse problems that required attention before bereavement intervention could be considered).

Clients in both conditions were contacted via telephone by a scheduling administrator. Assignment to modality was determined by participants' position on the CBCS waiting list, which operates on a "first come, first served" basis. This quasi-randomisation worked as follows: clients contacted for scheduling on certain days were offered telephone interviews to be scheduled at a convenient time, while those contacted on other days were offered in-person appointments. A limited number of potential participants declined telephone interviews for a variety of reasons, including hearing issues and discomfort speaking over the phone.

It is important to note that although previous epidemiological research has indicated people with anxiety and depressive disorders may be more likely to turn down interviews out of reluctance to be evaluated (Eaton et al., 1992) and might therefore prefer telephone interviews to in-person ones, the context of our naturalistic study makes it unlikely for severity of grief-related depression symptoms to have affected participation rates in the telephone condition any more or less than the in-person condition. Participants who had opted out of the telephone condition were excluded from the study (but not from assessment or potential intervention).

An additional number of participants opted out of the assessment interview in-person as well, but this number cannot be differentiated from clients who changed their minds and chose not to pursue support altogether.

The participants in the two conditions did not differ in terms of relationship to the deceased, $\chi^2(4, n = 445) = 8.22, p = .084$; cause of death, $\chi^2(2, n = 430) = .96, p = .619$; gender, $\chi^2(1, n = 441) = .22, p = .643$; or time since bereavement, measured as a scale variable, $\chi^2(5, n = 443) = 6.48, p = .263$. (Numbers differ slightly from the total study participation number as data for certain variables were missing in a few cases.) As data on participants' age had been collected in age ranges, according to standard procedure at the counselling organisation, another chi square test was conducted to determine differences between categories in terms of participants' ages. The results indicated a small but significant association between age and category, $\chi^2(5, n = 411) = 14.89, p = .011$, Cramer's $V = .19$. Bonferroni corrected Z-test of proportions revealed a significant difference in two age categories. A significantly greater proportion of those in the face-to-face method were 18 to 29 years (14%) compared to the proportion of those in the phone-based method (4%). In contrast, a significantly greater proportion of those in the phone-based method were aged 60 to 74 (28%) as opposed to face-to-face (15%). These group differences are presented in detail in Table 1. We explored whether this difference had any impact on the dependent variable (assessment results) using multiple regression analysis, as detailed below in the Results section, and found no significant effect.

Instruments

The assessment instrument used was the Indicator of Bereavement Adaptation—Cruse Scotland (IBACS). The IBACS was specifically designed to identify the level of risk and complexity of grief symptoms presented by the bereaved person, in order to provide a commensurate level of bereavement support. The IBACS total score is calculated

by the interviewer directly at the conclusion of the session. The IBACS is comprised of two sections:

1. Risk assessment. A semi-structured interview was conducted, addressing a number of risk factors that have been shown to contribute to complicated or prolonged grief (see Stroebe, Folkman, Hansson, & Schut, 2006; Zisook et al., 2014). These include the client's personal and health history (including previous bereavements, losses and traumas; personal health problems and past psychological problems), relationship to the deceased (for example, if the bereaved person has lost a child, if the relationship was complicated), social support (if the bereaved person was extremely lonely), and additional stressors (employment problems, caregiving responsibilities, financial problems, relocating) considered to contribute to complications in the grieving process. The risk assessment can produce a subtotal of 0 (standard) to a maximum of 7 points. Interviewers are instructed to provide no more than 1 point per category of risk.

2. Intensity of grief. This part was comprised of a 12-item self-report questionnaire developed from the Hogan Grief Reaction Checklist (Hogan, Greenfield, & Schmidt, 2001) and the Inventory of Complicated Grief -Revised (Prigerson et al., 1995; Prigerson & Jacobs, 2001) (with permission). Items were selected for a Scottish clientele and integrated to suit the Scottish context. Items on the questionnaire were rated on a 0-4 point Likert scale. Two specific items addressed client suicidal ideation. These items contributed to the total result, but were also tabulated separately to indicate the client's risk of suicide. Internal consistency of this section of the IBACS was assessed using a separate client sample that included data on each individual item. This sample ($N = 331$) showed acceptable internal consistency of the instrument, with a Cronbach's alpha of .75.

The IBACS total score consists of the sum of the 12 grief symptomatology items from the self-report, along with 0 to 7 additional discretionary risk assessment points allocated by the interviewer based on the client's responses

to the Part 1 risk assessment questions. A client's IBACS point total can range from 0 to 55. CBCS developed a tiered model whereby these points can be categorised into groups to enable clients to be assigned to an appropriate level of care (0-17 = No intervention / watchful waiting; 18-29 = Skilled Listener; 30-39 = Advanced Skills Listener; 39-55 = Counsellor). An exception is made when clients report a high score on the two suicidality questions (a cumulative score of 6 points or higher), which make up part of the 12-item self-report. These two suicidality items are included in the IBACS total, but are also considered as an independent subscale for suicide risk. In cases where a high suicide risk is reported, in-person and telephone interviewers alike are instructed to follow the CBCS suicide-risk protocol, which is designed to avail clients of appropriate and immediate support. This did not occur in the present study sample.

In the current sample, complete IBACS assessment forms were available for 125 participants, allowing for a comparison of risk assessment and grief scores across conditions. For the remaining 323 participants, only the IBACS point total was available for analysis.

Procedure

All interviewers had completed a bereavement-specific assessment training module provided by CBCS. The specific training for the IBACS role includes an e-learning module on the place of assessment in a tiered intervention model and an understanding of data protection and interview skills. Trainees are invited to think about their "script" for explaining these issues to a prospective client. Successful completion of the e-learning module is followed by two days of group training, where, on day one, the detailed working of the assessment interview is discussed, and skills are practiced and peer assessed. Following day one, trainees are provisionally licensed to conduct three IBACS sessions, which they then submit for evaluation, and one of which they present in detail on day two of the training. Discussion of issues raised is followed by a discussion around

discretionary points and ethical issues, such as supervision around conducting IBACS sessions by telephone. At the time of data collection, training specifically for telephone delivery of the IBACS consisted of approximately three hours of additional discussion and practice work.

All interviews were conducted between December 2010 and April 2011. The same group of experienced interviewers conducted interviews in both modalities. Because at the time of data collection only this group of CBCS interviewers had conducted IBACS both over the telephone in the pilot study and in-person, eligibility for inclusion in the scientific study was further restricted to those clients who had been interviewed by one of that group of interviewers. This inclusion criterion was intended to reduce differences between the telephone and in-person conditions by controlling for differences between individual interviewers.

Results

The first objective was to establish whether there were differences in participants' IBACS point totals (the composite level of grief symptomatology and risk assessment score) according to in-person or telephone modalities. An independent samples *t*-test was conducted on the IBACS point total and revealed a significant difference (with a medium effect size) between the telephone and in-person conditions, $t(442) = 2.96, p = .003, d = .33$. Participants in the telephone condition had significantly lower scores ($N = 112, M = 26.05, SD = 8.24$) than participants in the in-person condition ($N = 332, M = 28.76, SD = 8.42$).

Implications for assignment of clients to intervention categories based on the CBCS model were then considered. Further examination of the mean differences between the in-person and telephone conditions revealed that a client with an average in-person assessment total would be assigned to the Advanced Skills Listener intervention category, whereas the mean score in the telephone condition would indicate assignment to the Skilled Listener category.

However, as noted earlier, there was a slight difference in participants' ages between the two delivery methods. We therefore conducted a linear regression predicting total IBACS points, controlling for participant age group. This analysis was important in order to dismiss the possibility that differences in IBACS points between the two methods were due only to age differences between the delivery methods. The overall model with age group (dummy coded) and IBACS delivery method entered as predictors was significant, $F(6, 401) = 6.25, p < .001$ and accounted for 8.6% of the variance in total IBACS points. After controlling for the effects of age, IBACS delivery method was a significant predictor of total IBACS points ($t(437) = 2.96, p < .003$). Controlling for age group, those in the in-person group scored an average number of 2.96 points higher than the telephone delivery method ($SE = .97$).

To further assess this point, the resulting assignment to the intervention category for participants, based on IBACS cut-off points, was compared according to method of delivery. A Chi square test for independence indicated no statistically significant association between IBACS delivery method and assignment to specific intervention category $\chi^2(3, n = 444) = 6.34, p = .096$, Cramer's $V = .12$. Table 2 presents the percentage of assignments in this sample to each intervention category (including no intervention) by IBACS delivery method.

Table 2*Intervention category assignments (%)*

	<i>In-person</i>	<i>Telehealth</i>
No intervention	8%	13%
Skilled Listener	41%	50%
Advanced Skills Listener	37%	28%
Counsellor	14%	9%
<i>Total</i>	100%	100%

As Table 2 also illustrates, the proportion of IBACS interviewees in the telephone category who were found not to require intervention

was greater than the proportion of participants in the in-person condition (13% telephone; 8% in person). Although this effect was not statistically significant, the results illustrate a trend where those who received telephone assessment were more likely to be assigned to receive less complex intervention.

Although the mean difference between the conditions did not translate to a clinical difference in the IBACS system of cut-off points, it was considered important to investigate the mechanism underlying the difference in means between the telephone and the in-person conditions. It was determined the squared semi-partial correlation by regressing each individual predictor on the other predictors, then calculating and squaring the residual. This made it possible to calculate the percentage of the total variance in IBACS scores uniquely explained by each individual predictor while controlling for the others. The overall model was significant, $F(17, 377) = 3.68, p < .001$, and accounted for 14.2% of the variance in IBACS total (adjusted $R^2 = .10$). After controlling for the effects of the covariates, IBACS delivery method remained a significant predictor of total IBACS points ($t(426) = 3.03, p < .003$). Controlling for the covariates, those in the in-person group scored an average of 2.95 points higher than the telephone delivery method ($SE = .98$).

Risk assessment points. As noted above, data on the breakdown of total IBACS points into risk assessment points and intensity of grief points were available only for a subset of participants ($N = 124$; 81 in-person, 43 telephone). The subsample had a similar demographic composition to the larger sample, including a mixture of urban, suburban and rural locations, and as such was used to provide insight into whether the difference in total IBACS points between the two delivery methods may be attributed to differences in the risk assessment points, differences in the intensity of grief scores, or both when the size of the effect is large enough. When the total scores were analyzed, the difference in total IBACS points was not statistically significant (in person $n = 81, M = 29.20, SD = 9.13$;

telephone $N = 43$, $M = 27.19$, $SD = 7.18$), $t(122) = 1.25$, $p = .213$, $d = .24$. The effect size indicated a small effect for the differences between the telephone and in-person delivery groups on the grief symptom self-report. A post-hoc power analysis was conducted with the available samples of 81 and 42, an alpha of .05, and assuming the same effect size of $d = .33$ observed in the earlier sample. The post-hoc effect size of the t-test was revealed to be only .41, however, indicating that the test was underpowered, and the sample size may have been inadequate to show a significant difference.

An independent samples t -test with a correction for nonequivalent variances, however, did indicate a statistically significant mean difference in risk assessment point allocation between the in-person and telephone groups, $t(112) = 6.05$, $p < .001$, with a large effect size, $d = 1.08$. Participants in the in-person condition had higher risk assessment point allocations ($n = 81$, $M = 3.16$, $SD = 2.04$) than participants in the telephone condition ($n = 44$, $M = 1.23$, $SD = 1.49$). This finding was confirmed with a nonparametric Mann-Whiney test ($Z = 5.00$, $p < .001$), which we conducted due to slight violations in the normality of the risk assessment point total. Yet, when only the subtotal of the 12-item grief symptom self-report (i.e. Part 2 of the IBACS, the structured question set) was considered, there was no difference between the in-person ($n = 81$, $M = 26.02$, $SD = 6.99$) and telephone conditions ($n = 43$, $M = 26.04$, $SD = 8.91$), $t(122) = .01$, $p = .993$, $d < .01$

In order to check whether the difference in risk assessment point allocation remained after controlling for potential covariates, a multiple regression was used to predict risk point allocation from delivery method controlling for the client's age, gender, length of bereavement, relationship to the deceased, and the deceased person's cause of death. Preliminary analyses revealed no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. The covariates listed above were dummy coded. All covariates were entered into the model with delivery method. The resulting model was significant, $F(17, 96) = 3.48$, $p < .001$

and explained 37.8% of the variance in risk assessment (adjusted $R^2 = .27$). Controlling for the covariates, IBACS delivery method was still a significant predictor of risk assessment point allocation ($t(107) = 5.02, p < .001$). Those in the in-person group had risk point allocation scores that were an average of 1.91 points higher than those in the telephone delivery method ($SE = .38$).

To summarise the overall pattern of results: clients who had in-person intake assessments were assigned more IBACS risk points than were clients who had their intake assessments by telephone. In the data subset which included specific information on risk points, it was demonstrated that 20.7% of the variation specifically in risk assessment allocation could be uniquely predicted by delivery method, whereas intensity of grief scores did not differ as a function of mode of assessment. In sum, the assessment of clients' risk of developing complications in grief is higher when the interview is conducted in person, and lower when it conducted by telephone.

Discussion

The results of our analyses demonstrate a difference for intake modality on assessment for bereavement intervention. In the subset of the data where a breakdown of the total score was available (including specific information on risk points), it was demonstrated that variation in point allocation based on risk assessment could be uniquely predicted by intake interview delivery method, but intensity of grief scores (i.e., responses to the structured question set addressing symptoms of grief), did not differ. Clients who had in-person intake assessments received more IBACS risk points than did clients who had their intake assessments by telephone, but the assignment to intervention categories was shown not to differ, despite the significant difference in group means. We can cautiously conclude (while encouraging further investigation) that telephone assessment produces similar results, at least regarding grief symptom level evaluation. These finding fit with the broader mental health assessment literature, thus

telephone-based interviews can be integrated in bereavement intervention intake assessment procedures with proper training.

It is nevertheless important to note that the mean difference between the two conditions was demonstrated in further analysis to be consistent with differences in risk point allocation between the in-person and telephone conditions. The cutoff points for the IBACS were robust enough for intervention category allocation not to be affected, but the mean difference in risk assessment points, with a lower mean in the telephone condition, may have implications for other intake assessment programs that incorporate both in-person and telephone based delivery methods.

We can only speculate as to why participants in the telephone condition received fewer risk points than those in the in-person condition. It is possible that clients assessed remotely were less willing to report risk factors, or that clients assessed in person were more emphatic in their risk reporting. Rohde, Lewinsohn and Seeley (1997) found participants under-reported substance abuse symptoms—which, as they noted, stem from socially stigmatising behaviours—over the telephone. In Scotland, as in other countries with a strong Calvinist legacy, expression of symptoms of grief and difficulties coping may not comply with the social ideal of personal strength and unflappability; nevertheless, it is unlikely it would carry the same degree of stigma that (illegal) substance abuse might. Additionally, since results in the remote and in-person conditions were similar in the second part of the intake assessment, it seems improbable that remote clients would be as forthcoming as in-person clients in reporting grief symptoms, but more restrictive when it came to risk information.

Second, it may be that important cues, visual or otherwise, indicating risk were not perceived by the interviewers during telephone assessments, or were considered to be of greater importance during in-person assessments. However, it appears unlikely to be the case. Baigent and colleagues (1997) reported differences between clinical interviewers' assessments of blunting of affect and other observed behaviours when they were participating in an

assessment remotely (via telephone), compared to in person. While all observing clinical assessors had the same visual cues, but those conducting the assessment remotely rated blunting of affect lower than on-site assessors. For this reason, it would appear that absence of visual data itself might not be responsible.

Third, it is worth considering the specific effects of physical presence in the in-person assessment and the kinds of supra-segmental information that may be gained or lost in either scenario. In particular, examining how physical presence affects the transfer of such information, which may also be viewed in terms of the rapport established between the interviewer and the bereaved client, or even empathy. Depending on the client's expectations and circumstances, this kind of communication may be facilitated more effectively by means of a telephone- or an in-person encounter. Better understanding of the kind of supra-segmental information that is shared, and how it affects the development of rapport between an interviewer and a client in an assessment context, would be valuable for improving standards of care in both delivery modalities.

It is evident that the assignment of points across the two conditions warrants further empirical investigation. At present, it is important to consider the practical applications of the results for bereavement support practitioners. Although the present study does not include a golden standard for determining which condition produces the most accurate assessment of the complexity of the client's grief symptoms and risk level, we see an opportunity to increase uniformity in the assessment process in one of two ways. The first option would be to avoid this issue altogether by introducing only closed-ended questions in the risk segment of the assessment, thereby mirroring the grief symptom assessment section, and working entirely within a structured interview format. This would likely decrease variation across in-person and telephone IBACS results, but we could not be certain whether we were missing something. If the interview were restricted to closed-ended questions, the number of personal

history considerations that might possibly contribute to a complex grief reaction would be quite high. This could to a certain extent be abated by using a branching method of survey design, where an affirmative response to a question would lead to further questions about a particular issue. For very sensitive matters, however, a semi-structured approach might still be better, providing scope for clients to raise painful matters using their own language, for which counsellors are trained to listen. For example, the same client might respond negatively when asked outright about a history of abuse, yet refer to abusive physical punishment at the hands of a deceased parent. A semi-structured interview format with a clear protocol allows interviewers to focus the discussion on those points that are applicable to the bereaved person, and dispense with irrelevant or redundant questions. It may therefore be important to retain the idiosyncratic, “individually-tailored” nature of risk assessment.

An alternative to entirely structured risk assessment, then, would be to improve the semi-structured process in practice. Crippa and colleagues (2008) attributed the equivalence of the results demonstrated in their study in part to an extensive telephone assessment training process. Drawing from their experience, a first step could involve a thorough review of training principles for IBACS practitioners, and the development and dissemination of telephone-specific procedures. In our view, the results of our investigation indicate the necessity for a clear and consistent strategy to elicit relevant information in the semi-structured risk assessment component of the interview. Special consideration needs to be given to methods of establishing a rapport with clients remotely, and to being particularly observant of subtle responses over the telephone, including non-verbal, supra-segmental elements.

As we indicated at the outset, this is an exploratory investigation, and the naturalistic design introduced a number of limitations to our study. Because longitudinal data were not available for the sample examined, our investigation was limited to exploring differences between the telephone

and in-person assessment conditions. The decision to work with data that emerged from the usual intake process at CBCS (with client consent), and thus not disturb bereaved clients in the process of accessing support, meant forsaking a test-retest study design, which may have been more robust.

Taken in broader perspective, it is important to acknowledge that it is the interest in providing not just care but the *right* kind of care for grieving people that creates the need for assessment in a bereavement intervention support programme in the first place. Risk and symptom assessment enable a bereavement support system to operate a differentiated service model that accommodates clients with varying degrees of severity in their grief reactions or character of their complaints. It also enables interviewers to discern between symptoms of grief and other underlying issues, such as trauma or substance abuse, which may require attention before a grief intervention can be of any help.

Finally, we would like to stress the need for care in extending to telephone assessment. Throughout the literature reviewed for this study, a common theme that emerged was researchers' consistent recommendations for caution in making the decision to implement a telephone assessment modality for psychological and psychiatric services. This caution is especially important for practitioners and organisations considering the integration of telephone and in-person intake assessments into a single intake system—which is nearly always the case. In such situations, careful steps should be taken to account for differences introduced by a new assessment delivery method, to ensure that clients assessed remotely will ultimately receive equivalent treatment as clients assessed in person. From the client's perspective, a well-run intake assessment process may help alleviate any trepidation associated with seeking help. For bereaved clients in particular, some of whom are seeking help for the first time in their lives, this is no small matter.

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Chapter 3

Initial validation of a comprehensive assessment instrument for bereavement-related grief symptoms and risk of complications: The Indicator of Bereavement Adaptation—Cruse Scotland (IBACS)

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Abstract

Objective: This study assessed the validity of the Indicator of Bereavement Adaptation Cruse Scotland (IBACS). Designed for use in clinical and non-clinical settings, the IBACS measures severity of grief symptoms and risk of developing complications. **Method:** $N=196$ (44 male, 152 female) help-seeking, bereaved Scottish adults participated at two timepoints: T1 (baseline) and T2 (after 18 months). Four validated assessment instruments were administered: CORE-R, ICG-R, IES-R, SCL-90-R. Discriminative ability was assessed using ROC curve analysis. Concurrent validity was tested through correlation analysis at T1. Predictive validity was assessed using correlation analyses and ROC curve analysis. Optimal IBACS cutoff values were obtained by calculating a maximal Youden index J in ROC curve analysis. Clinical implications were compared across instruments. **Results:** ROC curve analysis results ($AUC = .84$, $p < .01$, 95% CI between .77 and .90) indicated the IBACS is a good diagnostic instrument for assessing complicated grief. Positive correlations ($p < .01$, 2-tailed) with all four instruments at T1 demonstrated the IBACS' concurrent validity, strongest with complicated grief measures ($r = .82$). Predictive validity was shown to be fair in T2 ROC curve analysis results ($n = 67$, $AUC = .78$, 95% CI between .65 and .92; $p < .01$). Predictive validity was also supported by stable positive correlations between IBACS and other instruments at T2. Clinical indications were found not to differ across instruments. **Conclusions:** The IBACS offers effective grief symptom and risk assessment for use by non-clinicians. Indications are sufficient to support intake assessment for a stepped model of bereavement intervention.

Researchers and practitioners alike frequently express the need for a systematic, scientifically based way to distinguish between those bereaved people who need and would benefit from intervention and others who could be expected to adjust to their loss without such aid (Aoun et al., 2015). Researchers (Aoun et al., 2015; Kersting, Brähler, Glaesmer, & Wagner, 2011) estimate that some 7% of bereaved adults meet the criteria

for complicated grief (CG), with dramatically higher estimates for certain risk groups. These complications can result in heightened psychological and physical distress, higher risk of mortality, suicidal ideation, and ruminative thought patterns, among other problems (Boelen & Prigerson, 2007; Boyle, Feng, & Raab, 2011; Buckley et al., 2012; Stephen et al., 2015; Stroebe, Schut, & Stroebe, 2007; Zisook et al., 2014). Symptoms that have been recognised as grief specific when presented by a bereaved person include yearning for the deceased person, intrusive thoughts about the deceased person and/or avoidance of reminders of him or her, anger, guilt, and the loss of a sense of meaning or purpose in life (Zisook et al., 2014). Within the first months post bereavement, it is considered normal to experience a wide range of symptom levels, from low to high (Zisook et al., 2010). Continued high symptom levels after an initial time period, estimates of which range from two to six months, have been considered indicative of complications (Zisook et al., 2010; Prigerson et al., 1999). In addition, specific risk factors have been recognised as increasing the likelihood that a bereaved person will develop complications in grieving. These factors include experiences such as multiple bereavements, previous trauma, or a problematic relationship with the deceased person; personal traits, such as an insecure attachment pattern; or additional current stressors, such as caregiving responsibilities, lack of social support, health problems, or substance abuse (Aoun et al., 2015; Burke & Neimeyer, 2013).

People with an increased risk of experiencing complications in grieving may benefit from intervention such as grief counselling and grief therapy (Currier, Holland, & Berman, 2008; Schut & Stroebe, 2005). In contrast, people who do not experience such complications will probably cope with their grief successfully on their own and will likely not require bereavement intervention. Identifying at-risk bereaved people seems to be both an efficient and effective strategy for bereavement support provision. To make this approach practical in an applied bereavement care context,

a sound assessment process is required to help those working in the sector recognise when intervention is likely to be effective for a client.

There are good reasons to argue that, in order to be effective, a grief screening process should assess risk factors for the development of complications in grieving, as well as grief symptoms (Schut et al., 2005). The inclusion of both grief symptoms and risk assessment in the bereavement support intake process is of particular importance in differentiated care models to ensure that commensurate levels of care are offered both to people who currently present high grief symptom levels, and those who present lower initial levels of grief symptoms but are at risk for developing high symptom levels. In addition to providing a more complete view of the complexity of a bereaved person's case, assessing risk factors creates an opportunity for the presentation of other underlying or coexisting conditions (such as a history of abuse), which might indicate a specific focus within treatment, or, depending on the condition, a different kind of intervention altogether.

Over the previous decades, a number of well-designed grief assessment instruments have been developed and validated both for the general bereaved population and for specific subcategories of bereaved people. These include the Adult Attitudes to Grief Scale (AAGS; Sim, Machin, & Bartlam, 2014); the Brief Grief Questionnaire (BGQ; Ito et al., 2012), the Inventory of Complicated Grief – Revised (ICG; Prigerson et al., 1995), the Grief Reaction Checklist (Hogan, Greenfield, & Schmidt, 2001; Shear & Skritskaya, 2012), and the Texas Revised Inventory of Grief (Faschingbauer, 1981). For a review of specific instruments, see (Neimeyer, Hogan, & Laurie, 2008; Sealey, Breen, O'Connor, & Aoun, 2015). These instruments—all self-reports—are often used for research purposes as stand-alone assessments. In clinical practice, however, they are more likely to be used as part of a larger assessment process, including a clinical interview. The interviewer would supplement the grief symptom assessment with a professional assessment. Such an assessment would

typically cover additional risk factors that might create further obstacles to coping with grief.

At present, the clinical interview remains a key component in this process. There have been no assessment indicators available to gather both grief symptom and risk information consistently outside the context of a clinical interview. Considering the limited availability of bereavement intervention in applied healthcare settings—which usually lack dedicated resources—it is often not possible for a trained clinical interviewer with knowledge of risk factors and grief symptoms to conduct intake assessments (Aoun et al., 2015). In the UK, for example, an estimated 80% to 90% of all bereavement support is provided by the voluntary (nonprofit) sector (see Stephen & Wimpenny, 2008, based on the London Bereavement Network's 2001 report on UK Standards for Bereavement Care; Feltham, 2000). It has been observed that a systematic approach is lacking in the way that care is offered, including what kind of care is offered to whom, and when (The Scottish Government, 2010, Stephen et al., 2009). There is a demonstrated need for a comprehensive intake assessment instrument that can distinguish between clinical, subclinical, and normal levels of grief symptoms and indicate the degree of risk of complications. Such an instrument would need to be easy to use and appropriate for use by both paraprofessionals and clinicians. It would enable bereavement support organisations to provide each client with a degree of care commensurate with case complexity.

The present study offers a validation of the Indicator of Bereavement Adaptation-Cruse Scotland (IBACS). Recently developed in close consultation with professional and volunteer bereavement support practitioners, the IBACS was designed for delivery by professional practitioners as well as nonprofessional practice staff or volunteers once a concise training process has been completed. The present study focused on the IBACS's discriminative ability and concurrent validity with existing assessment instruments, examining important aspects of the

instrument's psychometric quality (both reliability and validity). We also aimed to establish cutoff scores indicating a complicated response to grief.

Hypotheses were developed taking into consideration the IBACS's grief-specific focus, its practitioner-informed development, and the influence of two validated, grief-specific instruments on its formation. Particular attention was given to the IBACS's correlation with subscales assessing anxiety, depression, hyperarousal, and intrusive thoughts, all of which have been associated with grief (see Shear et al., 2012; Prigerson et al., 1996; Zisook, Chentsova-Dutton, & Shuchter, 1998). In contrast, given the indications in recent literature of a weak correlation between avoidance and CG measures (Eisma et al., 2013; Stroebe et al., 2007), lower expectations were placed around the IBACS's association with avoidance-related behaviours.

Under the broad hypothesis that the IBACS would detect levels of symptoms of complications in grieving, we formulated two sets of operational hypotheses. The first set of hypotheses concerned the IBACS's discriminative ability. We hypothesised that, using Receiver Operating Characteristic (ROC) curve analysis, the IBACS would demonstrate the ability to differentiate complex grief from cases of normal grief. The second set of hypotheses, which addressed the concurrent and predictive validity of the IBACS, stated that the IBACS would demonstrate medium to strong correlations with related measures in comparative instruments, as well as similar clinical implications.

Method

Because the present research was designed to test the validity of a new assessment instrument, details of this instrument are relevant to the participants and procedure sections of this study. For this reason, we will provide a description of the materials used in the analysis before presenting a description of study participants.

Materials

The Indicator of Bereavement Adaptation – Cruse Scotland (IBACS). The instrument examined in the present study, the IBACS, was developed to assess the severity of grief symptoms and the risk of developing complications in grieving. The IBACS was designed by Cruse Bereavement Care Scotland (CBCS) to fulfill two main purposes: first, to provide a standard, consistent client intake process that could be conducted by professional counsellors, volunteers, and staff across CBCS's Scotland-wide service; and second, to support a stepped model of care by assessing the severity of bereaved clients' grief symptoms and risk of complications. As such, the content needed to be bereavement specific and to assess grief symptoms as well as recognised risk factors for developing complications in grieving. In order to ensure the instrument's acceptability, the research team vetted the instrument with CBCS counsellors across Scotland, resulting in the following list of criteria for the instrument. It was agreed that items needed to be 1) brief, phrased in culturally acceptable terms and clear, accessible language 2) consistent across all service points; 3) easily scored, so that results of the assessment would be available directly at the conclusion of the assessment interview, and 4) designed to factor interviewers' observations and insights regarding participants' risk levels into the final assessment.

IBACS design. In order to meet the requirements detailed above, the IBACS needed to accommodate two somewhat conflicting needs: 1) the requirement for a consistent, structured assessment instrument, and 2) the need for an instrument that made allowances for a degree of observational (semi-structured) risk assessment and expert opinion. It was therefore decided to divide the IBACS into two sections: the risk factor assessment and the grief symptom self-report.

Part I: Risk factors. The risk factor assessment in the first section consists of a semi-structured interview. Questions address the interviewee's relationship with the person who died, the circumstances of that person's death, as well

as the interviewee's previous experiences with grief, pattern of attachment, and other sources of stress or support. The semistructured design of this section of the interview allows a breadth of issues to be raised and discussed. In particular, the design enables participants to bring up pressing matters or to discuss their circumstances—issues that might otherwise be missed in the confines of a structured question set. The semistructured interview approach also permits the interviewer to conduct further inquiry where needed in order to document the magnitude of the risk of complications that the participant is experiencing. Specific guidelines are provided to calculate the number of risk factor points to allot based on the risk factors that emerge in the course of the interview. Risk points range from 0 to a maximum of 7.

Part II: Grief symptoms. The second component of the interview, the grief symptom self-report, consists of a structured questionnaire that measures a number of grief-related symptoms. The individual questionnaire items were primarily drawn and adapted (with permission) from the Inventory for Complicated Grief (Prigerson et al., 1995; Prigerson & Jacobs, 2001). Selections were made by a panel of grief researchers and experienced bereavement support practitioners, and were chosen to provide a comprehensive but brief measure of loss-oriented behaviours (a mix of separation distress and traumatic distress items), along with two items (reverse-scored) measuring restoration-oriented behaviours, specifically personal growth. There are 12 items in this section of the interview, rated on a qualifying scale ranging from 0 (“Not at all”) to 4 (“All of the time”). Two items address suicidal ideation (“I have thought about ending my own life” and “I have done reckless things because I really don't care what happens to me”). In the present study, responses to individual IBACS items were not available; however, internal consistency was assessed in a previous study (Newsom, Schut, Stroebe, Birrell, & Wilson, 2015). In that study, with a sample of $N = 331$, internal consistency was found to be acceptable, with a Cronbach's alpha of .75. The IBACS scoring process,

cutoffs, and interviewer training process are discussed in the next section. The sum score of the IBACS, comprising the grief symptom section subtotal and the risk assessment score, can reach a maximum of 55 points.

To ensure the IBACS would be accessible to adults from a variety of educational backgrounds, a Flesch Reading Ease analysis was conducted using Microsoft Word 2011 (v14.4.9). Results indicated a readability score of 81.0 (out of 100), which can be interpreted as “Easy to read / conversational English”. A Flesch-Kincaid Grade Level analysis was also conducted using the same program. The analysis indicated the text was accessible at the 4.5 grade level. At this grade level, the text would be comprehensible to people with a primary school level of education.

Validated Measures

In the present study, four validated assessment measures were selected to provide a standard against which to measure the IBACS’s convergent and predictive validity. While all four instruments are widely used to assess symptoms of grief among bereaved people, two were designed to measure general psychological symptoms, and the other two measured symptoms for specific conditions prevalent among bereaved people: post-traumatic stress symptoms and grief-specific symptoms.

General psychological symptoms: 1. Clinical Outcomes in Routine Evaluation (CORE). The CORE is widely used by private and NHS psychological support service providers across the UK to assess a variety of psychological symptoms. It was designed to be a brief, accessible instrument for use on a regular basis to measure symptom levels over time (Evans et al., 2002). The CORE consists of 34 items that can be subdivided into four domains: symptoms (12 items), with item clusters around anxiety, depression, physical problems, and trauma; risk of harm (six items), including clusters around risk to self and risk to others; social functioning (12 items), including clusters around general functioning, close relationships, and social relationships; and well-being (four items).

The CORE is assessed with a 5-point qualifying rating scale (from 0, “Not at all”; to 4, “Extremely”). Sample questions include: “I have felt like crying” (problems/symptoms), “I have been physically violent to others” (risk of harm), “I have felt OK about myself” (well-being), and “Talking to people has felt too much for me” (social functioning). The CORE has demonstrated very good test–retest reliability (.75–.95; Evans et al., 2002). Construct validity has been shown through convergence with conceptually similar instruments (Evans et al., 2002; Barkham, Mellor-Clark, Connell, & Cahill, 2006). A high degree of scale reliability was also demonstrated in the present study ($\alpha = .90$).

General psychological symptoms: 2. The Symptom Checklist (Symptom Checklist 90 – Revised; SCL-90-R). The Symptom Checklist 90 –Revised consists of a 90-item self-report that can be used with both clinical and general populations (Derogatis & Unger, 2010; Prinz et al., 2010). Items are measured on a 5-point qualifying rating scale that ranges from 1 (“Not at all”) to 5 (“Extremely”). Responses to items are added together to create a total score that comprises the Global Severity Index. Items are further categorised into nine domains, which include anxiety, depression, hostility, interpersonal sensitivity (feelings of inadequacy), obsessive-compulsive, paranoid ideation, phobic anxiety (a persistent fear response with specific triggers, including agoraphobic symptoms), psychoticism, and somatisation (Derogatis, 1977). Construct validity has been established for all domains (Derogatis, 1977), while the depression, phobic anxiety, and interpersonal sensitivity subscales have also been subsequently validated as unidimensional scales (Bech, Bille, Møller, Hellström, & Østergaard, 2014). Population norms and normative data are available for a variety of psychological conditions. Reliability has been demonstrated through appropriate internal consistency measures ranging from $\alpha = .74$ to $.97$ (Prinz et al., 2013). In the present study, indications of scale reliability at baseline were extremely high ($\alpha = .98$).

Symptoms of Post-Traumatic Stress: The Impact of Event Scale – Revised. The Impact of Event Scale – Revised (IES-R; (Weiss & Marmar, 1997) was designed to assess symptoms associated with post-traumatic stress. Symptoms are measured through 22 items for a total subjective stress assessment, and can be further divided into three subscales: intrusion, avoidance, and hyperarousal. The instrument is administered as a self-report that refers to a certain life event (in the present study, a bereavement). Individual items present a specific difficulty, and participants indicate to what extent that difficulty has distressed or bothered them over the last seven days, using a qualifying rating scale. Sample questions include: “I felt watchful and on-guard” (hyperarousal), “I tried to remove it from my memory” (avoidance), and “Pictures about it popped into my mind” (intrusion). High test–retest reliability ($r = .89$ to $.94$) has been reported (Weiss et al., 1997) Convergent scale validity has also been demonstrated through a strong correlation ($r = .84$) with the PTSD Checklist (Creamer, Bell, & Failla, 2003). Strong scale reliability was also demonstrated in the current study sample at baseline ($\alpha = .93$).

Grief-specific symptoms. The Inventory of Complicated Grief. The Inventory of Complicated Grief (ICG) is a bereavement-specific, 30-item instrument designed to assess the severity of symptoms associated with CG that the respondent has experienced over the previous month (Prigerson et al., 2001). (For clarity we use the current name of the instrument, the ICG, in this manuscript, although the 30-item version published with the above citation was originally known as the Inventory of Traumatic Grief.) Different versions of the instrument are available under the name Inventory of Complicated Grief, including the most recent version, the Inventory of Complicated Grief-Revised (ICG-R). The ICG has demonstrated reliability through strong internal consistency (Cronbach’s $\alpha = .95$; (Prigerson et al., 2001). ICG items are measured using a 5-point frequency rating scale ranging from 1 (“Almost never”) to 5 (“Always”). Items form a single construct and address symptoms

of separation distress and cognitive, emotional, and behavioural disruption (Prigerson et al., 2001; Boelen & Prigerson, 2013). Construct validity for the ICG was demonstrated through convergence with the outcome of a structured clinical interview for traumatic grief (the Traumatic Grief Evaluation of Response to Loss; Prigerson et al., 2001). It was further examined using the Dutch version of the instrument (Boelen, Van den Bout, De Keijser, & Hoijsink, 2003), with convergent validity shown through a high correlation ($r = .71, p < .05$) with a grief-specific inventory (The Texas Revised Inventory of Grief), and a moderate correlation ($r = .59, p < .05$) with a depression measure (the Beck Depression Inventory). In the present study, baseline analyses also demonstrated a high degree of reliability ($\alpha = .96$). Although it is not recognised as a distinct diagnosis in *The Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013; Shear, 2012), CG is formulated as a collection of bereavement-related symptoms causing extreme distress, which is viewed to be distinct from depression or anxiety (Boelen et al., 2013; Prigerson & Maciejewski, 2006). Items include the statements: “I feel myself longing and yearning for [him/her]”, “I see [him/her] stand before me”, and “I feel disbelief over [his/her] death”.

The aggregate score of the ICG is commonly used as an indication of symptom severity in grief-related research. Different methods have been developed for calculating *caseness*, a dichotomous cutoff score for CG. In the present study, we used a method created by Prigerson and Jacobs (2001), which entails five criteria to establish caseness. In the present study, participants fulfilled three of these criteria at study enrollment (they were bereaved of a “significant other”; more than a minimum of two months had elapsed since the death; and they self-reported a severe degree of impairment stemming from their grief. The other two criteria stipulated a medium-to-high (self-report) rating on the separation distress symptom cluster (with at least three of five statements receiving a response of “4” or higher), and the traumatic distress symptom cluster (with at least six

of the twelve items receiving a response of “4” or higher. (To accommodate clinical use, in regular practice a professional’s opinion of caseness may also be factored into the final score.)

Participants

Recruitment for the study took place between January and December 2011 as part of a larger efficacy study of bereavement intervention, “Coping with Bereavement in Scotland”. Ethical review of the study was conducted by the NHS East of Scotland Research Ethics Committee 1 and approval was granted in September 2010. The sample of the larger study consisted of adult residents of Scotland (age 18+) who had been bereaved for at least six months, had requested bereavement support from CBCS, had yet to receive counselling services, and had no cognitive disabilities. Approximately 1,600 adults were approached to participate in the larger study, and received study recruitment packs containing information about the purpose of the study, the voluntary nature of participation, and how their confidentiality would be protected. Participants returned their signed consent forms via post. No compensation was offered for participation. Approximately 21% ($n = 341$) agreed to participate. Of these, 196 adults (44 male, 152 female) were assigned to the no-intervention control condition and were simultaneously enrolled in the present study. Assignment to conditions was quasi-randomised, working within the framework of the larger study’s naturalistic design. Participants who could not receive counselling support for logistical reasons (due to a waiting list in their local service areas, personal scheduling conflicts, or living too far away to reach a CBCS location) were assigned to the control condition.

Participation in the present study was limited to those people enrolled in the no-intervention control group of the larger study to avoid any confounding effects that intervention might have on follow-up questionnaire results. Table 1 presents the distribution of participants by age, gender, relationship to the deceased, and the deceased persons’ causes of death.

Table 1.*Participant Demographics**

	Male <i>n</i> = 44	Female <i>n</i> = 150	Total** <i>N</i> = 194	
Participant Age				
Mean	51.86	48.09	48.94	
Standard Deviation	11.32	14.15	13.63	
Relationship to the Deceased <i>The deceased person was:</i>	<i>n</i>	<i>n</i>	<i>n</i>	%
Child	3	15	18	9%
Parent	17	63	80	41%
Partner	22	53	75	38%
Sibling	1	12	13	7%
Other relative / friend	1	7	8	4%
Cause of Death				
Accident	3	10	13	7%
Homicide	0	1	1	<1%
Illness (Acute/chronic)	35	109	144	74%
Suicide	4	10	14	7%
Unknown	2	20	22	11%

Data in the table are frequencies except where otherwise indicated.

* Percentages do not sum to 100 owing to rounding.

Procedure

IBACS interviews (both Parts I and II) were conducted in sessions held either over the telephone or in person according to standard CBCS operating procedures by trained CBCS volunteers and staff. Participants also completed self-report postal questionnaires at intake (baseline, following the IBACS) and at follow-up after 18 months. IBACS scores were assessed by adding the risk of complication points (0 to 7) from Part I to the sum of the self-report responses from Part II (0 to 48 points) for a sum total score between 0 and 55 points. Preliminary cutoff scores for the assessment were provided as guidelines to indicate the level of added risk that the client is experiencing complications or will develop complications

in grieving. These cutoff scores were experimental and were based on face validity as determined by a committee of bereavement research specialists and experienced bereavement support practitioners. As such, they also required validation. Participants whose IBACS response sums measured 18 points or lower were considered to be following a normal grief trajectory and not to be in need of bereavement support at that time. Intervention was recommended for participants with IBACS results of 19 and above.

The IBACS was designed to facilitate client allocation to categories of support within a stepped model of care. At CBCS, following an IBACS interview, a client would be allocated to one of three intervention categories, tiered according to the complexity of symptoms and degree of risk, or to a fourth *no intervention/watchful waiting* category. Table 2 presents guidelines for interpreting IBACS results for a stepped model of care.

Table 2.*

IBACS outcome guidelines for intervention

<i>IBACS Result</i>	<i>Recommended intervention</i>
0-18	No intervention
19-28	Skilled listener intervention
29-38	Advanced skills listener
39-55	Counsellor

A different protocol was developed at CBCS for IBACS clients who reported high levels of suicidal ideation, indicated by a score of 6 points or higher on the two-question suicide subscale in Part II of the interview, or indicated verbally by the participant during Part I. Interviewers were trained to disregard the rest of the IBACS results in such circumstances and follow a suicide protocol, which included the involvement of outside specialised support depending on the severity of intent. Similarly, since substance abuse problems require attention before bereavement support

can be provided, clients who indicated advanced substance abuse problems were to be referred to specialised substance abuse support resources as a precursor to grief intervention. Additional instructions were also provided for supporting study recruits with an IBACS result of 18 or lower who presented with elevated symptoms of distress that was not bereavement-specific. For example, if a participant presented with problems related to domestic violence, the interviewer would refer the participant to an appropriate support resource.

Training for the IBACS. A condensed training module for delivering the IBACS was developed for the provision of consistent, comprehensive instruction to CBCS volunteers and staff. No professional qualifications or counselling skills were required of trainees beyond basic interpersonal skills. Training consisted of an online learning module followed by two group training workshops led by experienced professional counsellors who are also trainers approved by COSCA, Scotland's professional body for counselling and psychotherapy. The workshops were spaced several weeks apart and included supervised, role-playing dyad assignments and a discussion of techniques and procedures for a productive interview. In between these workshops, trainees conducted three trial IBACS sessions with supervision provided by experienced professional practitioners.

In addition to preparation for conducting Part I of the IBACS, the interview component, the training process also included preparation for administering Part II of the IBACS, the structured symptom self-report. Interviewers were trained to encourage clients to complete the items, but to maintain neutrality with respect to the nature of the responses. For example, if a client remarked, "I'm not sure how to respond to this one", training would instruct an interviewer to help the client refocus, gently reminding the client of the instructions, "just think about how you've been feeling over the last few weeks" or "take a moment to clear your thoughts, then read the item again... what's the first response that comes to your

mind?” Interviews for the present study were conducted by experienced IBACS interviewers who had completed the IBACS training module.

Participant Flow

At baseline, the sample numbered $N = 196$. Sixty-seven participants participated in the follow-up measure, which occurred 18 months later. A relatively high attrition rate was expected in the sample given the reports of previous longitudinal bereavement studies (Stroebe & Stroebe, 1989) and also due to the fact that participants in the present study constituted the no-intervention control group of a larger study, which may have made retention more challenging. In order to identify or rule out any potential attrition-led sources of bias in the sample, a logistic regression analysis was conducted to determine whether dropout at follow-up could be predicted by participants' age, relationship to the deceased person, education level, time elapsed since the bereavement, severity of grief-related symptoms at baseline (as measured by the ICG), or the deceased person's cause of death. The sample size for the regression analyses ($n = 186$) was slightly smaller than the total study sample because 10 cases were missing at least one variable. Results indicated that the full model, including all six independent predictor variables (dummy coded), was statistically significant ($\chi^2(7, n = 186) = 18.99, p < .001$), suggesting that there is a pattern in attrition. The model as a whole explained 9.7% (Cox and Snell R square) to 13.3% (Nagelkerke R square) of the variation in dropout, and correctly identified 66.1% of cases. This was, however, only a minimal increase over the baseline measure of 64.5% of cases correctly identified. Only one variable was found to make a statistically significant contribution to the model: relationship to the deceased. Those participants bereaved of a parent were 3.3 times more likely to drop out at follow-up compared to those who were bereaved of a child (OR = 3.3, $p < .001$). The increase offered by the total model in predicting dropout was minimal, however, and it appears unlikely that this attrition pattern would affect results.

Data Analysis

Two steps were taken for the validation of the IBACS in the present research. Below we discuss the operational hypotheses for each step, and the techniques used to test them. Statistical significance for the present study was set at $p < .05$.

1. Discriminative ability. Step one was to test the IBACS's discriminative ability. At present, there is no gold standard for measuring grief-related symptoms and complications (Zisook et al., 2014; Shear, 2015). In the absence of such a standard, we selected a high level of severity of symptoms associated with the construct of CG to serve as the indicator that a participant would benefit from tertiary intervention. This level of severity was represented by a dichotomous variable for CG *caseness*, which was calculated using participants' ICG responses at baseline following guidelines provided by Prigerson et al. (1995). To test the IBACS's ability to discriminate between positive and negative caseness, we used ROC curve analysis. ROC curve analysis is widely used in diagnostic test assessment to evaluate the inherent validity of a test in terms of sensitivity and specificity of diagnosis (Metz, 1978). In the present study, participant IBACS scores were entered as the test variable; the baseline caseness variable served as the dichotomous outcome variable. Then, to assess the validity of the IBACS as an indicator of caseness over time, the ROC curve analysis was repeated using the IBACS test variable at baseline. A second caseness outcome variable was calculated from ICG responses at follow-up.

Several guidelines for interpreting ROC curve results have been established for diagnostic tool assessment. Test performance is assessed by measuring the area that is calculated to lie under the curve (AUC; Swets, 1998). Guidelines in the literature to facilitate diagnostic tool assessment suggest that an AUC of .9 to 1.0 indicates high accuracy of test performance, .7 to .9 indicates moderate accuracy, .5 to .7 indicates lower

accuracy, and below .5 indicates that the instrument performs no better than chance (Greiner, Pfeiffer, & Smith, 2000). A grief-specific indication was also found in a study by Guldin and colleagues (2011). Using ROC curve analysis to compare a number of instruments' abilities to detect CG (calculated using an ICG cutoff score of 43), the highest AUC produced was .83 by the Beck's Depression Inventory.

Given the grief-specific focus of the IBACS and the influence of the ICG on its development, the IBACS was expected to successfully discriminate cases of CG. Specific operational hypotheses were formulated predicting that the ROC curve's AUC—which assesses performance of the IBACS in detecting caseness—would be above .8, demonstrating moderate accuracy. A further hypothesis was developed for using ROC curve analysis to test the predictive ability of the IBACS in discriminating caseness over time. Given indications in the literature that grief symptom levels generally decrease over time (Zisook et al., 2014), it was expected that the IBACS at baseline would continue to discriminate cases of CG with decreased but moderate accuracy, expecting an AUC of between .7 to .8. This analysis was conducted using IBACS scores at baseline as the predictor variable and a caseness variable at follow-up as the dichotomous outcome variable.

ROC curve analysis also facilitates the calculation of optimal cutoff thresholds for sensitivity and specificity. Due to the lack of reliable data concerning the prevalence of high levels of complications in grieving among a help-seeking bereaved population, it was not possible to inform our analysis with priors based on epidemiological prevalence. Instead, a maximal Youden's *J* statistic was selected as a gold standard. The maximal Youden's *J* ($J = \max_c \{Se(c) + Sp(c) - 1\}$) indicates the criterion value on the ROC curve when specificity and sensitivity are equally weighted and disease prevalence is set at 50% (Youden, 1950). We hypothesised that the criterion associated with the maximal Youden's *J* would correspond to the IBACS cutoff score criterion of 39, which indicates the most advanced

intervention level, the *counsellor* category. This category was designed to accommodate bereaved people for a tertiary intervention.

2. Concurrent and predictive validity. Concurrent validity was assessed by running correlation analyses with four selected assessment instruments at baseline. To minimise the effect of participant attrition on results, listwise deletion was used for each scale to include only data from participants with complete datasets at both timepoints. As detailed above, the instruments included in the analysis were: the CORE, ICG-R, IES-R, and SCL-90-R. Following Cohen (1988), we considered a correlation of 0.2 to be low, a correlation of 0.5 to be medium strength, and a correlation of 0.8 to be strong. A two-sided significance level ($\alpha = .05$) was used in all analyses. At baseline, a positive correlation with a large effect size was expected with all four instruments and their subscales, all of which measured psychological symptoms that ranged from closely associated with bereavement (CG) to not being congruous with bereavement (psychoticism). Given the ICG's grief specificity and influence on the IBACS's development, it was hypothesised that the IBACS would demonstrate:

1. The strongest correlation with the ICG, with a medium-to-high degree of correlation, articulated for present research purposes as ranging from $r = .60$ to $.70$.

2. A medium-strength correlation with subscales assessing anxiety, depression, hyperarousal, and intrusive thoughts. For research purposes, the range of correlation was specified as $r = .40$ to $.59$.

3. Low degrees of correlation (between $.30$ and $.39$) with scales assessing more general psychological symptoms, including the sum scores of the CORE and SCL, measures of well-being, and other psychological symptoms which are less frequently associated with grief, such as psychoticism and paranoia.

4. Similarly low correlation with an avoidance subscale, again specified for research purposes as between .30 and .39.

Following this set of correlations, a second set of correlation analyses was calculated to test the predictive validity of the IBACS. In this step, correlation was assessed between the IBACS measure at baseline and the follow-up measure of the same four assessment instruments after 18 months had passed. Again given indications in the literature that symptom levels decrease over time, we expected to find that correlations would also decrease due to greater variation. Finally, to consider the concurrency of the clinical implications of results across instruments, norms and cutoff scores for the two general symptom instruments, the CORE and the SCL-90-R, were compared to group means of IBACS intervention categories (which are based on IBACS cutoff scores).¹ It was hypothesised that the means of IBACS scores by intervention category would correspond to increasing mean scores on the CORE and SCL-90-R. It was also expected that the clinical recommendations yielded by the IBACS would indicate the same degree of case complexity as the other instruments, and to the degree indicated in the clinical interpretations of scores on the instruments to which it was compared.

Results

Discriminative ability. Figure 1 illustrates the results of the ROC curve analysis at baseline. The sample for the ROC curve analysis at baseline ($n = 169$) was somewhat smaller than the total study sample size. This was due to the exclusion of 27 participants from the analysis because they had missing data on their ICG measures, which prevented the calculation of a caseness variable. The results of the analysis were statistically significant ($p < .001$) and indicated an AUC of .84, with a 95% confidence interval between .77 and .90. Interpreting the results using the indications provided

¹ It was decided to exclude the ICG and IES-R from this process because the analysis would be redundant for the ICG after the ROC curve analysis, and IES-R cutoff indications are specific to a distinct condition—post-traumatic stress disorder—which may be present in some bereaved participants.

by Greiner, Pfeiffer, and Smith (2000) confirmed our hypothesis that the IBACS is a good diagnostic instrument for assessing CG.

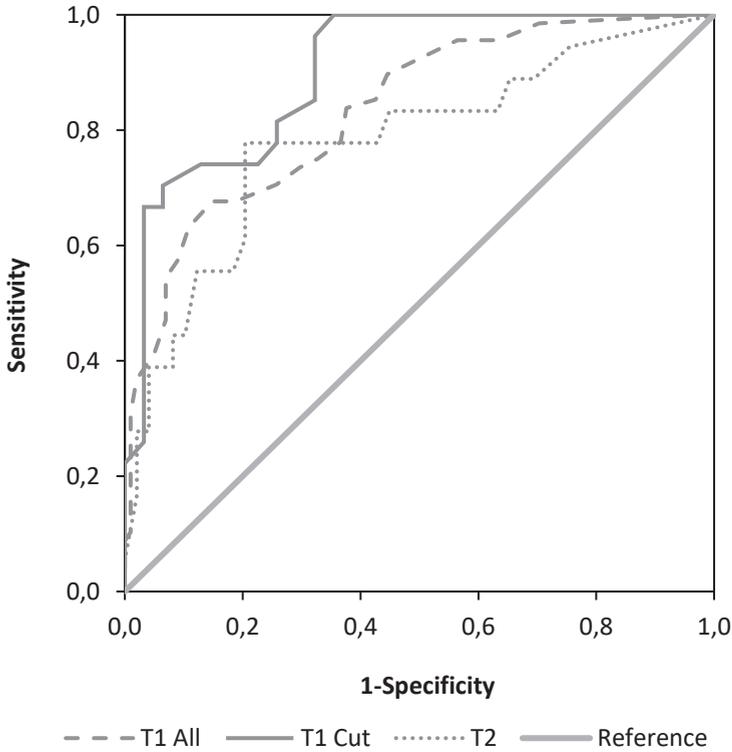


Figure 1. ROC Curve Analysis results at Time 1, Time 1 Cut (exclusively study completers) and Time 2.

The Youden's J statistic was calculated (.05) with a sensitivity of 67.65 and a specificity of 85.15. The value was associated with a criterion of >32 on the IBACS. This criterion was lower than our hypothesis of 39, which corresponded with the practice-based cutoff indicating the intervention category with the highest degree of severity. Its placement is approximately halfway along the current IBACS intervention scale. The criterion of 32 corresponds with the *advanced skills listener* category of intervention. Thus, within the existing IBACS allocation system, the majority of participants in the advanced skills listener category, and nearly all participants in the

counsellor category, can be expected to be positive for caseness. Participants in this system's skilled listener category fall under the >32 criterion, and would be expected to have negative caseness scores. The second ROC curve analysis, using the IBACS at baseline and a caseness outcome variable calculated at follow-up ($n = 67$, $p < .001$) produced an AUC of .78 with a 95% confidence interval between .65 and .92.² A DeLong's test was conducted to compare the AUCs of the ROC curves that illustrated the performance of study completers at Time 1 and Time 2 (DeLong, DeLong, & Clarke-Pearson, 1988). The DeLong's test indicated that there was no significant difference ($p = .314$) between the AUCs of the ROC curves at the two time points ($D = 1.012$, $df = 86.86$). These results indicate that the IBACS at baseline is a fair predictor of CG in participants 18 months later.

Concurrent and predictive validity. Table 3 shows the matrix of correlations between the IBACS and the instruments examined. As predicted, a positive correlation ($p < .001$, 2-tailed) was found between IBACS results at baseline, all four questionnaires (ICG, SCL-90, IES-R, and CORE-R) and their subscales at baseline, with the exception of the SCL-90 subscale for hostility and the IES-R subscale for avoidance. Consistent with the expectation that the IBACS would correlate most closely with a grief-specific instrument, the IBACS demonstrated the strongest correlation with the ICG sum score ($r = .82$), with a large effect size. Baseline correlations between the IBACS and measures for anxiety ($r = .46$), depression ($r = .41$), hyperarousal ($r = .40$)—all of which have been associated with bereavement-related grief in the literature—fell within the predicted low-medium range. The IBACS's correlation with a measure for avoidance was even lower than predicted ($r = .16$), with a small effect size. A surprising, medium-strength correlation was found between the IBACS and measures for psychoticism ($r = .54$) and paranoid ideation ($r = .49$), as well as obsessive compulsive symptoms ($r = .44$).

² Study attrition resulted in a smaller follow-up sample. For comparison purposes, the ROC curve analysis at baseline was also run using a sample restricted to those participants who were present at both timepoints.

Table 3.

Correlation between the IBACS and comparator instruments at baseline and follow-up

	Baseline	Follow-up	<i>n</i> *
<u>Symptom Checklist 90-Revised (SCL-90-R)</u>			
SCL-90-R global severity index	.48**	0.61**	61
SCL-90-R somatisation	0.29*	0.52**	55
SCL-90-R obsessive compulsive	0.44**	0.66**	59
SCL-90-R interpersonal sensitivity	0.38**	0.52**	60
SCL-90-R depression	0.41**	0.58**	51
SCL-90-R anxiety	0.46**	0.63**	54
SCL-90-R hostility	0.22	0.40**	62
SCL-90-R phobic anxiety	0.44**	0.52**	60
SCL-90-R paranoid ideation	0.49**	0.58**	60
SCL-90-R psychoticism	0.54**	0.62**	57
<u>Inventory of Complicated Grief-Revised</u>			
	.82**	.71**	55
<u>Impact of Event Scale- Revised (IES-R)</u>			
IES-R sum	.34**	.57**	65
IES-R avoidance	0.16	.43**	65
IES-R hyper-arousal	.40**	.59**	65
IES-R intrusive thoughts	.35**	.56**	65
<u>Clinical Outcomes in Routine Evaluation-Revised (CORE)</u>			
CORE Sum	.71**	.68**	50
CORE functioning	.35**	.40**	58
CORE problems	.60**	.56**	57
CORE risk	.64**	.56**	61
CORE well-being	.32**	.27*	63

*Sample sizes vary due to listwise deletion **p < .01

Scores on two general symptom assessment instruments, the CORE and SCL-90, were used to provide justification for the appropriateness of the IBACS cutoff scores. In order to do this, separate one-way analyses of variance (ANOVAs) with a Bonferroni correction were conducted to compare the IBACS cutoff points with the scores and severity levels

of the CORE and the SCL-90-R at baseline. Participants were divided into the four intervention categories indicated by their IBACS scores (as discussed above): *no intervention* (0-18), *skilled listener* (19-28), *advanced skills listener* (29-38), and *counsellor* (39 to 54).

Table 4 lists the IBACS intervention categories and their corresponding CORE and SCL-90 cutoffs. Each IBACS intervention category corresponded with an increasingly advanced degree of case severity, which all fell above the clinical threshold. There was a statistically significant difference in CORE scores for the four categories; $F(2, 179)^3 = 42.56$, $p < .001$. The effect size, calculated using eta squared, was medium (.32). ANOVAs comparing IBACS categories to SCL-90-R performance were conducted using separate global norms established for women and men (Arrindell & Ettema, 1986). The results for both analyses were significant at the $p < .001$ level with a Bonferroni adjustment; for women, the results indicated $F(3, 145) = 16.46$; and for men, $F(3, 42) = 8.71$. In sum, participants in different IBACS intervention categories also had distinct results on the CORE and the SCL-90-R, as demonstrated by the statistically significant differences between the IBACS intervention groups that were found in the results of these two assessment instruments. The mean CORE score and SCL-90-GSI mean for each IBACS intervention category (listed in Table 4) demonstrated that these categories correspond with increasing symptom complexity. A comparison was also made between the case severity level indicated by the IBACS and the cutoffs and clinical implications associated with each IBACS category mean on the CORE and the SCL-90-R. This comparison revealed that IBACS categories obtained mean scores on the CORE and SCL-90-R that corresponded with increasing degrees of case severity above the clinical threshold.

³ Due to missing (incomplete) data, some cases were excluded from the analysis.

Table 4.
Cut Off Score Convergence at Baseline

		IBACS Intervention Categories		
		Skilled Listener	Advanced Skills Listener	Counsellor
IBACS	<i>N</i> = 186*			
	(*excluding 8 “no intervention”)	<i>n</i> = 90	<i>n</i> = 61	<i>n</i> = 35
	Mean	22.90	32.89	43.29
	Standard Deviation	4.56	4.22	6.38
	Score Range	18 through 28	29 through 38	39 through 55
Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM)				
	<i>n</i> = 182	<i>n</i> = 89	<i>n</i> = 59	<i>n</i> = 34
	Mean	50.21	65.76	93.35
	Standard Deviation	22.77	23.76	23.97
	Clinical Indication	Mild severity (Clinical Range)	Moderate severity (Clinical Range)	Severe (Clinical Range)
Inventory of Complicated Grief Revised (ICG-R)				
	<i>n</i> = 164	<i>n</i> = 80	<i>n</i> = 55	<i>n</i> = 29
	Mean	83.97	103.00	131.00
	Standard Deviation	22.12	20.12	12.96
	Positive “Caseness”	19.8% (<i>N</i> = 16)	48.1% (<i>N</i> = 26)	92.6% (<i>N</i> = 25)
Symptom Checklist-90-Revised (SCL-90-R) Global Severity Index				
	<i>n</i> = 184	<i>n</i> = 90	<i>n</i> = 59	<i>n</i> = 35
	43 Men, 149 Women	21 Men, 69 Women	13 Men, 46 Women	6 Men, 29 Women
Men	Mean	1.00	1.69	2.45
	Standard Deviation	.63	.73	1.01
	Clinical Indication	Low	High	Very High
Women	Mean	1.47	1.85	2.55
	Standard Deviation	.82	.73	.86
	Clinical Indication	Above Average	High	Very High

As shown in Table 4, the mean scores in the three IBACS intervention categories corresponded with CORE results that were above the clinical threshold in the CORE classification system. They followed a similar pattern of increasing severity, with the IBACS skilled listener category ($M = 50.21$, $SD = 22.78$) indicating (clinical) mild level severity on the CORE, the IBACS advanced skills listener category's CORE mean ($M = 65.76$, $SD = 23.76$) indicating (clinical) moderate severity, and the IBACS counsellor category's CORE mean ($M = 93.35$, $SD = 23.97$) corresponding with the CORE's (clinical) severe category.

Predictive validity was assessed by calculating correlations between the IBACS at baseline and the four instruments at follow-up after 18 months had passed. The relationship between IBACS results at baseline and the ICG at follow-up remained strong ($r = .71$), implying a medium-to-large effect size. Some change was demonstrated in the results from other instruments. The strength of the correlation increased between the IBACS at baseline and all IES-R measures taken at follow-up. While hyperarousal ($r = .59$) and intrusive thoughts ($r = .56$) demonstrated a medium-strength correlations, correlation with the avoidance subscale, which was very low at baseline, increased at follow-up to a low-to-medium-strength ($r = .43$) and was significant at the $p < .001$ level. Correlations between the IBACS and all the SCL-90 subscales were also stronger at follow-up. This included an increase in the unexpected medium-strength correlation found with baseline measures for psychoticism (increased to $r = .62$ at follow-up) and paranoid ideation, ($r = .58$ at follow-up). The correlation with the obsessive-compulsive symptom subscale was the strongest of the SCL-90 subscales at follow-up ($r = .66$), followed by anxiety ($r = .63$). Correlations with the CORE and its subscales declined slightly but remained consistently medium strength for the sum score ($r = .57$), as well as the problems ($r = .56$) and risk ($r = .56$) subscales. A weaker correlation with the CORE well-being subscale remained low ($r = .27$), while correlation with the functioning subscale increased slightly ($r = .40$).

Discussion

The goals of this project were threefold: (a) to test the validity of the IBACS—an instrument developed for use by nonclinicians as well as professionals—against other valid measures, (b) to test the sensitivity of the cutoff point for intervention, and (c) to test the IBACS's discriminative ability concerning complex grief reactions as demonstrated in discerning CG caseness over time. The IBACS was an effective instrument for detecting moderate to severe difficulties coping with grief. The ROC curve analysis showed that the IBACS performed with satisfactory sensitivity and specificity in indicating caseness of the CG construct at a given time. The IBACS also demonstrated concurrency with other valid assessment instruments as an effective measure of grief-related symptoms. Assessing the IBACS's predictive validity, ROC analyses indicated only fair sensitivity to caseness over time. In contrast, the strength of correlation between the IBACS and the ICG, from which the caseness variable was calculated, remained equal over time.

The first set of hypotheses tested the strength of the relationship between the IBACS and a number of grief-related symptoms. A medium-strength relationship between the IBACS and subscales for anxiety, depression, and hyperarousal was confirmed. As expected, a weaker relationship between the IBACS and the IES-R avoidance subscale was also supported, given prior research indicating that overtly avoidant behaviours are low among bereaved people with symptoms of CG (Eisma et al., 2013). Instead, it has been theorised that in such cases, ruminative thoughts may themselves be a mechanism of avoidance (Eisma et al., 2013).

One finding was the stronger than expected correlation between the IBACS and three subscales on the SCL-90-R: measures of obsessive-compulsive behaviour, paranoid ideation, and psychoticism. Since prior research had not found a relationship between these constructs and bereavement-related grief symptoms, we examined the individual items in each subscale for possible explanations. We considered the standard

instructions that participants had been given to respond to items based on how they had felt over the previous month. Additionally, the instruments were administered during a study on coping with bereavement, which included several grief-specific instruments and questions about bereavement-related circumstances. Reviewing the paranoia, psychoticism, and obsessive-compulsive subscale items with this in mind, it became apparent that non-grief-specific items might have been interpreted in terms of bereavement-related grief behaviours. For example, the obsessive-compulsive scale items described behaviours that included obsessive thoughts, which in a bereavement context could relate to intrusive thoughts about the deceased person and other reminders connected to bereavement. Checking behaviours and insecurities about task completion could also relate to specific difficulties in adjustment common to bereaved people. Items on the paranoia subscale, such as discomfort in public and feelings of being observed or standing out in a crowd, were also found to be relevant to post-bereavement adjustment. Lastly, the psychoticism subscale included items that addressed auditory and visual hallucinations. While hallucinations themselves are not generally considered symptoms of grief, it is not uncommon for bereaved people to report seeing or hearing the deceased person. Examining the correlation between the IBACS and these three distinct (and at first, seemingly unrelated) constructs was important for a number of reasons. It was a reminder of the need for bereavement-specific norms in general symptom questionnaires, and the importance of not assuming that general symptom questionnaires generate general (and not grief-related) responses in a bereaved population.

The second set of hypotheses concerning the IBACS's ability to discriminate CG caseness was also confirmed using ROC curve analysis. The optimal cutoff point for the IBACS, which is >32 , was established using Youden's *J* statistic. We had expected to find parallels between the cutoff criterion for caseness and the most complex category in the current IBACS system, the counsellor category. Instead, using a standardised

prevalence rate and giving equal importance to sensitivity and specificity resulted in a criterion that closely mirrored the advanced listener category cutoff. This therefore suggests that not only the counsellor category participants, but also those people in the advanced skills listener group present strong grief symptoms, whereas those in the skilled listener group are at risk of developing grief symptoms. Further evaluation of IBACS cutoff criteria is needed, preferably with a prevalence statistic specific to the help-seeking bereaved population. Moreover, while Youden's J gives equal value to sensitivity and specificity, in practice, the necessary choice between caseness sensitivity and specificity should be carefully weighed. On the one hand, a false negative for CG could lead to a lack of intervention or assignment to a practitioner not suitably skilled to support the client. On the other hand, a false positive could mean pathologising aspects of the normal human condition, such as grief, which could be even more detrimental.

Overall, the results support the validity of the IBACS as an intake assessment instrument for bereavement-related grief. While at present there is no gold standard against which to compare the assessment of bereavement-related grief symptoms and risk of complications (attributable in part to the fact that an extreme grief response, although universally recognised as suffering, is not currently a unique diagnosis (Shear, 2012), the IBACS showed moderate concurrent validity with four widely used, validated assessment instruments, one of which was specific to grief responses. This represents an important step toward creating an effective intake instrument for nonclinicians. Such an instrument is of particular importance when considering current circumstances in bereavement care, where an estimated 70% of bereavement intervention services in the UK are provided by the nonprofit sector (Stephen et al., 2008) and the large majority of bereavement support offered in Australia, Canada, Japan, the UK and the USA does not entail targeted support

or the use of a formal risk assessment at intake (Breen, Aoun, O'Connor, & Rumbold, 2014).

We have assessed the instrument in the delivery context for which the IBACS was designed: assessment in a nonclinical setting. In this context, the IBACS appears to perform satisfactorily. Two things need to be considered when looking at this outcome. First, the correlation analyses were conducted with the other assessment instruments exclusively using their rating scale symptom assessments. Second, if the other assessment instruments had actually been administered in a clinical setting, professional opinion would have contributed to the final assessment, and assessment outcomes may have been different. Furthermore, as with any instrument, additional analyses must be conducted to establish a comprehensive evaluation of its validity. One critical issue concerns the application of the IBACS in other (cultural) settings. The current study was conducted in Scotland, where the instrument was developed, including guidelines for risk factor assessment that were found to be culturally appropriate for a British population. It will be important to revisit these guidelines when using the instrument in other cultures where different social norms for expressions of grief may need to be considered. Similarly, it is important to re-evaluate optimal cutoff points to ensure that appropriate thresholds for intervention are in place in distinct cultural settings.

There were several limitations to our study. First, the naturalistic design prevented further steps for examining the efficacy of the IBACS as an assessment instrument. An item-level factor analysis was not possible given the lack of item-level data. Also, the decision not to disturb standard intake procedures precluded testing inter-rater reliability. This would have required duplicate interviews or the presence of multiple interviewers at each IBACS session (or via video) to compare risk point allocation. Another significant limitation was the lack of low-level responders in the dataset. Because the participant sample consisted of help-seeking bereaved people who were participating in a larger research study, those who scored

under 18 on the IBACS were excluded from the dataset. To address this issue, additional research is recommended to conduct a psychometric validation using item-level responses and working with a sample that presents a broader spectrum of case complexity.

Finally, as for all longitudinal studies, participant attrition must be considered. Participant dropout reduced power in the correlation analyses at follow-up. Although the cause of study dropout is usually unknown, there are two issues worth considering. First, study design may have increased the likelihood of participant dropout; longitudinal studies using postal questionnaires have higher attrition rates than studies employing other methods, such as face-to-face interviews. Second, changing life circumstances for participants may have also impeded data collection due to a lack of accurate contact information. It is worth noting that low response rates are not uncommon in quantitative research among bereaved people (Aoun et al., 2015).

Despite the limitations, the IBACS appears to be a good intake assessment instrument for bereavement intervention. Although a definitive assessment of its accuracy cannot be made at this time, the IBACS offers moderately concurrent results with instruments that were (atypically) administered without a clinical assessment. One advantage is that the IBACS is easy to use in nonclinical settings. It can be delivered by interviewers who have completed a basic training module. This is of particular importance in countries like the UK, as noted above, where the large majority of bereavement support is provided by non- or paraprofessional resources who lack the training and professional qualification to offer clinical interviews.

Consistent and informed assessment of grief symptoms and risk of complications is almost never offered; yet the scientific literature indicates the importance of assessment in creating positive outcomes for help-seeking bereaved people and for promoting the effective use of resources. An accessible instrument like the IBACS can fill a critical gap

by enabling nonclinicians to assess bereaved people's symptom and risk levels in order to determine whether they would benefit from bereavement intervention. This supports expanding the availability of bereavement assessment, allowing for more targeted interventions and fewer wasted resources.

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Chapter 4

Effectiveness of bereavement counselling through a community-based organisation: A naturalistic, controlled trial

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Abstract

Objectives: This controlled, longitudinal investigation tested the effectiveness of a bereavement counselling model for adults on reducing complicated grief symptoms. Participants ($N = 341$; 79% female; mean age: 49.3 years) were adult residents of Scotland who were bereaved of a close relation or partner, experiencing elevated levels of CG, and/or risks of developing CG. It was hypothesised that participants who received intervention would experience a greater decline in CG levels immediately following the intervention compared to the control participants, but the difference would diminish at follow up (due to relapse). **Methods:** Data were collected via postal questionnaire at three time points: baseline (T), post-intervention (T+12 months), and follow-up (T+18 months). CG, posttraumatic stress, and general psychological distress were assessed at all time points. Multilevel analyses controlling for relevant covariates were conducted to examine group differences in symptom levels over time. A stepwise, serial gatekeeping procedure was used to correct for multiple hypothesis testing. **Results:** A main finding was that, contrary to expectations, counselling intervention and control group participants experienced a similar reduction in CG symptoms at post-measure. However, intervention participants demonstrated a greater reduction in symptom levels at follow-up ($M=53.64$; $d=.33$) compared to the control group ($M=62.00$). **Conclusion:** Results suggest community-based bereavement counselling may have long-term beneficial effects. Further longitudinal treatment effect investigations with extensive study intervals are needed.

Research and professional consensus suggest that the majority of bereaved people will cope with the pain of a “normal” grief reaction without professional help, and that, over time, they will begin to feel better (Kersting, Braehler, Glaesmer, & Wagner, 2011; Zisook et al., 2014). Still, bereavement is associated with a variety of negative mental and physical health outcomes (for reviews: Stroebe, Schut, & Stroebe,

2007; Zisook et al., 2014). Physical health outcomes include an increased risk of mortality (Buckley et al., 2012), suicidality (Prigerson et al., 1997; Zisook et al., 2014), and morbidity (Buckley et al., 2012; Keyes et al., 2014; O'Connor, Schultze-Florey, Irwin, Arevalo, & Cole, 2014). Mental health outcomes include depression, posttraumatic stress disorder (PTSD), and difficulties in grieving that extend in duration and severity beyond the scope of "normal" grief symptoms, also termed complicated grief (CG) (Zisook et al., 2014). For the sake of clarity, it is useful to note that varying labels and definitions of CG have been proposed (e.g., prolonged grief disorder, persistent complex bereavement disorder) (American Psychiatric Association, 2013; Maercker et al., 2013; Prigerson et al., 2009; Shear, 2015), with estimates of the prevalence and incidence of CG varying according to the definition and the population observed (for a brief review, see Rosner et al., 2011).

Given the patterns of difference in reactions to a loss experience, it is critically important that effective psychological interventions are developed for people experiencing difficulties in coping with bereavement. Systematic reviews, including meta-analyses, have identified the following characteristics of bereavement intervention programs that have been associated with intervention outcomes: 1) time since bereavement (interventions early after bereavement appear to be ineffective, cf. Bonanno, 2005; Currier, Neimeyer, & Berman, 2008; Schut, Stroebe, van den Bout, & Terheggen, 2001); 2) the way contact between client and counsellor is established (outreaching intervention being related to less positive effects than intervention instigated by the bereaved person) (cf. Schut et al., 2001); 3) the initial level of distress of the bereaved person and risk factors for experiencing complications grieving. Concerning the latter set of characteristics, it has been demonstrated that higher distress correlates with better results (cf. Prigerson & Jacobs, 2001; Shear, 2015; Zisook et al., 2014). Interventions aimed at treating bereaved people with high levels of grief-related distress have been termed tertiary interventions and have

been associated with positive outcomes (Schut et al., 2001). Outcomes for interventions focused on treating bereaved people with risk factors for developing complications, termed secondary interventions, have produced conflicting results (Schut et al., 2001). Nevertheless, recent investigations where participants were screened for risk factors have indicated better results for higher risk groups (cf. Burke & Neimeyer, 2013; Litz et al., 2014; Shear, 2015).

It can be surmised that an effective intervention would be aimed specifically at help-seeking bereaved people at least six months after bereavement who present with, or are seriously at risk of developing, psychopathology (Center for the Advancement of Health, 2003; Currier et al., 2008; Schut et al., 2001; Wimpenny et al., 2007). In line with these findings, meta-analysis showed that psychotherapeutic interventions yield moderate effect sizes in help-seeking bereaved people with elevated levels of grief or CG more than six months after loss (Wittouck, van Autreve, De Jaegere, Portzky, & van Heeringen, 2011; for examples of effective interventions: Boelen, de Keijser, van den Hout, & van den Bout, 2007; Shear et al., 2005).

Several recent randomised trials of psychotherapy for CG similarly yield moderate to strong effects when targeting indicated groups of bereaved people (e.g. Eisma et al., 2015; Litz et al., 2014; Rosner, Pfoh, Kotoučová, & Hagl, 2014; for a review: Doering & Eisma, 2016). Although these studies are of major importance in identifying which interventions work best for bereaved people experiencing complications in the grieving process, there are common limitations to many of them. First, due to practical and ethical limitations, most studies only assess short-term effects, which makes it difficult to assess any longer term benefits (for notable exceptions: de Groot et al., 2007; Kersting et al., 2013; Rosner, 2015). Second, the majority of recent studies concern interventions that are offered in a professional setting and not in the setting in which they are most often delivered; in the UK, the majority of bereavement intervention

services are provided by non-profit sector staff and volunteers (estimated at 70%–90% in the UK by Stephen et al. (2009) and similar situations of bereavement care offered by palliative care and hospice organisations in Australia, Japan, and the USA have been described by Breen, Aoun, O'Connor and Rumbold (2014)).

The Present Study

A unique situation of bereavement care in Scotland and a newly developed intervention at a Scottish national organisation, Cruse Bereavement Care Scotland (CBCS), have presented the opportunity to address these gaps in the research by conducting a naturalistic, longitudinal study on the effectiveness of community-based, one-to-one bereavement counselling. The CBCS intervention entails an intake assessment process to ensure the provision of care for bereaved people at the appropriate time (i.e., more than six months after loss) on an in-reaching basis. Pre-existing logistical issues (described below in greater detail) also provided for a quasi-randomised, no-intervention control condition to balance the study design.

The development of the CBCS model of bereavement intervention was theory-driven and guided by Schut and Stroebe's dual process model (DPM) of coping with bereavement (Stroebe & Schut, 1999). Following this model, bereaved people who engage in an adaptive coping process oscillate between loss-oriented and restoration-oriented behaviours, which facilitate positive and negative reappraisals. Bereaved people who experience complications may require support in finding pathways to permit this oscillation in everyday life. To offer this kind of support, the CBCS model was developed as a flexible, bereavement-specific counselling intervention, combining elements of a number of established therapeutic methods including cognitive behavioural therapy (Boelen et al., 2007), person-centred counselling (Larson, 2013), and the psychodynamic approach (Mikulincer & Shaver, 2008). Details of the CBCS intervention

model have been discussed in a qualitative study by Simonsen and Cooper (2015).

The aim of the present study was to establish – uniquely – whether grief counselling offered through a community-based organisation to help-seeking, highly distressed, and/or high risk bereaved individuals is effective in improving psychological and social functioning relative to a no-intervention control. There were three primary hypotheses. First, in line with the above-mentioned meta-analyses, we predicted a greater decline in CG symptom levels in the intervention as compared with the control group at post-test (one year after baseline). Second, following indications in the literature of a diminishment of effect with the passage of time (Currier et al., 2008), we expected to see a smaller difference between the slopes of symptom level change between the intervention and the control group in the post-measure to follow-up interval (one and a half years after baseline). Third, we also expected the difference within the study categories to be smaller between post-test and follow-up, given the potential for post-therapy relapse. Our secondary hypotheses predicted a similar pattern of results for symptoms associated with PTSD and symptoms of general psychological distress.

Method

Procedure

The present study was approved by the NHS East of Scotland Research Ethics Committee (IRAS project ID 56758) in November 2010, with study progress reports submitted on an annual basis until 2015. Recruitment for the study took place between January and September 2011 across all mainland locations of CBCS, an independent, voluntary sector organisation specialised in delivering informational and counselling support to bereaved people at no cost to them. Each year, approximately 12,000 people contact CBCS for information and support, and about 55,000 hours of service are provided to the Scottish community.

Participants of this study were adult (age 18+) residents across Scotland who had been bereaved for at least six months, had already received basic written information in the form of leaflets on coping with bereavement (Kuykendall, 2005; CBCS, 2010), and had contacted CBCS to request for one-to-one counselling support. Eligibility for the study was limited to people who were actively seeking help (i.e., no routine referrals) and were eligible to receive standard care from CBCS. Excluded from the study on these grounds were people with learning difficulties, cognitive difficulties, or special communication needs (since these clients are allocated directly to volunteers with specialised skills); people presenting with co-morbid psychological conditions such as substance abuse problems, schizophrenia, or psychosis (to whom referrals for specialist care were provided); and people presenting with strong suicidal ideation (who were supported following a different protocol). People receiving external psychological support were also excluded from the study. Use of anti-depressant and anti-anxiety medication among study participants at baseline was not an exclusion criterion if use of medication continued throughout data collection. This choice was made due to the widespread use of antidepressants and anti-anxiety medication in Scotland (The Scottish Government, 2014; cf. Shear et al., 2005).

Study information packs, including a written invitation to participate, were provided to eligible people either in person after a visit to CBCS or by post following telephone contact. Participants indicated their agreement to enroll in the study by signing and returning a study consent form by freepost. Approximately 1400 packs were distributed, and 349 people agreed to participate (24.9%) (This rate of acceptance is not unusual for bereavement research, as discussed below in the “Participant flow” paragraph of the Results section.) Of these, five people were excluded from the study (due to external professional help received), and 344 were enrolled in the study. Assignment to study conditions was quasi-randomised. Quasi-randomisation enabled us to include a no-intervention

control group and a participant observation period of 18 months, while adhering to ethical standards, and not denying care to help-seeking bereaved people. Participants for whom counselling sessions could be scheduled were assigned to the intervention condition ($n = 156$). The control group consisted of those who wanted counselling, but were unable to participate (in the near future) ($n = 188$). The majority of these were people who could not find a mutually agreeable time for counselling sessions and/or could not arrange transport to the service location. (Although CBCS has locations throughout Scotland, the topography of Scotland is such that a nearby location may in reality be difficult to reach.) There was also a small number of participants who remained on a waiting list for intervention services due to the organisation's limited capacity (at that time) to provide care in the short term.

Sample Characteristics

Demographic details and loss-related characteristics of the study sample are presented in Table 1 (for group comparisons, see results). Seventy-nine percent of participants were females⁴. The mean age of participants was 49.3 years ($SD = 14.20$), with a range from 20 to 85 years. The majority of the sample had lost a partner (38%) or parent (37%) within the previous 2 years (80%), and reported that the death had been unexpected (63%).

⁴ For further comments on this characteristic, please see below in the Discussion section.

Table 1.*Baseline personal characteristics of control and CBCS participants*

	Control (N = 188)		CBCS (N = 156)	
Demographic characteristics				
Age in years (Mean [SD])	48.5	(14.17)	50.1	(14.48)
	<i>n</i>	(Valid %)	<i>n</i>	(Valid %)
Gender	188		156	
female	146	(77.66%)	125	(80.13%)
Income	150		137	
below median	62	(41.33%)	40	(29.20%)
median	34	(22.67%)	46	(33.58%)
above median	54	(36.00%)	51	(37.23%)
Living with a partner	181		153	
yes	52	(28.73%)	51	(33.33%)
no	129	(71.27%)	102	(66.67%)
Participant has children **	185		153	
no	53	(28.65%)	63	(41.18%)
yes	132	(71.35%)	90	(58.82%)
Use of medication at baseline*	183		156	
no	91	(49.73%)	91	(58.33%)
yes, antianxiety/antidepressants	84	(45.90%)	58	(37.18%)
yes, other (incl. sleeping pills)	8	(4.37%)	7	(4.49%)
Loss-related characteristics				
Time since the death*	180		154	
6 months	38	(21.11%)	37	(24.03%)
between 6 - 12 months ago	64	(35.56%)	58	(37.66%)
1-2 years ago	44	(24.44%)	35	(22.73%)
2-5 years	23	(12.78%)	18	(11.69%)
5+ years ago	11	(6.11%)	6	(3.90%)
Relationship to the deceased**	186		155	
partner	75	(40.32%)	54	(34.84%)
parent	75	(40.32%)	53	(34.19%)
sibling	11	(5.91%)	17	(10.97%)
child	18	(9.68%)	19	(12.26%)
other friend /relative	7	(3.76%)	12	(7.74%)
Quality of the relationship	184		155	
very good / good	169	(91.85%)	144	(92.90%)
reasonable	7	(3.80%)	7	(4.52%)
not good / bad	8	(4.35%)	3	(1.94%)
no relations	0		1	(0.65%)
Expectedness of the death	182		154	
expected	35	(19.23%)	33	(21.43%)
neither expected nor unexpected	30	(16.48%)	22	(14.29%)
unexpected	117	(64.29%)	99	(64.29%)
Other resources contacted (prior to study)**	182		153	
no	116	(63.74%)	123	(80.39%)
yes (psychiatrist)	9	(4.95%)	5	(3.27%)
yes (psychologist, counsellor, therapist)	38	(20.88%)	18	(11.76%)
yes (support group, other social organization)	14	(7.69%)	7	(4.58%)
Outcome measures at T1 (<i>unadjusted means</i>)				
	<i>M</i>	<i>.SD</i>	<i>M</i>	<i>SD</i>
Impact of Event Scale	44.96	19.68	43.04	18.19
Inventory of Complicated Grief - Revised	68.42	25.86	64.78	23.68
Symptom Checklist 90 - R	151.72	80.10	132.33	71.11

Note. * = $p < .05$, ** = $p < .001$

Intervention

The CBCS intervention model was developed specifically for the provision of one-to-one counselling support to adults who are experiencing difficulties in coping with bereavement. Informed by the DPM of coping with bereavement (Stroebe & Schut, 1999), the intervention aims in part to normalise the participant's grief reaction when needed and to create a safe holding environment for the participant to express and confront emotions relating to the bereavement. This pluralistic model of bereavement intervention incorporates components of three therapeutic traditions. From the person-centred approach, these include unconditional positive regard, empathy, and congruence; from CBT they include guided exposure exercises adapted to meet individual needs; and from the psychodynamic tradition they include an awareness of attachment patterns that may inform grief reactions. (For more detail, as well as a client's perspective, see Simonsen & Cooper, 2015).

At baseline, an intake assessment was conducted by a purpose-trained volunteer using the IBACS, a validated assessment instrument for bereavement-related grief and risk factors (Newsom, Schut, Stroebe, Birrell, & Wilson, 2015; Newsom et al., in press). The minimum IBACS score was 0; the maximum was 55. Clinical indications for the IBACS currently maintained a minimum threshold of 19 points for bereavement intervention. Bereaved people who received fewer than 19 points were considered to be coping effectively on their own, and intervention is not indicated. Likewise, people who received more than 54 points were to be considered in need of urgent specialist care and would be accordingly referred to qualified professional resources. For bereaved people who received from 19 to 54 IBACS points, two further subcategorisations facilitated the assignment of appropriately-experienced counsellors. Participants who received an IBACS score between 19 and 28, which corresponds with marginal levels of CG, were allocated to the skilled listening category. Placing the current intervention design in the context of existing

categories (following the indications from Schut et al., 2001) described in the introduction, counselling for this category would be considered a *secondary* intervention, since it was a preventative intervention for people with elevated symptoms of grief who were at risk of developing CG. Participants who reached an IBACS score of 29 to 54, indicating high complicated grief levels, were allocated to the advanced skills/counsellor category. This score range roughly corresponds with CG caseness, and counselling in this category would be considered a *tertiary* intervention in Schut et al.'s (2001) framework.

Counsellors working with participants in the skilled listener category and those working with participants in the advanced skills listener category offer support based on the same intervention model; only their hours of experience are different. All counsellors have completed (at a minimum) a year-long diploma-level course in counselling (certified by the Scottish counselling authority, COSCA) as well as a COSCA-certified grief-specific training module (details can be requested through the national office of CBCS). Counsellors are promoted from the skilled listener to the advanced skills counsellor category after completing an additional 60 hours of supervised, client-facing work, along with requisite continuing professional development hours. A total of 66 volunteer counsellors delivered care in this study. Participants worked with the same counsellor at each session. Counselling sessions were held at CBCS locations across Scotland in quiet rooms with comfortable, non-clinical furnishings. Participants attended counselling sessions on a weekly basis, scheduled at their convenience in the day or evening. Sessions lasted 50 minutes. Standard CBCS procedure is to offer clients 6 sessions, though a participant and counsellor may mutually agree to adjust the number of sessions as needed. An average of six sessions of counselling was offered ($M = 6.32$, $SD = 3.09$).

Data Collection Procedure

Data for the present study were collected at three time points: baseline, T1; post-treatment, T2 (T1+12 months); and follow-up, T3 (T1+18 months). Time intervals were standardised to be uniform across conditions. Duration of the period from intake through completion of intervention varied from participant to participant, with an average length of nine months. Since the intake plus intervention period was universally completed by 12 months, we selected 12 months as a standard interval between T1 and T2.

Measures

Five instruments were used in the present investigation: a measure of demographic and loss-related characteristics (administered at T1); an intake assessment instrument measuring bereavement-related distress and risk of developing complications (administered at T1); a primary measure for CG symptoms; and secondary measures to assess PTSD symptoms and general psychological health symptoms (administered at T1, T2, and T3).

Bereavement-related distress and risk of complication (intake assessment). IBACS (Newsom et al., 2016) was administered to measure baseline levels of bereavement-related grief symptoms and the risk of developing complications while grieving due to the presence of known risk-factors. Risk-factors were assessed through a semi-structured interview; symptoms of bereavement-related distress were measured with a structured question set. A validation exercise for the IBACS demonstrated convergent validity with other instruments including the Inventory of Complicated Grief – Revised (ICG-R; Prigerson & Jacobs, 2001; $r = .82, p < .01$) and cutoff score convergence with CG “caseness” calculations using the ICG-R (Newsom et al., 2016).

Demographic and loss-related characteristics. A self-constructed questionnaire was used to assess demographic characteristics (gender, age,

lives with a partner (yes/no), has children (yes/no), income) and loss-related characteristics (time since loss; relationship with the deceased; expectedness of the death; quality of the relationship with the deceased; medication use).

Complicated grief. Symptoms of CG were assessed with the 30-item ICG-R (Prigerson & Jacobs, 2001). Strong internal consistency (Cronbach's $\alpha = .94$) has been reported for the ICG-R (Prigerson & Jacobs, 2001). Convergent validity for the ICG (Dutch version) was demonstrated through a high correlation ($r = .71, p < .05$) with The Texas Revised Inventory of Grief (Boelen, van den Bout, de Keijser, & Hoijsink, 2003). Convergence with the outcome of the structured clinical interview protocol, the Traumatic Grief Evaluation of Response to Loss (Prigerson & Jacobs, 2001) confirmed construct validity. In the present investigation, baseline reliability was excellent, $\alpha = .95$, and was minimally higher at the two subsequent time points ($\alpha = .96$).

PTSD-related symptoms. Symptoms of avoidance, hyper-arousal, and intrusion were assessed using the Impact of Event Scale – Revised (IES-R). The IES-R is a 22-item questionnaire, addressing the above-listed symptoms, which conform to DSM-IV criteria for PTSD. Strong test-retest reliability ($r = .89$ to $.94$) has been reported for the IES-R (Weiss & Marmar, 1996), and convergent validity with the PTSD checklist has been demonstrated with a high correlation of $r = .84$ (Creamer, Bell, & Failla, 2003). In the present study, reliability was excellent at baseline, $\alpha = .92$, and continued to be at T2, $\alpha = .94$, and at T3, $\alpha = .95$.

General psychological symptoms. The Symptom Checklist 90 Revised (SCL-90-R; Derogatis & Cleary, 1977) is a 90-item questionnaire addressing general psychological health symptoms that can be divided into nine domains: anxiety, depression, hostility, interpersonal sensitivity, obsessive compulsive symptoms, paranoid ideation, phobic anxiety, psychoticism, and somatisation. Internal consistency has been shown to range from $\alpha = .74$ to $.97$ (Prinz et al., 2013). Each domain has demonstrated construct

validity (Derogatis & Cleary, 1977), and validity as a unidimensional scale has been established for the depression, phobic anxiety, and interpersonal sensitivity subscales (Bech, Bille, Møller, Hellström, & Østergaard, 2014). Average positive symptom scores can be used to calculate the Global Severity Index, a general symptom severity rating, which was used in the present study (Derogatis & Cleary, 1977; Derogatis & Unger, 2010). Baseline reliability was excellent in the present investigation, $\alpha = .98$, and maintained at both T2 and T3.

Statistical Analyses

Three main operational hypotheses were formulated to investigate the primary research question. We expected to find: 1) the slope (i.e., decline) of mean grief symptoms in the intervention condition would be greater than in the control condition between T1 and T2; 2) a difference between the slopes of change of the intervention and the control conditions between T2 and T3; 3) a greater slope of change between T1 and T2 than between T2 and T3 in both study categories (this hypothesis was tested separately for each group). Next, the same hypotheses were to be tested for secondary outcomes (i.e. PTSD and general psychological health symptoms).

A random effects model for fixed occasions was developed to analyze the data (Snijders & Bosker, 2012). An average score was estimated for the outcome variable at each time point for the intervention and control conditions. Where baseline differences in demographic or loss-related variables between conditions were detected, these variables were added as covariates. Assumptions of linearity, multicollinearity, homoscedasticity, and normality of residuals were tested prior to analysis. To account for the longitudinal nature of the data, a multilevel regression was conducted using MLwiN (Rasbash, Steele, Browne, & Goldstein, 2015). with repeated measures nested within subjects, and a random effect of time included to account for within-subject correlations. Estimation of model

parameters and standard errors was conducted with full information maximum likelihood with robust standard errors.

Change in outcome variables across time was measured by calculating the slope of change of adjusted mean scores for both study conditions. For each condition, the adjusted mean at T2 was subtracted from that of T1, and the adjusted mean at T3 from that at T2. Positive values indicate a decline of grief-related symptom scores between time points. The slopes were compared across study conditions to answer research questions 1 and 2 and across time within both study conditions separately to answer research question 3. Two-sided tests were conducted with a significance level of $\alpha = 0.05$.

Following Wang and colleagues (2015), a stepwise serial gatekeeping procedure was selected to address multiple hypotheses testing in the output of the model and reduce the risk of Type 1 (false positive) errors. This procedure affords the flexibility of testing families of hypotheses in order of their relevance to the main research question, reserving power for the most critical research questions.

The first step of the process was to establish a hierarchy in the families of hypotheses. Since we planned to test our three operational hypotheses on three different sets of outcome measures (i.e., ICG-R, IES-R, SCL-90-R), we structured the analysis by placing the three operational hypotheses into three families, each defined according to the relevance of the outcome measures to the objectives of the bereavement intervention. Since symptoms of CG (ICG-R) are bereavement-specific complaints, this was the primary outcome measure, and its hypotheses were the first family in the hierarchy. PTSD symptomatology (IES-R) was a secondary outcome measure and the second family of hypotheses. This was due to the close association between the instruments' subscale measures (avoidance, intrusion, and hyperarousal) with grief symptoms (e.g., Boelen, Huntjens, van Deursen, & van den Hout, 2010; Boelen & Eisma, 2015). The family of hypotheses concerning general symptoms (SCL-90-R) was placed third,

since the impact of bereavement intervention on these non-grief specific measures was less direct.

Significance testing was then conducted, with the four null hypotheses for the primary outcome variable, grief, tested at $\alpha = 0.05$. Only if all of these were rejected would the null hypotheses for the secondary outcomes be tested and so forth down the hierarchy of families. In other words, if any null hypotheses in the family were not rejected, results of this first family of analysis would be retained, and no testing of subsequent families would be conducted.

Normality of residuals at both the repeated measures level and subject level was checked by means of QQ plots. Homoscedasticity of the residuals at both levels was checked by means of scatter plots in which the residuals were plotted as a function of predicted scores.

Clinical Significance

To evaluate the clinical significance of results within the framework of a naturalistic study where absolute recovery is not expected but a demonstrated reduction in symptoms is meaningful (cf. Wise, 2004), a categorical CG caseness variable was calculated by following the indications by Prigerson and Jacobs (2001) using a specific selection of items from the ICG (cf. Boelen et al., 2007). The variable was used to indicate whether mean CG symptoms exceeded a minimum clinical threshold value. To compare CG caseness across conditions, a crosstabs analysis was conducted in a subset of the data that only included participants who had provided complete data sets at all three measurement points.

Lastly, based on the ambiguous indications in the literature concerning the effectiveness and clinical relevance of secondary interventions, the opportunity was taken to conduct an additional exploratory analysis to determine whether there were differences in symptom changes between participants (within the intervention condition) who received intervention on a secondary or preventative basis, and those who received it on a tertiary

or indicated basis. Using a mixed, repeated measures analysis of variance and omitting incomplete cases, we compared the magnitude of symptom change among participants who received intervention on a secondary basis, and those who received it on a tertiary basis across time, specifically the intervals between T1-T2; T2-T3; and T1-T3. Although this test could provide only preliminary information, we believed this exploratory step would provide useful indications for future research.

Results

Participant Flow

Figure 1 provides details of study attrition by condition across time points. The response rate for all three time points (cumulatively) was 41%. Though the attrition rate may appear high, it is not unusual for longitudinal bereavement research involving postal questionnaires (Aoun et al., 2015). As Figure 1 illustrates, the majority of study attrition was through non-response. In order to respect participants' decisions to withdraw and to protect their confidentiality, after one reminder letter, no further steps were taken to track non-responsive participants. Voluntary withdrawal from the study ($n = 5$) was indicated either by telephone or through written notification by post. Study withdrawal was attributed to no longer wishing to reflect on their bereavement experiences. Of these, three participants attributed their decisions to feeling better, and two stated that reflecting on the bereavement evoked unwanted sad feelings. Nine participants were excluded because they received outside professional support for bereavement.

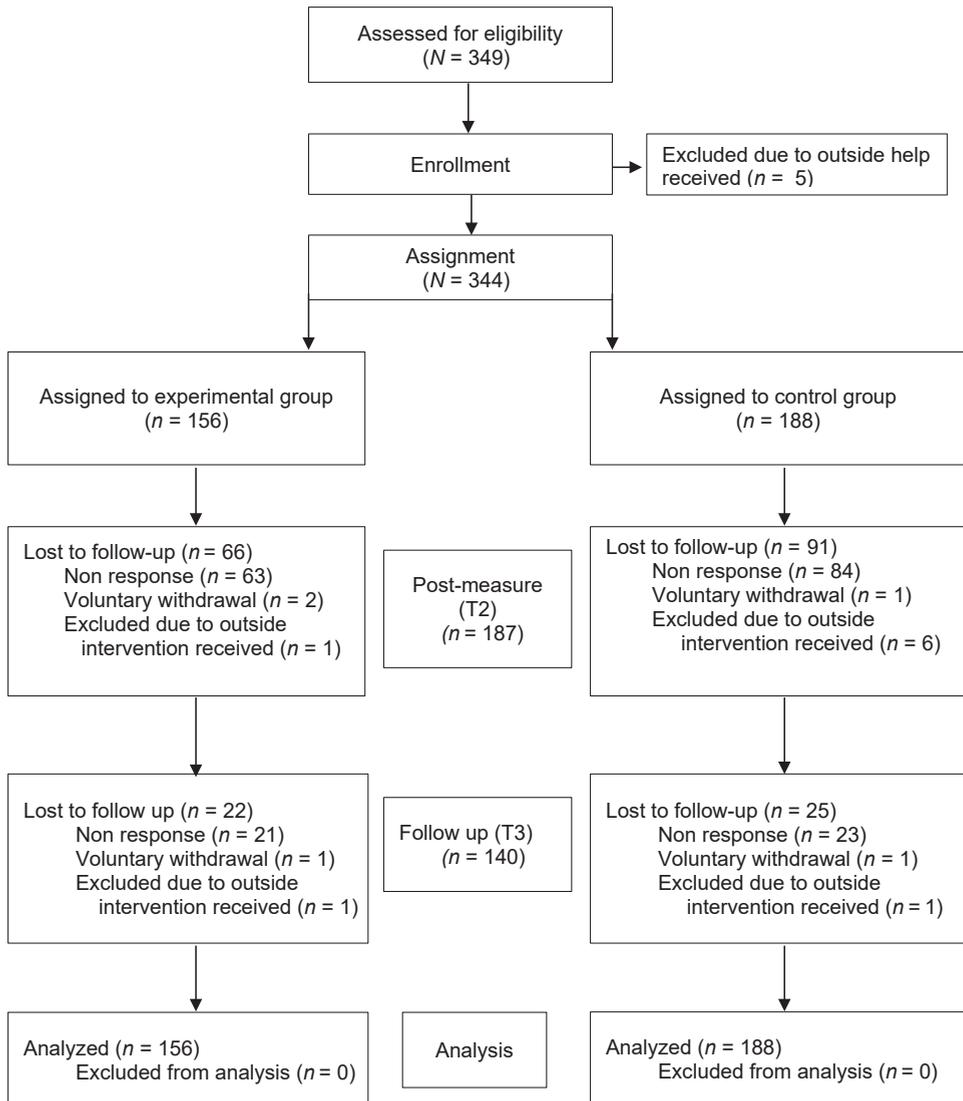


Figure 1. *Flow of participants*

Attrition

Completers of all measurements and non-completers did not significantly differ on gender, use of medication, expectedness of the death, contact with other support services prior to CBCS, or levels of complicated grief,

post-traumatic stress and general psychological functioning. However, a medium-sized difference ($d = .32$) was detected for age (study completers were older at baseline [$M = 52.23$, $SD = 13.14$] than non-completers [$M = 47.86$, $SD = 13.80$; $t(336) = 2.91$, $p = .004$]). Small differences were also detected for kinship (those who lost a partner were less likely to drop out; those who lost a parent were more likely to drop out, $\chi^2(4) = 15.14$, $p = .004$, $r = .21$) and time since bereavement (more participants who had been bereaved just six months prior to baseline were more likely to drop out; participants who were bereaved 1 to 2 years prior to baseline were less likely to drop out, $\chi^2(4) = 16.78$, $p = .002$, $r = .22$).

Completers also had a lower mean IES-R scores at baseline ($M = 41.62$, $SD = 18.49$) than non-completers ($M = 45.81$, $SD = 19.23$; $t(338) = 2.10$, $p = .045$), though again this difference was small, $d = .22$.

Baseline Characteristics

Table 1 shows baseline measures of demographic and loss-related characteristics, and outcome measure means of the study sample by condition. Chi Square tests revealed no significant differences between participants in the intervention and control conditions with respect to gender, household income, expectedness of the death, the reported quality of the relationship to the deceased person, or whether the participant was living with a partner. *T*-tests indicated that age and outcome measure scores were also not significantly different across conditions.

Nevertheless, some differences between groups existed at baseline. Control group participants were more likely to have lost a partner or parent, $\chi^2(5) = 22.39$, $p < .001$; contacted other support resources prior to the study, $\chi^2(6) = 31.68$, $p < .001$; and used anti-anxiety or anti-depression medication at baseline, $\chi^2(2) = 8.08$, $p = .018$. There was also a slight difference in the time since the death, detected in an independent sample *t* test treating time since loss as an ordinal variable, $t(1000) = 2.02$, $p =$

.044). These four variables (kinship, resources contacted, medication use, and time since the death) were used as covariates in the main analyses.

Statistical Tests

The overall focus of our analysis was the comparison of two slopes across conditions (intervention vs. control) for our three outcome measures, CG, posttraumatic stress, and general psychological health. We compared two slopes: slope 1 (between T1 and T2) and slope 2 (between T2 and T3). As noted, we expected that there would be differences between the slopes across conditions (Hypotheses 1 and 2). We also expected that in both study conditions, the first slope would differ from the second (Hypothesis 3).

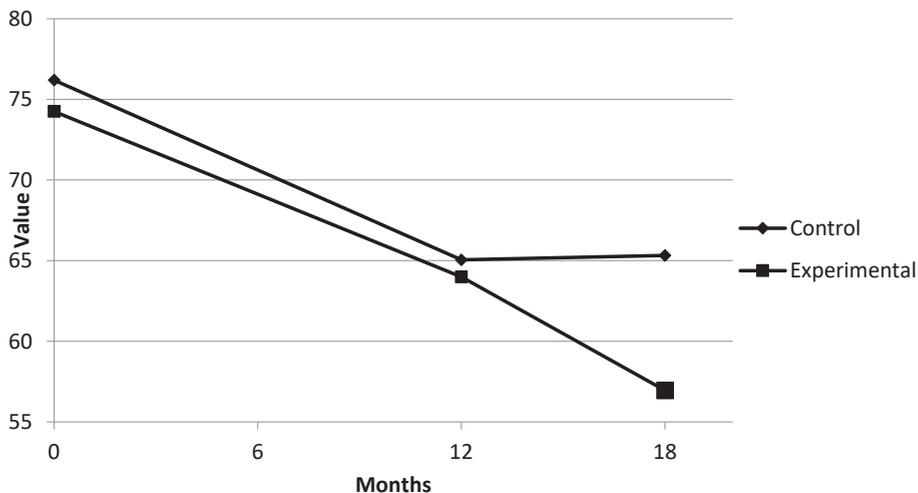
Model Assumptions for a Linear Multilevel Model

The outcomes in the present analysis were sum scores of subscales with a large enough number of values for the variables to be treated as continuous variables. Scatterplots were generated to examine the linearity of the relationship between sum score outcomes and the continuous variable covariate, time since death, which was an ordinal variable with eight categories. Scatterplots indicated a linear relationship between outcome and time since the death. The variance inflation factor (VIF) was calculated using dummy variables for each nominal variable, and the results ($VIF < 10$) ruled out multicollinearity. An examination of scatterplots of residuals at both levels revealed no violation of the assumption of homoscedasticity and PP plots showed no violation of normal distribution of residuals. Histograms indicated a normal distribution of variables at T1 for the ICG, and the IES-R sum score. SCL-90 sum scores were not normally distributed; however, this was not unexpected due to the inclusion criteria of the study, which limited participation to those people who presented with elevated levels of grief symptoms. Although histogram plotting revealed that the sum scores did not all follow a normal distribution, this

did not present a problem because the multilevel model assumes a normal distribution of residuals.

Complicated Grief Symptoms (ICG)

Figure 2 illustrates the covariate-adjusted means of the ICG scores across conditions over the three time points. The first family of tests contained the three groupings of hypotheses for CG symptoms measured by the ICG. Results for Hypothesis 1 indicated that symptom levels of CG declined over the 12 months between T1 and T2 in both study conditions with a similar slope of change, $\chi^2(1) = .113, p = .727$. In the intervention condition, the mean of grief symptom levels decreased from T1 ($M = 70.93$) to T2 ($M = 60.68$), and in the control condition, the mean decreased from T1 ($M = 72.87$) to T2 ($M = 61.73$). The difference in the decrease in grief levels between the two study conditions at these time points was not statistically significant. This indicates a rejection of Hypothesis 1, as the intervention had no apparent impact at the post-test shortly after its completion.



*Note: value scale does not begin at zero

Figure 2: ICG mean scores (adjusted for kinship to the deceased person, resources contacted, medication use, and time since the death) across time points

For Hypothesis 2, it was postulated that the slope of symptoms would differ between the intervention group and the control category between T2 and T3. Results confirmed Hypothesis 2, and revealed that the change in mean CG scores over the six months between T2 and T3 was greater for the intervention condition, with a decline from T2 ($M = 60.68$) to T3 ($M = 53.64$), compared to the control group, where mean symptom scores increased from T2 ($M = 61.73$) to T3 ($M = 62.00$), $\chi^2(1) = 6.01$, $p = .014$, $d = .33$. Complicated grief symptoms decreased relatively more in the intervention group between post-measure and follow up—after bereavement counselling was completed for some time—than between baseline and post-measure, when participants had just completed counselling.

Tests with the ICG also confirmed Hypothesis 3, which suggested that the slope of change in symptom levels would be greater within the intervention category and the control category between T1 and T2 than between T2 and T3. Results indicated that, for both groups, the slope of within-group change of mean symptom levels was greater between T1 and T2 than between T2 and T3; $\chi^2(1) = 5.48$, $p = .019$. Within the intervention group, the mean decreased 7.03 points between T2 and T3 compared to a decrease between T1 and T2 of 10.3 points. The effect size of this difference was small ($d = .27$). Within the control group, the mean decrease between T2 and T3 was negligible (0.27 points). The mean decrease between T1 and T2, in contrast, was 11.0 points, with a small-to-medium effect size ($d = .43$).

Although p -values for the results of Hypotheses 2 and 3 for CG was sufficient to reject the null hypotheses, the p -value for Hypotheses 1 was not. Following the serial gatekeeping procedure, to reduce the possibility of a false positive, results for this family were retained, and no further testing of families in the dataset was conducted. All null hypotheses for the second group of hypotheses, and indeed all subsequent groups, were therefore not tested.

Change Criteria

Figure 3 illustrates changes in CG caseness per study condition across the three time points. As an indicator of clinically meaningful change, CG caseness was calculated in both study conditions across time points and compared in a crosstabs analysis. Only cases with complete data across all three measurement points were included in the analysis; therefore, the available sample was smaller ($n = 116$; 62 intervention, 54 control) than the sample for the multilevel model. At baseline (T1), positive CG caseness was detected in 61% ($n = 38$) of the intervention conditions ($M = .61$, $SD = .49$) and 57% ($n = 31$) of the control conditions ($M = .57$, $SD = .50$), with no notable difference between the groups; $t(114) = .422$, $p = .674$. At follow up (T3), CG caseness was reduced to 31% ($n = 19$) of the intervention condition ($M = .31$, $SD = .46$) compared to 48% ($n = 26$) of the control group ($M = .48$, $SD = .50$). The difference between the groups at T3 indicated only marginal statistical significance, ($t(114) = 1.94$, $p = .054$).

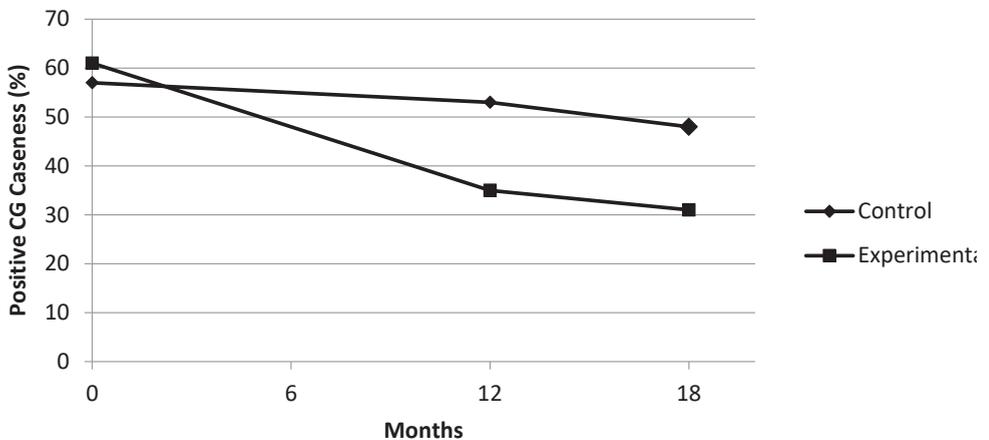


Figure 3. Change in complicated grief (CG) caseness over time, indicating above-threshold level symptoms of CG measured using the ICG.

Using the intervention category participants from this same subset of the sample, a mixed repeated measures analysis of variance was conducted to explore the differences in the change in grief symptom levels for secondary and tertiary intervention category participants over time. The sample was again restricted to intervention category participants who had complete data sets at all three time points (the inclusion of item-level T2 data in this analysis made the sample slightly smaller, $n = 56$; secondary $n = 31$; tertiary $n = 25$). The difference in symptom levels on the ICG was calculated as a continuous variable for T1-T2, T2-T3, and T1-T3 intervals. No interaction was detected between the intervention basis (secondary or tertiary) and time—Wilks' Lambda=.96, $F(2, 53) = 1.04$, $p = .359$, partial eta squared=.038—indicated a small to moderate effect size. A substantial main effect for time was detected—Wilks' Lambda=.59, $F(2, 53) = 18.61$, $p = <.001$, partial eta squared = .413—denoting a large effect size and indicating that both secondary and tertiary intervention categories experienced a decrease in symptom levels across time. The main effect comparing secondary and tertiary interventions indicated no detectable differences, $F(1, 54) = .517$, $p = .475$, partial eta squared=.009. The results suggest that there may be no difference in the change in CG symptom levels when bereavement intervention is offered on a secondary or a tertiary basis.

Discussion

The objective of this controlled intervention study was to test the effectiveness of a widely-available approach to bereavement counselling in reducing symptoms of grief-related distress among help-seeking, bereaved adults. Like most bereavement intervention, as noted in our introduction, the intervention was offered through the voluntary (non-profit) sector. Results of the investigation indicated that people who received bereavement counselling experienced a greater decrease in grief symptoms over time than a bereaved cohort that did not receive counselling. Time itself was found to have a strong effect on levels of grief in both

conditions between baseline and 12-month follow-up. In the intervention group, grief symptom levels continued to decline; however, between the 12-month post-measure and the 18-month follow-up —*after counselling had been completed*—the control group’s mean symptom levels remained unchanged. It therefore appears that distressed and at-risk bereaved people who receive counselling experience a reduction in CG symptoms in addition to the effect of time after the counselling is completed. Due to corrections for multiple hypothesis testing, we were unable to produce results for the other outcome variables included in the analysis. Though it appeared that no, or at best minimal, effects would be detected for bereavement counselling on symptoms of PTSD or general psychological health, further research is needed to make a valid assessment.

When considering the clinical implications of these results, two observations are notable. First, more clinical improvement was observed in CG symptom levels (as indicated by an analysis of a grief caseness variable) among participants who had received counselling intervention; however, this effect was only marginally significant. Second, while the results of the investigation indicated that counselling intervention had a positive effect, this effect was markedly protracted. A primary factor contributing to this result was the reduction in symptom levels in the control condition that approximately matched that of the intervention condition between baseline and 12-month follow up. Were it not for the second factor contributing to the study’s results—the substantial drop in CG symptoms *after* counselling in the intervention group relative to the control group—we might have considered the intervention to have had no effect at all.

One explanation for this delayed effect may be the experience of grief counselling itself. Since counselling sessions require participants to confront difficult aspects of bereavement, it is possible that intervention participants experienced slightly elevated grief symptom levels during the counselling period and even the short term thereafter, leading up to

post-measure. Then, in the months following the post-test, intervention participants' grief symptoms once again declined, and ultimately due to counselling, this decline was steeper than in the control group. In other words, the effort of "working through", which is integral to counselling, would initially be reflected in elevated grief scores, then by a decline once these disturbing aspects were dealt with.

This specific effect has not been demonstrated in previous psychotherapy research for CG (e.g., Boelen et al., 2007; Rosner, Pfoh, Kotoučová, & Hagl, 2014;), so it is important to consider additional reasons for the delayed effect on CG. Differences in study design between the present and previous investigations could offer a partial explanation. Most notably, while the length of intervention in the present study varied, there was a full year between baseline and post-test, which is longer than study intervals in nearly all previous intervention trials on CG employing a waitlist control (Doering & Eisma, 2016). It is therefore also possible that the healing effect of time may be more pronounced in our study compared to other trials.

The fact that greater symptom change was observed in the intervention group at 18-month follow-up is important for a number of reasons. First, for bereaved people who receive counselling, and for counsellors who provide it, the results provide a positive indication that counselling helps more than the passage of time alone. It may be that people initially attribute feeling better to counselling, whereas time alone might have reduced their suffering from grief as much; but in the long term, counselling has been shown to have a more beneficial effect and will reduce grief-related symptoms further. For bereavement researchers, the results demonstrate the importance of a longitudinal study design, including a lengthy period between measurements. Data collection at additional time points both during and after counselling could also provide more insight into when changes in grief levels occur over time.

The effectiveness of community-based counselling also suggests it to be a potentially cost-effective alternative to professional grief counselling. Though the effect is modest, it must be noted that community-based counselling initiatives currently have a larger reach than professional grief counselling interventions. Future research should include cost-effectiveness analyses of different intervention alternatives for distressed bereaved persons.

Limitations

The present study's naturalistic, longitudinal design was selected for scientific as well as ethical reasons, but it also introduced limitations that should be considered when interpreting the results. First, our study sample was divided into conditions through a quasi-randomised, and not a strictly random, procedure, which would have been preferable from a statistical perspective. Although previous meta-analytic studies of psychotherapeutic interventions for bereavement showed no statistically significant differences between outcomes of studies with a randomised or a non-randomised design (Currier et al., 2008), and despite our every effort to identify and control for any differences between our participant groups, it is impossible to be certain that there were no underlying differences that escaped measurement. A second limitation concerns the generalizability of results. Our sample, which was representative of the counselling organisation's usual client base, was predominantly female, as is commonly the case in bereavement research and indeed in grief counselling at large (Stroebe, 2001). In addition, a majority of our sample was bereaved of a parent or partner. Though research has indicated that both the relationship to the deceased person and being a woman increased the likelihood of developing a CG reaction (Burke & Neimeyer, 2011), men have also been shown to be at greater risk of experiencing difficulties specifically after a spousal bereavement (Stroebe, 1998). Further investigation of the effectiveness of bereavement counselling for men and with greater differentiation among bereaved

people's kinship ties to the deceased would be warranted. Lastly, excluding participants who take anti-depressant or anti-anxiety medication would have been preferable; however, this was not feasible, given the indications that one in seven Scottish residents takes anti-depressants (cf. Scottish Government, 2014; BBC 2012). No differences were found in the use of these types of medications across study groups, however, and though it is difficult to assess whether prescription drugs had an impact on participants' CG symptoms, indications from a recent large-scale trial by Shear et al. (2016) demonstrating a lack of efficacy for anti-depressant medication alone on CG symptoms, make it unlikely that medication use would have influenced outcomes. Lastly, though attrition analysis indicated some, predominantly small differences between completers and non-completers, which were in line with participation patterns in bereavement research (Stroebe & Stroebe, 1990), it is worth noting that completers had lower PTSD symptoms at baseline. It is possible that people experiencing elevated PTSD-related symptoms were underrepresented at post-treatment assessment, though the effect size for this difference was small.

Conclusion

The present study demonstrated the delayed, and possibly prolonged effect (at least for a period beyond a year) of a community-based, pluralistic model of bereavement counselling for people at risk of developing, or already experiencing, CG. The investigation incorporated a number of recommendations from scientific research: waiting a number of months post bereavement before providing counselling; offering counselling on an in-reaching basis; incorporating an intake assessment process to screen for CG symptoms and risk factors; and offering a tailored model of counselling. The effectiveness of this approach provides encouragement for supporting community-based initiatives to promote psychological wellbeing. Similar to an estimated 80–90% of all bereavement support services in the UK (Stephen et al., 2009), the counselling service in this investigation was delivered by trained, professional-grade volunteers at a non-profit organisation, where services are available to clients at no cost to themselves. Taken in a broader perspective, considering the long-term effects of elevated grief symptoms (e.g., increased days in hospital) and costs of acute care (cf. Stephen et al., 2015), there are good reasons to conclude that community-based bereavement counselling may allow health boards to increase the availability of support, reduce costs, and save rather than spend.

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Chapter 5

Community-based counselling reaches and helps bereaved people living in low-income households

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Abstract

Objective: Poverty is related to increased grief-related mental health problems, leading some to suggest bereavement counselling should be tailored to income. However, information about accessibility and effectiveness of such counselling programs serving low-income households is scarce. This longitudinal study therefore investigated the association between poverty and complicated grief (CG), and the effectiveness of a community-based bereavement counselling programme in serving low-income households. **Methods:** Two-hundred-eighty-eight participants (75% female) enrolled. Loss-related and demographic variables were assessed at baseline. Regression analyses were used to investigate household income as a predictor of CG, and examine bereavement counselling effectiveness by comparing CG symptom change across three household income categories across three time-points: baseline (T1), T1+12 months (T2), and T1+18 months (T3). **Results:** Of all participants, 35.8% reported below poverty-threshold income, twice the general population's rate. Multiple regression analysis indicated poverty-threshold income was a predictor of CG symptoms over and above demographic and loss-related characteristics. Three-way interaction analysis detected a significant treatment effect for study condition across time, but no differences in treatment effects across income. **Conclusion:** Lower household income was associated with higher CG symptoms. Since income did not predict differential treatment response, community-based bereavement counselling appeared no less efficacious for members of low-income households.

The role of poverty as a risk factor for complicated grief has been the subject of debate. Some research into responses to bereavement has associated low income with higher levels of grief-related symptoms (Burke & Neimeyer, 2013). Generally, lower absolute incomes correspond with greater psychological distress (Garratt, Chandola, Purdam, & Wood, 2016), and an increased likelihood of experiencing mental and physical health problems (Robson & Gray, 2007; Santiago, Kaltman, & Miranda,

2013). Notably, Cacciatore, Killian and Harper (2016) showed that low income had a stronger correlation with symptoms of depression, anxiety and posttraumatic stress than recognised loss-related and demographic predictors of grief symptom complexity in parents bereaved of a child. This has led these authors to suggest that bereavement counselling programs should be tailored to income, by countering structural and attitudinal barriers to counselling uptake. To assess the need for such tailoring, the present study aims to investigate: 1) the relationship between income and grief symptom severity in a counselling-seeking sample; and, equally important, 2) if the effectiveness of a community-based bereavement counselling intervention is influenced by participants' income levels.

Given that low income has been identified as a risk factor for mental health problems, there are good reasons to seek to clarify the impact of poverty on adaptation to bereavement (Burke & Neimeyer, 2013). One major concern is whether low-income bereaved people are able to receive healthcare if and when they need it: do they, for example, have as easy access to professional services as people in higher income groups? This may not be the case. Living in poverty can limit an individual's ability to access psychological support or practice psychological self-care (Doornbos, Zandee, de Groot, & Warpinski, 2003; Bevan, 2002). One reason for this may be that people living in low-income households hold negative attitudes toward help-seeking. This reluctance to seek help may partly stem from a prevailing social norm, that one should simply be "getting on with it" (Allen, 2007, p. 80). Additionally, structural barriers to receiving care may also play a part. First, service *accessibility* may be lower for the people from low-income households, that is, reflecting a lack of equitable distribution of services *vis-à-vis* the population they are intended to serve. Second, service *acceptability* may be inadequate for lower-income bereaved people, if for example the programme and its providers are inappropriate to the population they serve (WHO, 2017).

An additional challenge to evaluating the accessibility and acceptability of care to low-income bereaved people is the lack of basic information concerning the proportion of this group wishing to receive support, and the extent to which interventions for bereavement-related grief are currently available (Stephen et al., 2009). The present research took place in the United Kingdom, where all residents have full medical coverage through a state-supplied healthcare system, the National Health Service (NHS). (A similar degree of nearly universal medical coverage, independent of financial status, exists in most developed countries.) Pathways to bereavement care through biomedical resources such as the NHS in the UK remain largely uncharted. To date, NHS recordkeeping generally does not collect data on bereavement-related patient health visits, leaving little opportunity to document any grief support services delivered (Stephen et al., 2013). It is currently estimated that between 70% and 90% of bereavement support in the UK is delivered through the non-profit sector, with similar estimates for care provision through non-profit hospices and palliative care organisations in Australia, Japan and the U.S. (Breen, Aoun, O'Connor, & Rumbold, 2013). Whether such care is accessible, acceptable, and indeed efficacious for people living in relative poverty remains largely unexplored.

There are reasons to believe that an approach to bereavement intervention offering appropriate degrees of accessibility and acceptability for people from low-income households might be effective. For example, positive outcomes have been demonstrated for people from low-income households who received interventions tailored to increase acceptability and accessibility of therapy for other psychiatric disorders, including PTSD (Krupnik et al., 2002) and panic disorder (Roy-Byrne, 2006). In a review of successful, evidence-based psychotherapeutic interventions designed to support people from low-income households, Santiago et al. (2013) list a number of practices that have been shown to increase uptake of services among low-income study participants. These include the provision

of practical support, such as childcare and food, and additional outreach steps to encourage retention and participation. These recommendations, however, are at odds with another practice that has been shown to improve bereavement intervention outcomes, namely the provision of care on an in-reaching basis (i.e., bereaved people actively seek bereavement intervention themselves, instead of being contacted by the bereavement support organisation (Schut et al., 2001). It would seem that while *facilitating* uptake of bereavement support—making it possible for people to attend sessions—might be beneficial, *incentivising* uptake in such a way that encourages use of services where they may not actually need them could be unhelpful or even detrimental. (Incentivising use of counselling services in this context might consist of offering users certain benefits, such as free childcare or snacks during visits.) Efforts to tailor bereavement support services to increase acceptability and accessibility among people from low-income households must therefore keep a delicate balance between facilitating but not incentivising support.

With these considerations in mind, the present study sought to address the gaps in knowledge noted above by examining the uptake and effectiveness of bereavement support among bereaved people from households from below the poverty threshold. Specifically, we looked at a model of bereavement counselling offered nationwide through a community-based non-profit organisation that operates to professional standards. Working with longitudinal data from a larger research project, “Coping with Bereavement in Scotland”, the study featured a naturalistic, controlled design and compared outcomes for participants across income levels.

The investigation had three primary objectives. First, we aimed to establish a preliminary indication of the percentage of help-seeking bereaved people who were living in relative poverty. Specifically, we calculated which proportion of our naturalistic sample (comprised of people who had contacted a national community-based bereavement

support organisation in Scotland) represented people living at or below the poverty threshold. Although the non-profit organisation offers services free of charge and with extended hours, no specific strategies had been implemented to make the service available to people from low-income households. We therefore expected the proportion of participants living at or below the poverty threshold to be underrepresented.

Second, following indications from Cacciatore and colleagues (2016) that income is a strong predictor of loss-related depression, anxiety and posttraumatic stress symptoms, we examined the association between income and grief levels among help-seeking bereaved adults. We expected to find a strong effect of poverty on CG symptoms even compared to other recognised predictors of CG, including cause of death and gender. In line with Cacciatore and colleagues' (2016) suggestion that the ability to provide effective self-care is lower among people with lower incomes, we expected to find an inverse relationship between income and CG levels. For the purposes of this study, CG was defined as “[a] deviation from the normal (in cultural and societal terms) grief experience in either time course or intensity of specific or general / reactions or symptoms of grief” (Stroebe, Boerner, & Schut, 2017, p. 3).

Third, we examined the effectiveness of a community-based bereavement counselling programme in supporting bereaved adults living at or below the poverty threshold. In a quasi-randomised controlled effectiveness investigation, we used three-way multilevel regression interaction analysis to examine the effect of household income (poverty-threshold and below, low to below median, and median and above) and study condition (bereavement counselling vs. no intervention) on CG levels over an 18-month study period. While previous research has demonstrated the effectiveness of the same counselling intervention in reducing complicated grief symptoms as compared to a no-intervention control condition (Newsom et al., in press), income had not yet been examined as a moderator of treatment effects. Though the intervention was community-based, it was not tailored

specifically toward supporting people with low income levels. Following Cacciatore and colleagues (2016), this could mean that it would be less effective for people from low-income households. We therefore expected to see a smaller magnitude of change in CG means between treatment conditions over time among the low income group, compared to higher income groups.

Method

Two-hundred eighty-eight residents of Scotland (age 18+) who had been bereaved for at least six months and requested support from Cruse Bereavement Care Scotland (CBCS) participated in the study. People requiring specialised support (language interpretation, support for cognitive impairment) were excluded from the study, as were people who were already receiving outside professional help for grief or other/additional psychiatric conditions or diagnoses at baseline (e.g., substance abuse, psychosis, schizophrenia). All participants had received an intake assessment result of 18 or higher on the Indicator of Bereavement Adaptation–Cruse Scotland (IBACS) (Newsom et al., 2016), indicating that intervention would be appropriate.

Sample Characteristics

Table 1 presents details of participants' baseline characteristics. The majority (78%) of participants were female, with a mean age of 49.2 years ($SD = 13.35$), and were bereaved of a parent (37%) or spouse (37%). Sixty-three per cent of participants had been bereaved within the previous 12 months, and 92% within the last 3 years. Forty-three percent reported taking anti-anxiety or anti-depressant medication at baseline. Participants showed a range of income levels, with approximately a third (35.8%) from households at or below the poverty threshold; 27.8% from below-median income households, and 36.5% from households at median income and above. As residents of Scotland, all participants were entitled to full service

medical care from the National Health Service, including any prescription medication, at no cost to themselves.

Table 1*Baseline Personal Characteristics by Study Condition and Income Group*

	Lowest Income		Low-median Income		Median-high Income	
Study condition: Intervention*	40	38.8%	46	57.5%	51	48.6%
Demographic characteristics						
Age in years* (Mean [SD])	50.30	[13.88]	51.35	[12.86]	46.59	[12.86]
	<i>n</i>	(Valid %)	<i>n</i>	(Valid %)	<i>n</i>	(Valid %)
Gender: female	77	74.8%	59	73.8%	89	84.8
Use of medication: antianxiety/ antidepressants *	56	55.4%	28	35.4%	38	36.2%
Work status: unemployed (includes retired, medical leave)**	82	80.4%	31	38.8%	20	19.2%
Loss-related characteristics						
Time since loss: 6 months	21	21.0%	22	27.5%	21	20.4%
Time since loss: between 6 - 12 months ago	36	36.0%	31	38.8%	47	45.6%
Time since loss: 1-2 years ago	19	19.0%	15	18.8%	25	24.3%
Time since loss: 2+ years	24	24.0%	12	15.0%	10	9.7%
Kinship of deceased						
Kinship of deceased: partner	37	35.9%	39	49.4%	29	27.9%
Kinship of deceased: parent	44	42.7%	20	25.3%	42	40.4%
Kinship of deceased: sibling	8	7.8%	6	7.6%	13	12.5%
Kinship of deceased: child	11	10.7%	9	11.4%	12	11.5%
Kinship of deceased: other friend /relative	3	2.9%	5	6.3%	8	7.7%
Grief symptom levels at T1						
Inventory of Complicated Grief – Revised (<i>unadjusted means</i>) * (Mean [SD])	75.06	[25.15]	64.51	[22.90]	58.75	[23.01]

Note. * = $p < .05$, ** = $p < .001$.

Sampling Procedure

Participants for the present study were drawn from a larger efficacy study “Coping with bereavement in Scotland” (cf. Newsom et al., 2017). Of the 344 participants enrolled in that study, the 84% who provided household income details ($N = 288$) comprised the sample for the present study. There were no differences between study accepters and decliners (i.e. participants who did and did not provide income information, respectively) on age, gender, risk of complications and severity of grief symptoms (as indicated by IBACS intake assessment results—see next paragraph), use of medication or complicated grief symptom levels as measured by the Inventory of Complicated Grief-Revised (ICG-R; Prigerson & Jacobs, 2001).

An institutional ethics review was conducted with approval granted by the National Health Service (NHS) Tayside Research Ethics Committee 1 (IRAS project ID 56758) in November 2010. Recruitment for the larger study was conducted between January 2011 and September 2011. Prior to enrollment, participants received a written description of the research study and informed consent statements to sign and return. Participants also received informational materials from CBCS providing basic information about coping with grief, and spoke over the phone with a CBCS staff member or trained volunteer to provide details concerning the circumstances surrounding their bereavement, and contact and scheduling information. All participants also completed the IBACS, a semi-structured intake assessment for bereavement intervention, which was delivered either in person or over the telephone (Newsom et al., 2016).

Intervention Model

Organisational setting. CBCS is a non-profit organisation that provides counselling and informational support services to bereaved people. CBCS provides 55,000 hours of support each year and responds to over 12,000 requests for help. Help-seeking people contact CBCS via a national phone line and are then directed to their nearest service location. The national telephone line operates throughout the week, days and evenings. CBCS

service locations are distributed throughout Scotland across rural and urban settings. Local services contact clients by telephone, or receive calls from them, to schedule sessions at mutually agreeable times. Sessions are available days and evenings during the week, and, in many locations, during the daytime on weekends. No fees are charged for CBCS services, but clients are informed of how donations can be made to CBCS if they wish.

Counsellors are volunteers who have been professionally trained at a minimum to the standards of Scotland's professional body for counselling and psychotherapy (COSCA), and have completed a bereavement-specific training module. CBCS recruits volunteer counsellors on a semi-annual basis from within the communities that the organisation serves. A local selection committee works with national training staff to select volunteers for training, which takes a year (for volunteers who are not counsellors or psychologists by profession). Certification is transferrable and is paid for by CBCS. All counsellors receive regular professional supervision, and fulfill a minimum continuing professional development commitment of a minimum of 11 hours per year.

Counselling model. The CBCS model for bereavement counselling is a hybrid approach, combining elements of the cognitive behavioural, person-centred and psychodynamic traditions (see Newsom et al., 2017; Simonsen & Cooper, 2015). Following standard CBCS practice, bereaved people who have contacted the organisation seeking support—and who have been bereaved for at least six months, a point by which time the intensity of a typical bereavement response tends to subside (see Shear, 2015)—will participate in an intake process either in person or over the telephone. This intake process entails the use of the Indicator of Bereavement Adaptation Cruse Scotland (IBACS; see Newsom et al., 2016) to assess the risk and magnitude of the bereaved person's difficulties coping with grief. IBACS scores indicating that the bereaved person is coping successfully result in a recommendation for watchful waiting, whereas indications that the

bereaved person would benefit from intervention result in an allocation to a counsellor. Allocation to counsellors is based primarily on the level of symptoms and risks of developing complications at intake. Bereaved people with IBACS results >18 are assigned to counselling, and those with higher symptom levels (IBACS > 29) are assigned to more experienced counsellors. Scheduling compatibility is a secondary factor in allocation to a counsellor.

Procedure

A quasi-randomised approach was used to assign participants to study conditions. Following the naturalistic design of the larger study, participants who were allocated to a counsellor and attended sessions were assigned to the intervention category. Participants were assigned to the control condition when they were unable to receive intervention due to personal scheduling conflicts, found their local service location was too distant or inconvenient to attend, or were on a waiting list at their local service location.

In the present investigation, intervention participants were assigned to counsellors following standard CBCS procedure (as described above in the “Counselling model” section), with sessions were delivered on a one-to-one basis at CBCS service locations. Meeting rooms were simply and comfortably furnished and provide a quiet, private space for discussion. Sessions were held on a weekly basis, and participants met the same counsellor at each session. Participants attended an average of 6 sessions ($M = 5.80$, $SD = 2.95$).

Measures

Data collection was completed using postal questionnaires distributed at three time points: baseline (T1), 12 months later at post measure (T2), and 18 months after baseline at follow up (T3). Participants who did not respond to a questionnaire were sent a reminder letter. If they did not

respond to this second communication, they were considered to have dropped out of the study.

Complicated grief (CG). The Inventory of Complicated Grief-Revised (ICG-R, Prigerson & Jacobs, 2001), a 30-item questionnaire, was used to assess symptoms of complicated grief (CG). The ICG-R is widely used and has demonstrated strong internal consistency (Cronbach's $\alpha = .94$) (Prigerson & Jacobs, 2001). Construct validity for the ICG-R has also been demonstrated through convergence with the Traumatic Grief Evaluation of Response to Loss (Prigerson & Jacobs, 2001). Excellent reliability, $\alpha = .95$, was demonstrated at baseline, and increased slightly at post-measure and follow-up, $\alpha = .96$.

Demographic and bereavement-related characteristics (including income). A bespoke questionnaire was designed to assess demographic details (age in years, gender, medication use) including household income ("What is your yearly household income?"); and bereavement-related characteristics (cause of death, kinship of the deceased person, time since loss).

Gross household income was measured using a scale of six categories in addition to a seventh non-response option ("under £10,000; from £10,000-£19,999; from £20,000 to £29,999; £30,000 to £39,999; £40,000 to £49,999; £50,000 and above; prefer not to say"). The relative poverty metric, a widely-used approach for assessing household poverty in the UK, was applied to identify participants living in deprived circumstances. Following this approach, people whose household incomes are at least 60% less than the national median are considered to live in relative poverty (see Mack, 2016). Guidelines from the Scottish Government (2012), which were developed on this basis, indicated that the period of baseline data collection (2010-2011), one-person households reporting an income below £10,000 fell below the poverty threshold; those reporting £10,000-£19,999 and £20,000 to £29,999 were below median; and those reporting £30,000 and above were at or above the

median income level. In the present study, because in certain cases it was unclear how many people lived in participants' households, all participants were treated as single person households. Applying the highest cut-offs for income groups reduced the risk of false positives for poverty-level households; however, participants in the lowest and middle categories who had additional household members may therefore have experienced more deprivation than the income variable indicates. (Notably, Stephen et al. (2013) demonstrated that equivalised income (i.e. household income that has been recalculated to take into account differences in household size and composition) remained the same before and after bereavement.)

After data collection was completed, self-reported household income data were used to assign participants to one of three income categories: 1. *Lowest*, whose income levels were at or below the poverty threshold; 2. *Low-median*, whose income levels were above the poverty threshold but below the median, and still including households at risk of real deprivation; and 3. *Median-high*, whose income levels were median and above median.

For the 2010-11 period, which corresponds with data collection at baseline (including household income data) it was estimated that 14% of working age adults and 16% of pensioners in Scotland lived in relative poverty (Scottish Government, 2012).

Research Design/Analyses

Analyses for the present study were divided into three sets. First, to establish an indication of the percentage of help-seeking bereaved people who are living in relative poverty, a cross-sectional analysis was conducted to calculate the proportion of participants in our sample who were living at or below the poverty threshold. To provide an initial indication of the degree of the intervention programme's accessibility and acceptability for people from low-income households, we compared the proportion of participants in the "poverty" group to this proportion of the Scottish general population.

Second, to test the predictive value of income on complicated grief at baseline, a multiple regression model was developed. Seven independent variables were entered into the model as predictors. These included demographic characteristics: 1) participant's age; 2) gender 3) income group (3 categories: lowest, low-median, median-high) 4) use of antidepressant/ anxiolytic medication at baseline (yes, no); and bereavement-related characteristics: 5) cause of death (illness/health problem, accident, suicide, homicide, other/unknown); 6) kinship of the deceased (partner, parent, child, sibling, other relative/friend); and 7) time since bereavement (five categories: six months; between 6-12 months; between one and two years; between two and five years; five years or more). Following indications from Cacciatore et al. (2016), we expected income to demonstrate the strongest effect on complicated grief symptoms.

Third, to determine whether study condition and income interacted to predict mean scores in participants' CG symptom levels across time, a three-way multilevel multiple regression model using Maximum Likelihood estimation was developed in SPSS (version 23). To account for high inter-subject correlation (through repeated measures), a hierarchical linear mixed-effects approach was used, with a random effect for participant ID, and fixed effects for the three predictor variables: income group (3 categories), study condition (2 categories) and time (3 categories). Preliminary analyses were conducted to ensure there was no violation of the assumptions of linearity, an absence of multicollinearity, homoscedasticity, and normality of residuals. Personal and loss-related characteristics that were unevenly distributed across income groups were added to the statistical model as covariates to control for differences and to partly account for between-subject variability.

A significance level was established at $\alpha = 0.05$ (two-sided) and would pertain to all tests conducted in this study. To examine effect sizes within a mixed model, R^2 is reported. Because of the presence of random effects in the model, R^2 was computed from the residual variance by subtracting

the variance of the model with predictors from the variance of the null model, then dividing by the null model (Peugh, 2010; Selya, Rose, Dierker, Hedeker, & Mermelstein, 2012).

Results

Participant Flow

Figure 1 describes participation across the two study categories, including income category information. At baseline, a total of 288 participants were enrolled. One hundred thirty-seven participants were assigned to the intervention condition, and 151 to the control condition. A cumulative response rate was calculated for the three time points as 46%, following patterns common to bereavement research and longitudinal investigations using postal questionnaires (Aoun et al., 2015).

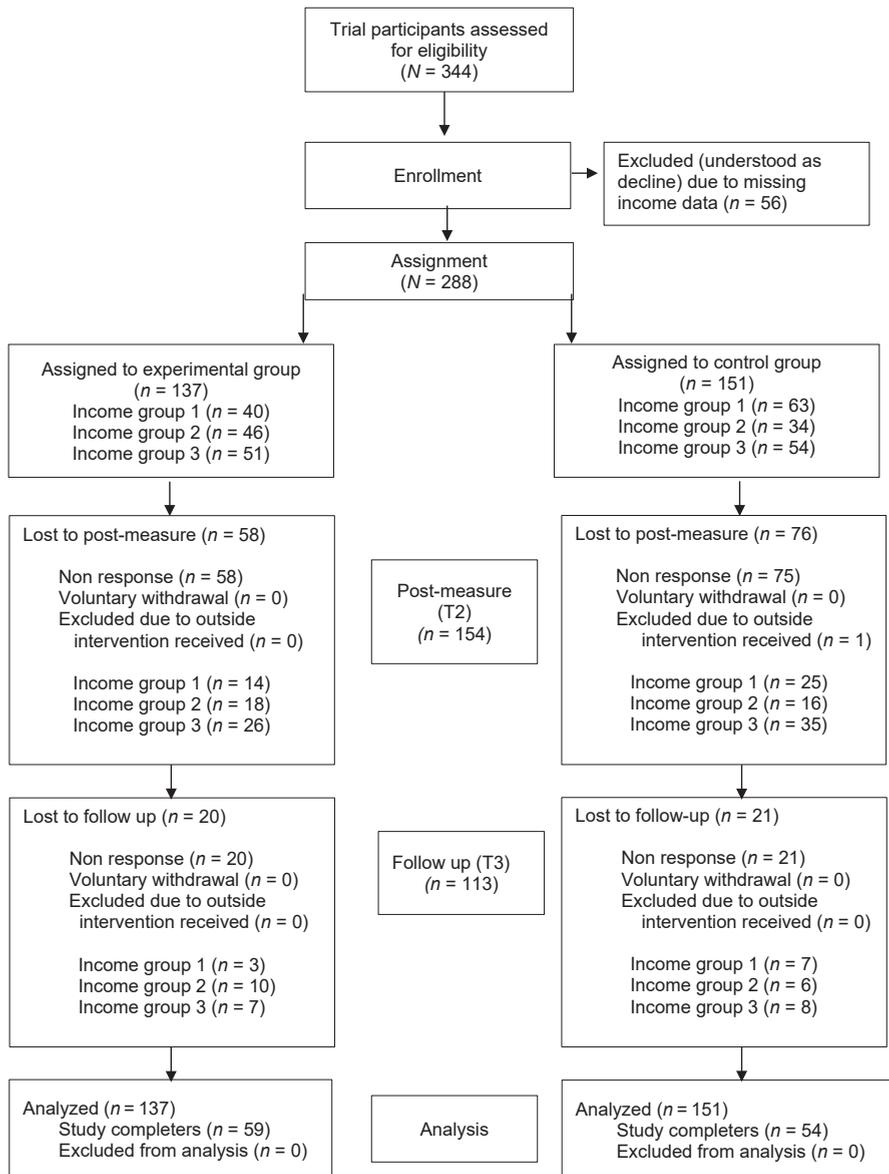


Figure 1. *Flow of participants*

Comparisons between study completers and dropouts by T3 (cumulative) showed no significant differences with respect to gender, income level, study condition, use of antidepressants or anxiolytics, or complicated grief symptoms at baseline.

Baseline Characteristics

Baseline measures of demographic and bereavement-related characteristics by income group are presented in Table 1. A small but significant intervention group difference, $\chi^2(2, N = 288) = 6.36; p = .042$, was shown for income. A higher proportion of the lowest income group participants were assigned to the control condition (61.2%) than to the intervention condition (38.8 %). No group differences were found with respect to other personal characteristics (age, gender, medication use or work status) or loss-related characteristics (cause of death, kinship to the deceased, time since loss).

Analyses also identified several differences between the income categories. Differences in kinship to the deceased, $\chi^2(6, n = 286) = 13.05; p = .042$, indicated that a higher proportion of low-median income group participants (49.4%) were bereaved of a partner, whereas the majority of the lowest income group (35.9%) and median-high income group participants (36.7%) were bereaved of a parent. A difference in mean ages was detected, $F(2, 285) = 3.44, p = .033$, with median-high income participants reporting the lowest average age of $M = 46.6$ years, $SD = 12.86$. The low-median income group reported the highest mean age, $M = 51.4$ years, $SD = 12.86$, while the lowest income group reported a mean age of $M = 50.30$ years, $SD = 13.88$). Work status also varied across groups, $\chi^2(2, n = 286) = 80.11; p < .001$, with 19.6% of the low income group reporting employment, compared to 61.3% of low-median and 80.8% of the median-high income categories. Lastly, differences between income groups were also found in their use of medication at baseline $\chi^2(2, n = 288) = 10.22; p = .006$, with 55.4% of the lowest income group participants reporting medication use at baseline, compared to 35.4% and 36.2% of low-median and median-high income groups, respectively. No differences were found between income categories with respect to cause of death, or time since loss.

Statistical Tests

Analysis 1: proportion of participants living below the poverty threshold. Cross-sectional analysis of baseline data showed that 103 participants (35.8%) reported a household income in the lowest income category. Crosstabs revealed that this was more than twice the rate of general population living at or below the poverty threshold, $\chi^2(1, N = 5,310,288) = 105.01, p < .001$, which was estimated at 14% for working-age adults and 16% for the elderly during the study period (Scottish Government, 2012). Eighty participants (27.8%) reported a household income in the low-median category, compared to 35% in the general population, and 105 (36.5%) reported a Median-high category income, compared to 50% in the general population.

Analysis 2: the association of income with CG at baseline. A multiple linear regression was conducted to examine the associations at baseline between income and covariates (i.e., gender, age, medication, time since bereavement, cause of death, and relationship to deceased) on the one hand, and CG levels on the other. Two hundred seventy-five cases were included in the model. Preliminary tests indicated no violation of assumptions of linearity, homoscedasticity, lack of multicollinearity, or normal distribution of CG residuals at baseline. Six of the variables in the model demonstrated an association with complicated grief.

Table 2 shows the unstandardised and standardised regression coefficients. Results show that participants in the lowest income group had significantly higher CG levels compared to participants in the median-high income group, $\beta = .32, SE = 3.34, p < .001$, while participants in the low-median income presented CG levels that did not differ significantly from those of participants in the median-high group, $\beta = .10, SE = 3.51, p = .129$. Several other covariates were significantly associated with CG at baseline, although none of the relationships were as strong as for income. Participants who lost a partner, $\beta = .23, SE = 3.65, p = .002$, or a child, $\beta = .18, SE = 5.39, p = .010$, had significantly higher CG than those

who lost a parent. Those who reported use of prescription medication had significantly higher CG than those who did not report prescription medication use, $\beta = .19$, $SE = 2.86$, $p = .001$, females had significantly higher grief than males, $\beta = .15$, $SE = 3.45$, $p = .008$. In addition, age was negatively associated with CG, $\beta = -.14$, $SE = .13$, $p = .042$, indicating that lower age was associated with higher CG. The model explained 19.7% of the total variance in CG mean scores at baseline, $F(13, 261) = 4.93$, $p < .001$, $R^2 = .20$.

Table 2*Variables Associated with Complicated Grief at Baseline*

<i>B</i>	SE;	β	<i>p</i>	
Study condition	.44	2.79	.01	.874
Participant gender**	9.17	3.45	.15	.008
Age in years*	-.26	0.13	-.14	.042
Use of medication**	9.28	2.86	.19	.001
Time since loss	-.96	1.03	-.05	.352
Cause of death: accident (vs other)	-10.79	5.53	-.12	.052
Cause of death: suicide (vs other)	-3.19	5.67	-.03	.575
Cause of death: unknown / other	4.21	4.13	.06	.309
Kinship of deceased: partner (vs. parent)**	11.66	3.65	.23	.002
Kinship of deceased: sibling/friend (vs. parent)	4.69	4.35	.07	.282
Kinship of deceased: child (vs. parent) **	13.90	5.39	.18	.01
Income: Lowest (vs. Median-high)**	16.13	3.34	.32	<.001
Income: Low-median (vs. Median-high)	5.34	3.51	.10	.129

Note. * $p < .05$; ** $p \leq .01$

Because the proportion of those below the poverty level was different between the control and intervention group, a multiple linear regression with the same covariates was conducted, which included an interaction term for study condition and income. No significant interaction was found, $F(2, 259) = 1.58$, $p = .207$, partial eta squared = .012, indicating that poverty was associated with CG in similar ways for the control and experimental group at baseline.

Analysis 3: change in CG means across income groups and study categories over time. Two hundred seventy-six participants were included in the model with 529 observations. Based on degrees of freedom, an upper limit of parameters that could be included in the model while retaining adequate power was set at 35.27. Due to an uneven distribution of some variables across income groups at baseline, the following variables were added to the model as covariates: use of medication at baseline (yes/no), gender, relationship to the deceased (partner, parent, child, sibling/friend/other), cause of death (illness, accident, suicide, unknown/other). Including covariates, the model contained a total of 18 parameters, which was within the acceptable range. As expected with a repeated measures design, inter-subject variance was high, 401.29, $p < .001$, with an interclass correlation for participant ID of $ICC=.73$, warranting the use of a hierarchical approach.

The hierarchical model with participant ID included as a random effect was evaluated using a two-step process. The model was first run without the three way interaction in order to reveal the main effects of the primary independent variables of time, group, and income category, before introducing the 3-way interaction to the model and evaluating the interaction effects. As shown in Table 3, the fixed effects model demonstrated significance for five lower order (main) effects on CG levels: income category, $F(2, 275.53) = 12.36, p < .001$; time, $F(2, 280.58) = 48.69, p < .001$; use of medication at baseline, $F(1, 276.95) = 11.47, p = .001, d = 1.20$; age, $F(1, 277.90) = 5.70, p = .018, d=.76$; and relationship to the deceased, $F(3, 275.50) = 3.86, p = .010$. These significant main effects for income, medication, and relationship to the deceased extend the earlier, baseline-only regression results by showing that the differences between demographic groups persist when CG scores are evaluated at all three time points. Pairwise comparisons showed large-magnitude differences between the poverty income category and the other two income categories, with CG scores that were on average 16.58 points higher than the mid-plus

income group ($p < .001$, $d = 1.79$) and 9.47 points higher than the low-mid income group ($p = .008$, $d = .98$) across all three time points. The Low-median income group also had higher mean CG scores than the Median-high income group, with a mean difference of 7.11 points ($p = .043$, $d = .72$) and a medium effect size. Participants who did not take antidepressants or anxiolytics at baseline had a mean CG score 9.67 points lower across all three time points than those who reported taking these medications ($p = .001$, $d = 1.20$), a large magnitude difference. Comparisons for time showed a large magnitude effect at two measurement points, with a reduction of 10.82 points in CG levels between T1 and T2 ($p < .001$, $d = 1.78$), and a cumulative reduction in CG means (13.75 points, $p < .001$, $d = 2.17$) occurring between T1 and T3.

Table 3

Hypothesis tests for the significance of each fixed effect

Main effect model				
	Numerator <i>df</i>	Denominator <i>df</i>	<i>F</i>	<i>p</i>
Intercept	1	284	107.532	<.001
Use of medication	1	277	10.125	0.002
Gender	1	274	4.169	0.042
Kinship of deceased	3	276	3.713	0.012
Cause of death	3	274	1.261	0.288
Age (participant)	1	279	4.59	0.033
Time since death)	1	290	0.375	0.541
Income category	2	307	11.226	<.001
Study condition	1	304	0.91	0.341
Time	2	279	46.44	<.001
2-way interaction: Income * Study condition	2	306	2.447	0.088
2-way interaction:Income * Time	4	280	0.97	0.424
2-way interaction: Study condition * Time	2	279	4.896	0.008
3-way interaction: Income* Study condition * Time	4	280	1.688	0.153

Figure 2 illustrates the change in CG symptom levels within income groups and across study conditions over time. As a next step, the three-way interaction term *time x study condition x income category*, along with each of the associated two way interactions, *time x study condition*, *time x income category*, and *study condition x income category*, were added to the hierarchical model. (All three interaction variables—*income*, *group*, and *time*—were categorical and dummy-coded for inclusion in the model.) The omnibus test for three-way interaction of *time x study condition x income category* was not significant, $F(4, 280) = 1.69, p = .150$, therefore the individual beta coefficients are presented but not interpreted further. Compared to the interaction term *Median-high income x experimental condition x T3*, the estimate for *Lowest income x control condition x T1* was not significant (Beta = 1.99, $SE = 7.13, p = .781$); the estimate for *Lowest income x control condition x T2* was not significant (Beta = 1.61, $SE = 7.33, p = .826$); the estimate for *Low-median income x control condition x T1* was significant (Beta = -16.48, $SE = 7.78, p = .035$); and the estimate for *Low-median income x control condition x T2* was not significant (Beta = -10.55, $SE = 8.03, p = .190$). (Due to the dummy coding, the other parameters were set to zero, as they were redundant to the given estimates.). The additional explained variance of the model with the interaction included was negligible in size (R^2 change < .01), suggesting that income did not affect the effectiveness of the intervention over time.

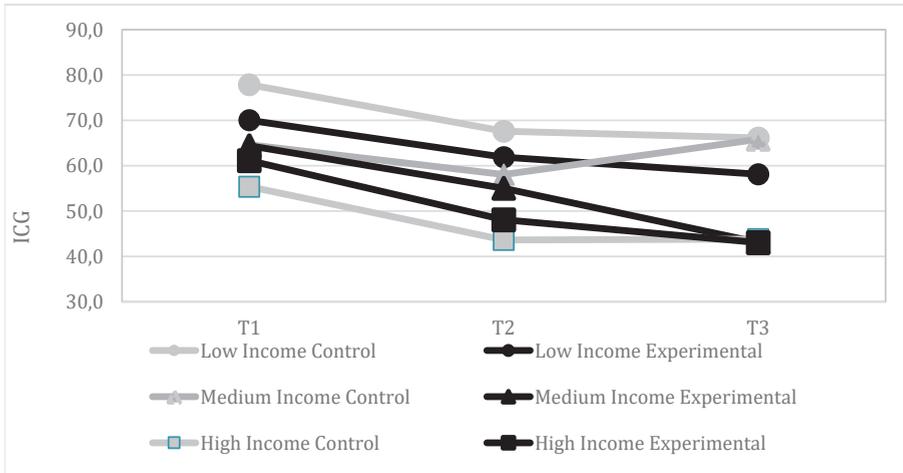


Figure 2. Change in mean complicated grief (ICG) symptom levels by income groups and study category over time

For informational purposes, the two-way interactions were also examined. The two-way interaction of *study condition* \times *time*, was significant, $F(2, 279.40) = 4.90$, $p = .008$, $R^2 = .17$, indicating that there was a difference in symptom levels between those who received intervention compared to those who did not over time. This conforms with the demonstration of intervention efficacy previously reported in Newsom et al., in press). The two-way interaction between *income category* \times *study condition*, however, was not significant, $F(2, 306.13) = 2.45$, $p = .088$, $R^2 = .18$, suggesting that overall, participants' study condition assignments were related to CG levels in a similar manner across income categories. Lastly, the two-way interaction of *income category* \times *time* was not significant, $F(4, 279.75) = .97$, $p = .424$, $R^2 = .18$, indicating that the degree to which complicated grief scores changed over time was not detectably different between income groups.

Discussion

The goals of this investigation were to examine the relationship between income levels and CG among help-seeking bereaved adults, and to explore

whether income levels influence the effectiveness of a community-based bereavement counselling intervention. Results indicated that a substantial number of bereaved people who were struggling to cope with grief and were seeking help were living in relative poverty. Over a third (36%) of this study's sample reported living in below poverty-threshold households—more than twice the proportion of Scottish people in this income category (estimated at 14% for working-age adults and 16% for the elderly) during the study period (Scottish Government, 2012). Results of the present study also indicated an association between (low) household income and complicated grief. At baseline, income quite remarkably showed the strongest effect on CG levels compared to other demographic and loss-related variables. Lastly, concerning the effectiveness of counselling for bereaved participants from different income levels, the analyses detected no effect of income level on CG levels in the intervention and control conditions over time. In other words, it appears that income did not influence counselling effects.

The results of this study have a number of important implications. First, the association between low household income and CG symptoms demonstrates the importance of low income as a potential risk factor in the development and persistence of CG. This association complements the study of Cacciatore et al. (2016), which demonstrated a correlation between poverty and grief-related symptoms of depression and PTSD in bereaved parents. In the present analysis, these findings are extended to a bereavement-specific outcome variable (CG), among a more heterogeneous sample of help-seeking bereaved adults. The association between low income and CG also appears congruent with Lazarus and Folkman's broader transactional model of stress (Lazarus & Folkman, 1984). Following this model, financial instability could be expected to (negatively) affect patterns of appraisal and coping, and in particular hinder the use of effective strategies for coping with bereavement (see Stroebe & Schut, 1999). Low household income may therefore be an important

factor to include when assessing an individual's risk of developing grief complications.

Next, the substantial percentage of participants living at or below the poverty threshold in our sample demonstrates their wish to receive support—and contrasts with the assumption of a “getting-on-with-it” social norm preventing people from low-income households from accessing support services (cf. Allen, 2007). Furthermore, this shows that the CBCS counselling programme is initially considered acceptable as a source of support to low-income participants. Though the organisation has not specifically tailored the intervention to income, certain provisions may have contributed towards service acceptability (e.g., providing professional training and certification of locally-based volunteers to serve as counsellors) and accessibility (e.g., not charging fees for services, operating a national phone line, and running local services with extended weekday and weekend hours).

The present study also showed that despite a quasi-randomised process of study condition assignment (which was shown to be equally effective in controlling for group differences in bereavement counselling research; Currier et al., 2008), a relatively higher percentage of low-income participants enrolled in the control condition. In other words, more bereaved people from below poverty-threshold households sought help from CBCS and went through the initial steps to receive it, but did not end up receiving counselling services. Reasons for not attending (when offered) often concerned logistical difficulties with scheduling or transport to the service location. Further investigation is recommended to identify any organisation- or location-specific barriers to service access. Taken together, these results suggest the need for all bereavement support organisations to carefully consider their strategies for making accessible and acceptable support available to members of low-income households.

Although not the primary aim of our study, another notable finding was that a baseline difference was found between income categories concerning

the use of anti-depressants and anxiolytics, which was relatively higher among the participants from low-income households. Considering recent evidence that anti-depressant medication did not affect CG symptoms in a randomised controlled trial of CG treatment (Shear et al., 2016), no impact from the use of these medications on CG was expected in the present study. It is nevertheless a puzzling indication that corresponds with recent observations of higher anti-depressant use in areas of deprivation (Gayle, 2017), and suggests the need for further investigation.

Limitations

Several limitations in this research should be noted. First, as is frequently the case in bereavement research, the present study sample predominantly consisted of women (74.8 %) bereaved of a spouse (or a parent). Future research needs to determine if results generalise across samples with more men, and different kinship ties to the deceased person. Participant attrition could be considered another concern for the present study, though it conformed with dropout patterns in bereavement research in general and postal questionnaire research in particular (Aoun et al., 2015). Dropout analyses indicated no detectable differences between participants who remained in the study for all three time-points and those who dropped out.

Another limitation is that due to a lack of detailed information about the number of household members, we applied poverty threshold guidelines for a single-person household. The incidence of poverty and deprivation in our sample therefore may be underestimated. Next, given the higher incidence of psychological health problems among people living in poverty, excluding people with pre-existing or co-existing psychiatric diagnoses may have limited participation among the lowest income group. Prevalence of CG in our lowest income category sample could therefore similarly underestimate the prevalence of CG in this income category in the general (bereaved) population. Lastly, while people were quasi-randomised

to study conditions, inclusion in the current investigation of household income was conducted on an opt-in basis, since people chose whether to provide household income information. It may be the case that people from a particular income group were more or less likely to provide income information and were therefore less likely to participate. While we cannot refute this argument entirely, our analyses detected no differences on demographic and loss-related variables (including variables that were distributed unevenly between income categories) between people who did and did not provide this income information. This suggests that income differences between study accepters and decliners are unlikely.

Conclusion

Despite indications that people from below-poverty threshold income households generally struggle to access services and practice self-care, approximately a third of the participants in this naturalistic study who had sought help from a volunteer-based counselling service came from this income category. Though the counselling programme in this study was not tailored to income, it was community-based, and several service characteristics may have improved its accessibility (i.e., local service locations, no services fees, extended hours service)—and acceptability (i.e., providing professionally-trained, local volunteer counsellors) to people from low-income households. On average, bereaved people from the lowest income households experienced relatively higher levels of grief symptoms, yet the effectiveness of the intervention in reducing grief levels did not appear to differ across income groups. Taken together, these results suggest community-based services are accessible, acceptable and beneficial to people with low incomes.

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Chapter 6

Summary and Conclusion

As was set out in the introduction, this project began with two main objectives. The first was to determine whether grief counselling for high distress and/or high risk bereaved people who requested help was effective, in particular when the intervention was tailored to the needs of the client. The second was to determine whether grief counselling was more effective for certain categories of bereaved people than for others. Since a valid intake assessment was essential to achieving each of these goals, an additional, operational objective was added, which consisted of testing the validity of the intake assessment process used in the CBCS intervention model, the Indicator of Bereavement Adaptation—Cruse Scotland (IBACS).

Summary of Results

The first chapter of this dissertation outlines the objectives and research background for the investigation, as well as the structure of the intervention model and the research setting. This controlled intervention study of grief counselling—the first of its kind—was naturalistic in design, conducted in close collaboration with the nation-wide support organisation Cruse Bereavement Care Scotland (CBCS). Informed by empirical evidence in the literature, the intervention model included an assessment process in order to offer people support fitting their level of symptoms and risk of complications. People who requested support but appeared to be coping effectively were placed in a watchful waiting category. Participants whose results indicated they would benefit from intervention were placed into one of three categories (based on increasing case complexity): skilled listener, advanced skills listener, and counsellor. (The same intervention model was used in each category, but the counsellors' years of experience increased for each.) For research purposes, a quasi-randomised control condition was

included in the study, consisting of participants who had requested support and presented elevated grief symptom and/or risk of complications (just like the intervention category participants), but for logistical reasons could not attend sessions.

In Chapter 2, the reliability of the delivery methods of the IBACS, the Indicator of Bereavement Adaptation Cruse Scotland, a grief specific intake assessment process, was examined. Specifically, we looked for differences between the results of the IBACS when delivered over the telephone versus in person. Results of this investigation demonstrated that on average, IBACS scores were approximately 2 points higher than IBACS conducted over the telephone. In practical terms, within CBCS's stepped model of support, which has 3 intervention categories based on increasing case complexity, these mean scores would indicate an assignment to the intermediate case complexity intervention category (Advanced Skills Listener) for in-person participants, and a lower case complexity intervention category (Skilled Listener) for telephone participants. Crosstabs analysis revealed, however, that despite the meant point difference, there was no statistically significant association between IBACS delivery method and assignment to specific intervention category.

Since the IBACS was comprised of two components, a semi-structured risk assessment segment, during which interviewers would allocate discretionary points for the presentation of specific risk factors, and a structured grief symptom questionnaire, further analyses were conducted to determine whether the point difference between the two delivery methods could be attributed to either of the two components. When a comparison of means for the two delivery categories in this sub-sample was conducted using only scores from the structured grief symptom questionnaire, no significant difference (on average .02 points) between the two delivery categories was detected. In contrast, testing the composite scores (i.e. include both section of the IBACS), a mean difference of over 2 points was detected; however, this result did not meet our alpha criterion

for significance. (This was probably because our test was underpowered, due to the smaller sample size). Despite the lack of statistical significance, we considered the emergence of the mean point difference with the inclusion of both structured and semi-structured components of the IBACS, and its absence when only the structured question results were included, to be an indication that the difference may be introduced in the semi-structured component of the IBACS, when interviewers may allocate discretionary points for risk levels. We therefore recommended further training for IBACS volunteers specific to the allocation of discretionary points in the risk assessment component of the assessment process to increase consistency across delivery formats.

In Chapter 3, an exercise was conducted to test the external validity of the IBACS against four validated, widely-used assessment instruments for 1) complicated grief symptoms (the Inventory of Complicated Grief-Revised; Prigerson & Jacobs, 2001); 2) post-traumatic stress symptoms (the Impact of Event Scale-Revised; Weiss & Marmar, 1997) and 3) two measures of general psychological symptoms (Clinical Outcomes in Routine Evaluation, Evans et al., 2000; and The Symptom Checklist 90—Revised, Derogatis & Cleary, 1977). Using our longitudinal data set, it was possible to test both concurrent validity (using baseline data) and predictive validity (using post-measure data). The IBACS demonstrated concurrent and predictive validity through a strong correlation with the ICG-R, and a moderate correlation with the IES-R and the general psychological symptom instruments. A cutoff for complicated grief “caseness” was established using ROC curve analysis and a metric for optimal sensitivity and specificity. This optimal cutoff corresponded closely, but not perfectly, with existing intervention guidelines for allocating more complex cases to more experienced counsellors. The validation of the IBACS meant that the intake process used by CBCS was an effective approach for assessing bereaved people’s risk of complications and determining whether they would benefit from counselling.

Chapter 4 presented the investigation that served as the focal point of this research project: whether CBCS grief counselling—a widely-available, voluntary sector service—provides an effective intervention for bereaved clients. This investigation was also timely, given increasing pressure on health services in Scotland to cope with rising demand for mental health support and increase service availability across the country (e.g., MacNab, 2017). The results of the intervention study showed that the counselling intervention was effective at reducing complicated grief symptoms over time, compared to the passage of time alone. This effect was not detected at post measure, where the non-intervention control also showed a significant and similar decrease in symptom levels. Instead, it was only evident at follow-up, when symptoms among intervention category participants had continued to decrease at a rate similar to the one seen at post measure, whereas control participants' symptoms plateaued. Among the intervention category, this effect was seen among both the skilled listener and the advanced skills listener/counsellor categories. This pattern of results was surprising for two reasons.

First, it is an indication of a distinctly positive result for grief counselling (when screening for risk factors is in place). This result stands in contrast to previous scientific research into the effectiveness of bereavement counselling, which had shown at best mixed results (Waller et al., 2015), leading to what Larson and Hoyt (2009) termed a “new pessimism” in the literature. While many argued against this pessimism (e.g.; Hoyt & Larson, 2010; Larson & Hoyt, 2009; Schut, 2010), and identified research-based recommendations for intervention criteria that appeared to improve intervention efficacy (e.g. Schut, Stroebe, Van den Bout, & Terheggen, 2001) empirical evidence of the effectiveness of a model incorporating their recommendations was lacking, until now. (These recommendations included offering bereavement intervention on request—not on an outreach basis; screening for risk factors and grief symptom severity through

a systematic intake assessment; and waiting for a minimum period of time post-bereavement to elapse before intervention is provided.)

Next, the difference between the intervention and the control groups in mean grief symptom levels was not detectable until follow up, demonstrating a delayed effect for grief counselling, visible at least six months after the intervention was completed. Overall, the positive results of the intervention demonstrated in this study were also the first longitudinal indications of effectiveness for a community-based grief counselling intervention.

After examining the efficacy of the model for a general bereaved population, the next step in the research was to consider the relative efficacy of the intervention model among specific categories of bereaved people. To this end, Chapter 5 looked specifically at the demand for and effect of bereavement intervention among a subgroup that is widely overlooked in psychological research: participants from below poverty threshold households. Analysis of baseline characteristics indicated that over a third of participants (36%) came from households at or below the U.K. poverty threshold, nearly twice the rate in the general population. This result indicates a substantial demand for the type of bereavement support offered by CBCS among people living in relative poverty. This proportion was also surprising, given indications in the literature that participants living in relative poverty struggle to access care in general (Cacciatore, Killian, & Harper, 2016), and are generally not represented in research (Henrich, Heine, & Norenzayan, 2010). Assignment to study condition revealed that, despite quasi-randomisation, a higher proportion of participants living in relative poverty were assigned in the control condition (61%) than the intervention category (39%). In practical terms, this meant that more than two-thirds of the study participants who had contacted CBCS for support and went through the IBACS intake assessment ultimately did not receive support services due to an inability to travel to the service location, or other scheduling difficulties. This pattern suggests

that there may be structural barriers in place—which could be practical or attitudinal—that prevent people from lowest-income households from accessing the support they seek. Analysis of intervention outcomes demonstrated no difference between lowest income category participants and participants from households above the poverty threshold, or those from households with a median income or above. This suggests that the intervention was as effective for lowest-income category participants as it was for others.

Scientific Implications

There are four main scientific implications of this work. First, and most directly, this naturalistic investigation provided evidence that a nation-wide bereavement support service, delivered by a voluntary sector organisation, improved outcomes for bereaved people from a wide range of circumstances and walks of life. To date there have been few scientifically rigorous, longitudinal studies of grief intervention methods (with some notable exceptions, including Kersting et al., 2013; Rosner et al., 2015) and none, as far as we are aware, specific to grief counselling (Waller et al., 2015). The effectiveness of this intervention for a sample comprised of men and women of a range of ages, living in a variety of types of households across Scotland, with different relationships to the deceased person, who had died under a range of circumstances, suggests that the model is robust enough to support the broad population it was designed to serve. It is also the only longitudinal study we know of that has examined a community-based, voluntary sector bereavement support service. This is of particular importance, considering that the voluntary/non-profit sector (as distinct from professional health services, including mental healthcare services) is where the majority of bereavement intervention is currently provided (See Stephen et al., 2009; Breen, Aoun, O'Connor, & Rumbold, 2014).

Next, and perhaps most strikingly, this research demonstrated a delayed but significant positive effect for grief counselling in the reduction

of participants' mean grief symptoms over time. Significantly lower mean grief symptoms for intervention participants (compared to a time-only control cohort) were evident only at follow up, and not at the previous measure. Chapter 4 includes some speculation as to why this may have been the case. One possibility for a partial explanation is that bereaved people seek help when their symptoms are most acute, so that a minimal degree of symptom level regression would be expected for all participants over time, simply on the principle of regression to the mean. In addition, a certain reduction in symptom levels in both categories would be expected, attributable to the healing effects of time. These considerations, however, do not address the delayed effect of counselling. To address this point, it is also possible that bereaved people who receive grief counselling experience a spike in grief levels during and shortly after intervention, due to the hard work of participating in grief counselling. This can include difficult exposure activities that increase the participant's confrontation of reminders of the death and being bereaved, or spur participants to re-engage in common activities while reflecting on their new status (e.g., without a child, no longer as a couple, etc.). In other words, at post-measure, the impact of counselling may have had exacerbating as well as positive effects in the short term. As time passes after intervention has ended, it may be that such elevated symptoms subside, and the effect of the completed work in grief counselling contributes to an increased ability to cope, leading to the subsequent decrease in grief symptoms. In contrast, among control participants, the plateau in symptom levels seen at follow up may be indicative of the limits of the healing effects of time, particularly for people who (like this study's participants) are at an increased risk of complications. As previous research has indicated, ruminative or avoidant behaviour in response to grief may hinder the ability of at-risk bereaved people to cope (Eisma et al., 2015). This can be challenging to change, particularly without support. Overall, however, such speculations are indeed only educated guesses, and will remain so without further confirmatory research. If this effect is detected elsewhere,

it could shed new light on the mixed outcomes reported in previous grief counselling research where the study periods were shorter.

A third scientific implication from the investigations of this bereavement intervention model concerns the importance of screening for grief symptom levels and risk factors to determine whether a bereaved person would benefit from grief counselling. The model investigated in this dissertation included a systematic intake assessment to distinguish between bereaved people who were suffering but coping effectively, and those who coping less effectively and needed extra support. Since complicated grief reactions stem from a complex interplay of factors, as discussed in the introduction, the intake assessment in this model screened for a variety of circumstances that have been found to increase the risk of complications (rather than offering intervention based on the presence of a single categorical risk factor, such as a specific kinship tie—e.g., bereaved parents of a deceased child; bereaved spouse who had caregiving responsibilities). The positive validation analyses for the IBACS intake assessment instrument, detailed in Chapter 3, provide an indication that screening for risk factors is an effective approach to predicting where intervention is warranted. The overall effectiveness of the intervention over time, shown in Chapter 4, further supports the idea that an intervention that is designed to support people with a higher risk of developing complications, and screens for them, is more effective. Nevertheless, this conclusion cannot be reached until analyses are conducted that include bereaved people with low (below intervention cut-off) symptom levels.

Fourth, this investigation demonstrated that CBCS, a community-based bereavement support service, was—at least in the first instance—accessible and acceptable to bereaved people living in relative poverty, and that no difference in the effectiveness of support was detected across income groups. It is important to consider these results in conjunction with longstanding observations that living in relative poverty entails both a greater risk of mental health difficulties (e.g., Santiago, Kaltman, &

Miranda, 2013) and lower rates of access to support resources (Doornbos, Zandee, de Groot, & Warpinski, 2003). Indications in this study that the rate of relative poverty among participants was both twice the rate in the general population demonstrates the degree of need for bereavement support services, and the accessibility and acceptability of CBCS services, among this income category. The presence of participants from this income category also demonstrates their willingness to participate in research. This fact is worth considering in light of the recent discourse concerning a perceived middle-class bias in psychology research. Whereas it has been argued that people from low income households are unwilling or unable to participate in research, recruitment for this research resulted in positive uptake among this segment of the population. Since recruitment was conducted under the auspices of a community-based support organisation that they themselves had chosen to contact, it is possible that personal familiarity with the institution conducting the research had a positive impact on their decisions to participate.

Implications for Practitioners

The outcomes of this research also have several implications for grief counselling practitioners and organisations. The effectiveness of the CBCS intervention model, a tailored approach to providing grief counselling through trained volunteer practitioners at a nation-wide third sector organisation, is the first of these. Given the indications that the large majority of bereavement intervention is provided by such not-for-profit organisations (such as bereavement support organisations, health condition-specific charities, and hospices), this result is an encouraging indication that these initiatives can provide effective support to the bereaved people they aim to help. From a public health and policy perspective, the broad reach of third sector organisations, along with the efficient cost model of their operations, suggests that adequate bereavement care could be made widely available to those who needed it at a moderate cost to funders/donors, and at little or no cost to end users, as at CBCS.

The validity of the IBACS intake assessment, and the effectiveness of its use both in person and over the telephone, also has implications for practitioners. First, using this or similar intake assessments will help practitioners recognise when bereavement intervention is warranted, and when a watchful waiting approach is more appropriate for a client's wellbeing. This step has been shown to have the potential to improve outcomes for bereaved people seeking support. It also allows clients and practitioners to make the best use of their time and efforts – by avoiding unnecessary and unwarranted intervention. Since the IBACS can be delivered by purpose-trained volunteers who do not need to have a background in counselling, its use can allow for organisations and practitioners to make more efficient use of their resources. In other words, counsellors can devote time to counselling without the need to conduct intake assessments, while purpose-trained IBACS volunteers and office staff can conduct intake assessments and reduce waiting times for bereaved clients.

Another important implication of this research for practitioners concerns the relative poverty analyses in Chapter 5. Results of analyses at baseline made it clear that over a third of people who sought support from CBCS were living in relative poverty. While this result is of direct importance to practitioners in Scotland, it is likely that bereaved people living in relative poverty in other Western countries are also seeking support. Since it was also the case in this quasi-randomised study sample that, as noted above, a higher percentage of the control category participants were living in relative poverty, it is likely that there are structural and/or attitudinal barriers to the uptake of bereavement support among people from lowest income households. Steps could be considered to reduce the potential costs of accessing support by offering more service locations closer to participants' homes or transport to/from service locations. Again, as noted above, options for intervention via telephone or internet might improve accessibility for bereaved people, which may not only increase

access but also reduce other indirect costs, such as the need to arrange for childcare or eldercare during transit times.

Limitations of These Studies

As is often the case in naturalistic research, though principles of scientific inquiry remained paramount, the practical realities of data collection in an applied context had a strong effect in shaping the investigation of the research questions set out in this dissertation. To the same extent that laboratory conditions do not always mimic the real world, the real world is not always a perfect laboratory. The availability of both kinds of research – laboratory and naturalistic – provides a necessary balance, and leads to a more comprehensive view of intervention efficacy. It is critically important however to bear in mind the limitations introduced by our naturalistic approach.

Solutions to practical challenges encountered in the research setting, without which this research would have been impossible, also introduced certain limitations to the research. Quasi-randomisation was one such solution. This approach to assigning participants to study conditions gave us a way of including a no-intervention control to our study that was ethically acceptable to the research committee and CBCS, the organisation hosting the research. As noted above, instead of a strictly random process that assigned participants to an intervention category or to a no-intervention control, we worked with the *ad hoc* reality of participants' actual situations, where some received intervention, and others were not able to receive sessions due to difficulties reaching the location or scheduling conflicts. Though our initial baseline analyses had shown no differences in the study condition's baseline characteristics with respect to mean reported income, subsequent more in-depth income analyses that included relative poverty calculations showed that the control group participants had a significantly higher rate of below poverty threshold income. As discussed in Chapter 5 with references to the transactional model of stress (Lazarus & Folkman,

1984), it is reasonable to consider that the challenges of living below the poverty threshold may have affected the ability of these study participants to schedule and attend sessions.

The limited availability of IBACS data also introduced challenges to our validation exercises for the intake assessment process. In the interest of client confidentiality, the host institution, CBCS, had a practice of documenting only the total IBACS score. This meant that neither an item-level documentation of individual IBACS results, nor a breakdown between the semi-structured risk assessment component and the structured grief symptom assessment, was available on the organisation's database. (This level of detail had simply not been needed by the organisation before this research study.) In the two sets of analyses examining the IBACS, work-around solutions were found that permitted reliability and validation exercises to be conducted. Nevertheless, item-level data would have enabled more in-depth analyses. Since the organisation now maintains more detailed records, future research exercises may produce more informative results.

Our study design would also have benefitted from the inclusion of low-symptom level participants (whose IBACS scores placed them in the 'no intervention/watchful waiting' category). These CBCS clients were not included in the proposed study sample at the design stage out of ethical concerns. It had seemed possible that some might be upset at not receiving intervention. IBACS interviewer training and subsequent contact with CBCS clients suggested this concern was unfounded; in fact, CBCS clients demonstrated an unexpected level of interest in the research.

Lastly, it should be noted that the scope of our study stopped short of the individual session level, and no measures were taken during the course of counselling sessions to examine the impact of specific components of the intervention that was studied in this research, the CBCS model. As described in Chapter 4, the CBCS model is a pluralistic approach to bereavement counselling that combines elements of three traditions

in psychology: cognitive behavioural therapy, the person-centred model, and the psychodynamic tradition. This model was designed (in line with the Dual Process Model of coping with bereavement, see Stroebe & Schut, 1999) with the objective of promoting effective coping strategies, helping the bereaved person address ruminative or avoidant thought patterns and behaviours that may be obstructive, and encouraging (re-)engagement with resources and activities that reinforce agency (e.g. on an intrapersonal level, reframing, and practising self-care; on an interpersonal level, re-connecting with a social circle or taking part in other personally-rewarding activities). Without interim measures taken during the intervention period, or the ability to examine session transcripts and compare outcomes, it was not possible to determine whether certain elements or strategies of this intervention model were more effective than others.

Directions for Future Research

In addition to the need for more (scientifically robust) confirmatory analysis needed to demonstrate the efficacy of grief counselling, there are three indications from the research in this dissertation that in particular warrant further investigation. First among these is the significant but delayed effect of the counselling intervention demonstrated in Chapter 4. This result was unexpected, and though it is possible to speculate about the underlying mechanism (as above), it remains unexplained. Future investigations that include a study period of similar length or longer, and both a post- and a follow-up measure, can confirm whether this phenomenon can be found in other populations, and with other counselling models. This issue could be further illuminated by including interim measures during the intervention period.

Directly related to the stepped-care model of intervention in this research, it would be worthwhile to investigate the relative efficacy of the different levels of intervention—in this case, the skilled listener, advanced skills listener and counsellor categories. Although our study enabled

a comparison of the relative efficacy of the CBCS intervention for subgroups of bereaved, our sample size did not permit an examination at this level.

The indication that low household income is a risk factor for complicated grief, shown in Chapter 5, also raises a number of questions. Given the limitations in our data set concerning household composition and income (as noted above), an investigation using more nuanced data including a reliable report of dependents and household members, work and civil status and total annual income, would permit a finer-grained analysis of the effect of income on grief symptoms and coping ability. To this effect, it would also be worthwhile to make the inclusion of a relative poverty index a standard practice when assessing participant characteristics.

Lastly, but perhaps most urgently, it would be useful to investigate what factors influence the pattern, also seen in Chapter 5, where a greater proportion of bereaved people from below poverty threshold households who had sought support did not receive it, compared to people from higher income groups. While the link between poverty and mental illness is well established, it also appears to be multi-directional. As such, it should be considered that the effects of complicated grief could be particularly devastating to people who are already struggling with the stresses of living in relative poverty. Conversely, as the stress model discussed above would suggest (Lazarus & Folkman, 1984), living in relative poverty may make it more difficult to cope with bereavement, since one's resources are already overtaxed. Either case could lead to a downward spiral, one that could be concurrent with or directly connected to the devastating effects of funeral poverty, which have recently been the source of much discussion in the UK (see Foster & Woodthorpe, 2013). More information about these issues could help find ways to stop what may be a negative cycle.

A Final Word: Collaborative Research

Long ago, the project team discussed the benefits and challenges of practitioners and researchers working together (Newsom, Wilson, Birrell, Stroebe, & Schut, 2011). At the time, we noted the many challenges our project group had faced. In addition to the logistical—falling between two countries and two jurisdictions (the Netherlands and Scotland), each of which we thought were the other’s problem—and the theoretical, such as the acceptability of quasi-randomisation in our recruitment strategy, we also had to address a number of preconceived notions inherent to the two institutions involved in the research. For the grassroots, support-providing organisation CBCS, this meant realising that academic researchers are not only interested in Likert scales and p values, and on the academic side, recognising that practitioners can provide valuable input into study design and methodology. The benefits of applied research were tangible for both institutions. CBCS received scientific validation of their assessment instrument and model, which can be useful evidence of the effectiveness of their approach to helping people cope with bereavement. The academic team had the opportunity to conduct a naturalistic study, which called for a robust study design, but delivered equally robust results. We also were able to witness some of our research recommendations implemented in practice. For example, IBACS volunteers were coached to be more stringent with their allocation of discretionary points. Designing and executing the study in a way that was acceptable to both researchers and practitioners on the team was not always easy. Then as now, however, we concluded that the collaboration was as fruitful as it was enjoyable.

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APPENDICES

Appendix A

Samenvatting in het Nederlands

Verlies door een sterfgeval is een van de moeilijkste gebeurtenissen in het leven en bijna iedereen van ons krijgt ermee te maken. De rouwreacties die gepaard gaan met dergelijk verlies wordt gedefinieerd als “de primair emotionele reactie op verlies, waaronder diverse psychische en fysieke reacties” (Stroebe, Schut, & Stroebe, 2007, p. 1960). Na verloop van tijd, vaak in de eerste zes maanden, lijkt de meerderheid van de nabestaanden zich redelijk goed aan te passen op eigen kracht en met hulp van familie en vrienden. Bij een klein deel van de nabestaanden — een geschat percentage dat schommelt tussen 10% en 20% — zal het lijden dermate hog zijn dat hun verdriet hun gezondheid en hun functioneren aantast en dat hulp van buitenaf nodig is.

In deze context kan het verlies beschouwd worden als zowel een zeer pijnlijke, maar onvermijdelijke levenservaring, als een conditie die geassocieerd wordt met een verhoogd risico op morbiditeit en mortaliteit (Boyle, Feng, & Raab, 2011; Stroebe, Schut, & Stroebe, 2007; Zisook et al., 2014). Bepaalde omstandigheden dragen bij tot een verhoogd risico op problemen. Deze omvatten factoren die verband houden met de relatie met de overledene (bijv. een specifieke verwantschap, zoals moeders van een overleden kind); persoonlijke karakteristieken, zoals onveilige gehechtheid; en de aard van het overlijden, zoals onverwacht overlijden of in geval van ziekte de perceptie dat de overledene veel heeft geleden. Een zwakke lichamelijke gezondheid impliceert ook een groter risico op gezondheidsproblemen.

In de afgelopen halve eeuw zijn er overal ter wereld rouwinterventieprogramma's ontwikkeld om mensen die een dierbare verloren hebben te helpen. In het Verenigd Koninkrijk en andere landen zoals Australië, Japan, Nederland en de Verenigde Staten, wordt

de meerderheid van dergelijke interventies aangeboden door non-profit- of vrijwilligersorganisaties, waaronder palliatieve zorgprogramma's en verpleeghuizen (zie Breen, Aoun, O'Connor, & Rumbold, 2014). Deze programma's worden over het algemeen geïmplementeerd zonder dat er een bewijs bestaat van hun effecten op nabestaanden. Slechts een beperkt aantal is onderworpen geweest enige test van effectiviteit. De meest voorkomende manier om dergelijke programma's te testen is de deelnemers zelf te vragen hoe tevreden ze zijn met het programma waaraan ze deelgenomen hebben. Hoewel tevredenheid belangrijk is, is het een subjectieve manier en weerspiegelt die niet noodzakelijkerwijs effecten van de interventie.

Het project dat het onderwerp vormt van dit proefschrift is ontwikkeld als antwoord op het gebrek aan een meer wetenschappelijke toetsing voor verliesinterventie *in de praktijk*. Dit project is gestart met twee hoofddoelstellingen: 1) bepalen of rouwinterventies voor nabestaanden met een hoog niveau van rouw en/of een hoog risico op complicaties die hulp hebben gezocht en bij wie de complexiteit van de interventietechnieken in overeenstemming is met de problemen van de nabestaande, effectief was; en 2) bepalen of de interventie effectiever was voor bepaalde categorieën van nabestaanden dan voor andere.

Het onderzoek in dit proefschrift rapporteert een interventiestudie die is uitgevoerd over geheel Schotland — de eerste in zijn soort. In deze studie werden personen die ten minste 6 maanden daarvoor iemand verloren hadden en die professionele hulp zochten, toegewezen aan een op maat interventiemodus op basis van een systematische evaluatie van hun niveau van rouw en aanwezige risicofactoren. Veranderingen in hun psychisch, sociaal en fysiek functioneren werden vergeleken met die van nabestaanden die ook hulp hadden gezocht, maar die dat vanwege logistieke redenen niet konden krijgen.

De in dit onderzoek onderzochte interventie was het Cruse Bereavement Care Schotland (CBCS)-model van rouwinterventie. Dit model van individuele interventie combineert elementen van drie tradities in de

psychologie: cognitieve gedragstherapie, person-centred counseling en de psychodynamische benadering. De counseling werd gegeven door getrainde vrijwilligers die (op zijn minst) voldeden aan de normen van COSCA, de Schotse beroepsorganisatie voor counseling en psychotherapie. Met inachtneming van de CBCS-praktijk werden de deelnemers toegewezen aan vrijwilligers op basis van de ernst en de complexiteit van hun symptomen, waarbij de meest complexe gevallen toegewezen werden aan de meest ervaren counselors.

Na een inleidend hoofdstuk behandelt hoofdstuk 2 van dit proefschrift een studie naar de verschillen tussen quasi-redandomiseerde vis-a-vis ($n = 115$) vs telefonische ($n=330$) semigestructureerde assessment van symptomen en risicofactoren. De assessment via de telefoon viel gemiddeld lager uit dan vis-a-vis. Nadere analyse suggereerde dat dit verschil zich voorla voordeed in het semigestructureerde deel van de assessment en niet in de gestructureerde assessment van symptomen.

In de studie in hoofdstuk 3 is de betrouwbaarheid en validiteit van een assessment geevalueerd, de Indicator of Bereavement Adaptation Cruse Scotland (IBACS). De IBACS is ontworpen voor gebruik in de klinische en niet-klinische praktijk, en inventariseert het niveau en de ernst van de rouwsymptomen en het risico op de ontwikkeling van complicaties. Aan deze studie hebben 196 hulpzoekende Schotse volwassenen die een dierbare verloren hadden (44 mannen en 152 vrouwen) deelgenomen. De gegevens werden verzameld op twee tijdstippen: bij aanvang van de interventie (T1) en 18 maanden later (T2). In deze vragenlijsten werden er vier gevalideerde beoordelingsinstrumenten gebruikt: CORE-R, ICG-R, IES-R, SCL-90-R. Het discriminatoire vermogen werd beoordeeld met behulp van de ROC curve analysis. De simultane validiteit werd getest door een correlatieanalyse bij aanvang. De predictieve validiteit werd beoordeeld met behulp van correlatieanalyses en de ROC curve analysis. De optimale IBACS-cutoff-waarden werden verkregen door een maximale Youden index J in de ROC curve analysis te berekenen. De klinische

implicaties werden vergeleken aan de hand van verschillende instrumenten. De resultaten van de ROC curve analysis gaven aan dat de IBACS een goed diagnostisch instrument is voor de evaluatie van gecompliceerde rouw. De positieve correlaties met alle vier instrumenten bij T1 toonden aan dat de gelijktijdige validiteit van IBACS het sterkste was bij assessment van gecompliceerde rouw. De predictieve validiteit leek redelijk te zijn in de resultaten van de T2 ROC curve analyse en werd ook ondersteund door stabiele positieve correlaties tussen de IBACS en andere instrumenten op T2. Er leken geen verschillen te zijn in de klinische indicaties tussen de verschillende instrumenten. Derhalve werd geconstateerd dat de IBACS een doelmatige assessment van rouwsymptomen en risicoanalyses biedt voor gebruik door niet-clinici. Er waren voldoende indicaties om de intake-assessments te gebruiken voor een model van rouwinterventie dat de interventie aanpast aan de complexiteit van de situatie.

In het onderzoek in hoofdstuk 4 werd de effectiviteit van een rouwcounselingmodel voor volwassenen onderzocht voor het verminderen van gecompliceerde rouwsymptomen. De deelnemers ($N = 341$; 79% vrouwelijk; gemiddelde leeftijd: 49.3 jaar) waren volwassen inwoners van Schotland die een naast familielid of een partner verloren hadden en die een verhoogd risico hadden op gecompliceerde rouw. De hypothese was dat de deelnemers die de rouwcounseling kregen een grotere afname van rouwsymptomen zouden rapporteren na afloop van de interventie dan de non-interventie controlegroep, maar dat het verschil kleiner zou zijn bij follow-up. De gegevens werden verzameld met behulp van een vragenlijst die per post opgestuurd werd op drie meetmomenten: kort voor aanvang van de interventie (T), na de interventie (T + 12 maanden) en bij follow-up (T 18+ maanden). Op alle meetmomenten werden rouwsymptomen, posttraumatische stress symptomen en de algemene psychische gesteldheid geëvalueerd. Er werden multilevelanalyses uitgevoerd om de verschillen tussen de groepen in de symptoombeloop in kaart te brengen. Er werd gecorrigeerd voor toetsing van meerdere hypothesen. De voornaamste

uitkomst was dat, in tegenstelling tot de verwachtingen, de deelnemers aan de counselinginterventie en die in de controlegroep een nagenoeg gelijke afname van de rouwsymptomen rapporteerden na de interventie. De deelnemers aan de interventie vertoonden echter een grotere vermindering van rouw bij follow-up in vergelijking met de controlegroep. De resultaten suggereren dat de rouwinterventie positieve effecten op lange termijn kan hebben.

In hoofdstuk 5 werd dieper ingegaan op een specifieke risicogroep: nabestaanden die in relatieve armoede leven (gebaseerd op het aangegeven gezinsinkomen). Armoede wordt geassocieerd met meer psychische problemen bij rouw, maar er is onvoldoende informatie over de toegankelijkheid en effectiviteit van rouwinterventieprogramma's voor mensen uit lage inkomensgroepen. Deze studie heeft daarom de effectiviteit van het CBCS interventieprogramma bestudeerd voor voor verschillende inkomensgroepen. Met behulp van regressieanalyses werd inkomen als een voorspeller van rouwsymptomen en de effectiviteit van rouwinterventie onderzocht.

Uit de resultaten blijkt dat 35,8% van de deelnemers een inkomen aangeeft onder de armoedegrens — bijna het dubbele van de Schotse algemene bevolking. De analyses gaven suggereren dat laag inkomen een sterkere voorspeller is van rouwsymptomen dan demografische en aan het verlies gerelateerde kenmerken. De interactieanalyse detecteerde een significant behandelingseffect in de loop van de tijd, maar geen verschillen in de behandelingseffecten voor de verschillende inkomensgroepen. Een laag gezinsinkomen werd geassocieerd met een hoger niveau van rouwsymptomen. Inkomensniveau hield evenwel geen verband met behandelingseffect, waaruit blijkt dat deze vorm van rouwhulpverlening ongevoelig is voor inkomensniveau.

In het conclusies hoofdstuk worden de belangrijkste wetenschappelijke en praktische implicaties van dit onderzoek besproken. Deze omvatten het volgende:

1. Een rouwinterventie op nationale schaal zoals in Scotland wordt geboden door een nationale vrijwilligersorganisatie levert over het algemeen positieve voor nabestaanden in diverse omstandigheden
2. Deze service werd toegankelijk en aanvaardbaar bevonden door ook nabestaanden die in relatieve armoede leven en er werd geen verschil in de effectiviteit van de interventie gevonden tussen de verschillende inkomensgroepen.
3. Er is sprake van een vertraagd, maar significant positief effect van de rouwinterventie die zichtbaar is in een grotere afname van de belangrijkste rouwsymptomen bij de interventieconditie in vergelijking met de non-interventie controleconditie.

Dit laatste punt kan gedeeltelijk verklaard worden door de neiging van nabestaanden om hulp te zoeken wanneer hun symptomen het meest ernstig zijn, zodat er een zekere regressie van het symptomenniveau verwacht wordt na verloop van tijd en ook gedeeltelijk door algemene heilzame effecten van tijd. Het kan ook zijn dat de nabestaanden die rouw hulp krijgen een piek in hun rouw ervaren tijdens en kort na de interventie, die het gevolg is van de aandacht voor pijnlijke aspecten gedurende de interventie. Dientengevolge kan direct na afloop van de interventie sprake zijn van tegengestelde mechanismen waarvan de effecten elkaar opheffen.

In de conclusie worden ook enkele beperkingen van het onderzoek besproken. Ten eerste bleek dat uit de inkomensanalyses dat de controlegroep een significant hoger percentage van deelnemers bevatte wier inkomen onder de armoedegrens lag. Dit kan het gevolg zijn geweest van de quasi-randomisatie procedure (in plaats van strikte randomisatie) bij het toewijzen van de deelnemers aan de studiecondities. Bovendien waren slechts IBACS-scores voor een kleine deelgroep van de deelnemers in detail beschikbaar, waardoor een gecompliceerde strategie voor validatie moesten gehanteerd moest worden. In onze studie waren deelnemers met lage rouwscores ondervertegenwoordigd, vier IBACS-scores geen interventie

indiceerden. Indien deze categorie toegevoegd was, zou dit geleid hebben tot betere analyses van de IBACS. Ten slotte zou het nuttig geweest zijn om gegevens gehad te hebben over de inhoud van de behandelsessies.

Er is verder onderzoek aanbevolen om het significante maar vertraagde effect van ruwinterventies te onderzoeken om te bevestigen of dit fenomeen in andere populaties voorkomt en met andere counselingmodellen. Verder raden we aan om een studieperiode op te nemen die vergelijkbaar is qua duur of langer is dan de studieperiode van deze onderzoeksstudie. Het zou ook waardevol zijn om de differentiële effecten van de verschillende interventieniveaus te onderzoeken. Onze aantal deelnemers was niet groot genoeg om dergelijke analyses uit te voeren. Een genuanceerdere analyse van het effect van het inkomen op rouwymptomen en copingstrategieën is eveneens aan te bevelen. Over het algemeen hopen we dat toekomstig onderzoek een relatieve armoede-index zal bevatten als standaardpraktijk bij het beoordelen van de kenmerken van de deelnemers en effecten van interventies.

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Appendix B

Scientific summary

In the UK and elsewhere (e.g., Australia, Japan, the Netherlands, the USA), the majority of bereavement intervention programmes are delivered by non-profit (voluntary sector) organisations and lack evidence of their effects on bereaved people. Though previous literature has been unable to provide much evidence for the effectiveness of grief counselling, specific risk factors have been identified that are associated with greater suffering in bereavement, and for bereaved people with risk factors, outcomes of intervention are better. The naturalistic research in this dissertation investigated the effectiveness of a stepped-care model of grief counselling for high distress and/or high risk, help-seeking bereaved people, which screened for risk factors, and was delivered by a non-profit bereavement support organisation in Scotland. Changes in psychological, social and medical functioning were compared with those for bereaved people who also sought help but who for logistical reasons could not receive it. Since previous research indicated support was more effective for bereaved people with elevated grief symptom levels and risk of developing complications, validating the intake assessment of this model, the Indicator of Bereavement Adaptation—Cruse Scotland (IBACS) was a critical step in this research.

The IBACS was designed to be delivered by purpose-trained volunteers in clinical and non-clinical settings. A first analysis comparing results of the IBACS delivered over the telephone versus in person ($N = 447$; $n = 332$ in-person; $n = 115$ telephone) demonstrated a small but significant difference, with lower composite scores in the telephone condition. Subsequent analyses provided indications that the difference may have occurred in the semi-structured risk assessment component. Careful training and clear guidelines around discretionary point allocation were therefore recommended. Next, the discriminative ability and the

concurrent and predictive validity of the IBACS were tested in a validation exercise comparing IBACS results to those of four validated, widely-used assessment instruments (CORE-R, ICG-R, IES-R, SCL-90-R.). ROC curve analysis demonstrated that the IBACS was a good diagnostic instrument for complicated grief, with strong concurrent validity shown for all four instruments, and fair predictive ability for complicated grief after 18 months. Optimal IBACS cutoff values were obtained by calculating a maximal Youden index J in ROC curve analysis, and clinical indications were found not to differ across instruments.

With the intake assessment validated, the effectiveness of the complete bereavement counselling intervention model could be assessed. Using a quasi-randomised, controlled design, participants ($N = 341$; 79% female; mean age: 49.3 years) were assigned to a counselling condition or to a no intervention control. Measures for complicated grief, posttraumatic stress, and general psychological distress were collected at baseline (T), post-measure (T+12 months) and follow up (T+18 months). Contrary to expectations, multilevel analyses revealed a similar reduction in CG symptoms in both conditions at post-measure; however, intervention participants demonstrated a greater reduction in symptom levels at follow-up ($M = 53.64$; $d = .33$) compared to the control group ($M = 62.00$). Bereavement counselling thus appeared to have long-term beneficial effects, while it was theorised that the short-term effects of the work done in grief counselling may cause a temporary increase in symptom severity in the short term—with implications for the mixed or lack of results demonstrated in some previous research.

A further investigation was conducted focusing on an often-overlooked risk category, bereaved people living in relative poverty. Analysis of baseline characteristics of participants ($N = 288$, 75% female) revealed that 35.8% of the participants in our naturalistic sample of help-seeking bereaved people with elevated grief symptoms reported a below-poverty level income; nearly double the general population's rate. Using longitudinal

data, multiple regression analysis indicated poverty-threshold income was a predictor of CG symptoms over and above demographic and loss-related characteristics. Three-way interaction analysis detected a significant treatment effect for study condition across time, but no differences in treatment effects across income. These results suggested that the community-based bereavement intervention was initially acceptable and accessible for participants from poverty threshold households, and that the positive effects of intervention in the main effects analysis were not demonstrably different for this category.

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Mom, David and Heather—it's definitely cocktail hour! Thank you for cheering me on, and on, and on.

James: High five! Thank you for all the coffees (even though you drink tea). Yes, I promise not to do another one.

Curriculum Vitae

A native of California, Cate Newsom grew up in San Francisco. She received her BA in film studies from Yale University in 1997. After learning Italian at the Università per Stranieri di Siena and film work in Milan, she received a Founder's Scholarship to attend New York University's Tisch School of the Arts/Graduate School of Arts and Sciences, where she obtained her MA in cinema studies in 2001. During this time, she also attended the Goethe Institut in Goettingen, Germany on a FLAS Fellowship. Cate went on to work in documentary film production in New York and Berlin, and to earn a second master's in medical anthropology (*summa cum laude*) at the University of Amsterdam in 2004. She then worked in applied social research in San Francisco, in addition to a brief stint at the U.S. Department of State, and obtained a certificate in project management from UC Berkeley in 2008. In 2009 she began working at Cruse Bereavement Care Scotland in conjunction with her doctoral studies in clinical psychology at Utrecht University in the Netherlands.

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