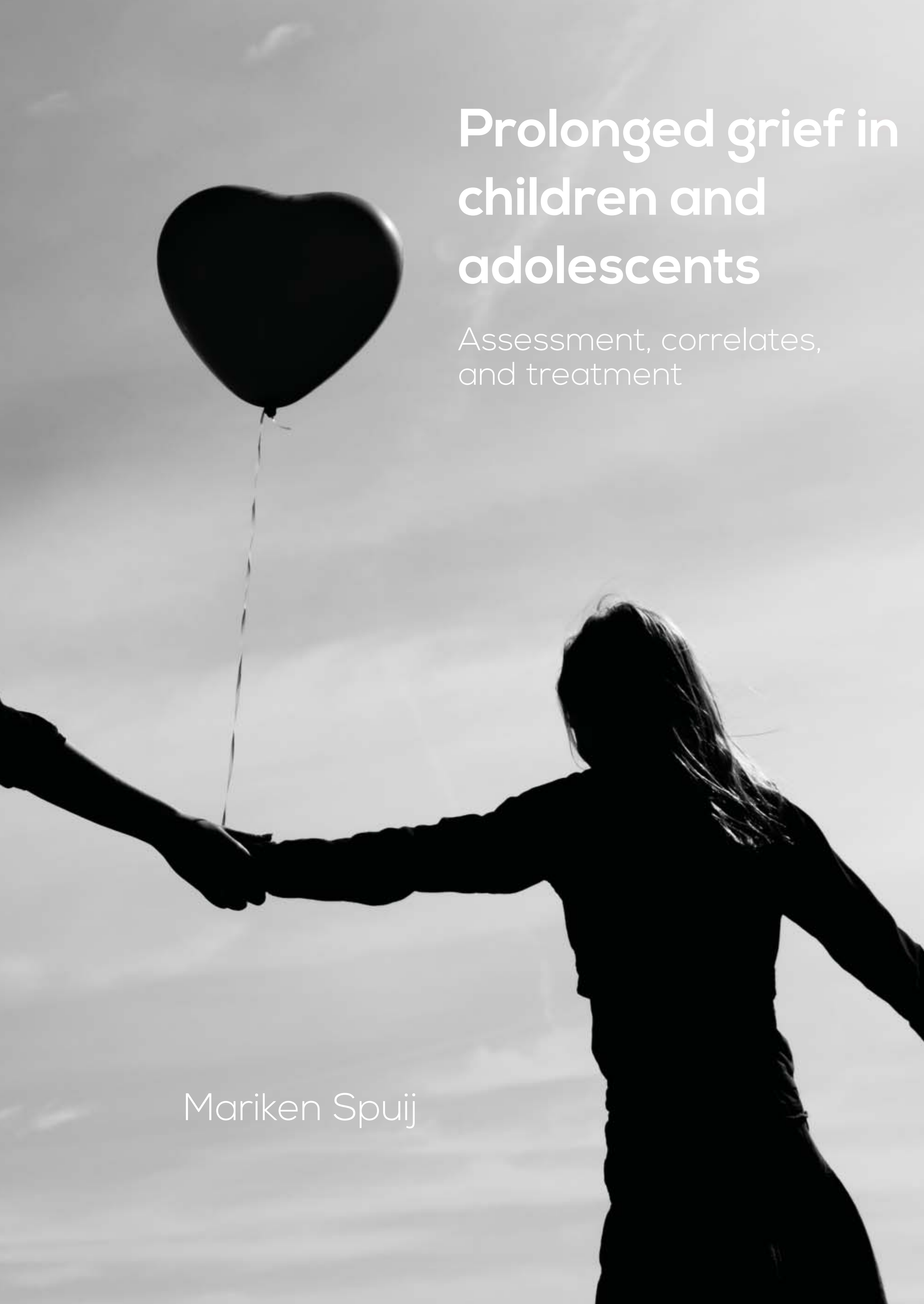

Prolonged grief in children and adolescents

Assessment, correlates, and treatment

Mariken Spuij

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Prolonged grief in children and adolescents

Assessment, correlates, and treatment

Gecompliceerde rouw bij kinderen en adolescenten

Meting, onderliggende mechanismen, en behandeling

(met een samenvatting in het Nederlands)

Proefschrift

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Universiteit Utrecht op gezag van de rector magnificus,
prof.dr. G.J. van der Zwaan, ingevolge het besluit van het
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door

Mariken Spuij

geboren op 12 april 1970
te Maassluis

Promotoren:	Prof.dr. P.A. Boelen Prof.dr. M. Deković
Co-promotor:	Dr. P. Prinzie

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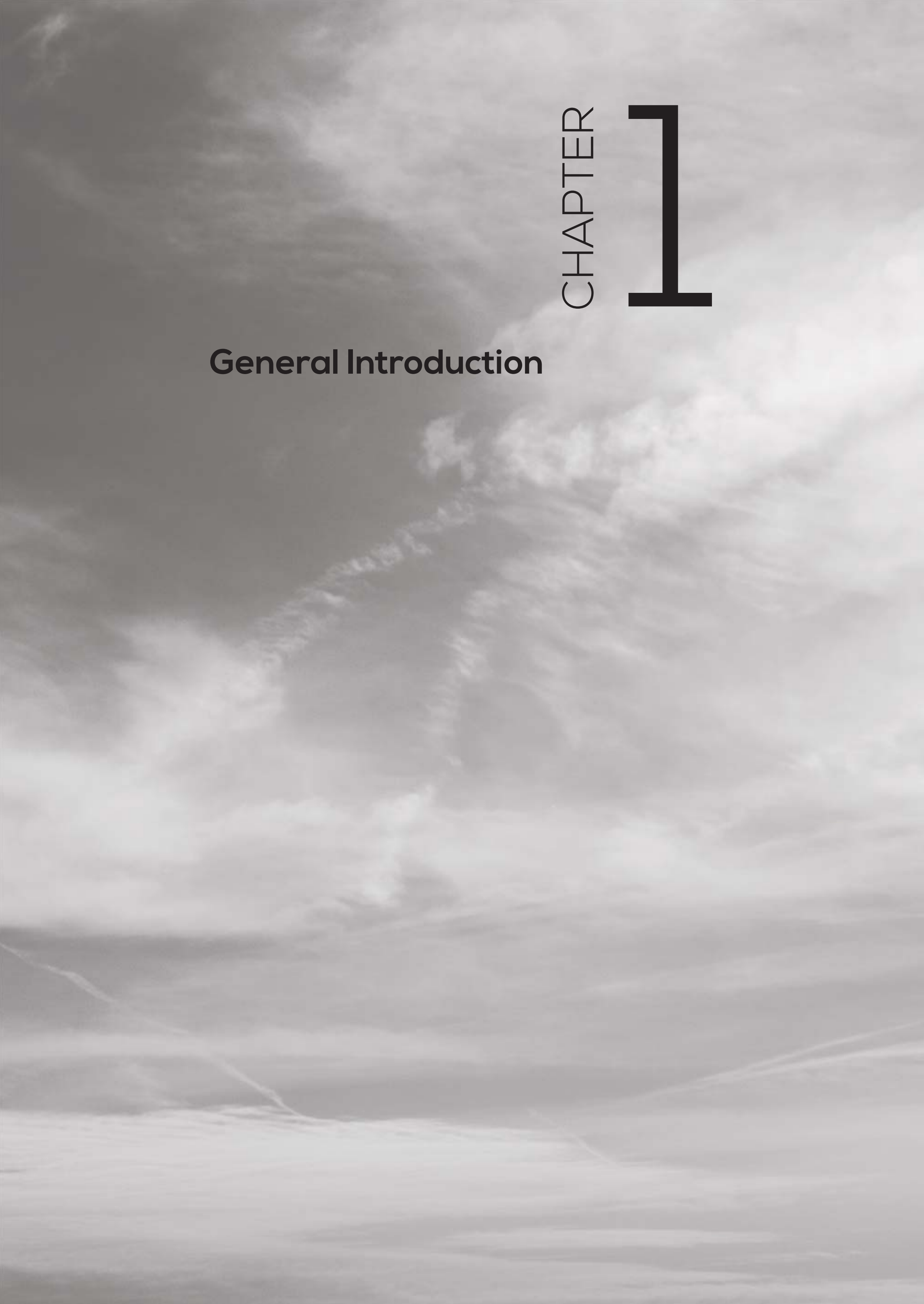
Contents



CHAPTER 1

General Introduction

Bas came to see a therapist when he was almost twelve years old. He was referred for help because of academic and sleeping problems. The referring general practitioner mentioned that his mother committed suicide when Bas was three years old. During the intake interview, the therapist found out that Bas knew about this since he was almost eight years old. He never spoke about his mother, because he thought it was a very special secret he was not allowed to talk about. His father thought Bas did not think a lot about his mother anymore, because Bas did not want to talk about his mother with him and never joined him to the cemetery. Meanwhile he had a lot of maladaptive negative thoughts about his mother (*"my mother went crazy"*), father (*"if I would talk about my mum with my father, he'd possibly get very upset and mad and I'd possibly lose him too"*) himself and his future (*"I'm not worth living for", "I will go crazy too"*). At night he could not sleep because he could not stop thinking about his mother. Most of the time he cried himself to sleep far beyond midnight. He did not want his father to know about this, because he did not want to make him feel sad or guilty about the death of his mother.

The nine-year-old Eva had been confronted with the death of her father seven months earlier. He died suddenly due to heart failure. Eva suffered from yearning for her father's presence. This was central to her problems. In addition, she experienced symptoms of a Posttraumatic Stress Disorder (PTSD) as she feared and tended to suppress memories of moments surrounding her father's death. Eva was afraid that she would 'go mad' if she would confront these memories. Coming from a Hindustan family, Eva's social context prescribed her to engage in active mourning for at least one year. She believed that during the first year following the loss, her father was still present in the house as a ghost and she felt that she would 'betray' him if she would go out of the house and have fun again.

These two cases illustrate the impact of the loss of a loved one on children.[1] We will use the case of Bas as an illustration in this introduction when we speak of grief in a developmental context and when we describe the theoretical framework of problematic grief. Eva's case is part of ***chapter 7*** of this dissertation, where the feasibility and potential effectiveness of *Grief-Help*, a 9-session cognitive behavioural treatment for bereaved children, is described.

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[1] In this introduction the term children is used to refer to children and adolescents.

AIMS OF THIS DISSERTATION

Many children like Bas and Eva experience stressful events as they grow up. They are faced with painful circumstances like parental divorce or the death of a loved one. Most children can overcome those experiences, but some develop such psychological problems that professional help is needed. The overall focus of this dissertation is the assessment and treatment of problematic grief in children like Bas and Eva. First, we give an overview of epidemiological aspects and a historical overview of research on problematic grief. Then we describe our aims and outline for this dissertation in more detail. Our three aims were (I) to increase our understanding of the phenomenology and correlates of Prolonged Grief Disorder (PGD), (II) to enhance knowledge on the role of negative thinking in the development of PGD in children and (III) to develop an intervention for children who suffer from loss and to examine its potential efficacy in two pilot studies.

BEREAVEMENT: PREVALENCE AND CONSEQUENCES

Epidemiological studies on rates of bereavement are scarce, but research in the United Kingdom of Harrinson and Harrington (2001) showed that most young people experience the death of at least one loved one at some point in childhood; as much as 77.6% reported the loss of at least one relative (first or second degree) or close friend. The death of a parent is considered to be one of the most disrupting losses in childhood. Approximately 4% of all children (through age of 18) in the Western world experience the death of a parent (Garmezy & Masten, 1994; Harrinson & Harrington, 2001). In the Netherlands, every year, about 6400 children lose a parent, 50% of them are between 12 and 18 years old (Nederlands Jeugdinstituut, 2013). Even more children are confronted with other types of loss such as the death of a close friend or grandparent, or a divorce. Furthermore, in a recent study, 14% of Dutch primary school children in a sample from the general population (*N* = 1,770, mean age 10.24 years) reported exposure to a traumatic event like a disaster, accident or domestic violence (Alisic, Van der Schoot, Van Ginkel, & Kleber, 2008). It is worth noting that the sudden death or serious injury of a loved one (such as a best friend who died suddenly or a sibling who has committed suicide) was the most frequent traumatic experience.

In light of these figures, it is an important question which consequences childhood grief may have. Longitudinal research on this topic is scarce, but stems hopeful: most children can overcome these painful experiences and go on with their life after a while (Bonanno & Mancini, 2008). A noteworthy minority of bereaved children experiences emotional or psychological problems to a level that professional help is needed. Approximately 20% suffer enduring and debilitating psychological symptoms like increased psychiatric problems including depression, anxiety, Posttraumatic Stress Disorder (PTSD) and somatisation disorders in the first two years following the loss (Brent, Melhem, Donohoe, & Walker, 2009; Cerel, Fristad, Verducci, Weller, & Weller, 2006; Dowdney, 2000, 2008; Worden & Silverman, 1996). Retrospective research of psychopathology in adults who were bereaved in childhood is inconclusive. Some studies suggest that there is a link between childhood bereavement and worse adult physical health (Agid et al., 1999; Krause, 1998) and increased psychopathology (Appleby et al., 1999; Kendler et al., 2002; Luecken, 2008; Morgan et al., 2007; Reinherz, Giaconia, Hauf, Wasserman, & Silverman, 1999; Wilcox et al., 2010). However, recent research on a large Dutch community sample (*N* = 7,076) found no link between parental loss in childhood and adult psychopathology (Cuijpers et al., 2011; Stikkelbroek, Prinzie, De Graaf, Ten Have, & Cuijpers, 2012). More prospective longitudinal data are needed to determine which characteristics of children and their social context help to overcome an adverse event like the loss of another person, and which characteristics decrease the risk of developing psychopathology among those children.

SHORT HISTORICAL OVERVIEW OF BEREAVEMENT RESEARCH

Grief Research until World War II

Bereavement research in children is only since a few decades the focus of research. Parkes (2001) gives a historical overview of scientific grief research in adults. As he summarises, interest in loss as a potential cause of physical and mental illness goes back a few centuries. According to Parkes, it all started in 1621 with Burton, who referred to grief as melancholia, which nowadays resembles clinical depression. In 1703 Vogther published a thesis in which he prescribed a variety of medications for pathological grief. A century later, Rush (1835) used the term ‘dying of a broken heart’ to describe post mortem findings in people who had died of rupture of the auricles and ventricles of the heart following bereavement. Also Darwin (1872) had ideas about the nature of grief. He thought that the unique facial expression of humans was due to ‘grief muscles’ and that these muscles were less under voluntary control than other facial muscles.

Early influences for current grief research can be found in the work of Freud (1917/1984), Deutsch (1937) and Lindemann (1944). Freud (1917/1984) started his work during World War I and was the first who differentiated between mourning (*Trauer*) as normal grieving and grieving and melancholia (*Melancholie*) as pathological grieving, based on clinical observations. Freud linked bereavement with attachment. He stated that bereavement is sometimes a cause of depression and suggested that it is most likely to arise when someone dies who has been ambivalently loved. Freud stated that melancholia was a pathological form of grief and was very much like mourning (normal grief) except that it had a certain characteristic feature of its own, namely, angry impulses toward the ambivalently 'loved' person turned inward (Freud, 1917). At the same time, Freud treated soldiers who suffered from multiple traumas where they 're-lived' the traumatic experiences. It was seen as an effective treatment, because many of them could return to the war front. Freud's treatment approach of both melancholia and war neuroses had the aim to find a way of helping people to abandon defensive avoidance and face the (painful) reality. Deutsch (1937) drew attention to the absence of grief as forerunner for mental problems and during World War II, Lindemann (1944) did one of the earliest attempts to look at normal grief reactions in a systematic way. He wrote his paper 'The symptomatology and management of acute grief', which was based on the observations of 101 recently bereaved patients.

Grief Research in the Second Half of the 20th Century

In the decades after World War II, grief researchers tried to distinguish between normal and pathological grief in adults. In this period, the recognition of childhood bereavement slowly started with the discussion whether children were able to grieve or not. During the 1950s to the mid 1980s, research was mostly based on retrospective case studies or very small samples, and findings were often interpreted from a psycho-analytic perspective (Walker, 1993). From this perspective it was thought that children were unable to grieve until they reached adolescence (Freud, 1917/1984). Others, however, thought that children only could grieve if they developed object constancy, which implicated that most children should first reach the age of two to four years. In the context of his attachment theory, Bowlby suggested that even very young children can grieve when they are separated from their attachment figure (Bowlby, 1969, 1973, 1980).

Marris (1958) was the first to do a systematic study of bereaved people not seeking help versus people seeking psychiatric help. One of the things he found in the population of widowers, was that hallucinations in bereaved people could not be taken as symptoms of psychiatric illness. Two decennia later, Parkes (1965) described a taxonomy to distinguish between normal and three abnormal grief reactions (chronic, inhibited, and delayed grief) which was elaborated by Jacobs in the early 1990s (Jacobs, 1993). In 1970, Bowlby and Parkes conducted a longitudinal study and described phases of grief: (a) numbness, (b) yearning and searching (c) disorganisation and despair, and (d) reorganisation. In the

1980s, Bowlby (1980) distinguished between chronic mourning and prolonged absence of grief and Parkes and Weiss (1983) linked pathological grief with features of the loss event and introduced two grief syndromes ('unexpected grief syndrome' and 'ambivalent grief syndrome'). A decade later, Rando (1992, 1993) formulated seven syndromes of grief (absent, delayed, inhibited, distorted, conflicted, unanticipated and chronic mourning). However, those different syndromes were never validated in empirical studies.

GRIEF IN THE CONTEXT OF CHILDHOOD

Today, to understand the nature of normal grief the Dual Process Model (DPM; Stroebe & Schut, 1999, 2010) and Grief Task Model of Worden (1982, 1991, 1996, 2009) are popular. Both models describe the ways adults cope with the loss. Since to our knowledge the DPM has not been adapted for children, we will not discuss this model further in this chapter. The Grief Task Model describes four grief tasks, which were refined for children by Baker, Sedney and Gross (1992, 1996). Cook and Oltjenbruns (1998) placed these tasks in a developmental context (see Table 1.1).

Worden stated *"The task model is more consonant with Freud's concept of 'grief work' and implies that the mourner needs to take action and can do something to heal him/herself"* (Worden, 2001, p. 26). The idea of grief tasks is based on Havighurst's (1956) idea of developmental tasks. There are certain developmental tasks (physical, social and emotional) that must be mastered as the child grows up. The idea is that adaptation to loss requires completion of four grief tasks (see Table 1.1 Task I to IV), which require effort from the bereaved person. Uncompleted grief tasks can impair further growth and development. The grief tasks do not follow a specific order, but there is an implicit order suggested in the definitions of the tasks. For example, it is not possible to work through the pain of grief if the person does not accept the reality of loss.

Baker et al. (1992, 1996) formulated children's tasks (see Table 1.1 Task 1 to 8). Even more important is the work from Cook and Oltjenbruns (1998) that placed the grief tasks in a developmental context. This context influences the completion of the grieving tasks and may foster 'regrieving' or 'inhibited grief' in children. For example in the case of Bas; an adolescent who lost his mother when he was only 3 years old and who came to see a therapist when he was almost 12 years old. He did not have any grief related problems until he became an adolescent. His grief was 'inhibited' or 'delayed'. His problems elevated when he tried to make sense of the loss in the context of his normal developmental task to develop an identity.

The Grief Task Model does not say much about problematic grief. This is a problem because a theoretical model of problematic grief can help enhance interventions for the

Table 1.1 Adult Tasks of Mourning Compared to Children's

Adult's tasks (Worden, 2009)	Child's tasks of mourning (Baker, Sedney, & Gross, 1992, 1996)	Developmental context: Child's life stage as an influence on grief (Cook & Oltjenbruns, 1998)
I Accept the reality of the loss.	1. Understand that someone has died.	• Mature understanding is tied to the cognitive capacity to understand that the death is permanent.
II To process the pain of grief.	2. Face the psychological pain of the loss. 3. Cope with periodic resurgence of pain.	• Immaturity of child's coping mechanisms influences certain grief responses. • As developmental tasks shift and cognitive capacity matures, individuals often re-grieve an earlier loss.
III To adjust to a world without the deceased.	4. Invest in new relationships. 5. Develop a new sense of identity that includes experience of the loss.	
IV To find an enduring connection with the deceased in the midst of embarking on a new life.	6. Re-evaluate the relationship to the person who is lost. 7. Maintain an internal relationship with the person who has died. 8. Return to age-appropriate developmental tasks.	• Over time, children use a variety of strategies to retain a connection with the deceased. • If the child is unable to master particular tasks at this time, future success in various developmental areas will be jeopardised.

group of children that suffer from loss. Since the mid 1990s there is a growing body of evidence that a condition like problematic grief exists. Below we describe the research on the definition of problematic grief and the status of problematic grief in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association [APA], 2013).

CONSENSUS CRITERIA FOR PROLONGED GRIEF DISORDER

Over the last decade, researchers have struggled with the terminology they should use for the same complex of feelings and behaviours. Over the years they used complicated grief, traumatic grief, prolonged grief. In this dissertation Prolonged Grief Disorder (PGD) will be used.

In the early 1990s, two different research groups concluded that the time was right for establishing a criterion-based definition of pathological grief in adults. First, Horowitz, a leading expert in the field of traumatology, and his collaborators worked on the development of empirically based criteria for a disorder of grief. Placed within the framework of the theory of stress response syndromes, Horowitz, Bonanno and Holen introduced their description of 'pathological grief' in 1993. Four years later the empirically validated criteria for 'complicated grief disorder' were published (Horowitz et al., 1997). Comparable to PTSD, this disorder was conceptualised as consisting of 'intrusive symptoms' (e.g., unbidden memories of the deceased, spells of emotions) and 'signs of avoidance' and 'failure to adapt' (e.g., avoiding reminders of the deceased, sleep disturbance). However, their proposal received little attention of other researchers in the following years. In 2005, one empirical validation of the condition in adults was published (Langer & Maercker, 2005).

At the same time as Horowitz conducted his work, Prigerson and colleagues (1995) published a study in which they differentiated between two syndomes of grief which they called 'complicated grief' and bereavement related depression, as two syndromes of grief. Among the symptoms that characterise complicated grief were yearning, searching for the deceased, pre-occupation, crying, and disbelief over the loss. Bereavement related depression was characterised by, among other things, apathy, insomnia, depressed mood, and low self-esteem. The study showed that the symptoms that constituted complicated grief were linked with various psychological and social impairments, whereas the depressive symptoms were not (Prigerson, Frank et al., 1995).

This formulation of complicated grief received much more attention in the literature. Several studies have replicated the distinctiveness of complicated grief from established mood and anxiety disorders in adults and in children (e.g., Boelen, Van de Schoot, Van den Hout, De Keijser, & Van den Bout, 2010; Chen et al., 1999; Dillen, Fontaine, & Verhofstadt-Denève, 2009; Prigerson et al., 1996). Other studies among adults and children have further examined its distinctiveness from normal grief (Boelen & Van den Bout, 2008; Dillen, Fontaine, & Verhofstadt-Denève, 2008; Prigerson, Maciejewski et al., 1995). Moreover, problematic grief and its clinical correlates among youths and adults have been studied (McDermot et al., 1997; Melhem et al., 2004; Melhem, Moritz, Walker, Shear, & Brent, 2007; Prigerson, Maciejewski et al., 1995). Finally, still other studies in adults have gathered evidence that complicated grief is predictive of significant mental and physical morbidity, and impairments in health and quality of life (Boelen & Huntjens, 2008; Boelen & Prigerson, 2007; Boelen & Van den Bout, 2008; Bonanno et al., 2007; Prigerson et al., 1997; Prigerson et al., 2009). PGD is phenomenologically different from normal grief in that people with PGD are essentially stuck in a state of chronic mourning in which symptoms of acute grief do not subside, but continue to interfere with normal functioning far beyond the first half year of bereavement (Boelen & Van den Bout, 2008; Prigerson, 2004).

Cohen and colleagues (2002) came up with a rough description, but no clear definition, of Childhood Traumatic Grief (CTG), a condition in which complicated grief, PTSD and depressive symptoms are present. It is thought that trauma symptoms (e.g., intrusive thoughts, memories and images) interfere with the child's ability to grieve. Research into this condition is limited and although its treatment is growing, it is still limited (e.g., Brown & Goodman, 2005; Cohen & Mannarino, 2004; Cohen, Mannarino, & Knudsen, 2004; Cohen, Mannarino & Staron, 2006).

In the late 1990s a panel of experts in the field of bereavement, trauma and nosological psychiatry convened to formulate standardised consensus criteria for complicated grief (for a description of the process see Jacobs, Mazure, & Prigerson, 2000). These consensus criteria were subjected to an empirical evaluation, which led to the 'refined consensus criteria' (Prigerson et al., 1999). Next, a total of 291 bereaved respondents were interviewed three times by Prigerson and colleagues (2009). Their main finding was that the criteria set for PGD appeared to be able to identify bereaved persons at risk of persistent distress and dysfunction, which can enhance the detection of those bereaved and in need of treatment. As these criteria will be referred to frequently in this dissertation, they are shown in Table 1.2. Another set of criteria for complicated grief was given by Shear and colleagues (2011).

Table 1.2 Criteria for PGD Proposed for DSM-5 and ICD-11 (Prigerson et al., 2009)

A	Event: Bereavement (loss of a significant other)
B	Separation distress: The bereaved person experiences yearning (e.g., craving, pining or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree.
C	Cognitive, emotional, and behavioural symptoms: The bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree: 1. Confusion about one's role in life or diminished sense of self (i.e., feeling that a part of oneself has died). 2. Difficulty accepting the loss. 3. Avoidance of reminders of the reality of the loss. 4. Inability to trust others since the loss. 5. Bitterness or anger related to the loss. 6. Difficulty moving on with life (e.g., making new friends, pursuing interests). 7. Numbness (absence of emotion) since the loss. 8. Feeling that life is unfulfilling, empty, or meaningless since the loss. 9. Feeling stunned, dazed or shocked by the loss.
D	Timing: Diagnosis should not be made until at least six months have elapsed since the death.
E	Impairment: The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities).
F	Relation to other mental disorders: The disturbance is not better accounted for by major depressive disorder, generalised anxiety disorder, or Posttraumatic Stress Disorder.

Since May 2013 'Persistent Complex Bereavement Disorder' (PCBD) has been defined as a disorder within the Appendix (section III) of the DSM-5 (APA, 2013); those criteria are a mix of those formulated by Prigerson et al. (2009) and Shear et al. (2011). As the disorders in the Appendix have a tentative status, researchers are invited to do more research on those diagnoses. In other words, those diagnoses are not 'official' disorders yet.

To summarise, many children lose a loved person, but only recently we started to examine loss in children in a systematic way. Findings suggest that most, but not all children, can overcome this devastating experience. There is evidence that the symptoms defining adult PGD also adequately represent pathological grief among children and adolescents. Although the body of knowledge on bereavement in children and adolescents is steadily growing, there are still several unresolved issues related to assessment, the role of cognitions and treatment.

OUTLINE OF THIS DISSERTATION

This dissertation project had three aims: (I) to increase our understanding of the phenomenology and correlates of childhood PGD, (II) to enhance knowledge on the role of negative thinking in the development of childhood PGD and (III) to develop an intervention for children who suffer from loss and to examine its potential efficacy in two pilot studies. The three aims were addressed in seven research-based articles and one narrative review of interventions for bereaved children. Below we give an overview of the studies and the review we conducted.

Part I Phenomenology and Correlates of Prolonged Grief Disorder

Construction of an instrument for PGD symptoms in children

Although studies (e.g., Layne, Savjak, Salzman, & Pynoos, 2001; Melhem et al., 2004, 2007) are beginning to shed light on the phenomenology and correlates of PGD among children, to our knowledge, no validated measures are yet available that are specifically designed to tap PGD in children. To inform research and theory about PGD in children, and to be able to assess the effectiveness of bereavement interventions, it is important to have a measure that is specifically designed to tap PGD symptoms among children. The fact that internalising problems are generally poorly recognised by parents (cf. De Los Reyes & Kazdin, 2005) emphasises that it is important that children can report about their own emotional suffering following loss. Our aim was to develop age-specific questionnaires to assess PGD symptoms in children and adolescents, and to examine their psychometric properties. In ***chapter 2*** of this dissertation, the development and psychometric evaluation of the Inventory of Prolonged Grief for Children (IPG-C) and the Inventory of Prolonged Grief for Adolescents (IPG-A) is described. Psychometric properties of these measures were examined in three samples, including mostly parentally bereaved children (aged 8 to 12 years) and adolescents (aged 13 to 18 years).

Distinctiveness of symptoms of PGD depression, and PTSD in children

Research on the distinctiveness and construct validity of childhood PGD is important. First, it can enhance our knowledge of the generalisability of findings in adults to younger bereaved individuals. Second, it can inform theory and research about underlying mechanisms of post-loss psychopathology and the development of methods for the assessment and treatment of such psychopathology.

In contrast with the literature on adults (e.g., Bonanno et al., 2007), only a few studies have examined the factorial distinctiveness of PGD in children and adolescents (cf. Dillen et al., 2009; Melhem et al., 2004). Both studies provide preliminary support that symptoms of PGD, depression and anxiety cluster into three distinct factors. However, those studies had some limitations. The study conducted by Melhem et al. (2004) is limited by its reliance on exploratory (and not confirmatory) factor analysis and the use of an instrument (the Texas Revised Inventory of Grief (TRIG)) that was developed as a measure of normal grief and not PGD (Neimeyer, Hogan, & Laurie, 2008). Dillen et al. (2009) reported two studies, which were limited by the fact that they only included children confronted with the loss of a grandparent (Study 1) and did not examine the PGD distinctiveness in younger children below 12 years of age (Study 2). Moreover, both studies did not include an assessment of PTSD symptoms, leaving the distinctiveness of PGD and PTSD still unexamined.

Therefore, the aim of ***chapter 3*** is to address gaps in the research literature with regard to the phenomenology of bereavement related emotional distress in children and adolescents. Studies among adults have shown that symptoms of PGD, PTSD and depression are distinct from each other (e.g., Boelen et al., 2010). We therefore aimed to replicate these findings among children. The distinctiveness of symptoms of PGD, PTSD, and depression were examined in separate samples of children (8 to 12 years) and adolescents (13 to 18 years) confronted with the death of a loved person. Using confirmatory factor analysis we compared the fit of a one-factor model with the fit of a three-factor model.

PTSD symptoms in bereaved children

PTSD among bereaved children is relatively well documented (e.g., Brent et al., 1993; Brown & Goodman, 2005; Cerel, Fristad, Weller, & Weller, 1999; Melhem et al., 2007; Stoppelbein & Greening, 2000). Many bereaved children experience PTSD symptoms in some way. Bereavement related PTSD symptoms can follow both violent (e.g., murder, suicide) and non-violent deaths (e.g., exposure to a dying parent, traffic accidents or distress seen in family members) (cf. Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012). In the study described in ***chapter 4***, we wanted to examine the structure of PTSD symptoms among bereaved children. In DSM-IV (APA, 2000) PTSD has three factors (reexperiencing, avoidance and hyperarousal), but other models have been proposed (Kassam-Adams, Marsac, & Cirilli, 2010). In our study, we examined the fit of six models of the factor structure of PTSD in bereaved children (aged 8 to 18 years). Understanding the structure of PTSD symptoms in bereaved children is important for creating useful diagnostic systems that can inform assessment and treatment (Kassam-Adams et al., 2010).

Part II The Role of Negative Thinking in Psychological Functioning after Bereavement

For treatment, it is very important to understand why some children can cope with loss, while others have difficulty dealing with it. Boelen, Van den Hout and Van den Bout (2006, 2012) formulated a cognitive behavioural model that attempts to explain why in some adults, acute grief reactions persist and exacerbate (see Box 1.1). Based on this model, interventions for prolonged grief for adults have been developed and validated in research. For bereaved youth no such model exists yet. As mentioned earlier, empirical findings suggest that PGD symptoms in children and adults have much in common; therefore we chose to use this framework for this dissertation.

As can be seen in the model, negative thinking plays a core role in in the endurance of grief reactions and the development of PGD in adults (Boelen & Lensvelt-Mulders, 2005; Boelen, Van den Bout, & Van den Hout, 2003). When we have a quick look at Bas, he had negative thoughts about his dead mother, surviving father, himself and his future. It can be hypothesised that those (persistent) thoughts account for intense and persistent grief-related feelings and therefore should be the focus of treatment. However, very limited research is available in children. Findings of a preliminary study with 30 adolescent girls, aged 13 to 18 years (Boelen & Spuij, 2008), showed that several types of cognitions were associated significantly with complicated grief and severity of depression. Global negative thinking about life and self and catastrophic misinterpretations were most strongly linked

Box 1.1 A Cognitive Behavioural Conceptualisation of Prolonged Grief

The cognitive behavioural model of Prolonged Grief (see Figure 1.1) is inspired by Beck's general cognitive behavioural model of psychopathology (Beck, 1976) and, more specifically, Ehlers and Clark's (2000) cognitive model of PTSD. The cognitive behavioural model of PGD proposes that three interrelated processes account for the fact that some people suffer from bereavement to a degree that it can be described as PGD (Prigerson et al., 2009): (1) insufficient elaboration and integration of the loss within autobiographical memory; (2) persistent negative thinking; and (3) anxious and depressive avoidance behaviours. Next, these three processes will be described in more detail.

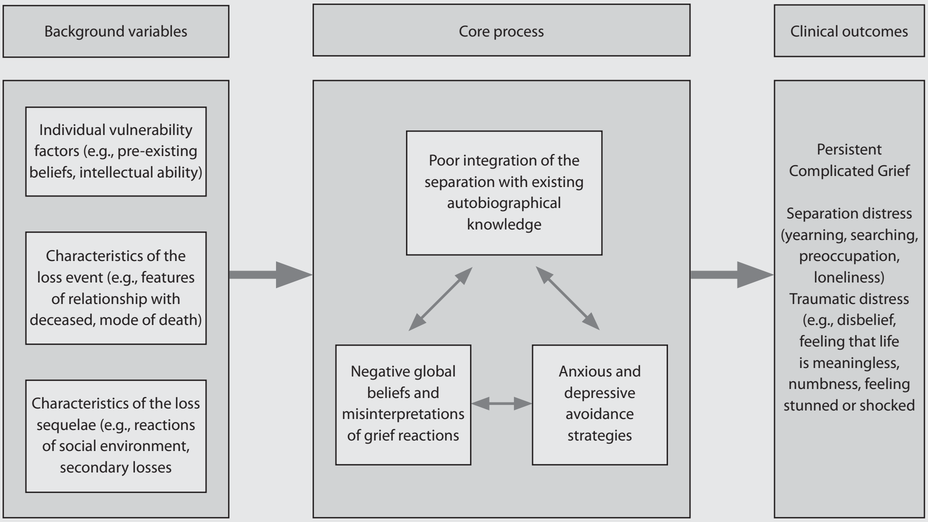

Figure 1.1 A Cognitive Behavioural Conceptualisation of Complicated Grief (Boelen, Van den Hout, & Van den Bout, 2006).

Insufficient elaboration and integration of the loss

The first process is insufficient integration of explicit knowledge about the irreversibility of the separation with preexisting knowledge about the self and the relationship with the lost person stored in autobiographical memory. This lack of integration maintains a sense of shock about the loss and a sense that the separation is reversible, causing yearning and a persistent urge to restore proximity to the lost person.

Persistent negative thinking

The second process is persistent negative thinking. Negative cognitions about the self, life, and the future, and catastrophic misinterpretations of one's grief reactions such as, e.g., signalling loss of control or insanity, are assumed to be very devastating. It is assumed that negative thoughts about the self, life, and the future directly contribute to a persistent preoccupation with everything that is lost. Catastrophic misinterpretations of one's grief reactions (e.g., "*If I would allow my feelings to run loose, I would go crazy*") fuel avoidant tendencies and emotional distress.

Anxious and depressive avoidance

Anxious avoidance refers to fear driven avoidance of stimuli that remind of the loss. Depressive avoidance exists of avoidance of activities that could foster adjustment, driven by pessimistic cognitions that one is unable to carry out and/or to enjoy such activities. Anxious avoidance maintains PGD by blocking elaboration and integration of the loss. Interventions like exposure are assumed to decrease symptoms. Depressive avoidance is detrimental because it maintains negative cognitions, alienation and isolation. It interferes with constructive action that could foster adjustment.

Box 1.1 *Continued*

Interaction between, and mediating role of, the three processes
As described in the model, the three processes are assumed not only to directly contribute to symptoms of PGD, but also assumed to influence each other. For instance, negative thoughts are assumed to block elaboration of the loss. When a child like Bas has a negative thought like for instance "*I am guilty of my mother's death*" it is not surprising that he would try to avoid this thought. This avoidance of a thought is likely to prevent integration of the loss in Bas' life and knowledge about himself, the world and his future. Cognitions and avoidance behaviours also have a mutual impact. For instance, negative cognitions about the self and life are likely to maintain a depressive cycle of withdrawal and inactivity. Catastrophic misinterpretations of grief reactions can contribute to anxious avoidance behaviours, which in turn, prevent correction of such misinterpretations.

Also important is that the three processes are assumed to mediate the impact of various established risk factors for poor bereavement outcome. These include personality characteristics of the bereaved individual (e.g., neuroticism or insecure attachment style), features characterising the loss (e.g., kinship to the deceased or the mode of death) and events and circumstances occurring in the aftermath (e.g., perceived social responses). In other words, it is proposed that the three processes are mediating mechanisms that explain why, for instance, people who are insecurely attached have an elevated chance of developing PGD. This is so because these people are likely to have more difficulties in accepting and integrating the reality of the loss (Process 1), maintaining a positive view of him/herself (Process 2), and engaging in helpful coping behaviours (Process 3), and thus have a greater chance of developing PGD. The notion of the mediating processes is important because it sheds a light on changeable mechanisms (e.g., negative thinking or avoidance behaviour) that can be targeted in treatment to curb the effect of more static, less easily changeable risk factors (e.g., personality features or mode of death) on the development and maintenance of PGD.

with symptoms of PGD. To our knowledge, no research is available about specific grief-related negative thoughts in bereaved children under the age of 13. Furthermore, cognitive restructuring has proven efficacious in the treatment of adult PGD (Boelen, De Keijser, Van den Hout, & Van den Bout, 2007) as well as in the treatment of psychopathology that overlaps with PGD, such as childhood anxiety and depression (David-Ferdon & Kaslow, 2008). In order to understand negative thinking in bereavement in youth an adequate measure is needed.

Therefore, ***chapter 5*** focuses on the construction of a questionnaire on negative thinking in bereaved children. In this study we developed the Grief Cognitions Questionnaire for Children (GCQ-C) and examined its psychometric properties. We studied the dimensionality, internal consistency, temporal stability and validity of the GCQ-C in bereaved children (aged 8 to 18 years)

Part III Development and Examination of *Grief-Help*

Our third aim was to develop an intervention for bereaved children. Although a lot of children are confronted with loss, very little research is done in the treatment of PGD in children. We found four review studies that were conducted in the past decade that included studies among children. First, a systematic review on bereavement care interventions was conducted by Forte, Hill, Pazder and Feudtner (2004). Aim of their research was to determine the best way to care for bereaved persons. From the 74 studies included in their review only nine studies were done among children and adolescents. Overall findings in both adults and children suggest that no consistent pattern of treatment benefit has been established. Second, Currier, Holland and Neimeyer (2007) conducted the first meta-analytic review on the effectiveness of bereavement interventions with children. Only 13 controlled studies could be included in the meta-analysis. It was found that the overall weighted effect size, representing the benefit of bereavement interventions compared to no-intervention at posttest, was $d = 0.14$, which did not differ significantly from zero. A third meta-analytic review conducted by Currier, Neimeyer and Berman (2008) on the effectiveness of bereavement interventions in both children and adults included 61 controlled studies. Their findings suggest that interventions should only target grievers who are in need for help. Fourth and finally, a meta-analytic review on 27 (controlled and uncontrolled) studies on interventions for bereaved children was conducted by Rosner, Kruse and Hagl (2010). Although the analyses of Rosner et al. (2010) and Currier et al. (2007) were both dealing with children, they differ in several ways. First, Rosner et al. (2010) included more controlled studies, however, there was an overlap of 73%. Also, Rosner et al. (2010) conducted a separate analysis of uncontrolled studies. The findings of Rosner et al. (2010) indicate small to moderate treatment effects (Hedges's $g = 0.35$ for controlled studies and an overall weighted effect size of 0.49 for uncontrolled studies) and were therefore less pessimistic about the effectiveness of grief interventions than Currier et al. (2007). Furthermore, Rosner et al. (2010) concluded that music-therapy interventions and trauma/grief-focused brief psychotherapy are the most promising treatment models. Despite these findings, in our view, those interventions also have limitations. For example, music-therapy has only been studied among children and in very small samples and trauma focused psychotherapy has only been studied in bereaved children who suffered a loss due to traumatic causes.

Given the lack of effective interventions for bereaved children and adolescents we aimed to develop an effective intervention. First we conducted a narrative review on published studies of existing interventions. In an intermezzo chapter (***chapter 6***) about interventions for bereaved children we give a description of those interventions. One of these interventions is *Grief-Help*, an intervention that we developed as a part of this dissertation project. In ***chapter 7*** of this dissertation we describe how we developed the *Grief-Help*[2] program. *Grief-Help* is a 9-session cognitive behavioural treatment for childhood

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[2] For a detailed description (in Dutch) of the protocol see Spuij and Boelen (2013).

PGD (8 to18 years), combined with 5 sessions of parental counselling. In the intermezzo we give a short description of *Grief-Help* and also describe how *Grief-Help* differs from existing interventions. ***Chapter 7*** includes a more detailed description of the content of *Grief-Help* and the findings of a multiple baseline study among six recently (between 6 to12 months) bereaved children and adolescents. All children participating in the *Grief-Help* program gave ratings of their satisfaction with each session, about the contact with their therapist and the information they received. ***Chapter 8*** describes a second pilot study of the potential effectiveness of *Grief-Help*. This open trial was conducted among 10 bereaved children and adolescents who were further removed from their loss than in the previous study. ***Chapter 9*** includes a study design of a multicentre randomised controlled trial of the *Grief-Help* intervention that is conducted in the Netherlands. In this study bereaved children (8 to 18 years) and their parent(s) will be included. Finally, ***chapter 10*** provides a summary and a general discussion of the studies presented in this dissertation.

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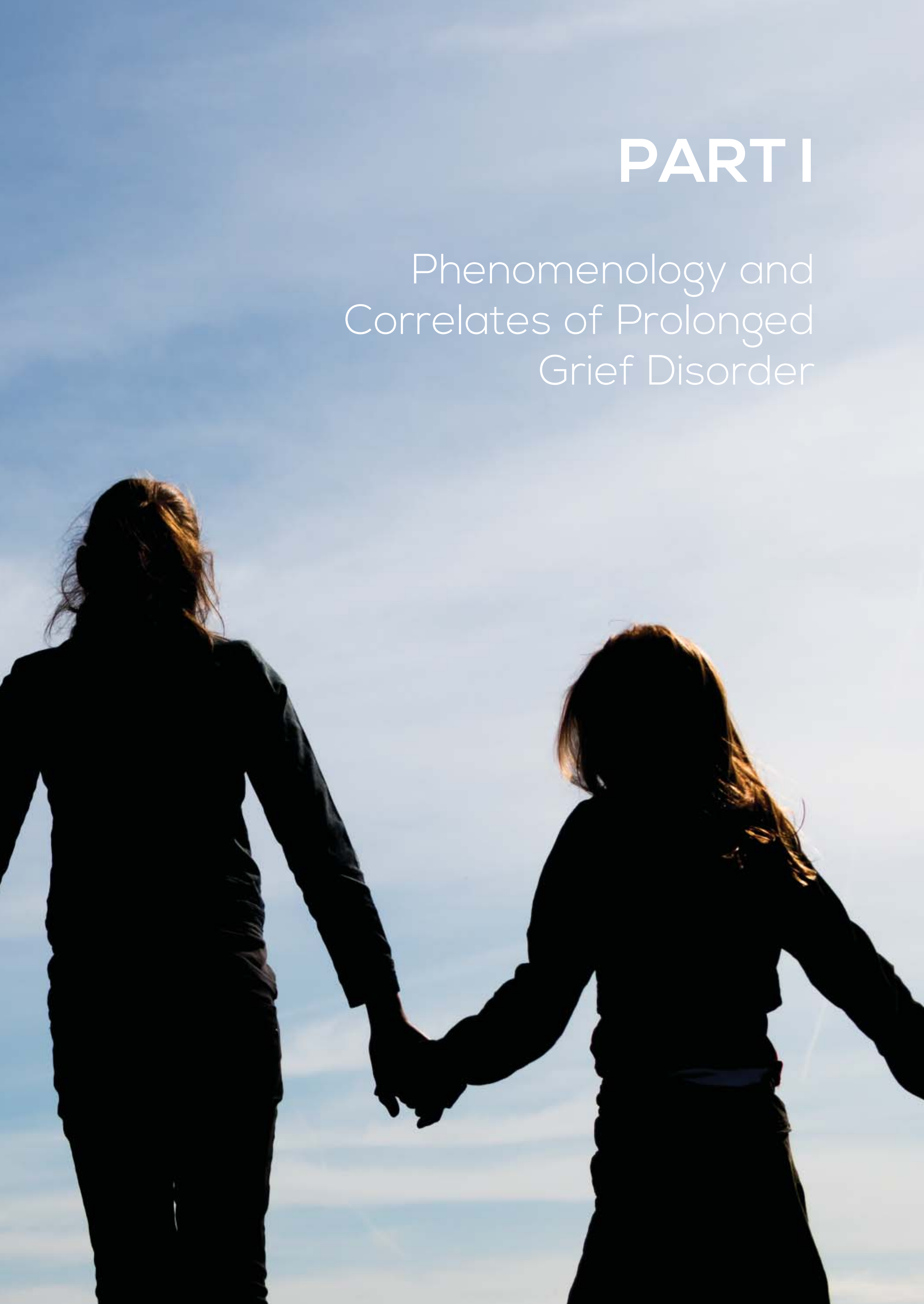
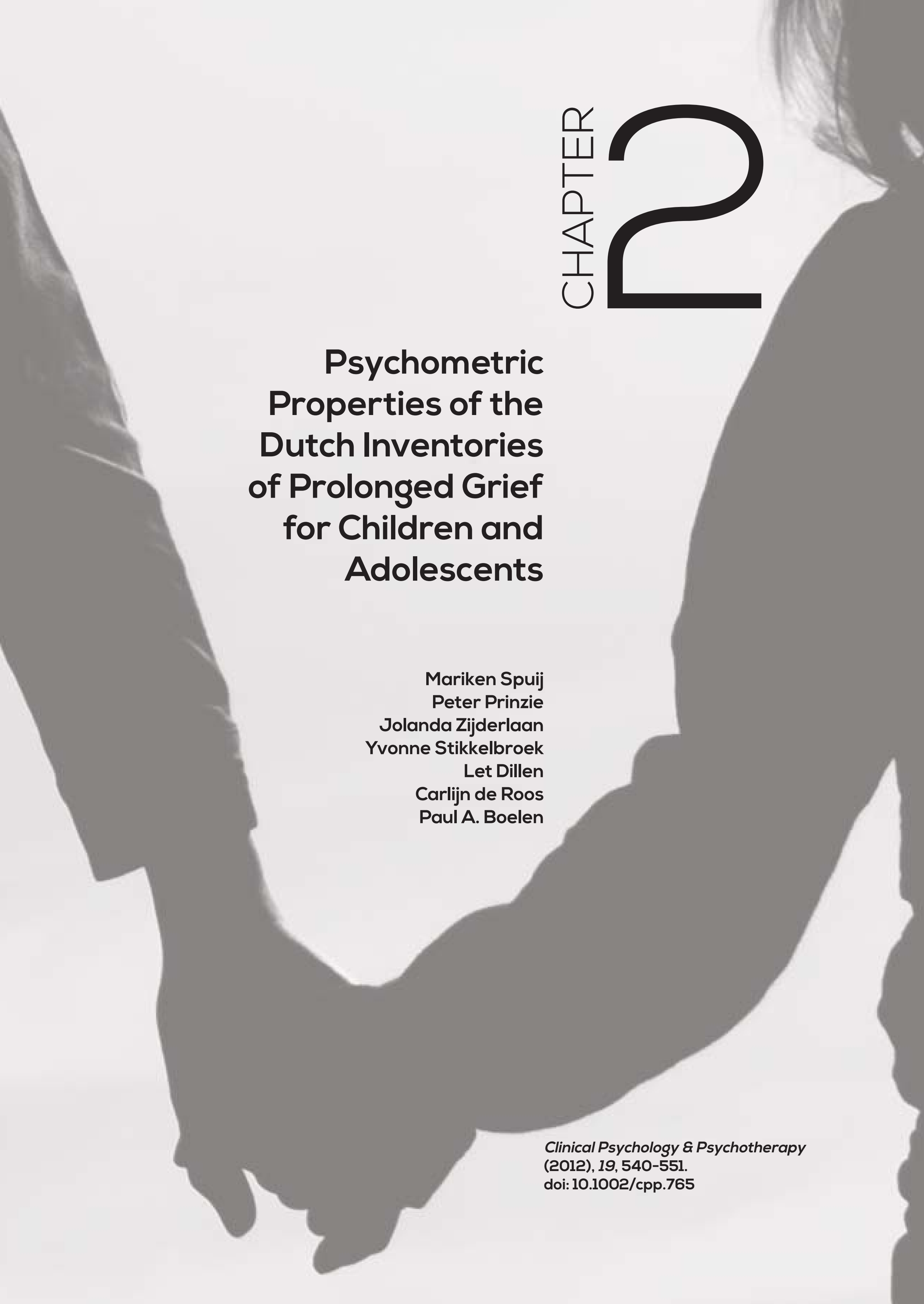
PART I

Phenomenology and Correlates of Prolonged Grief Disorder





CHAPTER 2

Psychometric Properties of the Dutch Inventories of Prolonged Grief for Children and Adolescents

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ABSTRACT

A significant minority of bereaved adults develops Prolonged Grief Disorder (PGD), a syndrome encompassing debilitating symptoms of grief distinct from depression and anxiety. Few studies have examined the phenomenology and correlates of PGD among children and adolescents. In part, this is due to the lack of a psychometrically sound questionnaire to assess PGD symptoms in these groups. Based on an adult-measure of PGD, we developed two questionnaires of PGD symptoms for children and adolescents respectively, named the Inventory of Prolonged Grief for Children (IPG-C) and Inventory of Prolonged Grief for Adolescents (IPG-A). Psychometric properties of these measures were examined in three samples, including mostly parentally bereaved children (8 to 12 years, total sample *N* = 169) and adolescents (13 to 18 years, total sample *N* = 153). First, findings showed that items of the IPG-C and IPG-A represented one underlying dimension. Second, the internal consistency and temporal stability of both questionnaires were adequate. Third, findings supported the concurrent validity (e.g., significant correlations with measures of depression and Postraumatic Stress Disorder [PTSD]), convergent and divergent validity (stronger correlations with similar questionnaires of 'traumatic grief' than with two dissimilar questionnaires of 'ongoing presence' and 'positive memories'), and incremental validity (significant correlations with an index of functional impairment, even when controlling for concomitant depression and PTSD) of the IPG-C and IPG-A. This report provides further evidence of the clinical significance of PGD symptoms among children and adolescents and promising psychometric properties of questionnaires that can be used to assess these symptoms.

INTRODUCTION

The loss of a relative to death is one of the most common and stressful life events that youths can experience (e.g., Alisic, Van der Schoot, Van Ginkel, & Kleber, 2008; Breslau, Wilcox, Storr, Lucia, & Anthony, 2004). Bereavement among youths has been associated with increased psychiatric problems including depression, anxiety, Postraumatic Stress Disorder (PTSD) and somatising disorders in the first two years following the loss (Brent, Melhem, Donohoe, & Walker, 2009; Cerel, Fristad, Verducci, Weller, & Weller, 2006). A growing literature has enhanced our knowledge about the phenomenology and correlates of pathological grief among youths, which has been variously labelled as traumatic, complicated, and prolonged grief (e.g., Melhem, Day, Shear, Day, Reynolds, & Brent, 2004; Melhem, Moritz, Walker, Shear, & Brent, 2007).

Recent research on pathological grief among youths has been informed by research among bereaved adults. Specifically, since the mid-1990s, there is growing recognition of a syndrome in adults that is referred to as Prolonged Grief Disorder (PGD). As currently defined, PGD is a disorder that encompasses grief specific symptoms including separation distress, a sense of disbelief regarding the death, numbness, and a sense that life is meaningless, present to a disabling and distressing degree at least six months following the death of a loved one (Prigerson et al., 2009). PGD has been found to be distinct from uncomplicated grief and from depression and PTSD, and to be associated with persistent impairments in health and quality of life (Boelen & Huntjens, 2008; Boelen & Prigerson, 2007; Boelen & Van den Bout, 2008; Bonanno, Neria, Mancini, Coifman, Litz, & Insel, 2007; Dillen, Fontaine, & Verhofstadt-Denève, 2008; Prigerson et al., 2009).

There is growing evidence that the symptoms defining adult PGD also adequately represent pathological grief among children and adolescents. For instance, Melhem et al. (2004) found PGD symptomatology among adolescents exposed to a peer's suicide to be distinct from normal grief and found a diagnosis of PGD – defined as a score in the upper 25% of summed PGD symptom scores – to predict the onset and course of depression and PTSD at subsequent assessments. In another study by these authors among parentally bereaved children and adolescents similar findings emerged, with PGD symptoms being associated with significant functional impairments beyond concurrent depression and PTSD (Melhem et al., 2007).

Although studies are beginning to shed light on the phenomenology and correlates of PGD among youths, to our knowledge, no validated measures are yet available that were specifically designed to tap PGD in this group. Melhem et al. (2004) used the Texas Revised Inventory of Grief (TRIG; Faschingbauer, Zisook, & DeVaul, 1987) to assess pathological grief that includes some but not all symptoms that denote the PGD syndrome. In their later study, Melhem et al. (2007) assessed PGD using the adult version of the revised Inventory of Complicated Grief (ICG-R; Prigerson & Jacobs, 2001). Although they modified the wording of some items, their ICG-R was not specifically constructed for youths who may have compromised the findings. Specific measures of grief in children and adolescent have in fact been constructed in earlier studies. For example, Layne, Savjak, Saltzman, and Pynoos (2001) developed the Expanded Grief Inventory (EGI). Nevertheless, although this measure has been found to have adequate psychometric properties (Brown & Goodman, 2005) it was designed to assess the construct of Childhood Traumatic Grief – defined as a combination of trauma symptoms and grief symptoms among traumatically bereaved children – rather than PGD symptoms *per se*.

To inform research and theorising about PGD in youths, and to be able to assess the effectiveness of bereavement interventions, it is important to have a measure that is specifically designed to tap PGD symptoms among children and adolescents. The fact that internalising problems are generally poorly recognised by parents (cf., De Los Reyes & Kazdin, 2005) emphasises that it is important that youths can report about their own emotional suffering following loss. The aim of the present study was to develop and examine Dutch questionnaires to assess PGD symptoms in children and adolescents. We constructed a children's version (for ages 8 through 12 years) and adolescents' version (for ages 13 through 18 years) of the 30-item ICG-R, a scale originally developed by Prigerson and Jacobs (2001) to assess symptoms of PGD (or Complicated Grief as it was formerly termed) in adults. Consistent with recent labelling, the questionnaires were named Inventory of Prolonged Grief for Children (IPG-C) and Inventory of Prolonged Grief for Adolescents (IPG-A). In this study, we examined the psychometric properties of the IPG-C and IPG-A. Specifically, we investigated their (a) dimensionality; (b) internal consistency; and (c) temporal stability, as well as their (d) concurrent; (e) convergent and divergent; and (f) incremental validity. Finally, we examined the extent to which scores on both questionnaires varied as a function of demographic and loss-related variables. Apart from seeking to contribute to the development of tools to assess PGD among youths, our secondary aim was to enhance knowledge about the phenomenology and (demographic and health-related) correlates of childhood PGD. The relevance of this is emphasised by the fact that Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) does not yet include a specific diagnostic category for a disorder of grief (American Psychatric Association [APA], 2000). Notably though, working groups preparing DSM-5 are now considering inclusion of such a disorder, although the naming and exact criteria of this disorder are still uncertain (APA, 2011; Prigerson et al., 2009; Shear et al., 2011).

METHOD

Participants and Procedure

Three samples were recruited from different sources. In all samples, participants aged 8 to 12 years comprised the children sample and completed the IPG-C. Participants aged 13 to 18 years comprised the adolescent sample and completed the IPG-A. Children, adolescents, and their parents from Sample 1 completed no additional questionnaires. Children, adolescents, and their parents from Samples 2 and 3 completed complementary scales to be described below. Table 2.1 shows characteristics of all participants. In total, 169 children completed the IPG-C and 153 adolescents completed the IPG-A.[1]

Sample 1

Sample 1 included youths who participated in bereavement projects in Flanders (the Dutch-speaking part of Belgium) led by L.D. They were recruited through (a) media publicity; (b) direct mailing of self-support organisations to their members; (c) contact with victim services; and (d) announcements among psychology graduate students. People were deemed eligible for participation in the bereavement projects if they had lost a parent, brother or sister. Consequently, those who lost other relatives were not included in this sample. Sample 1 included 32 children and 63 adolescents. Assent was obtained from children, informed consent from parents and adolescents.

Sample 2

Sample 2 was recruited through collaboration with a national grief support group for children in the Netherlands that offers council and advice to parents and children about grief and bereavement and organises support weekends for children and their parent(s). During the period of data-collection for the present study, all families that had a child or adolescent applying for such a weekend were sent a letter. The letter included a description of the study and a stamped refusal card. If no refusal card was received within two weeks, the family was contacted and – if parent(s) and child agreed to participate – a home visit was planned. Home visits were conducted by trained graduate students. During the visits, aims of the study were explained and questionnaires administered. If so needed, the

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[1] The response rate in Sample 2 was 86% and in Sample 3 was 99%; the distribution of study information in Sample 1 precluded exact monitoring of the response rate, but the impression was that this was over 90%. Reasons for non-participation were not systematically recorded, but it was our impression that most of the people who refused participation did so because they did not feel that they could profit from participation themselves.

Table 2.1 Demographic Characteristics, Loss Related Characteristics, and Scores on Prolonged Grief and Depression Measures Across Samples

	Sample 1		Sample 2		Sample 3		Combined samples	
	Children	Adolescents	Children	Adolescents	Children	Adolescents	Children	Adolescents
N	32	63	100	26	37	64	169	153
Demographic characteristics								
Gender (*N* (%))								
Male	11 (34.4)	30 (47.6)	51 (51.0)	7 (26.9)	23 (62.2)	17 (26.6)	85 (53.3)	54 (35.3)
Female	21 (65.6)	33 (52.4)	49 (49.0)	19 (73.1)	14 (37.8)	47 (73.4)	84 (49.7)	99 (64.7)
Age (*M* (*SD*))	9.97 (1.20)	15.17 (1.35)	9.71 (1.20)	14.35 (1.33)	9.97 (1.28)	15.27 (1.48)	9.82 (1.22)	15.07 (1.43)
Loss related characteristics								
Deceased is (*N* (%))								
Parent	17 (53.1)	41 (65.1)	93 (93.0)	23 (88.5)	20 (54.1)	41 (64.1)	130 (76.9)	105 (68.6)
Sibling	15 (46.9)	22 (34.9)	7 (7.0)	3 (11.5)	5 (13.5)	7 (10.9)	27 (16.0)	32 (20.9)
Other relative	-	-	-		12 (32.4)	16 (25.0)	12 (7.1)	16 (10.5)
Cause of death is (*N* (%))								
Illness	18 (56.2)	35 (55.6)	58 (58.0)	14 (53.8)	23 (65.7)	41 (64.1)	99 (58.6)	90 (58.8)
Traumatic (accident, suicide, homicide)	8 (25.0)	21 (33.3)	23 (23.0)	5 (19.2)	8 (22.9)	10 (15.6)	39 (23.1)	36 (23.5)
Sudden medical cause (e.g., heart attack)	3 (9.4)	7 (11.1)	14 (14.0)	7 (26.9)	2 (5.7)	10 (15.6)	19 (11.2)	24 (15.7)
Other	3 (9.4)	-	5 (5.0)	-	2 (5.7)	3 (4.7)	10 (5.9)	3 (2.0)
Death was expected by participants?								
Yes	9 (28.1)	22 (36.1)	25 (25.0)	7 (28.0)	13 (35.1)	25 (39.1)	47 (27.8)	54 (36.0)
No	23 (71.9)	39 (63.9)	75 (75.0)	19 (72.0)	24 (64.9)	39 (60.9)	122 (72.2)	96 (64.0)
Time since loss in months (*M* (*SD*))	29.26 (23.51)	50.77 (40.67)	32.7 (22.57)	29.64 (24.99)	38.88 (29.64)	41.38 (39.11)	33.05 (24.08)	43.48 (38.22)
Symptom scores								
IPG-C / IPG-A	51.77 (12.99)	50.52 (11.53)	51.40 (11.43)	50.23 (14.49)	47.95 (10.28)	50.59 (12.18)	50.71 (11.53)	50.50 (12.26)
CDI	-	-	9.10 (6.51)	10.35 (7.13)	9.20 (5.22)	14.26 (8.06)	9.13 (6.17)	13.13 (7.97)

Note. CDI = Children's Depression Inventory. IPG-C = Inventory of Prolonged Grief for Children. IPG-A = Inventory of Prolonged Grief for Adolescents.

students could help with the completion of the questionnaires. Assent was obtained from children, informed consent from parents and adolescents. Sample 2 included 100 children and 26 adolescents. Because the support-weekends were all focussed on children bereaved by the loss of a parent or sibling, this sample did not include any children who lost other relatives. Fourteen randomly selected children and 10 randomly selected adolescents filled in the IPG-C or IPG-A a second time, approximately six weeks (M = 35.79, SD = 5.47 days, range 25-45 days) later. These were all participants that were on a waiting list for a support group.

Sample 3

The third sample was recruited via several outpatients clinics in the Netherlands. During the period of data-collection, consecutive patients aged 8 to 18 years who reported emotional problems associated with the death of a parent, sibling, or other loved one among the complaints they sought help for were invited to participate. Those who did so completed questionnaires accompanied by their therapist. Assent was obtained from children, informed consent from parents and adolescents. Sample 3 included 37 children and 64 adolescents. Four randomly selected children and 10 randomly selected adolescents filled in the IPG-C or IPG-A a second time, approximately six weeks (M = 34.50, SD = 7.36 days, range 25-46 days) later. These were all participants that were on a waiting list for help.

Measures

All participants completed the IPG-C or IPG-A, together with a questionnaire about demographic (e.g., age) and loss-related (e.g., mode of death) variables. In addition, children and adolescents from Samples 2 and 3 completed the Child PTSD Symptom Scale (CPSS), Children's Depression Inventory (CDI), and Extended Grief Inventory (EGI). Adolescents from Samples 2 and 3 also completed the Youth Self Report (YSR). In Samples 2 and 3, at least one of the parents completed the Child Behaviour Checklist/6-18 (CBCL).

Inventory of Prolonged Grief for Children and Inventory of Prolonged Grief for Adolescents

Construction of the IPG-C and IPG-A was accomplished in five steps. We initially strove for a single children's version. Hence, for the *first step*, wording of the 30 items of the ICG-R (Prigerson & Jacobs, 2001; Dutch adult version by Boelen, Van den Bout, De Keijser, & Hoijtink, 2003) was simplified by three experts in the field of clinical child psychology. In the *second step*, this version was evaluated by five independent reviewers; two experts on psychological assessment for youths, one expert on child language, and two clinical child psychologists with expertise in grief. Reviewers provided narrative feedback on item clarity and appropriateness for the age group (8 to 18 years). Moreover, they gave suggestions for simplification of instructions and some of the items, for children below 13 years of age. Accordingly, in the *third step*, it was decided to construct two versions for children and adolescents, respectively. Moreover, it was decided to replace the original 5-point response scale (with anchors '*almost never*' to '*always*') by a 3-point scale, with categories 1 = *almost never*, 2 = *sometimes*, 3 = *always*. This decision was motivated by the fact that (a) the 3-point scale was deemed more easy to comprehend; (b) the 3-point scale matches other widely used questionnaire measures such as the CDI (Kovacs, 2003); and (c) a recent item-response theory analyses of the adult ICG-R indicated that response option thresholds were ordered when items were scored on 3-point scales but not when they were scored on 5-point scales (Boelen & Hoijtink, 2009). In the *fourth step*, the IPG-C was reviewed by five children between eight and twelve years old ($M = 10.05$ years) and the IPG-A by five adolescents aged thirteen to eighteen ($M = 15.30$ years). Children where asked to comment on the questionnaire's comprehensibility which led to minor additional changes in wording. In the *fifth step*, both measures were evaluated again by six other children (three girls) and six other adolescents (three girls).[2] This did not lead to further changes. Thus, the final versions of the IPG-C and IPG-A both included 30 items, representing symptoms of PGD and other putative markers of debilitating grief symptoms. The general content of each item is shown in Table 2.2; English translations of the Dutch IPG-C and IPG-A are shown in the Appendix. Respondents were instructed to rate the frequency of each symptom in the preceding month, on 3-point scales (1 = *almost never*, 2 = *sometimes*, 3 = *always*).

Child PTSD Symptom Scale (CPSS)

The CPSS is a 17-item questionnaire that taps symptoms of PTSD symptoms as defined in the DSM (APA, 2000). It was originally constructed by Foa, Johnson, Feeny, and Treadwell (2001; Dutch translation Engelhard, 2005). Respondents rate the occurrence of symptoms on 4-point scales ranging from 0 (*not at all/only once a week*) to 3 (*almost always/five or more times a week*). Psychometric properties have been found to be adequate (Foa et al., 2001). In the present sample, the internal consistencies (Cronbach's alphas) in the combined children sample ($N = 137$) and adolescent sample ($N = 90$) from Samples 2 and 3 were 0.85 and 0.91, respectively.

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[2] Children and adolescents reviewing the items in the fourth and fifth steps were all bereaved by the loss of a family member, other than a parent or sibling, within the last 3 years.

Children's Depression Inventory (CDI)

The CDI developed by Kovacs (2003) taps symptoms of depression. It contains 27 groups of three statements representing depressive symptoms at increasing levels of severity, scored from 0 (*symptom absent*) to 2 (*symptom present always/most of the time*). For all 27

Table 2.2 Abbreviated Items of the Dutch IPG-C and IPG-A and Factor-Loadings in the One-Factor Solutions

	Item content	Factor-loadings in combined children sample (*N* = 169)	Factor-loadings in combined adolescent sample (*N* = 153)
1	Loss feels devastating.	0.62	0.73
2	Thinking so much of him/her that it is difficult to do usual things.	0.75	0.73
3	Memories of him/her are upsetting.	0.47	0.53
4	Feel it's difficult to accept this loss.	0.68	0.65
5	I yearn for him/her and want to be with him/her.	0.65	0.69
6	I seek places and things that remind me of him/her.	0.36	0.42
7	Feel angry about his/her death.	0.50	0.62
8	Can hardly believe that he/she died.	0.52	0.68
9	Feel shocked and overwhelmed by loss.	0.60	0.89
10	Feel it is hard to trust people.	0.68	0.67
11	Feel distant from other people.	0.49	0.61
12	Do or feels things that he/she used to do/feel.	0.56	0.40
13	Avoid thinking that he/she is dead.	0.32	0.50
14	Life feels empty or meaningless.	0.64	0.83
15	Hear his/her voice.	0.59	0.42
16	I see him/her.	0.63	0.34
17	Have difficulties to experience feelings.	0.55	0.80
18	Feel guilty being alive while he/she is dead.	0.73	0.78
19	Feel bitter inside.	0.73	0.69
20	Feel jealous of others who didn't lose someone.	0.37	0.50
21	Feeling that the future is meaningless.	0.79	0.81
22	Feel lonely since he/she died.	0.68	0.79
23	Feel that life is worthless.	0.69	0.79
24	Feel like part of me died.	0.68	0.73
25	Feel that his/her death changed everything.	0.62	0.60
26	Feel unsafe.	0.74	0.66
27	Feel like having no control over things happening.	0.62	0.79
28	Do less well in different areas (in school, with friends).	0.65	0.69
29	Feel tense since he/she died.	0.72	0.73
30	Sleep poorly since he/she died.	0.49	0.58

Note. IPG-C = Inventory of Prolonged Grief for Children. IPG-A = Inventory of Prolonged Grief for Adolescents.

items, respondents select the statement that best describes the severity of the symptom during the preceding week. Items are summed to form an overall depression severity score. The original English (cf. Cole & Martin, 2005) and Dutch versions of the CDI (Timbremont, Braet, & Roelofs, 2008) have adequate psychometric properties. The alphas in the combined children sample ($N = 137$) and adolescent sample ($N = 90$) from Samples 2 and 3 were 0.83 and 0.87, respectively.

Extended Grief Inventory (EGI)

The EGI, constructed by Layne et al. (2001; Dutch version by Dillen, 2005), is a 28-item measure designed to assess Childhood Traumatic Grief – a combination of symptoms of grief and traumatic stress. Respondents rate the presence of each reaction during the previous month on 5-point scales ranging from 0 (*rarely*) to 4 (*almost always/daily*). The EGI constitutes three subscales: (a) Childhood Traumatic Grief; (b) Ongoing Presence; and (c) Positive Memories (Brown & Goodman, 2005). The first scale (23 items) assesses a combination of grief and posttraumatic stress reactions, the second (2 items) taps a sense of presence of the deceased, and the third (3 items) assesses the presence of positive memories of the deceased. Prior research has supported the psychometric properties of the EGI (Brown & Goodman, 2005). In the present samples it was found that the three subscales had alphas of 0.91, 0.49, and 0.64, respectively in the combined children samples, and 0.95, 0.47, and 0.54 in the combined adolescent samples from Sample 2 and 3.

Child Behaviour Checklist/6-18 (CBCL)

The CBCL is a measure of emotional and behavioural problems of children and adolescents (aged 6 to 18 years) constructed by Achenbach and Rescorla (2001; Dutch translation, Verhulst, Van der Ende, & Koot, 1996). It includes 118 items, representing different problem areas (e.g., anxious, depressive, somatic symptoms, aggressive behaviour, attentional problems). The measure can be completed by parents or other people close to the child. Items are rated on 3-point scales (0 = *not true*, 1 = *somewhat or sometimes true*, 2 = *very true/often true*) and tap into eight different problem areas. Scores on some of these areas can be summed to obtain indices of Internalising Problems and Externalising Problems, whereas the summed score of all items represents a Total Problem score. Psychometric properties of the original version (Achenbach & Rescorla, 2001) and Dutch version (Verhulst et al., 1996) are adequate. In Samples 2 and 3, at least one of the parents completed the CBCL. In case both parents completed the scale, we only used data from one randomly selected parent. Random selection of CBCLs was justified, given that correlations between the father's and mother's version, if available, were high.[3] The internal consistencies of the Internalising subscale, the Externalising subscale, and the Total scale in the combined children samples from Sample 2 and 3 were 0.95, 0.89, and 0.91 respectively, and in the combined adolescent samples from Sample 2 and 3 were 0.96, 0.88, and 0.92 respectively.

Youth Self Report (YSR)

The YSR, developed by Achenbach and Rescorla (2001), is a 120-item measure of emotional and behavioural problems among youngsters between 11 and 18 year. Its items are comparable to those of the CBCL except that they are written in the first person and completed by youngsters between 11 and 18 years of age. Items representing problems are rated using a forced-choice response format (0 = *not true*, 1 = *somewhat/sometimes true*, 2 = *very/often true*). As with the CBCL, indices of Internalising Problems and Externalising Problems, as well as a Total Problem score can be obtained from the measure. Psychometric properties of the original version (Achenbach & Rescorla, 2001) and the Dutch version (Verhulst, Van der Ende, & Koot, 1997) are adequate. In the present study the YSR was only completed by adolescents from Samples 2 and 3. The YSR yielded Cronbach's alphas of 0.94 (Internalising Problems), 0.89 (Externalising Problems), and 0.87 (Total scale) in the combined adolescents samples from Sample 2 and 3.

Statistical Analyses

First, the dimensionality of the IPG-C and the IPG-A was examined, using exploratory factor analysis implemented in Mplus 4 with maximum likelihood estimation (Muthén & Muthén, 2007). The dimensionality of the IPG-C was examined using the three combined children samples ($N = 169$). The dimensionality of the IPG-A was examined using the three combined adolescent samples ($N = 153$). Second, the internal consistency and temporal stability of the IPG-C and IPG-A were examined. Next, several predictions were tested with respect to the validity of the IPG-C and the IPG-A. With respect to the *concurrent validity*, it was expected that PGD severity as tapped by the IPG-C and IPG-A would be significantly and positively associated with the severity of concomitant depression severity (CDI), PTSD severity (CPSS), and Internalising Problems, Externalising Problems and Total Problems as indexed by the

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[3] Specifically, for 39 children from Sample 2 and 3 data were available from both parents. The correlations between scores of the fathers and mothers for the Internalising score was $r = 0.87$, for the Externalising score was $r = 0.92$, and for the Total score was $r = 0.87$ ($ps < 0.001$). For 40 adolescents from these samples data were also available from both parents. Correlations between scores of the fathers and mothers for the Internalising score was $r = 0.72$, for the Externalising score was $r = 0.85$, and for the Total score was $r = 0.78$ ($ps <0 .001$).

CBCL. In addition, IPG-A scores were expected to be positively associated with YSR scores. With respect to the *convergent* and *divergent validity*, it was expected that the IPG-C and IPG-A both would be more strongly (and positively) associated with the Childhood Traumatic Grief subscale from the EGI, tapping a construct that is similar to PGD, than with the Ongoing Presence and Positive Memories subscales from the EGI, tapping dissimilar constructs. With respect to the *incremental validity*, we predicted that scores on the IPG-C and IPG-A would be significantly and positively associated with the degree to which children and adolescents experienced impairments in functioning as a result of the loss (indexed by one item from the IPG-C and IPG-A), even when controlling for concomitant depression (CDI) and PTSD (CPSS) severity. Finally, we explored the extent to which IPG-C and IPG-A scores differed as a function of demographic and loss related variables that we assessed (see Table 2.1).

RESULTS

Characteristics of the Study Samples

Table 2.1 shows background and loss related characteristics of the three samples. Across the samples, most participants had lost a parent. Most losses were due to illness and were experienced as being unexpected. Scores on the IPG-C and IPG-A (minimum 30, maximum 90) and the CDI are also shown in Table 2.1. Scores on the IPG-C did not differ between the three children's samples ($F(2, 166) = 1.38$, $p = 0.26$). Likewise, scores on the IPG-A did not differ between the three adolescent samples ($F < 1$). Children and adolescents from Sample 2 and 3 completed the CDI. In comparison with reference groups from Timbremont et al. (2008) scores fell in the subclinical range.

Dimensionality

Inventory of Prolonged Grief for Children

Exploratory factor analysis on the IPG-C, using data from the combined children samples ($N = 169$), resulted in the emergence of seven factors with eigenvalues greater than 1.00 (i.e., 11.94, 2.05, 1.63, 1.56, 1.26, 1.05 and 1.02). However, there were reasons to conclude that the IPG-C items are best characterised as one factor. First, the first factor explained 38% of the variance in the ICG-C with the second through seventh factor each adding only 3 to 6% to the variance explained by the first factor. Second, inherent to that, the scree plot revealed a clear break after the first component. Third, as shown in Table 2.2, in the one factor solution, all 30 items had factor loadings ≥ 0.30. Finally, in the models with more than one factor, several items loaded highly on more than one factor and components could not be interpreted in a meaningful way. Overall, the findings suggested that, within the present dataset, the IPG-C items clustered together into one underlying dimension of PGD symptomatology.

Inventory of Prolonged Grief for Adolescents

Exploratory factor analysis on the IPG-A, using data from the combined adolescent samples (*N* = 153), resulted in the emergence of six factors with eigenvalues greater than 1.00 (i.e., 13.92, 2.23, 2.04, 1.58, 1.22, 1.02). However, as with the IPG-C, it seemed that the IPG-A items are best characterised as one factor. First, the first factor explained 45% of the variance in the ICG-C with the second through sixth factors each adding only 3.5% to 6.5% to the variance explained by the first factor. Second, the scree plot showed a clear break after the first component. Third, as shown in Table 2.2, in the one factor solution, all items had factor-loadings ≥ 0.30. Finally, in the models with more than one factor, several items again had strong loadings on more than one factor and factors did not seem to represent easily interpretable aspects of PGD. Overall, the findings suggested that, in the current dataset, the IPG-A items represented a single dimension of PGD symptomatology.

Internal Consistency

Inventory of Prolonged Grief for Children

Cronbach's α for the children in Sample 1 was 0.94, in Sample 2 was 0.91, and in Sample 3 was 0.89. For the combined children samples (*N* = 169), the α was 0.91. In line with the results of the exploratory factor analysis, in the combined children samples the item-total correlations were all positive and ranged from 0.24 (item 13) to 0.63 (item 26). Seventeen items had item-total correlation greater than 0.50 and the α did not increase with the deletion of a single item.

Inventory of Prolonged Grief for Adolescents

Cronbach's α for the adolescents in Sample 1 was 0.93, in Sample 2 was 0.96, and in Sample 3 was 0.93. For the combined adolescent samples (*N* = 153), the α was 0.94. In the combined samples the item-total correlations were all positive and ranged from 0.27 (item 16) to 0.75 (item 9). Twenty items had item-total correlation greater than 0.50 and the α did not increase with a deletion of a single item.

Temporal Stability

Inventory of Prolonged Grief for Children

The test-retest correlation for the 18 children from Samples 2 and 3 who completed the IPG-C twice with a four to six weeks interval was $r = 0.88$ ($p < 0.001$).

Inventory of Prolonged Grief for Adolescents

The test-retest correlation for the 20 adolescents from Samples 2 and 3 who completed the IPG-C twice with a four to six weeks interval was $r = 0.72$ ($p < 0.001$).

Concurrent Validity

Inventory of Prolonged Grief for Children

Correlations of the IPG-C with the CDI, CPSS, and CBCL scores for the combined children from Samples 2 and 3 are shown in Table 2.3. As predicted, the IPG-C was significantly and positively correlated with indices of depression (CDI) and PTSD (CPSS). Unexpectedly, IPG-C scores were not significantly correlated with CBCL scores.

Inventory of Prolonged Grief for Adolescents

Correlations of the IPG-A with the CDI, CPSS, CBCL, and YSR scores for the combined adolescent from Samples 2 and 3 ($N = 90$) are also shown in Table 2.3. As predicted, the IPG-A was significantly and positively correlated with measures of depression (CDI) and posttraumatic stress (CPSS), with scores on the CBCL, and with self-rated Internalising Problems and the Total Problems score on the YSR. Unexpectedly, IPG-A scores were unrelated to Externalising scores on the YSR.

Convergent and Divergent Validity

Inventory of Prolonged Grief for Children

Correlations of the IPG-C with the EGI subscales for the children from Samples 2 and 3 ($n = 135$) are shown in Table 2.3. As predicted, the IPG-C was more strongly associated with the Childhood Traumatic Grief subscale than with the Ongoing Presence and Positive Memories subscales. Differences between correlations were significant ($r = 0.86$ versus $r = 0.52$; $t = 7.01$, $p < 0.001$, and $r = 0.86$ versus $r = 0.38$; $t = 8.81$, $p <0 .001$).

Table 2.3 Correlations Between Study Measures among Children and Adolescents from Samples 2 and 3

	IPG-C		IPG-A	
	r	*n*	*r*	*n*
Posttraumatic Stress (CPSS)	0.78**	135	0.76**	90
Depression (CDI)	0.62**	134	0.69**	90
Childhood Traumatic Grief (EGI)	0.86**	135	0.91**	89
Ongoing Presence (EGI)	0.52**	135	0.30*	89
Positive Memories (EGI)	0.38**	135	0.21	89
Internalising Problems (CBCL)	0.09	134	0.33*	83
Externalising Problems (CBCL)	0.05	134	0.36*	83
Total Problems (CBCL)	0.11	134	0.40**	83
Internalising Problems (YSR)	-	-	0.62**	84
Externalising Problems (YSR)	-	-	0.21	84
Total Problems (YSR)	-	-	0.49**	84

Note. Samples sizes differ due to occasional missing values. CDI = Children's Depression Inventory. CBCL = Child Behaviour Checklist. CPSS = Child Posttraumatic Stress Disorder Symptom Scale. EGI = Extended Grief Inventory. IPG-C = Inventory of Prolonged Grief for Children. YSR = Youth Self Report.
* $p < 0.01$. ** $p < 0.001$.

Inventory of Prolonged Grief for Adolescents

Table 2.3 also shows correlations of the IPG-A with the EGI subscales for adolescents from Samples 2 and 3 ($N = 90$). As predicted, the correlation with the Childhood Traumatic Grief subscale was higher than with the Ongoing Presence and Positive Memories subscales. Again, differences between correlations were significant ($r = 0.91$ versus $r = 0.30$; $t = 9.35$, $p < 0.001$, and $r = 0.91$ versus $r = 0.21$; $t = 9.86$, $p < 0.001$).

Incremental Validity

Inventory of Prolonged Grief for Children

Among the children from Samples 2 and 3 ($n = 135$), higher scores on the impairment in functioning item of the IPG-C (item 28) were significantly correlated with the summed score of the other 29 items of the IPG-C: $r = 0.54$, $p < 0.001$. Regression analysis showed that – when controlling for the shared variance between scores on the IPG-C (without item 28), the CDI, and the CPSS – IPG-C scores ($\beta = 0.26$, $t = 2.29$, $p < 0.05$), but not scores on the CDI ($\beta = 0.19$, $t = 1.81$, $p < 0.10$) and the CPSS ($\beta = 0.21$, $t = 1.67$, $p < 0.10$) predicted scores on this impairment in functioning item.

Inventory of Prolonged Grief for Adolescents

Similarly, among the adolescents from Samples 2 and 3 (n = 90), higher scores on the impairment in functioning item from the IPG-A (item 28) were significantly correlated with higher total scores on the IPG-A (omitting this particular item); $r = 0.64$, $p < 0.001$. Regression analysis showed that – when controlling for the shared variance between scores on the IPG-A (without item 28), the CDI, and the CPSS –IPG-A scores ($\beta = 0.39$, $t = 2.84$, $p < 0.01$), but not scores on the CDI ($\beta = 0.08$, $t = 0.64$, $p = 0.53$) and the CPSS ($\beta = 0.21$, $t = 1.49$, $p = 0.14$) predicted scores on this item.

Demographic and Loss Related Correlates of PGD Severity

Inventory of Prolonged Grief for Children

In the combined children samples from Samples 1, 2, and 3 (N = 169) scores on the IPG-C varied as a function of time from loss ($r = -0.22$, $p < 0.05$) with lower scores being observed among those further removed from their loss. Scores did not vary as a function of age, gender, relationship to the deceased, cause of death, and expectedness of the death.

Inventory of Prolonged Grief for Adolescents

In the combined adolescent samples from Samples 1, 2, and 3 (N = 153) scores on the IPG-A also varied as a function of time from loss ($r = -0.23$, $p < 0.05$) but none of the other background and loss-related variables that we assessed.

DISCUSSION

The aim of the present study was to examine psychometric properties of two questionnaires for the assessment of PGD symptoms among children (aged 8 to 12 years) and adolescents (aged 13 to 18 years), called the IPG-C and IPG-A respectively. Is doing so, we also aimed to enhance knowledge about the phenomenology and correlates of PGD symptoms in these groups. The questionnaires were adjusted versions of the 30-item revised Inventory of Complicated Grief (ICG-R), a scale originally developed by Prigerson and Jacobs (2001) to assess PGD in adults. The main findings can be summarised as follows.

First, it was found that both the IPG-C and IPG-A represented one underlying dimension of PGD symptom severity. These findings are consistent with prior research among children and adolescents (e.g., Melhem et al., 2007) and adults (e.g., Boelen et al., 2003; Boelen & Hoijtink, 2009) which have also shown that PGD symptoms form a unidimensional construct.

Second, Cronbach's alphas of both questionnaires were high, further supporting that the variety of emotional (e.g., yearning), behavioural (e.g., avoidance), cognitive (e.g., reduced sense of meaning), interpersonal (e.g., reduced trust), and experiential (e.g., seeing the lost person) symptoms form a unitary and internally consistent construct. Third, test-retest analyses showed that the endorsement of items was stable across a six-week period.

The fourth main finding was that higher scores on the IPG-C and IPG-A were significantly correlated with symptoms of depression and PTSD, attesting to the concurrent validity of both questionnaires. Notably, among children, scores on the IPG-C were not significantly correlated with their parent's rating of Internalising and Externalising Problems as indexed by the CBCL. However, among adolescents, scores on the IPG-A were in fact correlated with CBCL-scores. These findings can be interpreted as indicating that parent's estimation of the severity of loss related problems of their offspring is more accurate when these children are older (i.e., > 12 years). Moreover, the findings suggest that it is important to be able to have young children (i.e., < 13 years) report about their own grief, instead of solely relying on their parents' observation of their degree of emotional suffering following loss. The finding that parents seem more aware of the suffering of adolescents than of children seems unexpected. It is notable though, that this may be due to the composition of the present study groups. That is, the combined *adolescents* from Samples 2 and 3 included relatively more participants who sought help at outpatient clinics (i.e., 64/90 = 71%) compared to the combined *children* (i.e., 37/137 = 27%). To the extent that adolescents who seek help are more inclined to communicate about their feelings than children who do not seek help, it is likely that parents of adolescents were more aware of their children's suffering than were parents of younger children. At the same time, it is also possible that parents are generally more aware of the possible devastation a loss may bring about, and more inclined to monitor the effects thereof, when their children are older.

We also examined the correlations of the IPG-C and IPG-A with symptoms of Childhood Traumatic Grief, and the experience of 'Ongoing Presence' and 'Positive Memories' as tapped by the EGI (Brown & Goodman, 2005). As predicted, both the IPG-C and IPG-A were more strongly associated with Childhood Traumatic Grief – a construct that is similar to PGD – than with a sense of ongoing presence and positive memories of the lost person, constructs that are different from PGD symptoms. These findings support the convergent and divergent validity of the IPG-C and IPG-A. Furthermore, these findings indicate that PGD symptoms in children and adolescents are phenomenologically similar to combination of grief and posttraumatic stress symptoms implicated in the concept of Childhood Traumatic Grief. Findings obtained with the EGI should be interpreted with some caution, given that the internal consistencies of its subscales were not very strong.

Our findings also revealed that scores on the IPG-C and IPG-A were significantly correlated with the degree to which participants reported impairments in functioning as a result of the loss. These associations remained significant when controlling for concomitant depression and PTSD symptom severity. These particular findings provide initial support for the incremental validity of the IPG-C and IPG-A. Moreover, they are in keeping with prior findings among children and adolescents (Melhem et al., 2007) and adults (Boelen & Prigerson, 2007; Bonanno et al., 2007) that PGD symptoms have a specific linkage with impairments in functioning beyond symptoms of depression and posttraumatic stress.

In our final rounds of analyses, we found that scores on the IPG-C and IPG-A were lower among children and adolescents that were further removed from their loss, but did not vary as a function of other demographic and loss related variables, including age, gender, and mode and expectedness of the death. Again, these findings are fully consistent with findings from Melhem et al. (2007). Although more studies are needed to further elucidate possible correlates and risk factors for increased PGD severity in children and adolescents, these findings suggest that factors other than demographic variables and aspects of the loss event – possibly including cognitive behavioural variables such as thinking and coping styles – are more important determinants of PGD symptom severity (cf. Boelen & Spuij, 2008).

Altogether, the present findings suggest that the IPG-C and IPG-A are reliable and valid tools to examine PGD symptomatology among children and adolescents. Thus, both scales may be used in future research examining causes and consequences of PGD in these groups, as well as in treatment studies examining the effectiveness of bereavement interventions for youths. Moreover, the findings enhance our knowledge of the phenomenology of childhood PGD in showing that PGD symptoms form a unidimensional construct that is associated with depression, PTSD, functional impairments, and – at least among adolescents older than 12 years of age – with the severity of Internalising and Externalising Problems as observed by their parents.

Some limitations should be taken into account when interpreting the present findings. First and foremost, both the IPG-C and IPG-A are adjusted versions of an adult measure of PGD, the ICG-R. Consequently, the conceptualisation of childhood PGD as examined in this study is an extension of PGD as defined in adults (Prigerson et al., 1999; Prigerson & Jacobs, 2001). It would be useful for future studies to investigate if there are other symptoms, beyond those included in the item pool of the ICG-R, that are also, or even more specifically indicative of problematic grief among youths. Second, the present study tested Dutch versions of the IPG-C and IPG-A. Although it is conceivable that the present findings are generalisable to other Western, including English speaking, cultures, the psychometric properties of versions of the questionnaires in other languages remain to be tested. Third, given the variety of methods of recruitment, most of the analyses we conducted relied on a rather heterogeneous group of children and adolescents. Thus, it would be interesting for future studies to further examine psychometric properties of the IPG-C and IPG-A, and – more generally – the phenomenology of childhood PGD, in more specified and homogeneous groups (e.g., children suffering severe emotional problems following loss). As a related point, although the cultural background of participants was not systematically assessed, it was our impression that most participants had a Western origin. Thus, generalisation of the present findings to non-Western subgroups remains to be determined. Fourthly, CBCLs for participants from Samples 2 and 3 were completed by parents. Because of their own grief, these parents possibly were not the most reliable informants of their children's problems. Thus, it would be relevant for future studies to correlate PGD severity with indices of children's impairments rated by other, more distant informants such as teachers. A final point is that in Samples 2 and 3, participants completed questionnaires with the possible assistance of a student or their therapist respectively. Such assistance was not present in Sample 1. Although this likely has not affected the current findings (particularly since most analyses were based on data from Samples 2 and 3) future studies should preferably provide assistance to all participants comprising the study group.

Notwithstanding these considerations, the current findings indicate that PGD symptoms can be reliably assessed among children and adolescents, using adjusted versions of the ICG-R (Boelen et al., 2003; Prigerson & Jacobs, 2001). The current study findings also provide further evidence of the existence and clinical significance of PGD symptoms among children and adolescents. Further studies are needed to examine causes, correlates, and consequences of these symptoms and, taking into account the lack of effective interventions for childhood grief (Currier, Holland, & Neimeyer 2007), useful treatments for these symptoms. The importance of such studies is stressed by the fact that, as noted, working groups preparing DSM-5 are considering inclusion of a new category for a specific disorder of grief in this influential diagnostic system (see APA, 2011).

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Appendix 2.1 English Translations of the Dutch Inventory of Prolonged Grief for Children (IPG-C) and Dutch Inventory of Prolonged Grief for Adolescents (IPG-A)

	IPG-C	IPG-A
1	That he/she died, feels as something that has torn everything apart.	Idem.
2	I find it hard to do the things I normally do, because I think of him/her so much.	I think of him/her so often, that it's hard for me to do the things I usually do.
3	Thinking of him/her confuses me	Memories of him/her upset me.
4	It feels difficult that s/he died; I think it's not fair.	I find it hard to accept that he/she is dead.
5	I would like to be with him/her.	I long for him/her.
6	I want to go to places that are related to him/her.	I seek out and feel attracted to places and things that are associated with him/her.
7	I am angry about his/her death.	Idem.
8	I cannot believe that s/he died.	I can hardly believe that he/she died.
9	His/her death has scared me; I am totally upset by it.	I feel numb or overwhelmed by his/her death; I am totally upset by it.
10	I find it difficult to trust other people since he/she has died.	Idem.
11	I find it difficult to love other people since he/she died.	I feel unable to love other people or feel distant from other people, since he/she died.
12	I do or feel the same things as he/she did.	Idem.
13	I don't want to think about the fact that he/she is dead.	I do everything to avoid thinking about the fact that he/she is dead.
14	I feel no interest in things since he/she died.	Life feels empty or meaningless since he/she died.
15	I hear his/her voice speak to me.	Idem.
16	I see him/her stand in front of me.	Idem.
17	It feels as if nothing really touches me.	Idem.
18	It feels unfair that I am still alive while he/she is dead; I feel guilty about that.	I feel guilty about the fact that I am still alive while he/she is dead.
19	I continue to feel angry about his/her death.	I feel bitter and angry inside, because of his/her death.
20	I am jealous of people who did not lose someone.	Idem.
21	I think that the future has no purpose without him/her.	Idem.
22	I feel very alone since he/she died.	I feel lonely since he/she died.
23	My life can only be pleasant if he/she is around.	Life feels meaningless without him/her.
24	It feels as if a part of me is dead.	It feels as if part of me has died with his/her death.
25	It feels as if his/her death has changed everything.	Idem.
26	I feel less safe since he/she died.	Idem.
27	I have no control over things happening in my life.	Since he/she died, it feels as if I cannot control things happening in my life.
28	I am doing worse (in school and with friends) since he/she died.	Since he/she died, my functioning in different areas is impaired (for instance my functioning in school, with friend, in my job).
29	I am more easily angry, nervous and scared since he/she died.	I feel tensed and easily annoyed since he/she died.
30	I sleep poorly, since he/she died.	Idem.

CHAPTER 3

Distinctiveness of Symptoms of Prolonged Grief, Depression, and Posttraumatic Stress in Bereaved Children and Adolescents

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ABSTRACT

Studies among adults have shown that symptoms of Prolonged Grief Disorder (PGD) are distinct from those of bereavement-related depression and Posttraumatic Stress Disorder (PTSD). This study was an attempt to replicate that finding in two distinct samples of bereaved children (*N* = 197; aged 8 to 12 years) and adolescents (*N* = 135; 13 to 18 years), confronted with the death of a parent, sibling or other close relative. Using confirmatory factor analyses, we compared the fit of a one-factor model with the fit of a three-factor model in which symptoms formed three distinct, correlated factors. In both samples, findings showed that the model in which symptoms of PGD, depression, and PTSD loaded on separate factors was superior to a one-factor model and displayed excellent model fit. Summed scores on the PGD, depression, and PTSD items were significantly associated with functional impairment, attesting to the concurrent validity of the PGD, depression, and PTSD factors. The current findings complement prior evidence from adult samples that PGD is a distinct syndrome and suggest that PGD symptoms should be addressed in the assessment and treatment of bereaved children and adolescent seeking help following their loss.

INTRODUCTION

There is growing evidence that the death of a loved one can precipitate the development of different forms of psychopathology, including depressive and anxious symptoms and syndromes, and Prolonged Grief Disorder (PGD), also named Complicated Grief (Bonanno et al., 2007; Prigerson et al., 2009; Shear et al., 2011). PGD is a syndrome that includes persistent, disruptive yearning, trouble accepting the death, detachment, excessive bitterness, difficulties to move on, and a sense that the loss has shattered one's view of self, life, and future, present to the point of dysfunction beyond six months post loss (American Psychiatric Association [APA], 2012; Prigerson et al., 2009; Shear et al., 2011).

Evidence of the existence and clinical significance of PGD has mainly been gathered in adult samples. Nonetheless, there is growing evidence that PGD symptoms can also occur in bereaved children and adolescents. For instance, in a study among 146 (11- to 23-year-old) friends and acquaintances of suicide victims, Melhem et al. (2004) found that symptoms of what they called 'traumatic grief' assessed as six months post loss clustered together and predicted symptom levels of depression and Posttraumatic Stress Disorder (PTSD) at subsequent assessments. In another study among 129 parentally bereaved children (aged 7 to 18 years), PGD symptoms were associated with significant functional impairment beyond concurrent depression and PTSD (Melhem, Moritz, Walker, Shear, & Brent, 2007).

Findings that PGD symptoms predict health impairments over and above other forms of distress (e.g., depression and PTSD) attest to the incremental validity of PGD. However, the phenomenology of dysfunctional grief in children and adolescents is still not very well understood. For instance, in contrast with the adult literature (Bonanno et al., 2007; Prigerson et al., 2009; Shear et al., 2011) few studies have examined the factorial distinctiveness of PGD in children and adolescents. Such research is important because it can enhance our knowledge of the generalisability of adult findings to younger bereaved individuals. This is timely given upcoming revisions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) to create the fifth edition (DSM-5) that is likely to include a new disorder of grief (APA, 2012; Boelen & Prigerson, 2012a). Moreover, research on the distinctiveness versus overlap of PGD, depression, and anxiety in bereaved children and adolescents can inform theorising and research about underlying mechanisms of post loss psychopathology and the development of methods for the assessment and treatment of such psychopathology.

There are only a few studies which have addressed the distinctiveness of PGD in children and adolescents. For instance, Melhem et al. (2004) subjected items of the Texas

Revised Inventory of Grief (TRIG; Faschingbauer, Zisook, & DeVaul, 1987) to principal component analysis and found these items to cluster together into one cluster of traumatic grief and a second cluster of what they called 'milder or even normal grief reactions' (p. 1411). Dillen, Fontaine and Verhofstadt-Denève (2009) conducted two studies, one among 14- to 18-year-old adolescents confronted with the death of a grandparent, and a second among 12- to 19-year-old adolescents confronted with losses of different relatives. Both studies indicated that symptoms of PGD, depression, and anxiety clustered into three distinct factors. These studies provide preliminary support of the distinctiveness of PGD. Nonetheless, the study by Melhem et al. (2004) is limited by its reliance on exploratory (and not confirmatory) factor analysis and the use of the TRIG that was developed as a measure of normal grief, not PGD (Neimeyer, Hogan, & Laurie, 2008). The two studies by Dillen et al. (2009) are limited by the fact that they only relied on children confronted with the loss of a grandparent (Study 1), did not examine the PGD distinctiveness in younger children, below 12 years of age (Study 2), and included no assessment of PTSD symptoms (Studies 1 and 2) which leaves the distinctiveness of PGD and PTSD still unexamined.

The aim of the current analyses was to address gaps in the research literature with regard to the phenomenology of bereavement-related emotional distress in children and adolescents. To this end, we examined the distinctiveness of symptoms of PGD, PTSD, and depression, in separate samples of 8- to 12-year-old children and 13- to 18-year-old adolescents, all confronted with the death of a parent, sibling, or other close loved one. Two related reasons guided our decision to conduct analyses in separate samples; the first is that the cognitive capacity to verbalise and contemplate the consequences of loss differs between children in primary versus secondary education (Dowdney, 2005), the second is that, accordingly we used two different (though strongly similar) measurement instruments to assess PGD symptoms among 8- to 12-year-old children and 13- to 18-year-old adolescents, respectively (Spuij et al., 2012) (see below).

Using confirmatory factor analysis (CFA), our first aim was to test the prediction that a three-factor model with symptoms loading on three distinct factors of PGD, depression, and PTSD, would be more suitable than a one-factor model. Our second aim was to examine associations between PGD, depression, and PTSD symptom-clusters on the one hand and indices of functional impairment on the other. We expected that the three symptom-clusters would all be correlated with functional impairment.

METHOD

Participants and Procedure

Data were available from 332 children and adolescents, aged 8 to 18 years. Approximately, half of all participants were recruited via lay mental health care workers who organise individual support and mutual support groups for bereaved children and adolescents. Other participants were recruited via outpatient mental health clinics in the Netherlands. Questionnaires administered for the present study were completed in the presence of either a research assistant or a health care worker. Assent was obtained from children (aged 8 to 12 years), and informed consent from parents and adolescents (aged 13 to 18 years). For the present study, separate analyses were conducted with data from $N = 197$ children (8 to 12 years) and $N = 135$ adolescents (13 to 18 years). Characteristics of participants are shown in Table 3.1. Most participants had suffered the death of a parent, mostly due to an illness.

Measures

Demographic and loss related variables

We registered the participant's age and gender and collected information about the relationship to the deceased (categorised as mother, father, sibling, or other loved one), cause of death [loss was due to illness, a violent cause (accident, suicide, homicide), unexpected medical cause (e.g., heart attack), or some other cause], whether the death was experienced as unexpected (yes/no), and the time passed since the death occurred.

Inventory of Prolonged Grief for Children (IPG-C) and Inventory of Prolonged Grief for Adolescents (IPG-A)

PGD items were taken from the IPG-C and IPG-A. The IPG-C and IPG-A are both 30-item questionnaires, designed to assess symptoms of PGD among children and adolescents, respectively. Both measures are based on the Inventory of Complicated Grief designed to assess PGD among adults (Prigerson & Jacobs, 2001). The IPG-C and IPG-A are very similar, although the wording of some of the items differs between the versions. Sample items include "*I want to go to places that are related to him/her*", "*I find it difficult to love other people since she/he died*" (IPG-C), and "*I seek out and feel attracted to places and things that are associated with him/her*", "*I feel unable to love other people or feel distant from other people, since she/he died*" (IPG-A). Respondents rate the frequency of each symptom in the preceding month, on 3-point scales (1 = *almost never*, 2 = *sometimes*, 3 = *always*). A recent study by

Table 3.1 Demographic Variables, Loss Related Characteristics, and Symptom Scores in Children and Adolescents Samples

	Children (*N* = 197)	Adolescents (*N* = 135)
Demographic characteristics		
Gender (*N* (%))		
Boys	99 (50.3)	44 (32.6)
Girls	98 (49.7)	91 (67.4)
Age (years) (*M* (*SD*); range)	9.9 (1.3); 8-12	14.9 (1.5); 13-18
Loss characteristics		
Deceased is (*N* (%))		
Mother	38 (19.3)	42 (31.1)
Father	123 (62.4)	63 (46.7)
Sibling	16 (8.1)	13 (9.6)
Other relative	17 (8.6)	15 (11.1)
Cause of death is (*N* (%))		
Illness	105 (53.3)	77 (57.0)
Violent (accident, suicide, homicide)	48 (24.4)	26 (19.3)
Unexpected medical cause	34 (17.3)	28 (20.7)
Other cause	8 (4.1)	4 (3.0)
Experienced loss as unexpected? (*N* (%))		
Yes	57 (28.9)	46 (34.1)
No	140 (71.1)	86 (63.7)
Time since loss (months) (*M* (*SD*); range)	31.7 (23.6); 1-119	34.0 (28.4); 2-119
Symptom severity scores		
Prolonged Grief (IPG)	50.8 (11.2)	50.3 (12.8)
Depression (CDI)	6.4 (6.6)	12.8 (7.5)
PTSD (CPSS)	13.3 (9.4)	14.5 (10.7)

Note. Samples sizes differ due to occasional missing values. CDI = Children's Depression Inventory. CPSS = Child Posttraumatic Stress-Disorder Symptom Scale. IPG = Inventory of Prolonged Grief.
* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Spuij et al. (2012) supported the psychometric properties of both questionnaires. In the current study, the IPG-C yielded an α of 0.91 and the α of the IPG-A was 0.94.

Child PTSD Symptom Scale (CPSS)

Symptoms of PTSD were measures with the CPSS, a 24-item self-report questionnaire with 17 items corresponding to symptoms of PTSD as defined in DSM-IV (APA, 2000), all rated on 4-point scales ranging from 0 (*not at all/only once a week*) to 3 (*almost always/five or more times a week*), and 7 items tapping functional impairment resulting from these symptoms, dichotomously rated as *absent* or *present*. The index event was defined as 'the death of your loved one'. The CPSS was constructed by Foa, Johnson, Feeny and Treadwell (2001; Dutch translation by Engelhard, 2005) and has adequate psychometric properties. The alphas for the 17 symptoms and 7 functional impairment items in the children sample were 0.88 and 0.66, respectively. In the adolescent sample, the alphas were 0.92 and 0.67, respectively.

Children's Depression Inventory (CDI)

Symptoms of depression were taken from the 27-item CDI (Kovacs, 2003; Timbremont, Braet, & Roelofs, 2008). Each item contains three statements representing depressive symptoms at increasing levels of severity from which respondents select the statement that best describes their feelings in the preceding week, scored on a 0 to 2 scale, representing increasing symptom severity. In the children and adolescent sample alphas were 0.85 and 0.87, respectively.

Statistical Analyses

Constraints of the sample sizes limited the number of items that could be included in the analyses. Consequently, we selected five items from each of the three symptom measures. Items for the factors were selected before any of the models were tested. Specifically, from the IPG-C and IPG-A we selected the 'yearning/longing' item, which is seen as a hallmark symptoms of PGD, and four items which are all included in the symptom criteria proposed by Prigerson et al. (2009) and were among the items most highly correlated with the IPG-C and IPG-A total scores. For the PTSD factor, we selected two items from the reexperiencing cluster, two items from the avoidance cluster, and one item from the (hyperarousal cluster) that were most strongly correlated with the total score of each symptom cluster. Finally, from the CDI we selected five items that represented DSM criteria for a depressive episode and were among the items most highly correlated with the CDI total score. Items are shown in Table 3.3.

To test the prediction that a three-factor model with symptoms loading on three distinct factors of PGD, depression, and PTSD would be more suitable than a one-factor model, CFA was conducted using Mplus-6.12 (Muthén & Muthén, 2007). As item scores were non-normally distributed, a robust weighted least squares (WLSMV) estimator was used. As missing data were rare (i.e., a maximum of 2% per item) and completely at random, participants with missing data were included in the model estimations using full information maximum likelihood estimation (Enders & Bandolos, 2001). Goodness-of-fit was evaluated using the comparative fit index (CFI), Tucker–Lewis index (TLI), and root mean square error of approximation (RMSEA). Although there is little consensus on cut-off values for adequate fit (Lance, Butts, & Michels, 2006), conventional guidelines were followed whereby fit is considered adequate if CFI and TLI values are > 0.90, and RMSEA is < 0.05. χ^2 difference tests, calculated using the DIFF TEST option of Mplus-6.12 (Muthén & Muthén, 2007), were used to compare the fit of competing models. To examine associations between PGD, depression, and PTSD factor scores on the one hand, and CPSS functional impairment scores on the other hand, correlation and regression analyses were conducted.

RESULTS

Descriptive Statistics

Mean scores on the symptom measures of PGD, depression, and PTSD are shown in Table 3.1. Compared with reference groups for the IPG-C and IPG-A (Spuij et al., 2012), the CDI (Kovacs, 2003; Timbremont et al., 2008), and CPSS (Foa et al., 2001), the current samples seemed best described as subclinical, rather than clinical samples.

Confirmatory Factor Analyses

Outcomes of the CFA among children showed that the three-factor model with symptoms loading on three distinct but correlated factors fit significantly better than the unitary model ($\Delta\chi^2 = 43.708$, $\Delta df = 3$, $p < 0.001$). Fit estimates (shown in Table 3.2) showed that the three-factor model fits very well to the data as indexed by, for instance, a non-significant χ^2 and very low RMSEA value. Correlations between factors were 0.54 for PGD with depression, 0.84 for PGD with PTSD, and 0.67 for depression with PTSD.

Table 3.2 Fit Statistics for Competing Models of the Factor Structure of Prolonged Grief, Depression, and Posttraumatic Stress Symptoms

Samples and models	χ^2	DF	*p*	χ^2/df	TLI	CFI	RMSEA
Children							
One-factor model	140.941	90	0.0005	1.57	0.939	0.947	0.054
Three-factor model	75.355	87	0.8090	0.87	1.015	1.000	0.000
Adolescents							
One-factor model	132.298	90	0.0025	1.47	0.919	0.934	0.059
Three-factor model	94.412	87	0.2753	1.09	0.962	0.988	0.025

Note. CFI = comparative fit index; RMSEA = root mean square error of approximation; TLI = Tucker-Lewis index.

Similarly, outcomes of the CFA among adolescents showed that the three-factor model fits significantly better than the unitary model ($\Delta\chi^2 = 27.965$, $\Delta df = 3$, $p < 0.001$). Fit estimates (Table 3.2) showed that the three-factor model again fits very well to the data as indexed by, for instance, a non-significant χ^2 and very low RMSEA value. Correlations between factors were 0.54 for PGD with depression, 0.80 for PGD with PTSD, and 0.66 for depression with PTSD.

Table 3.3 shows standardized factor-loadings from the three-factor models in both samples. All items loaded highly (> 0.40) on their respective factors. Cronbach's alphas of the items constituting each cluster were all ≥ 0.70, except the α of the depression items in the children's sample, which was 0.58.

Associations of PGD, Depression, and PTSD Factor Scores with Functional Impairment

Items on the three factors were summed to obtain PGD, depression, and PTSD factor scores. In the children sample ($N = 197$), the functional impairment score from the CPSS was significantly correlated with the PGD factor score ($r = 0.41$), the depression factor score ($r = 0.34$), and the PTSD factor score ($r = 0.46$, $ps < 0.001$). When the three factor scores were simultaneously entered in a regression equation predicting CPSS functional impairment, a significant model emerged [$F(3,194) = 22.70$, $R^2 = 26\%$, $p < 0.001$], in which the PGD factor score ($\beta = 0.19$, $t = 2.48$, $p < 0.05$), the depression factor score ($\beta = 0.15$, $t = 2.14$, $p < 0.05$), and the PTSD factor score ($\beta = 0.29$, $t = 3.63$, $p < 0.01$) all explained unique variance in CPSS functional impairment.

In the adolescent sample ($N = 135$), the functional impairment score from the CPSS was also significantly correlated with the PGD ($r = 0.42$), depression ($r = 0.44$), and PTSD factor-scores ($r = 0.55$, $ps < 0.001$). A regression analysis in which the CPSS impairment scores were regressed on factor scores entered together yielded a significant model [$F(3,134) = 21.91$, $R^2 = 33\%$, $p < 0.001$). The PTSD factor-score ($\beta = 0.38$, $t = 4.03$, $p < 0.01$), and, as a trend, the depression factor ($\beta = 0.16$, $t = 1.79$, $p < 0.08$), but not the PGD factor ($\beta = 0.13$, $t = 1.50$, $p = 0.14$) predicted unique variance in CPSS impairment scores.

Associations of PGD, Depression, and PTSD Factor Scores with Background and Loss-related variables

We examined if the PGD, depression, and PTSD factor scores varied as a function of demographic variables (age, gender) and loss-related variables (kinship, cause of death,

Table 3.3 Factor-Loadings for Symptoms of Prolonged Grief, Depression, and Post-Traumatic Stress in Children and Adolescent Samples

	Loadings on PG		Loadings on PTS factor		Loadings on depression factor	
	Children	Adolescents	Children	Adolescents	Children	Adolescents
Feels difficult to accept the loss.	0.681	0.661				
Longing/yearning for lost person.	0.654	0.627				
Feeling angry/bitter about the loss.	0.776	0.806				
Life is only pleasant/meaningful with lost person.	0.659	0.668				
Feeling like part of self died.	0.588	0.571				
Intrusive thoughts about loss.			0.772	0.737		
Experiencing flashbacks about loss.			0.762	0.797		
Avoiding reminders of loss.			0.567	0.595		
Restricted affect/numbness since loss.			0.612	0.623		
Exaggerated startle since loss.			0.661	0.591		
Reduced pleasure/fun doing things.					0.701	0.717
Having thought about killing oneself.					0.587	0.598
Feeling tired.					0.449	0.465
Reduced pleasure/fun doing things.					0.719	0.670
Having thought about killing oneself.					0.538	0.585
Cronbach's alpha of factor:	0.70	0.75	0.74	0.75	0.58	0.70

Note. PG = Prolonged Grief. PTS = Posttraumatic Stress.
* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

unexpectedness of death, and time since loss). In the children sample, no significant associations emerged, except for a negative correlation between the PTSD factor score and age ($r = -0.23$, $p < 0.001$). In the adolescent sample, age was positively correlated with PGD ($r = 0.19$), depression ($r = 0.20$), and PTSD ($r = 0.17$, $ps < 0.05$). In addition, girls had higher scores than boys on the PGD factor ($M = 9.9$, $SD = 2.4$ vs. $M = 8.6$, $SD = 2.6$; $F(1, 134) = 7.48$, $p < 0.01$, $d = 0.53$), the depression factor ($M = 3.1$, $SD = 1.9$ vs $M = 1.7$, $SD = 1.8$; $F(1, 134) = 16.16$, $p < 0.001$, $d = 0.76$), and the PTSD factor ($M = 3.9$, SD = 3.2 vs. $M = 2.6$, $SD = 2.8$; $F(1, 134) = 5.49$, $p < 0.01$, $d = 0.43$). No other significant associations emerged between factor scores and the loss related variables in the adolescent sample.

DISCUSSION

The aim of the present study was to examine the distinctiveness and correlates of PGD, depression, and bereavement-related PTSD in bereaved children and adolescents. The main finding of this study was that, in both these groups, CFA showed that a model in which symptoms of PGD, depression, and PTSD loaded on three factors was superior to a unitary model and had good excellent fit-estimates. Correlations between factors were moderate, indicating that the symptom clusters represent distinguishable, but related constructs.

The current findings extend prior research in adult samples (Boelen & Prigerson, 2012a; Bonanno et al., 2007; Prigerson et al., 2009; Shear et al., 2011) and children and adolescent samples (Dillen et al., 2009; Melhem et al., 2004) which have shown that symptoms of intense yearning, difficulties to accept the loss, anger, and a sense that life is meaningless constitute a unique cluster of grief symptoms that can be distinguished from other emotional symptoms that can occur post loss. The few prior studies among bereaved children that tested the distinctiveness of PGD were limited by their reliance on exploratory analyses, on children exposed to grandparental loss, relatively older children, and inclusion of generic measures of anxiety rather than PTSD (Dillen et al., 2009; Melhem et al., 2009). Thus, the present findings are an important extension of these prior findings by showing that the distinctiveness of PGD from its diagnostic 'nearest neighbors' (i.e., syndromes from DSM which are phenomenologically close to PGD) is generalisable across a wide range covering childhood and adolescence.

A second main finding was that, in both the children and adolescent samples, summed scores of the PGD, depression, and PTSD items were all significantly associated with a measure of functional impairment obtained from the CPSS. This attests to the concurrent validity of the three factors. In the children sample, the PGD, depression, and PTSD factor scores predicted unique variance in functional impairment when controlling for the shared variance between the three factor scores. In the adolescent sample, the PTSD factor was the single factor explaining unique variance in functional impairment. The findings could be taken to indicate that symptoms of PGD have a more specific invaliding impact in children compared to adolescents, and that symptoms of PTSD are relatively more invalidating in this later group. Yet, this conclusion seems premature, taking into account that our analyses relied on a single index of functional impairment, which was part of the PTSD measures, and that the size of the adolescent sample may have been too small to detect unique significant associations between PGD and functional impairment. Thus, future studies are needed to further examine this aspect of incremental validity of PGD in adolescents.

There are other limitations that should be taken into account. All data were obtained from self-report measures. It is possible that model fit and patterns of associations with other variables would have been different in case data were obtained from interview measures. A further limitation is that, given the variety of methods of recruitment, analyses relied on a rather heterogeneous group of children and adolescents. Thus, it would be interesting for future studies to further examine the factor structure and correlates of loss related emotional symptoms following loss in more specified and homogeneous groups (e.g., children suffering severe emotional problems following loss). Finally, because of constraints of the sample size, we could only include a limited number of PGD symptom criteria in our analyses. The distinctiveness of the more complete list of PGD symptoms thus requires further research with larger samples.

Notwithstanding these limitations, the results of this study provide further evidence that the complications of bereavement in children and adolescents may include symptoms of PGD that constitute a clinical entity that is distinct from bereavement related depression and PTSD. These findings seem particularly timely given that a new disorder of grief will possibly be included in upcoming revisions of the DSM (APA, 2012; Boelen & Prigerson, 2012b). The results also underscore that different treatment methods may be required for the various syndromes that may develop in children and adolescents who fail to recover from a loss. For instance, activation-based methods may be indicated for depression, imaginary and in vivo exposure treatment may be useful for PTSD, and cognitive behavioural interventions targeting dysfunctional meanings assigned to the loss and maladaptive coping may be indicated for typical grief related symptoms. The development and evaluation of such specific treatment methods is an important challenge for future research.

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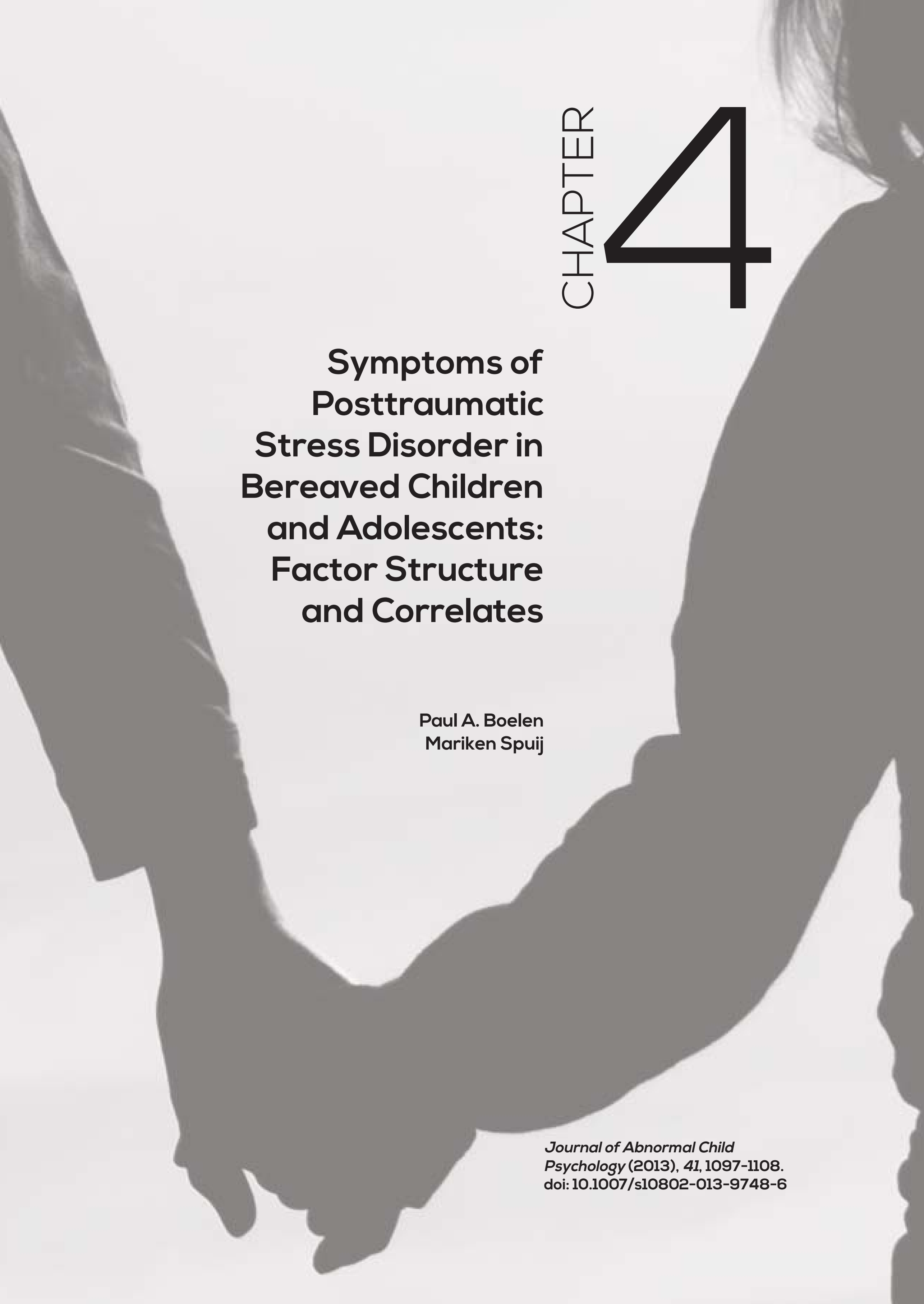

CHAPTER 4

Symptoms of Posttraumatic Stress Disorder in Bereaved Children and Adolescents: Factor Structure and Correlates

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ABSTRACT

This study investigated the factor structure and correlates of Posttraumatic Stress Disorder (PTSD) symptoms among children and adolescents confronted with the death of a loved one. Three hundred thirty-two bereaved children and adolescents (aged 8 to 18 years; 56.9% girls) who all received some form of psychosocial support after their loss, completed self-report measures of PTSD, together with measures tapping demographic and loss-related variables, depression, prolonged grief, and functional impairment. Parent-rated indices of impairment were also collected. We first evaluated the fit of six alternative models of the factor structure of PTSD symptoms, using confirmatory factor analyses. Outcomes showed that the four-factor numbing model (King, Leskinn, King, & Weathers, 1998), with distinct factors of reexperiencing, avoidance, emotional numbing, and hyperarousal fit the data best. Of all participants, 51.5% met the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria for PTSD. PTSD status and scores on the PTSD factors varied as a function of age and gender, but were unrelated to other demographic and loss-related variables. PTSD-status and scores on the PTSD factors were significantly associated symptom levels of depression, prolonged grief, and functional impairment. Findings complement prior evidence that the DSM-IV model of the factor structure of PTSD symptoms may not represent the best conceptualisation of these symptoms and highlight the importance of addressing PTSD symptoms in children and adolescents seeking help after bereavement.

INTRODUCTION

The death of a loved one is one of the most stressful life events that children and adolescents can experience (e.g., Alisic, Van der Schoot, Van Ginkel, & Kleber, 2008; Breslau, Wilcox, Storr, Lucia, & Anthony, 2004). Childhood bereavement may precipitate the development of diverse anxiety and depression syndromes and prolonged grief disorder (e.g., Melhem, Moritz, Walker, Shear, & Brent, 2007; Prigerson et al., 2009). Prolonged Grief Disorder is a recently defined syndrome that includes separation distress, disbelief regarding the death, numbness, and a sense of purposelessness and meaninglessness, present to a disabling and distressing degree beyond the first half year of bereavement (Prigerson et al., 2009; Shear et al., 2011). PGD is not an established disorder in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association [APA], 2000). However, there is growing evidence in studies among children (Melhem et al., 2007; Melhem, Porta, Shamseddeen, Walker Payne, & Brent, 2011; Spuij, Reitz et al., 2012) and adults (Boelen & Prigerson, 2013) that symptoms of prolonged grief are distinct from both depression and posttraumatic stress disorder (PTSD) and are associated with functional impairment. In light of these findings, prolonged grief disorder will likely be included in the DSM-5, albeit that it is uncertain how exactly this condition will be named (e.g., Prolonged Grief Disorder, Complicated Grief, or Persistent Complex Bereavement Related Disorder) and whether it will be placed in the main text or in the appendix of the DSM-5 (for discussions see Boelen & Prigerson, 2012; Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012; Nader & Layne, 2009; Wakefield, 2012).

PTSD is a relatively well-documented consequence of different types of violent and nonviolent deaths among children and adolescents. For instance, increased rates of PTSD symptomatology have been observed among friends of adolescent suicide victims (e.g., Brent et al., 1993), children confronted with parental death due to illness (Cerel, Fristad, Weller, & Weller, 1999; Stoppelbein & Greening, 2000), children of parents who were killed in the World Trade Center attacks of September 11, 2001 (Brown & Goodman, 2005), and youth confronted with sudden parental death (Melhem et al., 2007). Although it may seem strange that nonviolent losses can induce PTSD, circumstances surrounding 'natural' losses (e.g., exposure to a dying parent, or distress seen in family members) can be just as 'traumatic' as circumstances surrounding violent deaths (cf. Kaplow et al., 2012).

Our knowledge about the phenomenology and correlates of PTSD symptoms following loss in children and adolescents is limited. A first understudied issue is the factor structure of PTSD symptoms associated with childhood bereavement. Several studies have examined the factor structure of PTSD symptoms as described in DSM-IV (APA, 2000) and have provided evidence that the DSM-IV clustering might not be the best conceptualisation of PTSD symptoms. For instance, several adult studies have yielded evidence that PTSD symptoms are better conceptualised as representing two factors (e.g., Buckley, Blanchard, & Hickling, 1998; Taylor, Kuch, Koch, Crockett, & Passey, 1998) or four factors (e.g., Baschnagel, O'Connor, Colder, & Hawk, 2005; King et al., 1998; Marshall, 2004; Palmieri, Weathers, Difede, & King, 2007; Simms, Watson, & Doebbeling, 2002). Similar findings have been obtained in studies among traumatised children and adolescents (Ford, Elhai, Ruggiero, & Frueh, 2009; Kassam-Adams, Marsac, & Cirilli, 2010; Saul, Grant, & Carter, 2008). To our knowledge, no studies have yet examined the factor structure of PTSD symptoms among children and adolescents confronted with the death of a loved one. Such an examination is important because it can increase knowledge about the generalisability of the structure of PTSD symptoms across a broad range of age groups and life events. Moreover, understanding the structure of PTSD symptoms is important in creating useful diagnostic symptoms that can inform assessment and treatment (Kassam-Adams et al., 2010).

Accordingly, the first aim of this study – conducted in the Netherlands – was to examine the factor structure of PTSD symptoms among bereaved children and adolescents (aged 8 to 18 years). We compared the fit of six models that represent the main hypothesised models of PTSD symptoms from studies among adults, children, and adolescents, using confirmatory factor analysis (CFA). Models are summarised in Table 4.1. *Model 1* was a one-factor model in which all 17 PTSD symptoms loaded on a unitary factor. In accord with prior studies (e.g., Kassam-Adams et al., 2010) this model served as the 'baseline model' with which other models were compared. *Model 2* was a two-factor model with distinct dimensions of reexperiencing/avoidance and numbing/hyperarousal. This model has, to our knowledge, not been tested in children but has received some support in studies with adults (Buckley et al., 1998; Taylor et al., 1998). *Model 3* was the three-factor DSM-IV model with dimensions of reexperiencing, avoidance, and hyperarousal. This model has received some support in studies among students exposed to community violence (Foy, Wood, King, & Resnick, 1997) and children exposed to an earthquake (Bal & Jensen, 2007; Giannopoulou et al., 2006). *Model 4* was the four-factor numbing model in which the avoidance factor from the DSM model was distinguished into a two-item factor tapping active avoidance and a five-item factor tapping emotional numbing. This model was originally proposed by King et al. (1998) and has received substantial support in studies among adults (e.g., DuHamel et al., 2004; Marshall, 2004). Notably, this model has also received the most supporting evidence in studies among children and adolescents exposed to trauma (Kassam-Adams et al., 2010). *Model 5* was the four-factor dysphoria model with four dimensions of reexperiencing, avoidance, dysphoria, and hyperarousal. This model was proposed by Simms et al. (2002)

Table 4.1 Abbreviated Item Content, Item Mapping for Tested Models, and Item Descriptives ($N = 332$)

		Models tested						All participants		Non cases PTSD	Cases PTSD	Test for difference
		1	2	3	4	5	6	*M* (*SD*)	% 2 or 3	*M* (*SD*)	*M* (*SD*)	*F*
1	Intrusive thoughts	P	RE/AV	RE	RE	RE	RE	0.86 (0.91)	22.9	0.47 (0.67)	1.24 (0.94)	72.77*
2	Distressing dreams	P	RE/AV	RE	RE	RE	RE	0.63 (0.91)	16.6	0.30 (0.66)	0.94 (1.00)	45.96*
3	Flashbacks	P	RE/AV	RE	RE	RE	RE	0.64 (0.84)	16.6	0.27 (0.55)	0.99 (0.92)	71.39*
4	Upset at reminders	P	RE/AV	RE	RE	RE	RE	1.27 (0.94)	38.9	0.75 (0.74)	1.75 (0.86)	128.75*
5	Physical reactivity	P	RE/AV	RE	RE	RE	RE	0.85 (0.97)	24.1	0.35 (0.63)	1.32 (1.01)	107.97*
6	Avoiding thoughts	P	RE/AV	AV	AV	AV	AV/HY	1.09 (1.05)	32.6	0.57 (0.79)	1.58 (1.03)	101.21*
7	Avoiding reminders	P	RE/AV	AV	AV	AV	AV/HY	0.72 (0.95)	18.7	0.20 (0.45)	1.20 (1.03)	128.51*
8	Inability to recall important part	P	EN/HY	AV	EN	DY	-	0.65 (0.94)	17.5	0.36 (0.75)	0.92 (1.02)	31.55*
9	Loss of interest	P	EN/HY	AV	EN	DY	-	0.68 (0.93)	18.4	0.19 (0.48)	1.13 (1.02)	111.92*
10	Detachment	P	EN/HY	AV	EN	DY	AV/HY	0.53 (0.82)	13.0	0.10 (0.35)	0.94 (0.92)	117.04*
11	Restricted affect	P	EN/HY	AV	EN	DY	AV/HY	0.68 (0.89)	16.6	0.24 (0.54)	1.09 (0.95)	96.25*
12	Foreshortened future	P	EN/HY	AV	EN	DY	AV/HY	0.50 (0.85)	13.9	0.09 (0.38)	0.89 (0.97)	92.91*
13	Disturbed sleep	P	EN/HY	HY	HY	DY	-	1.24 (1.22)	40.7	0.71 (1.03)	1.73 (1.18)	68.91*
14	Irritability/anger	P	EN/HY	HY	HY	DY	-	1.11 (0.97)	31.9	0.53 (0.71)	1.65 (0.86)	164.53*
15	Trouble concentrating	P	EN/HY	HY	HY	DY	-	1.19 (1.11)	37.3	0.69 (0.93)	1.67 (1.06)	78.60*
16	Hypervigilance	P	EN/HY	HY	HY	HY	AV/HY	0.51 (0.82)	11.7	0.25 (0.60)	0.75 (0.92)	33.46*
17	Exaggerated startle	P	EN/HY	HY	HY	HY	AV/HY	0.62 (0.86)	16.6	0.26 (0.59)	0.95 (0.94)	62.86*

Note. DY = Dysphoria. EN = Emotional Numbing. HY = Hyperarousal. P = Posttraumatic Stress. RE = Reexperiencing. AV = Avoidance.
* $p < 0.001$.

and has also received substantial support in studies with adults (e.g., Baschnagel et al., 2005; Boelen, Van den Hout, & Van den Bout, 2008; Palmieri et al., 2007) and children and adolescents (Kassam-Adams et al., 2010). Finally, *Model 6* was a model with 12 of the 17 PTSD symptoms constituting two dimensions of reexperiening and combined avoidance/numbing/hyperarousal symptoms. This model was put forth by Elhai, Gurbaugh, Kashdan, and Frueh (2008), based on Spitzer, First, and Wakefield's (2007) proposal to remove five symptoms that overlap with depression or anxiety. This model has yielded some support among traumatised adolescents (Ford et al., 2009). We compared this relatively large number of models because, to our knowledge, the factor structure of bereavement related PTSD symptoms among children and adolescents has not yet been studied before (cf. Elhai & Palmieri, 2011).

Although our main interest was to examine the structure and correlates of PTSD symptoms, we also examined the prevalence of PTSD 'caseness', i.e., the number of participants who did vs. did not meet criteria for PTSD from DSM-IV (APA, 2000). Consistent with these criteria, PTSD-cases were defined as children endorsing at least one reexperiencing symptom, three avoidance symptoms, and two hyperarousal symptoms (Foa, Johnson, Feeny, & Treadwell, 2001). A further aim of this study was to examine the ability of the 17 PTSD items to distinguish between participants who did vs. did not meet criteria for PTSD caseness. This was deemed relevant because, as said, little is known about bereavement-related PTSD in children and adolescents, including the strength of items in distinguishing between high and low levels of PTSD. The third aim of this study was to examine the extent to which particular demographic variables and characteristics of the loss were associated with PTSD severity. Specifically, we examined the degree to which PTSD caseness (i.e., meeting vs. not meeting PTSD criteria) and PTSD factor scores varied as a function of demographic variables (e.g., gender, age) and loss related variables (e.g., kinship relationship with deceased, cause of loss, time since loss). Knowledge about variables associated with PTSD caseness and PTSD factor scores is important because it sheds light on possible risk factors for elevated PTSD following loss.

The fourth aim of this study was to examine associations of PTSD-status and scores on the PTSD factors on the one hand, and indices of mental health problems (including symptom levels of depression, prolonged grief, and Internalising and Externalising Problems) on the other hand. This issue was examined in order to enhance knowledge about the degree to which bereavement related PTSD co-occurs with other poor bereavement-outcomes. In addition, examining the relative strength of the associations of the different PTSD factor scores with these indices of psychopathology adds to knowledge about the construct validity of these factors and could have clinical implications (e.g., by elucidating the most distressing aspects of bereavement related PTSD that should receive most clinical attention). Finally, we sought to compare the relative impact of elevated levels of PTSD, depression, and prolonged grief disorder on functional impairment. To this end, we calculated and compared correlations of these symptom clusters with self-rated and parent-rated impairment.

METHOD

Participants and Procedure

Data were available from 332 children and adolescents, aged 8 to 18 years, who were recruited from different sources. A first group of 126 participants was recruited via a grief support group that offers council and advice to parents as well as children and adolescents about grief and bereavement and organises support-weekends for these individuals. During the period of data-collection, children and adolescent applying for support-weekends were sent a letter. The letter included a description of the study and a stamped refusal card. If no refusal card was received within two weeks, the family was contacted and – if the parent(s) and their child agreed to participate – a home visit was planned. Home visits were conducted by a team of six master students with a bachelor degree in pedagogical sciences, who received a one day training from the second author (focused on explanation of study design and protocol and administration of questionnaires), that was followed up by regular supervision meetings. During home visits, students handed out questionnaires and, if needed, could help with the completion of the questionnaires. Assent was obtained from children (aged 8 to 12 years), informed consent from parents and adolescents (aged 13 to 18 years).

A second group of 206 participants was recruited via several outpatient clinics in the Netherlands. During the period of data collection, consecutive patients aged 8 to 18 years who reported emotional problems associated with the death of a parent, sibling, or other loved ones were invited to participate. Those who did so completed questionnaires accompanied by their therapist. Assent was obtained from children, informed consent from parents and adolescents. Groups did not differ on variables assessed for the present study and were combined in the analyses. The present study's protocol was approved by a local review board.

Of the total group of participants, almost all (*n* = 330; 99%) had the Dutch nationality. No data were collected on socio-economic status. Table 4.2 shows additional characteristics

Table 4.2 Demographic Variables, Loss Related Characteristics, and Symptom-Scores in Total Sample and Subsamples Distinguished by PTSD Status

	Total group ($N = 332$)	PTSD no ($n = 161$)	PTSD yes ($n = 171$)	Test for difference
Demographic characteristics				
Gender (*N* (%))				Fisher's exact test, $p < 0.006$
Boys	143 (43.1)	82 (50.9)	61 (35.7)	
Girls	189 (56.9)	79 (49.1)	110 (64.3)	
Age (years) (*M* (*SD*); range)	11.9 (2.9); 8-18	11.6 (2.7)	12.3 (3.0)	$F = 4.91$ *
Religiously active (*N* (%))				Fisher's exact test = 0.56
Yes	110 (33.3)	56 (35.0)	54 (31.8)	
No	220 (66.7)	104 (65.0)	116 (68.2)	
Loss characteristics				
Deceased is (*N* (%))				$\chi^2 = 3.63$
Mother	80 (24.5)	34 (21.4)	46 (27.4)	
Father	186 (56.9)	95 (59.7)	91 (54.2)	
Sibling	29 (8.9)	17 (10.7)	12 (7.1)	
Other relative	32 (9.8)	13 (8.2)	19 (11.3)	

Cause of death is (*N* (%))				X² = 0.54
Illness	182 (55.2)	85 (53.1)	97 (57.1)	
Violent (accident, suicide, homicide)	74 (22.4)	38 (23.8)	36 (21.2)	
Unexpected medical cause	62 (18.8)	31 (19.4)	31 (18.2)	
Other cause	12 (3.6)	6 (3.8)	6 (3.5)	
Experienced loss as unexpected? (*N* (%))				Fisher's exact test = 0.29
Yes	103 (31.3)	55 (34.2)	48 (28.6)	
No	226 (68.7)	106 (65.8)	120 (71.4)	
Time since loss (months) (*M* (*SD*); range)	32.6 (25.5); 1-119	33.5 (26.3); 1-119	31.9 (24.8); 1-119	*F* = 0.31
Symptom severity scores				
PTSD functional impairment	12.15 (1.74)	13.02 (1.43)	11.33 (1.61)	*F* = 102.11***
Depression (CDI)	10.78 (7.17)	6.77 (4.86)	14.54 (6.95	*F* = 136.67***
Prolonged Grief (IPG)	50.57 (11.84)	43.42 (8.07)	57.30 (10.86	*F* = 172.68***
Internalising Problems (CBCL)	12.85 (9.29)	11.36 (8.35)	14.24 (9.92)	*F* = 7.71 **
Externalising Problems (CBCL)	9.79 (8.61)	9.27 (8.18)	10.29 (8.99)	*F* = 1.11
Total Problems (CBCL)	39.59 (25.55)	36.57 (24.89)	42.42 (25.91)	*F* = 4.18*

Note. Samples sizes differ due to occasional missing values. CDI = Children's Depression Inventory. CBCL = Child Behaviour Checklist. CPSS = Child Posttraumatic Stress-Disorder Symptom Scale. IPG = Inventory of Prolonged Grief.
* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

of the sample. The mean age of participants was 11.9 (*SD* = 2.9) years; 189 (56.9%) participants were girls. Most participants had experienced the death a parent, and most losses were caused by illness.

Measures

Demographic and loss related variables

We collected information on the participants' gender, age, and whether or not he/she was actively religious (yes/no). Furthermore, information was gathered about the relationship to the deceased (categorised as mother, father, sibling, other loved one), cause of death (loss was due to illness, a violent cause [accident, suicide, homicide], unexpected medical cause [e.g., heart attack], or some other cause), whether the death was experienced as unexpected (yes/no), and the time passed since the death occurred.

Child PTSD Symptom Scale (CPSS)

Symptoms of PTSD were assessed with the CPSS, a 24-item self-report questionnaire. The first 17 items correspond to symptoms of PTSD as defined in DSM-IV (APA, 2000). Respondents rated the occurrence of symptoms on 4-point scales ranging from 0 (*not at all/only once a week*) to 3 (*almost always/five or more times a week*). The index event was defined as the death of your loved one. In case a participant had experienced the death of more than one close person, he/she was instructed to keep in mind the loss that, at present, affected him/her most. The other 7 items assess functional impairment that is experienced as a result of these symptoms, rated as *absent* or *present*. The CPSS was constructed by Foa et al. (2001; Dutch translation Engelhard, 2005) and has adequate psychometric properties. For instance, the CPSS was found to have adequate internal consistency, test retest reliability, and convergent validity (high correlation with other measure of PTSD symptoms) in a study among young earthquake survivors (Foa et al., 2001) and is increasingly used in studies with bereaved children and adolescents (e.g., Hamdam et al., 2012; Melhem et al., 2007). The α in the present sample for the first 17 items was 0.90 and for the seven functional impairment items was 0.67.

Inventory of Prolonged Grief for Children (IPG-C) and Inventory of Prolonged Grief for Adolescents (IPG-A)

The IPG-C and IPG-A are adjusted versions of the 30-item Inventory of Complicated Grief (Prigerson & Jacobs, 2001), a measure tapping adult Prolonged Grief Disorder. The IPG-C and IPG-A were constructed by Spuij, Prinzie et al. (2012) to assess such symptoms among children and adolescents, respectively. Development of the measures happened in distinct steps, including evaluation of the items' clarity and appropriateness for the age group by experts on psychological assessment for youths, child language, and childhood grief. The study by Spuij, Prinzie et al. (2012) supported the internal consistency and temporal stability of both questionnaires, and provided evidence for the concurrent validity (e.g., significant correlations with measures of depression) and convergent and divergent validity (stronger correlations with other indices of grief than with indices of 'Ongoing Presence' and 'Positive Memories') of the measures. The IPG-C and IPG-A are similar, although the wording of some of the items differ between the versions. Respondents rate the frequency of 30 symptoms on 3-point scales (1 = *almost never*, 2 = *sometimes*, 3 = *always*). The α in the present sample was 0.92.

Children's Depression Inventory (CDI)

The CDI is a 27-item measure of depression symptoms (Kovacs, 2003; Dutch version, Timbremont, Braet, & Roelofs, 2008). Each item contains three statements representing depressive symptoms at increasing levels of severity from which respondents select the one statement that best describes how they felt in the preceding week. The α in the present sample was 0.86.

Child Behaviour Checklist/6-18 (CBCL)

The CBCL is a measure of emotional and behavioural problems constructed by Achenbach and Rescorla (2001; Dutch version Verhulst, Van der Ende, & Koot, 1996). Its 118 items represent different problem areas (e.g., anxious, depressive, somatic symptoms, aggression). The measure can be completed by parents or other people close to the child. Items are rated on 3-point scales (0 = *not true*, 2 = *very true/often true*) and can be summed to obtain indices of Internalising Problems and Externalising Problems. The summed score of all items represents a Total Problem score. Research has supported the psychometric properties of the CBCL (Achenbach & Rescorla, 2001). In the current sample, at least one of the parents completed the CBCL. In case both parents completed the scale, we only used data from one randomly selected parent. Random selection was justified given that correlations between the father's and mother's Internalising Problems, Externalising Problems, and Total Problem scores, if available, were high (all rs > 0.70, all ps < 0.001). In the current sample, the alphas of the Internalising subscale, the Externalising subscale, and the total scale were 0.95, 0.89, and 0.91 respectively.

Statistical Analyses

CFA was conducted using Amos 5.0 (Arbuckle, 2003). Goodness-of-fit was evaluated using the comparative fit index (CFI), Tucker-Lewis index (TLI), root mean square error of approximation (RMSEA), and standardised root mean square residual (SRMR). Conventional guidelines were followed whereby fit is considered adequate if CFI and TLI values are > 0.90, RMSEA is < 0.08, and SRMR is < 0.05. χ^2 difference tests and Akaike information criterion (AIC) were used to compare the fit of competing models. CPSS data were positively skewed and were log-transformed in the CFA (West, Finch, & Curran, 1995). Analysis of variance (ANOVA) was used to examine the ability of CPSS items to distinguish between participants who did vs. did not meet DSM-IV criteria for PTSD. The degree to which demographic variables, loss related variables, and indicators of impairment differed between participants who did vs. did not meet PTSD criteria was examined using χ^2 analysis (for categorical variables) and ANOVAs (for continuous variables). The degree to which these scores were associated with PTSD factor scores was examined using ANOVA and correlational analysis. To explore and compare associations of symptom levels of PTSD, depression, and prolonged grief with indices of functional impairment, we calculated correlations between CPSS, CDI, and IPG total scores on the one hand, and CBCL scores and CPSS functional impairment scores on the other hand, and compared the strength of these correlations using Steiger's *Z*-tests.

RESULTS

Item Descriptives

We first explored mean scores on the items of the CPSS and item endorsement. Table 4.1 shows that items 4 (upset at reminders), 13 (disturbed sleep), and 15 (trouble concentrating) from the CPSS received the highest mean scores and were most frequently endorsed with a 2 or 3 response (on a scale with anchors 0, 1, 2, and 3). Items 10 (detachment), 12 (foreshortened future), and 16 (hypervigilance) received the lowest scores and were least frequently endorsed with a 2 or 3 response.

Confirmatory Factor Analyses

We examined the factor structure of PTSD items using CFA to compare the fit of six hypothesised models of PTSD symptoms, summarised in Table 4.1. Table 4.3 shows fit-indices of these six models. Models 2 to 5 were all nested in Model 1 and all fit better than

Table 4.3 Fit Statistics for Six Competing Models of the Factor Structure of Posttraumatic Stress Symptoms

Model		DF	χ^2	χ^2/df	TLI	CFI	SRMR	RMSEA	AIC
I.	1-Factor Posttraumatic Stress	119	249.983	2.101	.916	.926	.0459	.058	317.983
II.	2-Factor model	118	227.193	1.925	.929	.939	.0436	.053	297.193
III.	3-Factor DSM-IV model	116	212.908	1.835	.936	.946	.0425	.050	286.908
IV.	4-Factor King et al. (1998) Numbing Model	113	192.960	1.708	.946	.955	.0399	.046	272.960
V.	4-Factor Simms et al. (2002) Dysphoria Model	113	204.754	1.812	.938	.948	.0412	.050	284.754
VI.	12-item 2-Factor Model	53	113.147	2.135	.937	.949	.0430	.059	163.147

Note. AIC = Akaike information criterion; CFI = comparative fit index; RMSEA = root mean square error of approximation; SRMR = standardised root mean square residual. TLI = Tucker-Lewis index.

this unitary model (all $\Delta\chi^2 \geq 22.79$, all *p*s < 0.001). The 4-factor King et al. (1998) numbing model (Model 4) fit the data best: it had the largest difference in χ^2 value between any of the models and the unitary model (Model 1), the lowest AIC, and the best fit according to the TLI, CFI, SRMR, and RMSEA. Correlations between the four factors ranged from 0.78 (between factors 'avoidance' and 'emotional numbing') to 0.92 (between factors 'reexperiencing' and 'hyperarousal').

In this best fitting King et al. (1998) numbing model, item loadings were all higher than 0.50, with the exception of 'inability to recall important part of the event' from the 'emotional numbing' factor (loading = 0.27). Because this latter item had a low factor-loading in all six models that we tested, CFAs were conducted again, omitting this item. Outcomes of these additional analyses showed that the King et al. (1998) numbing model (Model 4) remained the best fitting model (e.g., TLI = 0.940, CFI = 0.951, RMSEA = 0.052). We also reran the models leaving out the 'foreshortened future' item, an item that has been said to be less plausible among children (Scheeringa, Wright, Hunt, & Zeanah, 2006). Again, Model 4 fit the data best (e.g., TLI = 0.943, CFI = 0.954, RMSEA = 0.051; additional fit statistics are available from the corresponding author).

PTSD Prevalence

Next, we examined the prevalence of PTSD 'caseness'. In accord with PTSD criteria from DSM-IV (APA, 2000) the prevalence of full PTSD was 51.5%, using the scoring rule that symptom scores were at least 1 (*once per week or less/a little bit/once in a while*) for at least one reexperiencing symptom, three avoidance symptoms, and two hyperarousal symptoms (cf. Foa et al., 2001; Foa, Riggs, Dancu, & Rothbaum, 1993). Based on an alternative method of scoring in which CPSS items were only counted toward a PTSD diagnosis if they were scored 2 or more (cf. Brewin, Adrews, & Rose, 2000), PTSD prevalence was 15.7%. Analyses described below were conducted using the > 1 scoring rule, because this is the recommended scoring rule to estimate diagnoses of PTSD based on the CPSS (Foa et al., 1993, 2001).

Individual Item Differentiation between Cases and Non-Cases of PTSD

We examined the ability of each of the 17 PTSD items to distinguish between participants who did vs. did not meet criteria for PTSD from DSM-IV (APA, 2000). ANOVAs were conducted to evaluate the mean scores for each item of the CPSS by PTSD-status (Table 4.1). Outcomes showed that participants who met PTSD criteria scored higher on every item than those who did not meet PTSD criteria. Based on inspection of the outcomes shown in Table 4.1, items 14 (irritability/anger), 4 (upset at reminders), and 7 (avoiding reminders) were among the items that differentiated best between cases and non-cases of PTSD, whereas items 2 (distressing dreams), 8 (inability to recall important part), and 16 (hypervigilance) were among the items that differentiated worst between the two groups. When we rerun these analyses controlling for age and sex, similar outcomes emerged. All 17 items discriminated between cases and non-cases of PTSD (all Fs > 34.37, all ps < 0.0005). Item 14 differentiated best ($F(1, 331) = 152.31$, $p < 0.0001$) and item 8 differentiated worst between cases and non-cases ($F(1, 331) = 34.37$, $p < 0.001$).

Demographic and Loss Related Characteristics of PTSD

A further aim was to examine the extent to which PTSD caseness and severity varied as a function of demographic variables and characteristics of the loss. As shown in Table 4.2, a diagnosis of PTSD was significantly more prevalent among girls than among boys (Fisher's exact test, $p < 0.006$). Moreover, age differed according to PTSD status such that those who met PTSD criteria were older compared to those with did not ($F(1, 332) = 4.91$, $p < 0.05$). In a logistic regression analysis, in which PTSD status was regressed on age and gender (coded as 0 = boy, 1 = girl) entered simultaneously, gender (OR = 1.75, 95% CI 1.12-1.74, $p < 0.05$) but not age (OR = 1.07, 95% CI 0.99-1.16, $p = 0.08$) was a significant predictor of PTSD status, indicating that girls had a 75% increase in odds likelihood to meet criteria for PTSD caseness compared with boys.

We then examined the degree to which PTSD symptom severity (i.e., the summed CPSS item scores) varied as a function of demographic and loss related variables. These analyses showed that PTSD-severity was significantly higher among girls than boys ($M = 14.8$, $SD = 10.3$ vs. $M = 12.4$, $SD = 9.3$; $F(1, 331) = 4.71$, $p < 0.05$) but did not vary as a function of the other variables we examined. Similar analyses were done using scores on the factors from the King et al. (1998) numbing model as dependent variables (calculated as the summed item responses on the reexperiencing, avoidance, emotional numbing, and hyperarousal factors respectively). Scores on the reexperiencing factor were higher among girls than boys ($M = 4.67$, $SD = 3.61$ vs. $M = 3.69$, $SD = 3.10$; $F(1, 331) = 6.67$, $p < 0.02$). Scores on the avoidance factor were higher among those who perceived the loss as unexpected vs. expected ($M = 1.96$, $SD = 1.76$ vs. $M = 1.48$, $SD = 1.52$; $F(1, 328) = 5.67$, $p < 0.02$). No other significant associations between scores on the four factors from the numbing model and demographic and loss related variables were found.

Clinical Correlates of PTSD in Bereaved Children and Adolescents

Next, we examined associations between PTSD-status on the one hand and indices of mental health problems (including symptom-levels of depression, prolonged grief, and Internalising and Externalising Problems) on the other hand. As shown in Table 4.2, children and adolescents meeting criteria for PTSD caseness scored higher on the functional impairment index and on the CDI and IPG compared to participants who did not meet these criteria. Parent-rated Internalising Problems (CBCL) and Total Problem behaviour (CBCL), but not Externalising Problems (CBCL), were also higher among PTSD cases. As could be expected, compared to participants who did not meet PTSD criteria, those who met PTSD criteria also had significantly higher scores on the summed item scores of the reexperiencing factor ($M = 6.23$, $SD = 3.25$ vs. $M = 2.13$, $SD = 2.11$; $F(1, 331) = 182.62$), the avoidance factor ($M = 2.78$, $SD = 1.65$ vs. $M = 0.76$, $SD = 0.96$; $F(1, 331) = 183.01$), the emotional numbing factor ($M = 4.97$, $SD = 2.89$ vs. $M = 0.98$, $SD = 1.31$; $F(1, 331) = 255.87$), and the hyperarousal factor ($M = 6.75$, $SD = 3.10$ vs. $M = 2.44$, $SD = 2.49$; $F(1, 331) = 193.21$, all $ps < 0.001$) from the King et al. (1998) numbing model. All these findings of significant associations between PTSD caseness and concurrent symptoms attest to the concurrent validity of the PTSD construct.

We also calculated summed scores for all other factors that are distinguished in the six hypothesised models of PTSD (summarised in Table 4.1) and calculated correlations between each of these PTSD factor scores and indices of impairment. These are shown in Table 4.4. All correlations were statistically significant at $p < 0.05$. Notably, PTSD factor scores were more strongly associated with self-rated depression and prolonged grief, than with parent-rated Internalising and Externalising Problems.

Table 4.4 Correlations of PTSD Total Score and PTSD Factor Scores with Concomitant Clinical Symptoms and Functional Impairment

	Item number	Alpha reliability	Mean score (*SD*)	Depression (CDI)	Prolonged Grief (IPG)	Internalising (CBCL)	Externalising (CBCL)	Total Problems (CBCL)	Functional impairment (CPSS)
Total PTSD severity	1-17	.90	13.75 (9.93)	.70***	.79***	.26***	.20**	.25***	.59***
Reexperiencing/avoidance	1-7	.83	6.05 (4.63)	.58***	.76***	.24***	.18**	.23***	.51***
Numbing/hyperarousal	8-17	.83	7.70 (5.97)	.72***	.73***	.25***	.18**	.24***	.58***
DSM-IV Reexperiencing	1-5	.80	4.24 (3.43)	.57***	.75***	.20***	.16**	.19**	.50***
DSM-IV Avoidance	6-12	.76	4.84 (4.15)	.64***	.70****	.20***	.15**	.20***	.54***
DSM-IV Hyperarousal	13-17	.74	4.66 (3.54)	.67***	.67***	.30***	.21***	.28***	.53***
Efforful Avoidance	6-7	.60	1.80 (1.69)	.43***	.56***	.25***	.17**	.24***	.37***
Emotional Numbing	8-12	.71	3.03 (3.01)	.64***	.66***	.13*	.12*	.14*	.53***
Dysphoria	8-15	.80	6.57 (5.04)	.73***	.71***	.23***	.18**	.22***	.58***
Arousal	16-17	.60	1.12 (1.43)	.44***	.57***	.23***	.12*	.21***	.38***
Avoidance Hyperarousal	6-7, 10-12, 16-17	.79	4.65 (4.17)	.63***	.72***	.24***	.16**	.23***	.53***

Note. CDI = Children's Depression Inventory. CBCL = Child Behaviour Checklist. CPSS = Child Posttraumatic Stress Disorder Symptom Scale. IPG = Inventory of Prolonged Grief.
* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Associations of PTSD, Prolonged Grief, and Depression with Functional Impairment

Finally, we examined associations between symptom levels of PTSD, depression, and PGD and functional impairment. To this end, we calculated Pearson correlations between total scores on the CPSS, CDI, and IPG on the one hand, and CBCL Internalising, CBCL Externalising, CBCL Total scores, and the CPSS functional impairment score on the other hand. As shown in Table 4.4, associations of PTSD severity (CPSS) with these scores were 0.26, 0.20, 0.25, and 0.59, respectively (*ps* < 0.01). Associations of depression severity (CDI) with these scores were 0.28, 0.23, 0.27, and 0.56, respectively (*ps* < 0.01). Associations of prolonged grief severity (IPG) with these indices were 0.17, 0.11, 0.16, and 0.51 (*ps* < 0.05), respectively. (Correlations remained statistically significant at a Bonferroni corrected *p*-level (0.05/4) of 0.013, with the exception of the correlation of $r = 0.11$ between the IPG and CBCL Externalising score with a *p*-level of $p = 0.049$.)

Internalising Problems were significantly more strongly correlated with PTSD and depression severity than with prolonged grief ($Z > 2.02$, $p < .05$), whereas correlations of Internalising Problems with PTSD and depression did not differ ($Z = 0.49$). Similarly, Externalising Problems were significantly more strongly correlated with PTSD and depression severity than with prolonged grief ($Z > 2.47$, $p < 0.05$), whereas correlations of Externalising Problems with PTSD and depression did not differ significantly ($Z = 0.72$). CBCL Total scores were also more strongly correlated with PTSD and depression severity than with prolonged grief ($Z > 2.29$, $p < .05$), whereas correlations of Externalising Problems with PTSD and depression did not differ significantly ($Z = 0.49$). CPSS functional impairment scores were significantly more strongly correlated with PTSD severity than with prolonged grief ($Z = 2.41$, $p < 0.01$); correlations of CPSS functional impairment scores with PTSD and depression did not differ ($Z = 0.89$), and correlations of CPSS functional impairment scores with depression and prolonged grief also did not differ significantly ($Z = 1.00$).

DISCUSSION

This study examined the factor structure of PTSD symptoms in bereaved children and adolescents. In addition, we examined the ability of these symptoms to distinguish between participants who did vs. did not meet DSM-IV (APA, 2000) criteria for PTSD. Associations of demographic variables, characteristics of the loss, and indicators of impairment with PTSD status (meeting vs. not meeting DSM-criteria) and PTSD factor scores were also investigated.

We first examined the factor structure of PTSD items comparing the fit of six competing models (see Table 4.1). Outcomes of the CFA showed that the four-factor numbing model – initially put forth by King et al. (1998) – provided the best representation of the latent structure of PTSD symptoms in this sample. In this model, PTSD symptoms constitute distinct factors of (a) reexperiencing (similar to the formulation of this cluster in DSM-IV), (b) active avoidance of thoughts and activities, people, or places related to the death of the loved one, (c) emotional numbing (i.e., passive avoidance in the form of, e.g., loss of interest, detachment, and restricted affect), and (d) hyperarousal. The findings are consistent with those of studies among children and adolescents confronted with unintentional injury (Kassam-Adams et al., 2010), victimized homeless adolescents (Stewart et al., 2004), and adolescents exposed to a variety of trauma types (Saul et al., 2008) in which the same model was supported. Findings also accord with several studies among adult trauma victims – e.g., studies among veterans of the Gulf-war (Simms et al., 2002) and studies with civilians exposed to terrorism related trauma (Baschnagel et al., 2005; Palmieri et al., 2007) – which also showed that the numbing model represented the best model of PTSD symptoms.

It is noteworthy that, following conventional criteria for good model fit, the other models that we tested, including the three-factor DSM-IV model, also fit the data quit well. This is not totally unexpected given that prior studies, among adults as well as children and adolescents, have also found differences in fit of different models to be relatively small (e.g., Boelen et al., 2008; Kassam-Adams et al., 2010). Nevertheless, although the DSM-factor structure received some support in this study, the stronger support for the four-factor numbing model suggests that it makes sense to separate active avoidance from passive avoidance in conceptualising bereavement related PTSD among bereaved children and adolescents.

Next, we examined the prevalence of PTSD caseness. Based on criteria from DSM-IV (APA, 2000), the prevalence of PTSD caseness in this sample was 51.5%. This rate is not totally unexpected given that all participants were recruited via grief support groups or mental health care institutions. Thus, many if not all participants conceivably experienced some emotional suffering related to their loss. This rate should obviously not be generalised to the general population of children and adolescents confronted with loss but does suggest that PTSD is prevalent among those who seek help. It may seem strange to base estimates of PTSD-caseness on the DSM-IV scoring algorithm, given that the DSM-IV factor structure was not found to be the best fitting model in our CFA. Yet, this is the only algorithm available; no such algorithm exists for the King et al. (1998) numbing model or any of the other models we tested. It is also important to recall that, as said, the 3-factor DSM-IV model did not receive the best fit, but still fit the data reasonably well. Moreover, irrespective of the nature of the revisions that will be made to the PTSD criteria and scoring algorithms, the high rate of 51.5% does suggest that PTSD-symptoms are central to the suffering of children and adolescents seeking help after the death of a loved one.

We also investigated the ability of each of the 17 PTSD items to distinguish between PTSD cases and non-cases. Each of these symptoms discriminated well between cases and non-cases, even when controlling for age and gender. Items tapping irritability/anger, the tendency to get upset when confronted with reminders of the death, and the urge to avoid such reminders, differentiated best between cases and non-cases. Items assessing distressing dreams, amnesia, and hypervigilance differentiated worst between cases and non-cases of PTSD. Notably, the relatively poor performance of the amnesia item (item 8) accords with prior findings and suggests that this item might be excluded from the PTSD diagnostic picture (Boelen et al., 2008; Kassam-Adams et al., 2010).

We also explored whether or not demographic variables and characteristics of the loss were associated with PTSD caseness and severity. Only few associations were found. Gender and age were associated with PTSD status. Specifically, PTSD was more prevalent among girls than among boys, and more prevalent among older participants compared to younger participants. Girls also scored higher than boys on the total PTSD severity score (summed CPSS items). The findings of gender differences in PTSD caseness and PTSD severity accord with a large body of studies showing that women have a considerable higher risk of experiencing PTSD following exposure to traumatic events (Tolin & Foa, 2006). Few significant findings emerged in our examination of associations between demographic and loss related variables and PTSD factor scores based on the numbing model: reexperiencing scores were significantly higher among girls than among boys, and scores on the active avoidance factor were higher among those who perceived the loss as unexpected vs. expected. The fact that PTSD scores hardly varied as a function of demographic and loss-related variables suggests that other variables instead of these (rather static) background variables (e.g., variation in coping behaviours, thinking patterns, social support) may increase PTSD symptoms following the death of a loved one.

Next, we examined clinical correlates of PTSD. As expected, children and adolescents who met DSM-IV criteria for PTSD scored higher on self-report measures of depression, prolonged grief, and functional impairment compared to participants who did not meet these criteria. Parent-rated Internalising Problems, but not parent-rated Externalising Problems were also higher among participants meeting criteria for PTSD. These findings provide further evidence of the clinical significance of childhood PTSD (Brent et al., 1993; Brown & Goodman, 2005; Kassam-Adams et al., 2010). Compared with prolonged grief severity, PTSD severity and depression severity were more strongly correlated with parent-rated problems tapped with the CBCL, suggesting that PTSD and depression are relatively more debilitating outcomes of bereavement.

We calculated PTSD factor scores for all factors hypothesised by the models that we tested (summing item ratings from the appropriate items in each case) and correlated these scores with indices of concomitant symptoms and functional impairment. PTSD factor scores were all significantly and positively correlated with self-rated depression, prolonged grief, and functional impairment. Associations between factor scores and parent-rated impairment were also significant. Notably, there were no salient differences in the magnitude of the correlations of the different PTSD factor scores with indicators of impairment. However, it is notable that the emotional numbing factor from the King et al. (1998) numbing model was more strongly associated with impairment than was the active avoidance factor from that same model. This provides further support that active and passive avoidance are distinct components of bereavement related PTSD among children and adolescents. More generally, the finding of differential relations between different PTSD factors and theorized correlates accords with recent research among children (Kassam-Adams et al., 2010) and adults (e.g., Elhai, Contractor, Palmieri, Forbes, & Richardson, 2011; Ford et al., 2009). The correlations between summed scores on the PTSD factors on the one hand and self-rated symptoms of depression and prolonged grief (obtained from the CDI and IPG, respectively) seemed considerably stronger than the associations between summed scores on the PTSD factors and parent-rated Internalising and Externalising scores (obtained from the CBCL). This may indicate that parents are not always sufficiently aware of the intensity of their children's suffering following the death of a loved one. It also underscores that it is important to obtain information about the suffering of bereaved children themselves, and not only to rely on the parent's estimations of the degree of suffering.

A limitation of this study is that PTSD data were obtained from self-report measures. It is possible that CFA outcomes would have been different in case PTSD data were obtained from interview measures. However, Kasam-Addams et al. (2010) recently found evidence that CFA results based on self-report questionnaires and interview measures were similar. That said, it is likely that our reliance on a self-report measure of PTSD symptoms resulted in an overestimation of prevalence rates of PTSD-caseness in this sample (cf. Engelhard et al., 2007); the fact that PTSD prevalence rates decreased when a more conservative cut-off was used to count items toward a PTSD diagnosis supports this notion. Thus replication of this study using interview based measures of PTSD seems useful.

A second limitation is that we only gathered limited information about the circumstances surrounding the death, limiting our categorisation to whether the death was due to illness, a violent cause, an unexpected medical cause, or a miscellaneous category of 'other causes'. Although children were all confronted with the death of a loved one, we do not know for how many of them this death occurred in the context of a traumatic event as defined in DSM-IV criterion A1 and how many of them had responses as defined in criterion A2 (i.e., experience of fear, helplessness, horror during the event). Therefore, we were unable to examine whether or not the factor structure differed between participants who did and those who did not meet DSM-IV criterion A. It is relevant to examine this issue taking into account recent evidence that criterion A2 endorsement moderates the factor structure of PTSS symptoms (Armour et al., 2011; Elhai & Palmieri, 2011).

Our limited assessment of the circumstances surrounding the loss may also explain our somewhat unexpected finding that mode of death was unrelated with PTSD scores in this study. That is, although Cerel and colleagues (1999) observed no significant difference in PTSD-levels between children whose parents died to violent vs. nonviolent means, there is also evidence that violent deaths lead to poorer outcomes compared to nonviolent deaths (e.g., Melhem et al., 2004). Traumatogenic elements may be found in a variety of death circumstances, including prolonged illness, sudden natural deaths, and accidents (e.g., seeing the person die, exposure to injury or suffering, witnessing distress in relatives) and may be more subjective for children than for adults, given the child's less developed capacity to make sense of the circumstances (cf. Kaplow et al., 2012; Nader & Layne, 2009; Pynoos et al., 2009). As the degree of exposure to potentially traumatogenic elements of the death cannot be examined with the present data, it would be relevant for future research to examine which of these elements inflate the risk of PTSD.

A third limitation is that, given the variety of methods of recruitment, analyses relied on a rather heterogeneous group of children and adolescents. Thus, it would be interesting for future studies to further examine the factor structure and correlates of bereavement related PTSD in more specified and homogeneous groups (e.g., bereaved children suffering severe emotional problems). A fourth limitation is that the present study relied on data obtained in the Netherlands. Thus, results should be viewed cautiously with regard to their generalisation to populations from other countries. A final limitation is that the construct of Prolonged Grief Disorder (assessed as a possible clinical correlate of PTSD) is not yet an established diagnostic category and is undergoing change. The measure of prolonged grief used in this study relied on Prigerson et al.'s (2009) conceptualisation of the construct, more than on Shear et al.'s (2011) conceptualisation, or criteria for Persistent Complex Bereavement Related Disorder proposed for DSM-5 that are a mixture of Prigerson et al.'s and Shear et al.'s proposals (see Boelen & Prigerson, 2012, 2013). Consequently, associations between bereavement-related PTSD and prolonged grief could be different if other conceptualisations and measures of prolonged grief would be used.

Notwithstanding these limitations, this study is the first to examine the factor structure of bereavement-related PTSD symptoms among bereaved children and adolescents. Findings suggest that the DSM-IV conceptualisation of PTSD might not be the best description of PTSD symptoms and that avoidance symptoms may better be conceived as separate clusters of effortful avoidance and emotional numbing symptoms. The current study also provides preliminary evidence that elevated PTSD following childhood bereavement is associated with increased severity of depression, prolonged grief, and parent-rated functional impairment. Further studies are needed to examine individual processes that contribute to the development and maintenance of PTSD in bereaved children and adolescents in order to inform treatment interventions.

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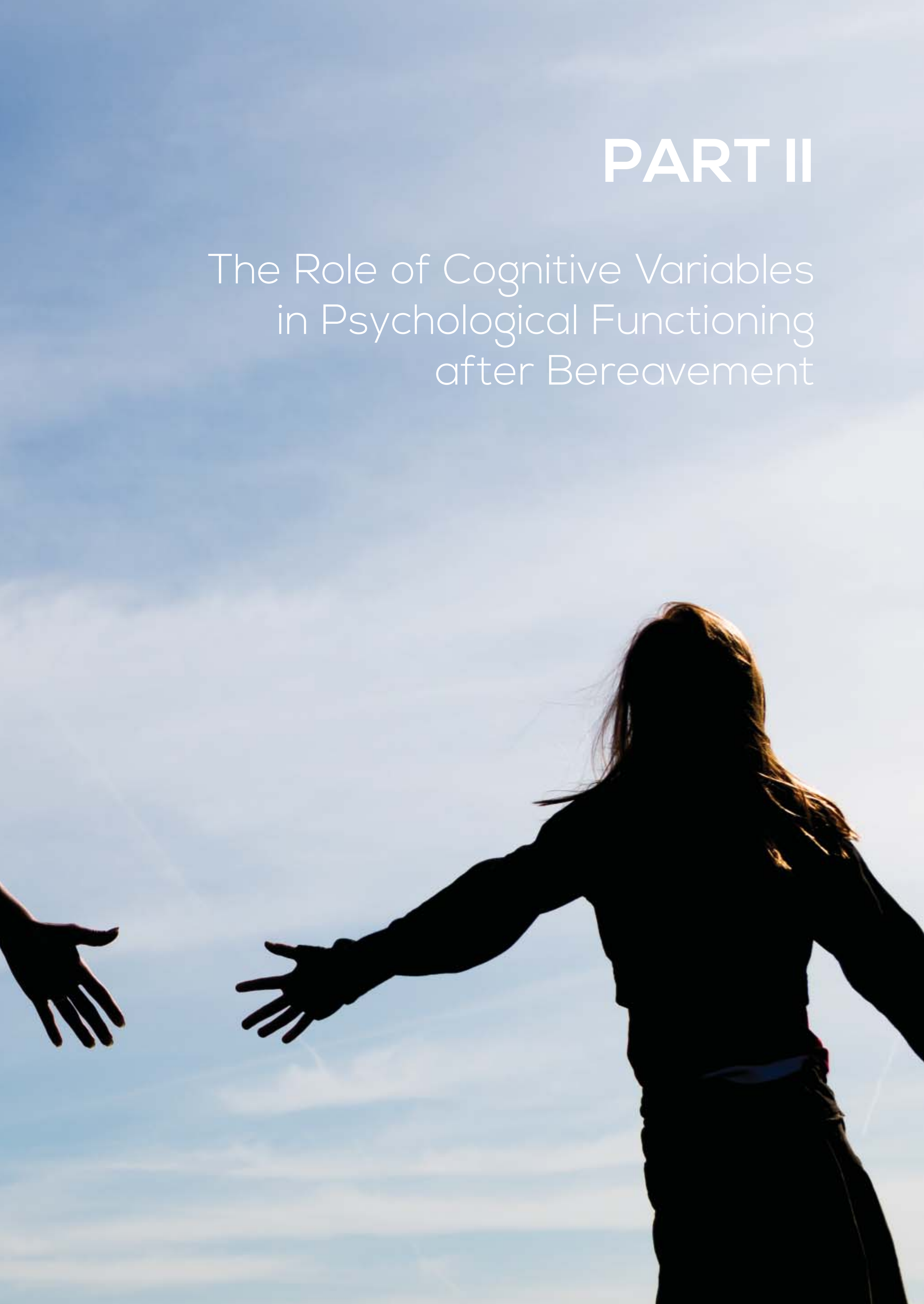
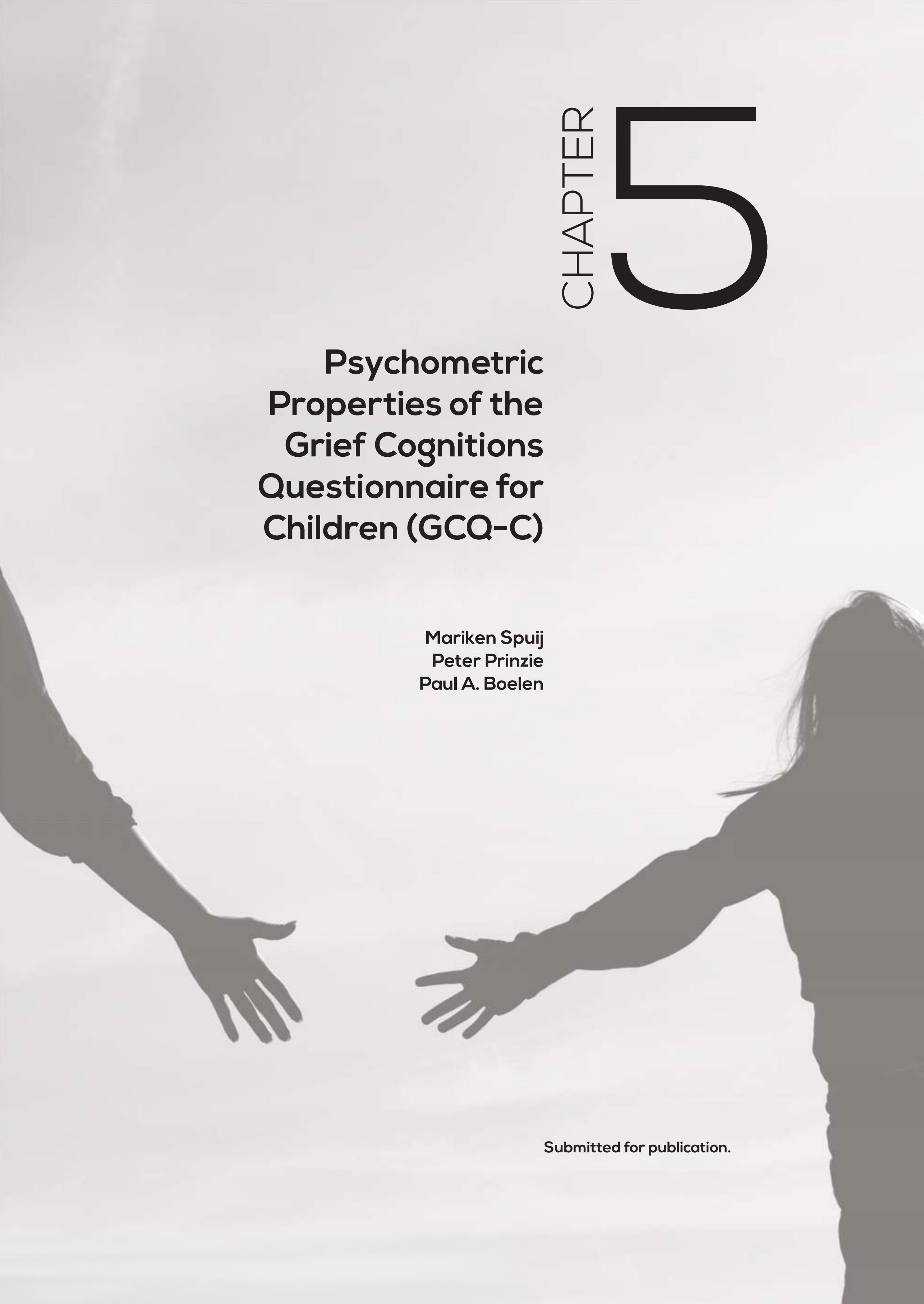
PART II

The Role of Cognitive Variables in Psychological Functioning after Bereavement





CHAPTER 5

Psychometric Properties of the Grief Cognitions Questionnaire for Children (GCQ-C)

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Submitted for publication.

ABSTRACT

Negative thinking is seen as an important mediating factor in the development of Prolonged Grief Disorder (PGD), a syndrome encompassing debilitating symptoms of grief. No measure of specific grief related cognitions is available yet. Based on an adult measure of negative thinking in adults we developed a questionnaire for children, the Grief Cognitions Questionnaire for Children (GCQ-C). This study investigated the psychometric properties of the GCQ-C. Both reliability and validity were investigated in this study, in which hundred fifty-one children and adolescents (aged 8 to 18 years) participated. Findings showed that items of the GCQ-C represented one underlying dimension. Furthermore, the internal consistency and temporal stability is adequate. Third, the findings supported the concurrent validity (e.g., significant positive correlations with self-report indices of PGD, depression and Posttraumatic Stress Disorder [PTSD]), convergent and divergent validity (stronger correlations with similar questionnaires for negative thinking) of the GCQ-C. This report provides further evidence for the role negative thinking plays in the development and maintenance of PGD in children and adolescents.

INTRODUCTION

There is evidence that, in a significant minority of bereaved children, adolescents and adults, acute grief reactions turn into chronic debilitating distress, blocking reestablishment of normal routines (e.g., Dowdney, 2008; Melhem, Moritz, Walker, Shear, & Brent, 2007; Melhem, Porta, Shamseddeen, Walker, & Brent, 2011). This evidence has led to the inclusion of Persistent Complex Bereavement Disorder in the Appendix of the fifth edition of the Diagnostic and Statistical Manual of mental disorders (DSM-5; American Psychiatric Association [APA], 2013; for discussions see Boelen & Prigerson, 2012; Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012; Wakefield, 2012). Consistent with many recent studies (see Kaplow et al., 2012), we refer to this syndrome as Prolonged Grief Disorder (PGD). PGD includes symptoms of separation distress, numbness, avoidance and detachment present to the point of functional impairment at least six months following the death of a loved one (Prigerson et al., 2009). To date most research on PGD has been done in adults, but there is a growing body of research done in children and adolescents. There is strong evidence that symptoms of PGD are distinct from symptoms of depression, Posttraumatic Stress Disorder (PTSD) and other anxiety disorders (Boelen & Prigerson, 2012; Lichtenthal, Cruess, & Prigerson, 2004; Prigerson et al., 2009; Shear et al., 2011; Spuij, Prinzie et al., 2012; Spuij, Reitz et al., 2012).

In order to understand why some children cope with loss more easily than others, it is important to identify variables that mediate the development and maintenance of PGD. Given the lack of effective interventions for bereaved youth (Currier, Holland, & Neimeyer, 2007), this knowledge can be very helpful for the development of interventions for bereaved children who fail to recover from loss. Recent cognitive behavioural conceptualisations of PGD propose that negative thinking and avoidance behaviours play a significant role in the development and maintenance of the disorder (Boelen, Van den Hout, & Van den Bout, 2006; Maccallum & Bryant, 2013). Empirical findings, mostly from adults, have confirmed that some bereaved individuals develop negative thinking that contributes to the development of PGD (Boelen & Lensvelt-Mulders, 2005; Boelen, Van den Bout, & Van den Hout, 2003). However, little is known about negative thoughts associated with emotional distress in bereaved children. Findings of a preliminary study with 30 adolescent girls, aged 13-18 years (Boelen & Spuij, 2008), showed that different types of cognitions were significantly associated with symptom levels of PGD and depression; global negative thinking about life and self and catastrophic misinterpretations were most strongly linked with these symptoms. To our knowledge, no research is available about specific grief related negative thoughts in bereaved children under the age of 13. This is remarkable, as many children are confronted with loss (Harrinson & Harrington, 2001). Understanding the cognitive profile that is associated with specific grief related psychopathology in children is important for the conceptualisation and treatment of this psychopathology.

Despite the widespread idea that alleviation of mood and anxiety symptom requires changes in underlying maladaptive thinking patterns (cf. Beck, 1967; Ellis & Grieger, 1977; Meiser-Stedman, Dalgleish, Glucksman, Yule, & Smith, 2009; Treadwell & Kendall, 1996), there is a scarcity of measures to assess negative thinking in children who suffer from depression, PTSD or anxiety. Moreover, there is no measure of negative thoughts involved in the development and maintenance of PGD. Examples of measures that do assess negative thinking in youth are the Automatic Thoughts Questionnaire (ATQ, Hollon & Kendall, 1980; Kazdin, 1990), and the Negative Affectivity Self Statement Questionnaire (NASSQ; Ronan, Kendall, & Rowe, 1994). Campbell, Rapee and Spence (2000) stated that the majority of childhood cognitive measures, including the ATQ, are limited by the fact that they are downward extensions of questionnaires developed for adults. Other measures, like the NASSQ, have different versions for children and adolescents, which is a limitation for e.g. research purposes. In light of these limitations, Schniering and Rapee (2002) developed the Children's Automatic Thoughts Scale (CATS), a measure specifically designed to assess negative thinking in children and adolescents. The authors first started with a pool of items that was generated from in depth interviews with children and adolescents with various forms of emotional problems. Items relating to affect or behavior were removed, so only items that reflect cognition remained. The final measure consists of 40 items covering a broad range of negative automatic thoughts (e.g., "*There is something very wrong with me*", "*I look like an idiot*", "*I'm worthless*" and "*Most people are against me*").

Given the lack of measures for negative thinking in children in general and more specific for bereaved children, our aim was to develop a measure for the latter group. Specifically, the current study sought to enhance knowledge on the role of negative thinking in PGD and other forms of emotional distress among children confronted with the death of a loved one. To this end, as described in more detail below, we constructed the so called Grief Cognitions Questionnaire for Children (GCQ-C) for bereaved children aged 8 to 18 years, drawing from earlier work on negative cognitions in adult PGD (Boelen & Lensvelt-Mulders, 2005). Because of the limitations mentioned by Campbell et al. (2000) about the usefulness of adult measures in children, we asked child psychologists, children and adolescents to help us with the development of this specific child version. We describe this process below. Furthermore, our aim was to evaluate several psychometric properties of this GCQ-C. Specifically, we studied the dimensionality, internal consistency, and temporal stability of the GCQ-C. In addition, we studied several predictions concerning the validity of the GCQ-C. With respect to the concurrent validity, we expected that stronger endorsement of negative cognitions tapped by the GCQ-C would be associated with increased symptom levels of PGD, depression, and PTSD as well as Internalising and Externalising Problems. In addition, we expected elevated negative thinking – tapped by the GCQ-C – to be associated with reduced *coping efficacy*, defined as the participant's own perceived capability to adjust to the loss (cf. Benight & Bandura, 2004). With respect to the convergent and divergent validity, we expected scores on the GCQ-C to be more strongly associated with cognitions associated with depressive and anxious states (tapped by the subscales Social Threat, Physical Threat and Personal Failure of the CATS; Schniering & Rapee, 2002), than cognitions associated with anger (tapped by the subscale Hostile Intent of the CATS; cf. Schniering & Lyneham, 2007). In addition, it was predicted that, compared to the summed scores on the CATS (tapping cognitions related to depressive, anxious, and angry states not specifically linked with the loss participants had confronted), summed scores on the GCQ-C (tapping loss related negative thoughts) would be more strongly associated with the degree to which children and adolescents experienced impairments in functioning as a result of the loss. Finally, we explored the extent to which scores on both questionnaires varied as a function of demographic and loss related variables (e.g., time since loss and cause of death).

METHOD

Participants and Procedure

Participants were recruited from two sources, as described below. Children, adolescents, and their parents from both samples completed the CGQ-C and additional questionnaires. All participants had the Dutch nationality. No data were collected on socio-economic status. Table 5.1 shows the characteristics of all participants. In total, 151 children, aged 8 to 18 years, completed the measures.

Sample 1

Sample 1 was recruited through collaboration with a national grief support group for children in the Netherlands that offers counselling and advice to parents and children about grief and bereavement and that organises support-weekends for children and their parent(s). During the period of data-collection for the present study, all families that had a child or adolescent applying for such a weekend were sent a letter. The letter included a description of the study and a stamped refusal card. If no refusal card was received in two weeks, the family was contacted and – if parent(s) and child agreed to participate – a home

Table 5.1 Demographic Characteristics, Loss Related Characteristics, and Scores on Prolonged Grief and Depression Measures across Samples

	Sample 1 *N* = 83	Sample 2 *N* = 68
Demographic characteristics		
Gender (*N* (%))		
Male	36 (43.4)	30 (44.1)
Female	47 (56.6)	38 (55.9)
Age (*M* (*SD*))	11.08 (2.54)	13.24 (2.75)
Loss related characteristics		
Deceased is (*N* (%))		
Parent	74 (89.2)	55 (80.9)
Sibling	7 (8.4)	4 (5.9)
Other relative	2 (2.4)	9 (13.3)
Cause of death is (*N* (%))		
Illness	31 (37.3)	40 (58,8)
Traumatic (accident, suicide, homicide)	17 (20.5)	17 (25.0)
Sudden medical cause (e.g. heart attack)	35 (42.2)	11 (16.2)
Death was expected by participants?		
Yes	19 (22.9)	26 (38.2)
No	62 (74.7)	43 (61.8)
Time since loss in months (*M* (*SD*))	30.84 (20.40)	37.94 (39.85)
Symptom scores		
IPG-C	52.24 (12.14)	52.69 (11.99)
CDI	10.50 (7.71)	12.39 (6.82)

Note. CDI = Children's Depression Inventory. IPG-C = Inventory of Prolonged Grief for Children.

visit was planned. In total, 121 families were approached and parents and children of 83 (68.6%) agreed to participate. Home visits were conducted by trained graduate students. During the visits, aims of the study were explained and questionnaires were administered. Before completion of the questionnaires, assent was obtained from children (aged 8 to 12 years), whereas informed consent from parents and adolescents (aged 13 to 18 years). If needed, the students could help with completion of the questionnaires (e.g., read questions for dyslectic youth). Sample 1 included 83 children. Thirty children and adolescents were on a waiting list for a support group. They filled in the GCQ-C a second time, approximately six weeks later (*M* = 5.67, *SD* = 1.67 weeks, range 3 to 9 weeks) and a third time after 30 weeks (*M* = 28.97, *SD* = 2.12 weeks, range 25 to 34 weeks). These children and adolescents did not receive psychotherapy or other professional aid during this time interval.

Sample 2

The second sample was recruited via an outpatient clinic of Utrecht University. During the period of data-collection for the present study, consecutive patients aged 8 to 18 years who reported loss related emotional problems among the complaints they sought help for, were invited to participate. In total, 68 children were approached and they all agreed to participate. Participants completed questionnaires, accompanied by their therapist. Before entering the study, assent was obtained from children, informed consent from parents and adolescents. Sample 2 included 68 children and adolescents; they were not asked to complete measures a second time.

Measures

All participants completed the CGQ-C, together with a brief questionnaire about demographic and loss-related (e.g., cause of death) variables. Participants also rated their coping self-efficacy. In addition, children completed the Inventory of Prolonged Grief for Children (IPG-C), Child PTSD Symptom Scale (CPSS), Children's Depression Inventory (CDI) and Children's Automatic Thoughts Scale (CATS). Children aged 11 to 18 years from both samples also completed the Youth Self Report (YSR). In both samples, at least one of the parents completed the Child Behaviour Checklist/6-18 (CBCL).

Grief Cognitions Questionnaire for Children (CGQ-C)

The CGQ-C is based on the 38-item CGQ developed by Boelen et al. (2003; see also Boelen & Lensvelt-Mulders, 2005). A confirmatory factor analysis revealed that the CGQ represented nine categories of negative bereavement related thoughts: global negative beliefs about the self, the world, life and the future; negative cognitions about self-blame; other people's responses after the loss, and the appropriateness of one's grief reactions; and cognitions about the importance of cherishing the pain of the loss and threatening interpretations of one's reactions to the loss (Boelen & Lensvelt-Mulders, 2005). We constructed the GCQ-C, the adaptation for children, in three steps.

In the first step two experts in clinical child psychology were asked to simplify the wording of all 38 items of the adult GCQ, and to add items tapping the nine categories of cognitions distinguished in the adult GCQ, if so needed. This resulted in provisional list of 55 items.

Our next step was to evaluate this draft version with two independent reviewers (both clinical child psychologists with many years of working experience with bereaved children) and 20 children who were not included in further analyses of this study ($M = 11.04$, $SD = 2.05$

years). We interviewed all people face to face with two specific aims. First, we wanted their general opinion about the wording of items (i.e., did they understand what we asked them) and, second, we wanted their opinion about relatively weak items that could potentially be removed from the scale in order to reduce the number of items. It was our intention to develop a short questionnaire with two or three items for all categories of cognitions distinguished in the adult GCQ. Comments about the comprehensibility of questionnaires led to minor changes in wording. Importantly, the experts suggested to include a number of items tapping 'death anxiety' (e.g., "*I'm afraid that my (foster)parent or another loved one also will die very soon*", "*I always think about the possibility that I also can die very soon*") a theme that was not distinguished in the adult GCQ but was deemed pertinent to the emotional experiences of bereaved children.

As mentioned earlier we wanted to reduce the items. Therefore, our last step was that we asked the reviewers and children to select 1 to 3 items for each of the 10 categories of cognitions that were tapped by the list. This resulted in the final 20-item version of the GCQ-C that is included in Appendix 5.1. Respondents were instructed to rate the frequency of each thought in the preceding two weeks on a 3-point Likert scale with categories 0 = *hardly ever*, 1 = *sometimes*, and 2 = *always*. Specifically, instructions were as follows: "*Below are possible thoughts that bereaved children can have. Indicate which answer fits best to your experience in the past month. You can answer as follows: 0 = hardly ever, 1 = sometimes and 2 = always.*"

Inventory of Prolonged Grief for Children (IPG-C)[1]

The IPG-C is a 30-item measure to assess PGD symptoms in children. Respondents rate the frequency of each symptom in the preceding month on 3-point scales (1 = *hardly ever*, 2 = *sometimes*, 3 = *always*). The IPG-C also includes one item (# 28) assessing impairment in functioning as a result of the loss (i.e., "*I am doing worse (in school and with friends) since she or he died*"). A recent study by Spuij, Prinzie et al. (2012) showed psychometric properties of this questionnaire; the measure has good internal consistency, stability and concurrent validity. In this study Cronbach's alphas were 0.93 (sample 1) and 0.91 (sample 2), respectively.

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[1] Spuij, Prinzie et al. (2012) developed the IPG-C and IPG-A for children and adolescents, respectively. Both inventories had 30 items and minor differences in wording in 17-items. Because of power considerations we only used the IPG-C in the present study. Before data-collection started we asked 20 children and adolescent for their opinion about the GCQ-C items, in addition we asked the adolescents whether they understood the items of the IPG-C and whether they thought the IPG-C items for children were comprehensible. Adolescents confirmed the usefulness of the IPG-C items for their age-group.

Child PTSD Symptom Scale (CPSS)

The CPSS is a 17-item questionnaire that taps symptoms of PTSD symptoms as defined in the Diagnostic and Statistical Manual of mental disorders (DSM-IV-TR; APA, 2000). It was originally constructed by Foa, Johnson, Feeny, and Treadwell (2001; Dutch translation Engelhard, 2005) and further examined by Nixon et al. (2013). Respondents rate the occurrence of symptoms on 4-point scales ranging from 0 (*not at all/only once a week*) to 3 (*almost always/five or more times a week*). Psychometric properties have been found to be adequate (Foa et al., 2001). The internal consistencies (Cronbach's α) were 0.94 in Sample 1 and 0.89 in Sample 2, respectively.

Children's Depression Inventory (CDI)

The CDI developed by Kovacs (2003) measures symptoms of depression. It contains 27 groups of three statements representing depressive symptoms at increasing levels of severity, scored from 0 = *symptom absent* to 2 = *symptom present always/most of the time*. For all 27 items, respondents select the statement that best describes the severity of the symptom during the preceding week. Items are summed to form an overall depression severity score. The original English (cf. Cole & Martin, 2005) and Dutch versions of the CDI (Timbremont, Braet, & Roelofs, 2008) have adequate psychometric properties. In the present samples, it was found that Cronbach's α in Sample 1 was 0.87 and 0.83 in Sample 2.

Children's Automatic Thoughts Scale (CATS)

The CATS (Schniering & Rapee, 2002), assesses automatic thoughts in youth associated with a broad spectrum of negative emotional states. It consists of 40 items in four subscales: (a) Physical Threat (e.g., "*There is something very wrong with me*"); (b) Social Threat (e.g., "*I look like an idiot*"); (c) Personal Failure (e.g., "*I'm worthless*"); and (d) Hostile Intent (e.g., "*Most people are against me*"). The CATS is tested in multiple studies with clinical and non-clinical populations (Micco & Ehrenreigh, 2009; Schniering & Lyneham, 2007; Schniering & Rapee, 2002, 2004). It is a reliable and valid measure that shows good convergent validity with related anxiety and depression scales. The CATS yielded Cronbachs's alphas of 0.91 (Physical Threat), 0.93 (Social Threat), 0.94 (Personal Failure) and 0.89 (Hostile Intent) in Sample 1, and 0.91 (Physical Threat), 0.87 (Social Threat), 0.90 (Personal Failure) and 0.85 (Hostile Intent) in Sample 2.

Coping self-efficacy

We formulated one item to assess coping self-efficacy: "Please rate how well you feel that you have processed this loss", rated on a scale ranging from 0 = *I have not processed the loss at all* to 10 = *I have processed the loss very well.*

Child Behaviour Checklist/6-18 (CBCL)

The CBCL is a measure of emotional and behavioural problems of children and adolescents ages 6 to 18 years constructed by Achenbach and Rescorla (2001; Dutch translation, Verhulst, Van der Ende, & Koot, 1996). It includes 118 items, representing different problem areas (e.g., anxious, depressive, somatic symptoms, aggressive behaviour, and attentional problems). The measure is completed by parents. Items are rated on 3-point scales (0 = *not true*, 1 = *somewhat or sometimes true*, 2 = *very true/often true*) and represent eight different problem areas. Scores on some of these areas can be summed to obtain indices of Internalising Problems and Externalising Problems, whereas the summed score of all items represents a Total Problem score. Psychometric properties of the original (Achenbach & Rescorla, 2001) and Dutch versions (Verhulst et al., 1996) are adequate. At least one of the parents of each participant completed the CBCL. In case both parents completed the scale, we only used data from one randomly selected parent. This random selection was justified, given that correlations between the father's and mother's version, if available, were high.[2] The internal consistencies of the Internalising subscale, the Externalising subscale, and the Total scale in the combined children samples from Sample 1 were 0.83, 0.93, and 0.94 respectively, and in Sample 2 these were 0.85, 0.87, and 0.93 respectively.

Youth Self Report (YSR)

The YSR, developed by Achenbach and Rescorla (2001), is a 120 item measure of emotional and behavioural problems among youngsters between 11 and 18 years. Its items are comparable to those of the CBCL except that they are written in the first person and completed by youngsters between 11 and 18 years of age. Items representing problems are rated using a forced-choice response format (0 = *not true*, 1 = *somewhat/sometimes true*, 2 = *very/often true*). As with the CBCL, indices of Internalising Problems and Externalising Problems, as well as a Total Problem score can be obtained from the measure. Psychometric properties of the original version (Achenbach & Rescorla, 2001) and the Dutch version (Verhulst, Van der Ende, & Koot, 1997) are adequate. In the present study the YSR was only completed by adolescents (participants aged 13 to 18 years) from both samples. The YSR yielded Cronbach's α of 0.88 (Internalising Problems), 0.83 (Externalising Problems), and 0.90 (Total scale) in Sample 1 and 0.85 (Internalising Problems), 0.84 (Externalising Problems) and 0.91 (Total scale) in Sample 2.

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[2] Specifically, for 21 children from Sample 1 and 2 data were available from both parents. The correlations between scores of the fathers and mothers for the Internalising score was $r = 0.60$ ($p < 0.01$), for the Externalising score was $r = 0.73$ ($p < 0.001$), and for the Total score was $r = 0.61$ ($p < 0.01$).

Statistical Analyses

First, we examined the dimensionality of the GCQ-C, using exploratory factor analysis with a varimax rotation, implemented in Mplus 4 with maximum likelihood estimation (Muthén & Muthén, 2007). In order to have a sufficient number of participants for this analyses, data of both samples ($N = 151$) were combined. Secondly, the internal consistency and temporal stability of the GCQ-C were examined. Next, several predictions were tested with respect to the validity of the GCQ-C. With respect to the *concurrent validity*, it was expected that negative cognitions as tapped by the GCQ-C would be significantly (positively) correlated with the severity of Prolonged Grief (IPG-C), depression severity (CDI), PTSD severity (CPSS), and internalising and externalising problems as measured by the CBCL and YSR, and significantly inversely correlated with coping self-efficacy (cf. Haine, Ayers, Sandler, & Wolchik, 2008; Melhem et al., 2007; Spuij, Prinzie et al., 2012).

With respect to the *convergent and divergent validity*, it was expected that the GCQ-C would be more strongly associated with the CATS scales 'Physical Threat', 'Social Threat', and 'Personal Failure' than with the CATS scale 'Hostile Intent' (see Schniering & Lyneham, 2007). We also expected GCQ-C scores to be more strongly associated with the IPG-C item that assesses impairment in functioning as a result of the loss than summed scores on the CATS. Finally, we used correlational analyses and analysis of variance to explore the extent to which scores on the GCQ-C differed as a function of demographic and loss related variables that were assessed (see Table 5.1).

RESULTS

Characteristics of the Study Samples

Table 5.1 shows background and loss related characteristics of both samples. As can be seen, most participants had lost a parent. Most losses were due to illness and most losses were experienced as being unexpected. Scores on the IPG-C (minimum 30, maximum 90) and the CDI are also shown in Table 5.1. Scores on the IPG-C did not differ between Sample 1 ($M = 52.24$, $SD = 12.14$) and Sample 2 ($M = 52.69$, $SD = 11.99$); $t(149) = - 0.23$, $p = 0.74$). In comparison with reference groups from Timbremont et al. (2008) scores on the CDI in both samples fell in the subclinical range.

Dimensionality

The exploratory factor analysis resulted in the emergence of four factors with eigenvalues greater than 1.00 (i.e., 11.76, 1.45, 1.19, 1.08). However, there were reasons to conclude that the GCQ-C items are best characterised as one factor. Firstly, the first factor explained almost 45% of the variance in the GCQ-C with the second through fourth factor each adding very little the variance explained by the first factor. Secondly, inherent to that, the scree plot revealed a clear break after the first component. Thirdly, as shown in Table 5.2, in the one factor solution, all 20 items had factor-loadings ≥ 0.50. Finally, in the models with more than one factor, several items loaded highly on more than one factor and factors could not be interpreted in a meaningful way. Overall, the findings suggested that, within the present dataset, the GCQ-C items clustered together into one underlying dimension of 'overall loss related negative thinking'.

Table 5.2 Abbreviated Items of the GCQ-C and Factor-Loadings in the One-Factor Solutions

Item content	Factor-loadings in Sample 1 and 2 (*N* = 151)
I don't feel confident about the future.	0.88
Think of myself as a weak person.	0.88
Feel frightened about all the things I feel.	0.87
I am of no use to anyone anymore.	0.87
The world is worthless.	0.86
Life has little to offer now he/she died.	0.85
Something is wrong with me, because I feel so sad.	0.83
Blame myself for not having cared for him/her.	0.82
My life is worthless.	0.82
The future will be no fun.	0.82
It can also happen to me.	0.79
I can also die.	0.78
Have seen to it that he/she would not have died.	0.75
My feelings about this loss are not normal.	0.75
Not nice when I will begin to feel less sad.	0.72
I don't show others what I think and feel.	0.68
As long as I am sad, I don't have to let him/her go.	0.66
The world is bad.	0.61
Want to hold on to my sorrow.	0.60
Others should pay attention to how I am doing.	0.50

Internal Consistency

Cronbach's α for the 20 items of the GCQ-C was 0.95 in Sample 1 ($n = 83$), 0.96 in Sample 2 ($n = 63$), and 0.94 in the combined sample ($N = 151$). In line with the results of the exploratory factor analysis, in the combined sample the item-total correlations were all positive and ranged from 0.52 (item 17: "*I think there is something wrong with me because I feel such intense grief*") to 0.81 (item 12: "*I want to hold on to my feelings of sorrow about his/her death for as long as possible*"). All 20 items had item-total correlation greater than 0.50 and the internal consistency did not increase with a deletion of a single item.

Temporal Stability

Thirty children completed the GCQ-C three to nine weeks after the first time and 25 to 34 weeks after the first assessment. The test-retest correlation for the 30 children between scores at assessment 1 and assessment 2 was $r = 0.84$ ($p < 0.001$). The test-retest correlation for the scores at assessment 1 and assessment 3 was $r = 0.73$ ($p < 0.001$).

Concurrent Validity

Correlations of the GCQ-C with the IPG-C, CDI, CPSS, and CBCL scores are shown in Table 5.3. As predicted, the GCQ-C total score was significantly and positively correlated with indices of PGD (IPG-C), depression (CDI), posttraumatic stress (CPSS) and Internalising Problems (CBCL-Internalising); correlations were all large. Unexpectedly, GCQ-C scores were not significantly correlated with the CBCL-Externalising scale and the CBCL Total Problems score. Also as we expected, higher scores on the GCQ-C were correlated with lower scores on the item tapping the perceived ability to cope with the loss (i.e., coping self-efficacy); $r = -0.24$, $n = 147$, $p < 0.01$.

Convergent and Divergent Validity

Correlations of the GCQ-C with the CATS subscales ($N = 151$) are also shown in Table 5.3. As predicted, the GCQ-C was more strongly associated with Personal Failure ($r = 0.78$), Physical Threat ($r = 0.78$) and Social Threat ($r = 0.66$), than with the Hostility subscale ($r = 0.54$, all *ps* < 0.01). Differences between correlations were significant ($r = 0.78$ vs. $r = 0.54$, $z = -4.97$, $p < 0.001$; $r = 0.78$ vs. $r = 0.54$, $z = -4.87$, $p < 0.001$; $r = 0.66$ vs. $r = 0.54$, $z = -2.11$, $p < 0.02$.

Finally, both the GCQ-C total score and the summed score on the CATS were significantly associated with the IPG-C item that assesses impairment in functioning as a

Table 5.3 Correlations between Study Measures in Children

	GCQ-C *r*
Prolonged Grief Disorder (IPG-C)	0.76**
Depression (CDI)	0.67**
Posttraumatic Stress (CPSS)	0.78**
CATS-Physical Threat	0.78**
CATS-Social Threat	0.66**
CATS-Personal Failure	0.78**
CATS-Hostile Intent	0.54**
Internalising Problems (CBCL)	0.18*
Externalising Problems (CBCL)	0.02
Total Problems (CBCL)	0.14
Internalising Problems (YSR)	0.74**
Externalising Problems (YSR)	0.30**
Total Problems (YSR)	0.63**

Note. Samples sizes differ due to occasional missing values; IPG-C, CDI, CPSS and CATS were filled in by N = 151, CBCL by 144 parents and YSR by 92 adolescents.
CDI = Children's Depression Inventory. CBCL = Child Behaviour Checklist. CPSS = Child Posttraumatic Stress Disorder Symptom Scale. IPG-C = Inventory of Prolonged Grief for Children. YSR = Youth Self Report.
* $p < 0.01$. ** $p < 0.001$.

result of the loss but, in contrast with what was expected, the correlation of the GCQ-C total score with functional impairment ($r = 0.46$, $p < 0.001$) was numerically but not significantly higher than the correlation of the CATS score with functional impairment ($r = 0.43$, $p < 0.001$; $z = 0.32$, $p = 0.37$).

Demographic and Loss Related Correlates of GCQ-C Total Scores

Scores on the GCQ-C did not vary as a function of time from loss, age, gender, relationship to the deceased, cause of death, amount of losses the child reported and whether or not the death was expected (all *p*s > 0.08).

DISCUSSION

The aims of the present study were to examine psychometric properties of the Grief Cognitions Questionnaire for Children (GCQ-C) and, more generally, to enhance knowledge about maladaptive thinking in bereaved children (aged 8 to 18 years). The GCQ-C was modeled after the adult Grief Cognitions Questionnaire (Boelen et al., 2003) and designed to measure grief-related negative cognitions that are assumed to play a role in the development and persistence of childhood PGD and other symptoms of post loss psychopathology.

With regard to the dimensionality of the GCQ-C, outcomes of an exploratory factor analysis showed that the GCQ-C represented one underlying dimension of negative loss related cognitions. This finding is inconsistent with research based on the adult GCQ, in which negative cognitions clustered into different factors representing different themes, including negative cognitions about the self, life, the future, and catastrophic misinterpretations of grief reactions (Boelen & Lensvelt-Mulders, 2005). A possible explanation for these different findings is that there are fundamental differences between thinking patterns of bereaved children and adults; perhaps bereaved children do not differentiate between types of cognitions as much as adults do. More research on this topic in larger populations is needed to gain more knowledge about the phenomenology of maladaptive thinking in bereaved children. Reliability analyses showed that the GCQ-C had adequate internal consistency and temporal stability.

With respect to the concurrent validity, the GCQ-C total score was significantly and positively correlated (moderate to strong correlations) with self-report indices of PGD, depression and PTSD. It was also significantly, but with a weak correlation, correlated with Internalising Problems as reported by parents, but not with Externalising Problems. This finding is in line with prior research (e.g., Melhem et al., 2007; Spuij, Prinzie et al., 2012) indicating that clinicians should ask children as informants about their grief related cognitions. Furthermore, as expected, higher scores on the GCQ-C were correlated with lower scores on the perceived ability to cope with the loss indicating that more negative cognitions associated with the loss coincided with a more negative view of children about their own ability to cope with the loss.

Several findings supported the convergent and divergent validity of the GCQ-C. GCQ-C scores were significantly related to automatic thoughts associated with a broad spectrum of negative emotional states, tapped by the CATS (Schniering & Rapee, 2002); as predicted, the GCQ-C was more strongly associated with CATS subscales measuring cognitions associated with Personal Failure, Physical Threat, and Social Threat, than with the CATS subscale measuring cognitions associated with Hostility. It is noteworthy that endorsement of negative cognitions tapped by the GCQ-Q did not differ as a function of the background and loss related variables that we assessed. These findings accord with prior findings of a weak link between background and loss related variables and PGD symptoms (Spuij, Prinzie et al., 2012) and suggest that background and loss related variables generally are not associated with high levels of loss related problems.

Some limitations should be taken into account when interpreting the present findings. First, the sample size (*N* = 151) may be considered somewhat small for exploratory factor analyses. Notably though, Guadognoli and Velicer (1988) argued that a factor is reliable, regardless of sample size, when it has four or more loadings greater than 0.6 and that with all communalities above 0.6 samples less than 100 may be adequate and with communalities in the 0.5 range samples between 100 and 200 can be good enough. This is why we decided that although the N was quite small, it was worth to explore the factors in this sample. Second, given the variety of methods of recruitment, most of the analyses that we conducted relied on a rather homogeneous group, as most children lost a parent who died from cancer. Maybe there are differences in origin and severity of grief cognitions between subgroups (e.g., children who suffered from traumatic loss, children who lost a sibling or other relative). Third, CBCLs for participants were completed by parents. Because of their own grief, these parents possibly were not the most reliable informants of their children's problems. Thus, it would be relevant for future studies to correlate grief cognitions of children and PGD severity also with indices of children's problems obtained from other, more distant informants such as teachers. Fourth, the present study tested a Dutch version of the GCQ-C. Although it is conceivable that the present findings are generalisable to other Western – including English-speaking – cultures, the psychometric properties of versions of the questionnaire in other languages remain to be tested. As a related point, the cultural background of participants had a Western origin. Thus, generalisation of the present findings to non-Western subgroups or religions remains to be determined. A final limitation of this study was its cross-sectional design that precluded any conclusions about the direction of causality between negative cognitions and emotional problems. It would be interesting for future research to use prospective-longitudinal designs to disentangle the linkage between negative thinking and emotional problems further.

Notwithstanding these considerations, results of the present study indicate that the GCQ-C is a promising measure for the assessment of negative loss related cognitions in children and adolescents confronted with bereavement. As such it may be used in future studies on the role of cognitive variables in emotional problems after bereavement. To our knowledge, this is the first study that provides evidence for a strong link between negative thinking associated with different themes on the one hand, and elevated PGD and other symptoms of depression and PTSD on the other hand. Moreover, the measure may be useful in clinical practice for the identification of cognitions that are important targets of the treatment of PGD symptoms. Given the lack of effective interventions for childhood grief (Currier et al., 2007), it is very important to know which factors can mediate emotional problems in children after a loss. We recently conducted two studies that provided preliminary evidence that cognitive behavioural interventions are fruitful in ameliorating PGD symptoms and other symptoms of distress in bereaved children and adolescents (Spuij, Deković, & Boelen, 2013; Spuij, Van Londen-Huiberts, & Boelen, 2013). The findings of these prior studies and the current study suggest that negative thinking plays an important role in childhood PGD and should be targeted in the treatment of this condition. This is in line with research from Meiser-Stedman, Dalgleish, Glucksman, Yule and Smith (2009) who showed that maladaptive cognitions in children with PTSD are causally implicated in the unfolding and maintenance of the posttraumatic stress response over time and that it should be the focus of treatment of PTSD in children.

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Appendix 5.1 English Translations of the Grief Cognitions Questionnaire for Children (GCQ-C)

Global negative thoughts about the self	1	Since he/she died, I think of myself as a weak person.
	2	Since he/she is dead, I am of no use to anyone anymore.
Global negative thoughts about the world	3	Since he/she is dead, I think the world is bad.
	4	Since he/she is dead, I think the world is worthless.
Negative thoughts about the other people's responses after the loss	5	I think that others should pay attention to how I am doing.
	6	I don't show others what I think and feel, because I am afraid that that only makes things worse for them.
Negative cognitions about self-blame	7	I should have seen to it that he/she would not have died.
	8	I blame myself for not having cared for him/her better than I did.
Global negative thoughts about the future	9	I don't think that I will ever feel better; I don't feel confidence about the future without him/her.
	10	I think that the future will be no fun without him/her.
Cognitions about cherishing the pain	11	As long as I am sad, I don't have to let him/her go.
	12	I want to hold on to my sorrow for as long as possible.
	13	It is not nice toward him/her, when I will begin to feel less sad.
Appropriateness of one's grief reactions	14	I think that my feelings about this loss are not normal.
Global negative thoughts about the world	15	My life has little to offer now he/she died.
	16	My life is worthless since he/she died.
Threatening interpretations of one's reactions to the loss	17	Sometimes I think that something is wrong with me, because I feel so sad about his/her death.
	18	When I think about his death, I feel frightened about all the things I feel.
Death anxiety	19	I continue to think that the thing that happened to him/her can also happen to me.
	20	Ever since he/she died, I continue to think that I can also die.

PART III

Development and Examination of *Grief-Help*

CHAPTER 6

Intermezzo: Interventions for Bereaved Children

Mariken Spuij
Paul A. Boelen

INTRODUCTION

The third aim of our project was to develop an intervention for bereaved children. To this end, we first conducted a review of existing interventions. In our general introduction (see p. 21), we described the main findings of one systematic review (Forte, Hill, Pazder, & Feudtner, 2004) and three meta-analytic review studies (Currier, Holland, & Berman, 2008; Currier, Holland, & Neimeyer, 2007; Rosner, Kruse, & Hagl, 2010). In this intermezzo we will discuss 25 interventions that are relevant for bereaved children and adolescents. We started by including all studies from the review studies mentioned above. Then we selected studies that were published in peer-reviewed journals and we were conducted among children. And then we excluded unpublished studies, studies that were published as a part of a dissertation and/or only published as an abstract, and studies among adults. Based on these selection criteria we included 17 studies. In addition to those studies we included two studies that were not included in the review studies for reasons unknown to us (Cohen, Mannarino, & Staron, 2006; McClatchey, Vonk, & Palardy, 2009). In addition to the bereavement intervention studies, we included six studies on two interventions that are frequently used by Dutch practitioners when they treat children who suffer from grief; Cognitive Behavioural Writing Therapy (CBWT) and Interpersonal Therapy for Adolescents (IPT-A). CBWT provides a specific focus for traumatically bereaved children and IPT-A has a section for adolescents who are experiencing grief related problems. We included one study on CBWT and five studies on IPT-A. All studies on IPT-A were included in a meta-analysis conducted by Cuijpers et al. (2011). See Table 6.1 for an overview of all studies on those interventions and their main results.

In the following section we start with discussing seven studies on Trauma Focused Cognitive Behavioural Therapy (TF-CBT). We then give a description of CBWT. Only the results of one pilot study are available. Then, five studies on IPT-A are described and discussed. Then, eleven bereavement (support) groups are discussed. Finally, the intervention that we developed as a part of this dissertation project, *Grief-Help*, is discussed.

Table 6.1 Interventions for Bereaved Children and Adolescents

Study	Sample	Treatment condition(s)	Measure moments	Summary of main findings
Trauma Focused Cognitive Behavioural Therapy (TF-CBT)				
Cohen et al., 2004	16 bereaved children (10 children aged 6-8 years; 6 children aged 9-12 years) and 6 adolescents (13-17 years) who suffer from Childhood Traumatic Grief (CTG) *and* their primary caretakers participated.	Children received an individual treatment (TF-CBT, 16 weekly sessions). There was no control condition.	Pre- and post-treatment.	Significant improvements on CTG, PTSD, depression, anxiety and behavioural problems. Findings supported (1) the use of CBT for this group, (2) the sequential use of trauma-and grief-focused components, (3) benefit of including parents in the treatment.
Cohen et al., 2006	27 bereaved children (8 children aged 6-8 years; 19 children aged 9-12 years) and 12 adolescents (aged 13-17 years) who suffer from CTG and their primary caretakers participated.	Children received individual treatment (TF-CBT, 12 sessions). There was no control condition.	Pre- and post-treatment.	Significant decrease of psychopathology, replication of findings mentioned by Cohen et al., 2004. In this study PTSD symptoms improved only during the trauma focused module and grief improved significantly during both trauma and grief focused modules. Satisfaction of participants for this shortened protocol was high, suggesting that a shortened protocol may be acceptable and efficacious for this population.
Goenjian et al., 1997, 2005	64 early adolescents who survived an earthquake in Armenia (*mean age* 13.2 years, 3 years after the earthquake).	Children who attended one particular school were located to a school-based brief group psychotherapy in combination with individual psychotherapy sessions (TF-CBT). Treatment was provided 1½ year after the earthquake and completed within a 6-week period. Children of two other schools were located to a control condition (no intervention).	Pre- and post-treatment (pre-test took place 1½ years and post-treatment 3 years after the earthquake); follow-up 5 years after the earthquake.	Findings of both studies demonstrate the efficacy of TF-CBT in alleviating PTSD symptoms and preventing the worsening of comorbid depression among early adolescents after a catastrophic disaster. Also the cross-cultural applicability of Western psychotherapeutic approaches is demonstrated.

Table 6.1 continues on next page

Table 6.1 *Continued*

Study	Sample	Treatment condition(s)	Measure moments	Summary of main findings
Layne et al., 2001	55 adolescents (15-19 years, $M = 17.05$, $SD = 1.17$) who survived the Bosnian civil war.	Children received school-based group psychotherapy (TF-CBT; 20 sessions). There was no control condition.	Pre- and post-treatment.	Significant reductions of symptoms of PTSD, depression and grief. Furthermore, reduced psychological distress and positive associations between distress reduction and psychosocial adaptation were found.
Layne et al., 2008	127 adolescents (aged 13-19 years) who survived the Bosnian Civil war.	At random allocation to an experimental intervention (school-based group psychotherapy; TF-CBT; 17-20 sessions; 60-90 minutes per session) or control condition (classroom-based psycho-education and skills intervention). 66 adolescents (*mean age* = 15.9, $SD = 1.11$) received the TF-CBT and 61 adolescents (*mean age* = 16.0, $SD = 1.13$) received the control condition.	Pre- and post-treatment, 4-month follow-up.	Significant pre- to post-treatment reductions in maladaptive grief reactions were only found in the treatment condition. Reduction of depression and PTSD symptoms was found in both conditions, suggesting that the intervention may be effective and an efficient method for delivering beneficial low-risk services to war-exposed youths living in resource-poor regions.
McClatchey et al., 2009	100 children (aged 6-16) who all lost a parent due to a sudden death within the past 1-48 months.	Children joined a weekend bereavement camp. Camp A and B were two weeks apart. Camp B was the control condition (delayed treatment group)	Pre- and post-treatment, follow-up was tested 4 weeks after camp A and 2 weeks after camp B.	Findings suggest that a short-term TF-CBT intervention reduce symptoms of traumatic grief and PTSD symptoms among parentally bereaved children.
Salloum et al., 2001	45 adolescents (aged 11-19 years) who all lost a loved one because of homicide.	Adolescents followed a short group psychotherapy (8-10 sessions). There was no control condition.	Pre- and post-treatment.	Findings suggest that a short group psychotherapy reduces PTSD symptoms among survivors of homicide. Participants reported an overall significant decrease in re-experiencing and avoidance symptoms.

Saltzman et al., 2001	Participants were 812 students (aged 11-14 years) who completed a PTSD screening survey; 58 of them met the criteria for group treatment and 26 of them participated in the group; 7 of them suffered from a traumatic loss.	The 26 participants were located to five therapy groups. Homogeneity was maximized. Sessions were during school hours and took place on school grounds. Each session lasted at least 50 minutes. Groups met for 20 weeks.	Pre- and post-treatment.	Findings suggest that severe PTSD is related with impaired academic functioning and that reducing PTSD symptoms may be related to increasing academic functioning.
Cognitive Behavioural Writing Therapy (CBWT)				
Van der Oord et al., 2010	23 children and adolescents (aged 8-18 years, $M = 11.89$, $SD = 2.47$) participated. All children experienced a range of single or recurrent traumatic experiences; no data about amount of bereaved participants is available.	Partcipants received individual CBWT (*mean amount of sessions* = 5.5, SD = 2.2). There was no control condition.	Pre- and post-treatment, 6 month follow-up.	Significant reduction of PTSD, depressive symptoms, trauma-related cognitions and general behaviour problems at post-test and follow-up. Findings suggest that CBWT is a potentially effective intervention for clinically referred traumatised children.
Interpersonal Therapy for Adolescents (IPT-A)				
Mufson et al., 1994	14 adolescents (14 females, *mean age* = 14.0 years; 2 males *mean age* = 15.5 years; no SDs available) with clinical depression; no data about amount of bereaved participants available.	Participants received individual treatment (IPT-A; 12 sessions). There was no control condition.	Pre- and post-treatment.	Significant decrease of depressive symptoms and symptoms of psychological distress, improvement of functioning over the course of the treatment. At termination, none of the participants met DSM-III-R criteria of depression.

Table 6.1 continues on next page

Table 6.1 *Continued*

Study	Sample	Treatment condition(s)	Measure moments	Summary of main findings
Mufson et al., 1999	32 adolescents (aged 12-18 years) with clinical depression participated; sample consisted of Latino, low economic status adolescents; no data about amount of bereaved participants available.	Randomly assignment to individual treatment (IPT-A; 12 sessions) or blinded clinical monitoring. 21 adolescents (*mean age* = 15.9, *SD* = 1.7) received IPT-A and 11 adolescents (*mean age* = 15.7, *SD* = 1.4) were located to clinical monitoring.	Pre- and post-treatment.	Findings support the feasibility, acceptability and efficacy in reducing depressive symptoms and improving social functioning and interpersonal problem solving skills. Further studies in other populations must be conducted to confirm the generalisability of these findings.
Rosselló & Bernal, 1999	71 Puerto Rican adolescents with clinical depression participated, *mean age* = 14.7, *SD* = 1.4; no data about amount of bereaved participants available.	23 adolescents were randomly assignment to individual CBT (12 weekly sessions). Another 25 participants received individual IPT-A, (also 12 weekly sessions) and 23 adolescents were located to a control condition (waiting list).	Pre- and post-treatment, 3 month follow-up.	Significant decrease of depressive symptoms in both CBT and IPT conditions compared to the waitinglist group. Findings suggest that both IPT and CBT are efficacious treatments for depressed Puerto Rican adolescents.
Rosselló et al., 2012	112 adolescents with clinical depression participated, aged 12-18 years (*M* = 14.52, *SD* = 1.85); no data about amount of bereaved participants available.	Randomly assignment to a treatment condition (CBT individual, CBT group, IPT-A individual of IPT-A group). All conditions consisted of 12 weekly sessions, individual therapy lasted 60 minutes, group therapy 120 minutes. 22 adolescents received CBT individual; 29 were assigned to CBT group; 31 were located to IPT-A individual and 29 received IPT-A group.	Pre- and post-treatment.	Findings suggest that both CBT and IPT-A are robust interventions in both group and individual formats. However, CBT produced greater decreases in depressive symptoms and improved self-concept compared to IPT-A.

Young et al., 2006	41 adolescents with clinical depression participated; no data about amount of bereaved participants available.	Randomly assignment to IPT-A (27 adolescents, *mean age* 13.5, *SD* = 1.3) or school counselling (14 adolescents, *mean age* 13.1, *SD* = 1.1). Both individual interventions.	Pre- and post-treatment, 3 and 6-month follow-up.	Significant decrease of depressive symptoms and overall functioning at post-test and follow-up in adolescents who were assigned to the IPT-A intervention. They also reported fewer depression diagnoses than the school counselling group.
Bereavement (support) groups				
Black & Urbanowicz, 1987	67 children (aged 0-16 years) from 45 families.	33 children were assigned to a family treatment (6 sessions at the home of the bereaved family, 2-3 months after bereavement) and 34 children to a control condition children (no intervention).	Pre-treatment and 1 year and 2 year after bereavement.	There were no significant differences between the treatment and control group. In both groups a favourable outcome was associated with (a) the wellbeing of the surviving parent, and (b) crying and talking about the deceased parent (especially when the child was > 5 years). Treatment was associated with increased crying scores and a decrease of behavioural problems.
Hilliard, 2001	18 bereaved children (aged 6-11 years) who lost a parent or sibling.	Children of two elementary school participated. Schools were randomly assigned to an intervention (music group therapy, 8 sessions) or control condition (no intervention).	Pre- and post-treatment.	Findings suggested that participating in a music therapy group decreases behavioural problems at home, but self-reports and teacher ratings were less conclusive. More research of music bereavement groups should be done.

Table 6.1 continues on next page

Table 6.1 *Continued*

Study	Sample	Treatment condition(s)	Measure moments	Summary of main findings
Hilliard, 2007	26 bereaved children (aged 5-11 years) who lost a loved one within the past 2 years.	Children of three elementary schools participated. Schools were randomly assigned to an orff-based music group therapy (8 sessions), social work (8 sessions) or waitinglist condition.	Pre- and post-treatment.	Findings support the use of Orff-based music therapy. Particpants of the music therapy group showed a significant decrease in both grief symptoms and behaviour problems. Participants of the social work group showed a significant decrease in behaviour problems. Participants who were on a waitinglist showed no significant improvements in behaviour problems or grief symptoms.
Huss & Ritchie, 1999	17 bereaved children (aged 10-12 years) who all lost a parents > 2 years prior to treatment.	Children were randomly assigned to a intervention or control group. A Solomon four-group design was used. 9 children in the intervention group (6 week support group) and 8 children in the control group.	Pre- and post-treatment.	According to parental and teacher reports no significant differences were found. However, self-reports of children and observations of the group leader suggested positive effects of the support group.
Opie et al., 1992	8 elementary school (aged 9-13 years) and 8 high school (aged 12-15 years) children who lost a parent, sibling or important caregiver (e.g., grandparent)	Both, the child and adolescent group received 8 weekly sessions. Sessions took place at the school ground. Due to school activities adolescents' mean attendance was only 4.6 sessions. Each single session lasted 50 minutes. Aims of the group were to discuss perceptions and feelings about the loss and coping strategies.	Pre- and post-treatment.	In this study no significant improvements were found on an emotional distress scale. In the elementary school group there was a significant decrease of somatic complaints.

Pfeffer et al., 2002	75 children (aged 6-15 years) from 52 families who lost a parent or sibling through suicide.	39 children (*mean age* = 9.6, *SD* = 2.9) were randomly assigned to a bereavement group intervention (10 weekly sessions, each session lasted 90 minutes; 2-5 children per group) and another 36 children (*mean age* = 11.4, *SD* = 3.5) to a control condition (no intervention).	Pre- and post-treatment.	Significant reduction of anxiety and depressive symptoms was found in participants of the experimental intervention group. Furthermore, findings suggest that a bereavement group intervention focusing on reactions to death and suicide and strengthening of coping skills can reduce distress of children who lost a parent or sibling due to suicide.
Sandler et al., 2003 (6 year follow-up studies: Luecken et al., 2010; Sandler, Ayers, et al. 2010; Sandler, Ma et al., 2010)	135 parentally bereaved children assigned to the study; 75 children 8-11 years and 60 children 12-16 years).	Randomly assignment to the FBP (group intervention 14 weekly sessions; separate groups for children, adolescents and parents, 12 group sessions and 2 individual sessions) or control condition (self-study).	Pre- and post-treatment, 11 month and 6 year follow-up.	The FBP led to improved parenting, coping, and caregiver mental health and to reductions in stressful events at post-treatment. At follow-up the FBP led to decrease of Internalising and Externalising problems in girls and those who had higher problem scores at baseline. At 6 years follow-up the FBP-group had significantly lower behaviour problems (Internalising and Externalising) and problematic grief levels. Furthermore FBP participants had significantly higher cortisol levels compared to the self-study group (lower cortisol was associated with higher levels of Externalising problems). Parents in the FBP had lower depression scores.
Sandler et al., 1992	54 parentally bereaved children (8-17 years; 24 children below 11 years and 30 children 12-17 years).	Families were randomly assigned to an immediate treatment versus a 6-month delayed treatment control condition. One child of each family was randomly selected as the target child.	Pre- and 6 months later (for the treatment group this is after completion of the program and for the control group this is prior to the delayed beginning of the program.	The FBP was found to increase the perceptions of parental warmth, parental satisfaction with their social support and to prevent a decrease in parent reports of grief discussions. Parents also reported a significant decrease of depression and conduct problems in older children. Children did not report any significant changes.

Table 6.1 continues on next page

Table 6.1 *Continued*

Study	Sample	Treatment condition(s)	Measure moments	Summary of main findings
Schilling et al., 1992	38 parentally bereaved children (aged 6-12 years), 29 of them completed posttests. All children lost their caregiver within 30 months prior to the time of pretest.	Children received 12 group sessions over a 10 months period.	Pre- and post-treatment.	Main finding is that the majority of children remained depressed after treatment. But on the other hand, it is suggested that after treatment children were better able to express their grief to their surviving caregivers.
Tonkins & Lambert, 1996	16 children (aged 7-11, mean age 9.1; no SD available) were confronted with the death of a parent or sibling.	10 children were assigned to a bereavement group (8 weekly sessions) and another 6 children to a waiting list condition.	Pre- and post-treatment.	Findings suggested that participating in a bereavement group is more effective than a waiting list condition; there was a decrease in depression (according to self-reports), decrease of overall emotions (according to primary caretaker) and behavioural disturbances (according to caretaker and teacher).
Quarmby, 1993	6 parentally bereaved adolescents (12-15 years) joined a support group.	Adolescents followed a support group for six weeks. In the group talking about various facets of the experience of bereavement was facilitated.	Pre- and post-treatment.	Findings showed improvement in several social areas. According to the author, findings underscore the need to bring outside pastoral counselling in the school.

Description of Interventions for Children who Suffer from Loss

Trauma Focused Cognitive Behavioural Therapy

An important research line includes studies among traumatically bereaved children, e.g., children who are bereaved after a hurricane, war, suicide or homicide. Cognitive Behavioural Therapy (CBT) is effective in decreasing PTSD symptoms in children (Cohen, Berliner, & March, 2000) and a number of treatment protocols have been proposed for traumatically bereaved children by using Trauma Focused CBT (TF-CBT). The TF-CBT interventions we found are (school-based) group interventions for adolescents (Goenjian et al., 1997, 2005; Layne et al., 2001, 2008; Saltzman, Pynoos, Layne, Steinberg, & Aisenberg, 2001; Salloum, Avery, & McClain, 2001), a camp-based intervention (McClatchey et al., 2009) or individual interventions for both children and adolescents combined with parental sessions (Cohen et al., 2004, 2006). TF-CBT is a short-term treatment, typically completed in 12 to 18 sessions, depending on treatment needs. Components of the TF-CBT protocol can be abbreviated to form the acronym 'PRACTICE'; see Box 6.1 for a short description of the components of TF-CBT interventions.

Box 6.1 'PRACTICE' - Components of Trauma Focused Cognitive Behavioural Therapy for Bereaved Children and Adolescents

P - Psychoeducation and parenting skills; information about reactions to traumatic events in general and more specific about loss-related reactions is given. Furthermore parents learn child behaviour management strategies and effective communication about the traumatic event (e.g., the death of a loved one).
R - Relaxation methods are taught to the child (e.g., focused breathing, progressive muscle relaxation and visual imagery).
A - Affective expression and regulation; the child (and parent) learn to manage their emotional reactions to reminders of the trauma, improve their ability to identify and express emotions in general and more specifically about the trauma, and participate in self-soothing activities.
C - Cognitive coping and processing; the child and the parent learn to understand the connection between thoughts, feelings, and behaviours and are encouraged to explore and correct inaccurate attributions related to everyday events.
T - Trauma narrative and processing includes various CBT techniques such as gradual exposure exercises (including verbal, written, or symbolic recounting of traumatic events) and cognitive restructuring of maladaptive thoughts about the loss.
I - In vivo exposure includes gradual exposure to trauma reminders in the child's environment so the child learns to control his or her own emotional reactions.
C - Conjoint parent/child sessions; family work is conducted to enhance communication and create opportunities for therapeutic discussion regarding the trauma and the loss and for the child to share his/her trauma narrative.
E - Enhancing future growth; training is giving on interpersonal relationships, and the use of new skills in managing future stressors and trauma reminders.

Despite the relatively positive findings of TF-CBT studies as summarised in Table 6.1, more work on the development and evaluation of TF-CBT grief interventions for children and adolescents is needed. The interventions studied by Goenjian et al. (1997, 2005) and Layne et al. (2001, 2008) have only been tested in adolescents. Moreover, these adolescents were all confronted with specific, community-based traumatic losses (after an earthquake and post war). The studies of Cohen et al. (2004, 2006) are relevant for traumatically bereaved children and adolescents. Finally, this potentially effective treatment of Cohen and colleagues has not yet been tested in a controlled study.

Writing Therapy

Writing therapy (see Box 6.2), or structured writing is thought to be an alternative treatment approach for PTSD in both adults and children next to conventional cognitive behavioural procedures, for instance in vitro and in vivo exposure and cognitive restructuring (e.g., Lange et al., 2003; Van der Oord, Lucassen, Van Emmerik, & Emmelkamp, 2010; Van Emmerik, Kamphuis, & Emmelkamp, 2008). It is thought to be effective because of the combination of conventional cognitive behaviour techniques (Sloan, Marx, & Epstein, 2005; Sloan, Marx, Epstein & Lexington, 2007) and social sharing (Lange et al., 2003). Research among adults showed that Cognitive Behavioural Writing Therapy (CBWT) for PTSD and face-to-face cognitive behavioural treatment are equally effective (Van Emmerik et al., 2008). The research on writing therapy among children is promising, but still very limited. To our knowledge only one pilot study has been conducted on the efficacy of CBWT among children (Van der Oord et al., 2010). In this uncontrolled study, 23 children suffering from PTSD symptoms were included. It is unclear how many bereaved children were included in the study of Van der Oord and colleagues (2010). The findings suggest that CBWT is a potentially effective intervention for children with PTSD. There was a significant reduction of PTSD, depressive symptoms, trauma related cognitions and general behaviour problems and these effects persisted six months after treatment. Limitations in light of bereavement intervention research is that the focus of the study was PTSD symptomology and not grief related problems per se. Furthermore, findings have to be established in a Randomised Controlled Trial (RCT) since the only study conducted so far was a pilot study.

Box 6.2 WRITEjunior (Lucassen & Van der Oord, 2008)

WRITEjunior is an individual writing therapy for children (aged 8 to 18 years) who suffer from a traumatic event. The protocol contains special sections for the treatment of trauma after sexual assault, the sudden death of a loved one or the treatment of children after trauma due to a psychiatric disorder of a parent (e.g., due to a personality disorder). The treatment manual allows therapists and clients to make the treatment 'tailor made' depending on the child's age and the nature of the traumatic event(s); e.g., older children write down their story themselves on a computer while younger children formulate their story while the writing is done by their therapist. The number of sessions varies from child to child; the therapy ends when every detail of the traumatic event is included in the story that the child has written down and the therapist can no longer identify any maladaptive thoughts. Van der Oord et al. (2010) found a mean of 5.5 sessions (*SD* = 2.2) was needed in order to reach those aims. Important elements of the treatment are psycho-education, exposure, cognitive restructuring, promoting adequate coping and social sharing.

The therapy starts with psycho-education on PTSD symptoms and a rationale of the treatment. During the sessions the child (or in case of younger children the therapist) writes a report of the trauma on the computer. The first step is to give a title to the story. Next, the child writes down the traumatic event. By asking questions the therapist helps the child with writing down their thoughts, feelings and behaviours. Besides explicit questions, the therapist also helps the child to restructure their thoughts by using CBT techniques (e.g., verbal cognitive restructuring techniques and Socratic questioning), and teaches the child to identify and restructure his/her own maladaptive thoughts. Both maladaptive and helpful thoughts are written down in the story. At every subsequent session the child rereads his/her story and continues the story. At the end of the story the child writes down useful coping strategies for the future. The last step is 'social sharing'; the child and therapist discuss who are allowed to read the story. Without the presence of the child these 'eligible' persons read the story and give a written and a verbal reaction to the story.

Interpersonal Therapy for Adolescents (IPT-A)

Interpersonal Therapy (IPT) was originally developed for depressed adults (Klerman, Weissman, Rounsaville, & Chevron, 1984). Clinical research had established the efficacy of IPT for this group (e.g., Elkin et al., 1989; Frank, Kupfer, Perel, Cornes, & Jarret, 1990). IPT has been modified for adolescents suffering from depression (IPT-A) by Mufson, Moreau, Weissman and Klerman (1993). We included IPT-A in our overview because the intervention has unresolved grief as one of the four focus areas for treatment. See Box 6.3 for a description of the intervention.

Mufson and colleagues (1994) were the first to study the efficacy of IPT-A in adolescents. Over the years there has been growing evidence for the efficacy of IPT-A (e.g., Mufson, Weissman, Moreau, & Garfinkel, 1999; Rosselló & Berndal, 1999; Rosselló, Bernal, & Rivera-Medina, 2012; Young, Mufson, & Davies, 2006). Furthermore, David-Ferdon and Kaslow (2008) and Cuijpers et al. (2011) came to the conclusion that IPT-A has a well-established efficacy. Limitations are that IPT-A has not yet been studied in children and all studies were conducted in depressed adolescents (and not in bereaved adolescents per se).

Box 6.3 Interpersonal Therapy for Adolescents (IPT-A, Mufson et al., 1993)

IPT has four major focus areas, with bereavement being one of them (next to conflict in significant relationships, difficulties in adapting changes in relationships or life circumstances and problems related to social isolation). The treatment is designed as a once-a-week (12-week long) intervention. The goals are to reduce depressive symptoms and to address the interpersonal problems associated with the onset of the depression. The central idea in IPT is that depression occurs in the context of the individual's relationships and that depression affects people's relationships and these relationships affect our mood. IPT-A is specifically aimed at training interpersonal problems associated with adolescent depression, mostly occurring in the family. The therapy focuses on a topic that seems to be most associated with the onset of the depression. When an adolescent is suffering from loss the therapist helps the client to re-establish interests and relationships that can begin to fill the void of what has been lost. Parents and siblings are encouraged to become involved in the treatment for two reasons, first for support of the adolescent and secondly for direct intervention to change patterns in familial relations, or to affect communications within the family. IPT-A attempts extrapolate strategies learned to change family relationships to relationships outside the family system and to provide the adolescent with skills that will be helpful in the future as well.

The therapy is divided in three phases: (1) the initial phase with a focus on psychoeducation, exploration of the patient's significant interpersonal relationships and the identification of the problem area that will be the focus of treatment, (2) the middle phase, during which the therapist focuses on identifying specific strategies that can help the adolescent negotiate his/her interpersonal difficulties and (3) the termination phase, aiming to clarify warning symptoms of future depressive episodes, identifying successful strategies used in the middle phase and to foster generalisation of skills.

Bereavement (Support) Groups

Bereavement support groups are very widely used. They use creative techniques like drawing, story telling, and play therapy and while most techniques are well described (see for instance Webb, 2010), to our knowledge there is (almost) no empirical research available on the effects of these techniques in support groups for bereaved children.

Despite the fact that support groups are widely used, the findings of most studies do not support their effectiveness. First, Black and Urbanowicz (1987) studied a preventive family intervention for parentally bereaved children (maximum 16 years old). Two to three months after a parent died families were randomly assigned to a treatment condition (family therapy) or no treatment. The aims of the treatment were to promote mourning in both children and parents by playing and talking about the loss. Both groups were interviewed again one and two years after the los. Findings indicated that there were no significant differences between groups. Other support-group studies also found no significant improvements (Huss and Ritchie, 1999; Opie et al., 1992; Schilling, Koh, Abramovitz, & Gilbert, 1992). However, a few studies on bereavement groups did find improvements in functioning (Hilliard, 2001, 2007; Tonkins & Lambert, 1996). But these studies had limitations in sample size and sample composition (for example, exclusive reliance on children and not adolescents). Despite those limitations, both studies conducted by Hilliard give support to the use of Orff-music therapy groups for bereaved children. See Box 6.4 for a description of the support group interventions.

Box 6.4 Support Groups for Bereaved Families

a) *Family intervention* (Black & Urbanowicz, 1987)
Recently bereaved families receive treatment at home. They are offered six sessions (two to three week intervals), two-to three months after bereavement. Families learn to talk about the loss and the deceased loved one. Therapists use play materials that are appropriate for age and developmental stage. Furthermore, therapists model appropriate verbal responses and behaviours. When an individual session with the parent is needed (e.g., to enable him/her about their own grief, feelings or needs) such can be provided.

b) *Support group* (Huss & Ritchie, 1999) and *Peer-support group* (Tonkins & Lambert, 1996)
The support group of Huss and Ritchie (1999) has six weekly sessions and the Peer-support group of Tonkins and Lambert (1996) consist of 8 weekly sessions. Both programs have much overlap. In the first session both groups try to create a positive group atmosphere and to increase the reality of death by discussing the deceased parent's life and death. In subsequent sessions, information about grief-related feelings is provided and feelings are shared with group members. Tonkins and Lambert's group uses art-projects to encourage the expression of feelings of grief and unfinished business. In the final part of the groupsessions children are encouraged to discuss grief with their family members and to make new relationships and adapt new family roles.

c) *Orff-based music therapy* (Hilliard, 2001, 2007; Register & Hilliard, 2008)
Studies on the (potential) effectiveness of Orff-based music therapy have been conducted by Hilliard (2001, 2007). The intervention is described by Register and Hilliard (2008). Sessions begin with a song about different themes (e.g., confidentially, memories, feelings etc). Children can express their thoughts and feelings with music. In addition the therapist discusses those themes with the children.

There are also interventions that can be described as bereavement groups that were very well studied. For instance, Pfeffer, Jiang, Kakuma, Hwang and Metch (2002) developed a 10-week Bereavement Group Intervention (BGI) for children bereaved from suicide. Groups consisted of two to five children with similar levels of development and grouped by age. BGI aims to tap adjustment after parental or a sibling's death and focuses on children's understanding of and responses to the death, unique features of suicide and loss of personal and environmental resources (see Box 6.5 for more detailed information about BGI). BGI is based on theoretical models of attachment, responses to loss and cognitive coping (Pfeffer et al., 2002). Findings among 75 participants showed a significant reduction of anxiety and depressive symptoms in 39 children bereaved by suicide (aged 6 to15 years) who were randomly assigned to a bereavement support group compared to 36 children who received no intervention. It is unclear whether reductions of symptoms were sustained, as no follow up was conducted.

Box 6.5 The Bereavement Group Intervention (Pfeffer et al., 2002)

The BGI provides psychoeduction and support for both children and parents.

For children three components are provided: (I) Psychoeducation; discussing children's concepts of death and its permanence, identifying feelings of grief, suicide related themes (defining what is suicide, discussing why people commit suicide, discussing prevention of children's suicidal urges); (II) enhancing children's skills in problem-solving; (III) support; facilitating children's expressions of grief, empowering them to feel more optimistic, help them managing traumatic thoughts and stigmatizing concerns about the suicide, and developing new supportive interpersonal relationships.

Parents get information to help them to understand childhood bereavement, foster children's expressions of grief, discuss the suicide, identify children's morbid reactions, and promote children's emotional and social functioning. Support is provided to ventilate their own grief.

Finally, another bereavement group intervention that is very well studied is the Family Bereavement Program (FBP, Sandler et al., 1992, 2003). The FBP is developed for parentally bereaved children and is based on the Transitional Events Model (Felner, Terre, & Rowlison, 1988) and was developed to change variables that were hypothesised to affect the mental health of children who suffer from loss. The program targets variables on a family level (e.g., parenting skills) and on an individual level (e.g., coping skills), and these were selected on the basis of empirical evidence or case studies with bereaved families. In Box 6.6 a short description of the program is given (for a more detailed description and theoretical basis of the program, see also Sandler, Ayers, & Romer, 2002; Sandler et al., 2003). A considerable amount of research has been done on the effectiveness of this program (Luecken et al., 2010; Sandler et al., 1992, 2003; Sandler, Ayers, et al., 2010; Sandler, Ma, et al., 2010). The FBP has been found to reduce immediate as well as long-term grief problems in children confronted with parental loss. Despite these positive findings, limitations of the FBP are that the program is only for parentally bereaved children and the FBP is a group intervention. This may yield practical problems and may therefore be less effective.

Box 6.6 Family Bereavement Program (Sandler et al., 1992, 2003)

The 2003 Family Bereavement Program (FBP) is a modified version of the FBP developed in 1992 (Sandler et al., 1992). It is a 14-session program (12 group, 2 individual) with separate groups for children (aged 8 to 12 years), adolescents (aged 13 to 16 years) and their parents. Each group receives 14 sessions (12 group sessions – 2 hours per session – and 2 individual sessions) over the course of 12 weeks. Parts of some sessions are offered conjointly in the parent groups.

Individual factors that are targeted in child groups are improvement of the ability to cope with stress, increasing the ability to deal with grief related feelings and support in communication with families. Family factors in the program primarily aim to improve the ability to build a stable and positive family environment in the face of the parentally bereaved families, to help parents to use effective discipline, to help them dealing with their own grief and depression and to encourage caregivers not to involve children in stressors that are primarily caregivers' responsibility (e.g., financial troubles).

Box 6.6 *Continued*

A summary of the child and parent sessions is given in Table 6.2. As can be seen from Table 6.2 children and parents follow a similar process. The program builds motivation in participants to work with both program goals and with personal goals that children and parents set for themselves. Participants are encouraged to set goals to deal with stressors in their lives. Children learn skills to accomplish goals like problem solving, communication, positive reframing of problems, distinguishing controllable from uncontrollable events and to decrease negative thinking. They also learn a sense of efficacy in dealing with the stressors in their lives, and with feelings and their roles as contributors to their family strengths. To accomplish their goals they are encouraged to plan their own homework assignments by formulating concrete steps outside the course and to monitor how effective their actions are in helping them to accomplish their own goals. Parents learn skills to help them deal with their own grief and to shield their children from overwhelming stressors. The focus of the group is on enhancing existing parenting skills and building and developing new parenting practices. Parents are encouraged to try the new skills at home and to discuss their successes and failures in the upcoming sessions. A key component of the program is to build individual child and family relationship skills to promote resilience. This goal is accomplished by weekly assignments, called 'Family Fun Time' where the families have to engage in enjoyable activities together as a family.

Table 6.2 Summary of FBP Curriculum (2003): Sessions and Topics for Both Children and Parents

Session	Child/adolescent	Parent
1	Introduction to the program.	Introduction to the program.
2	Family time.	Family time.
3	The event-thought-feeling link.	Communication part 1: Catch 'em being good and listening.
	Individual session (1)	Individual session (1)
4	Distinguishing between types of hurtful and hopeful thoughts.	Communication part 2 & 3: One-to-one time and listening.
5	Replacing hurtful thoughts with hopeful thoughts.	Communication part 4: Feeling responses and saying no.
6	Good communication: sharing your feelings.	Guided problem solving and using listening skills to hear your children talk about grief.
7	Teaching appropriate responsibility for problems and avoiding negative appraisals about excess responsibility.	Parent demoralisation.
8	Problem solving.	Discipline Part 1. Steps 1 and 2: adopting clear and realistic expectations and sizing up the problem.
9	I-message for problem solving.	Discipline Part 2. Step 3: Developing a change plan .
	Individual session (2)	Individual session (2)
10	Integrating of program skills.	Discipline Part 3. Step 4: Using the change plan, evaluating and reevaluating it if necessary.
11	Skill review and relapse prevention.	Helping your kid deal with tough times.
12	Review and closure.	Review, maintenance of strategies and closure.

Grief-Help

Given the need for a targeted intervention for bereaved children and adolescents we developed *Grief-Help* (Spuij & Boelen, 2013). In chapter 7 the intervention is described in more detail. To summarise, based on a theoretical framework PGD (Boelen et al., 2006, 2012), *Grief-Help* consist of five parts: '*Who Died*', '*What Is Grief*', '*Cognitive Restructuring*', '*Maladaptive Behaviours*' and '*Moving Forward After Loss*'. There are nine sessions for the bereaved child and five separate sessions for the primary caregiver(s). *Grief-Help* uses techniques that are established in CBT and have been found to effectively reduce PGD in adults, such as *imaginary exposure*, *exposure in vivo*, *confrontational writing*, *cognitive restructuring by Socratic questioning* or *behavioural experiments* and *behavioural activation*. See for a description of cognitive restructuring for example Spuij and Boelen (2012).

Conclusion: *Grief-Help* Compared to Other Interventions

To summarise, so far very little research has been done among bereaved children in general and no studies are available among children who suffer from PGD. *Grief-Help* appears to be unique to other interventions in several ways. First, it is the only intervention for bereaved children, that is based on a theoretical framework for PGD. TF-CBT and CBWT interventions are developed for children suffering from Childhood Traumatic Grief (CTG; described as a combination of PTSD, depression and PGD) and IPT-A for depressed adolescents. The FBP is developed to foster resilience in parentally bereaved children. Second, in general most interventions were developed for specific groups, which can be seen both a strength and limitation (e.g., adolescents versus children; only parentally bereaved children; bereavement after a community trauma like a war or natural disaster; bereavement after suicide). *Grief-Help* can be used for all bereaved children between 8 to 18 years of age who suffer from loss. Third, where most interventions are group interventions, *Grief-Help* is an individual treatment, which has several advantages; children can start treatment when they want to, and the therapy will be more tailor made (idiosyncratic thoughts and behaviour can be addressed). Finally, many interventions involve parents in the treatment, but they vary widely from only psycho-education to an intensive cooperation (e.g., the FBP). In *Grief-Help* there is also an intensive and systematic cooperation with parents. For instance, we also include exercises to encourage positive parenting as well as a form of so called 'Family Fun Time', an exercise from the FBP. We encourage parents to spend 15 minutes a day with their child on an activity the child chooses.

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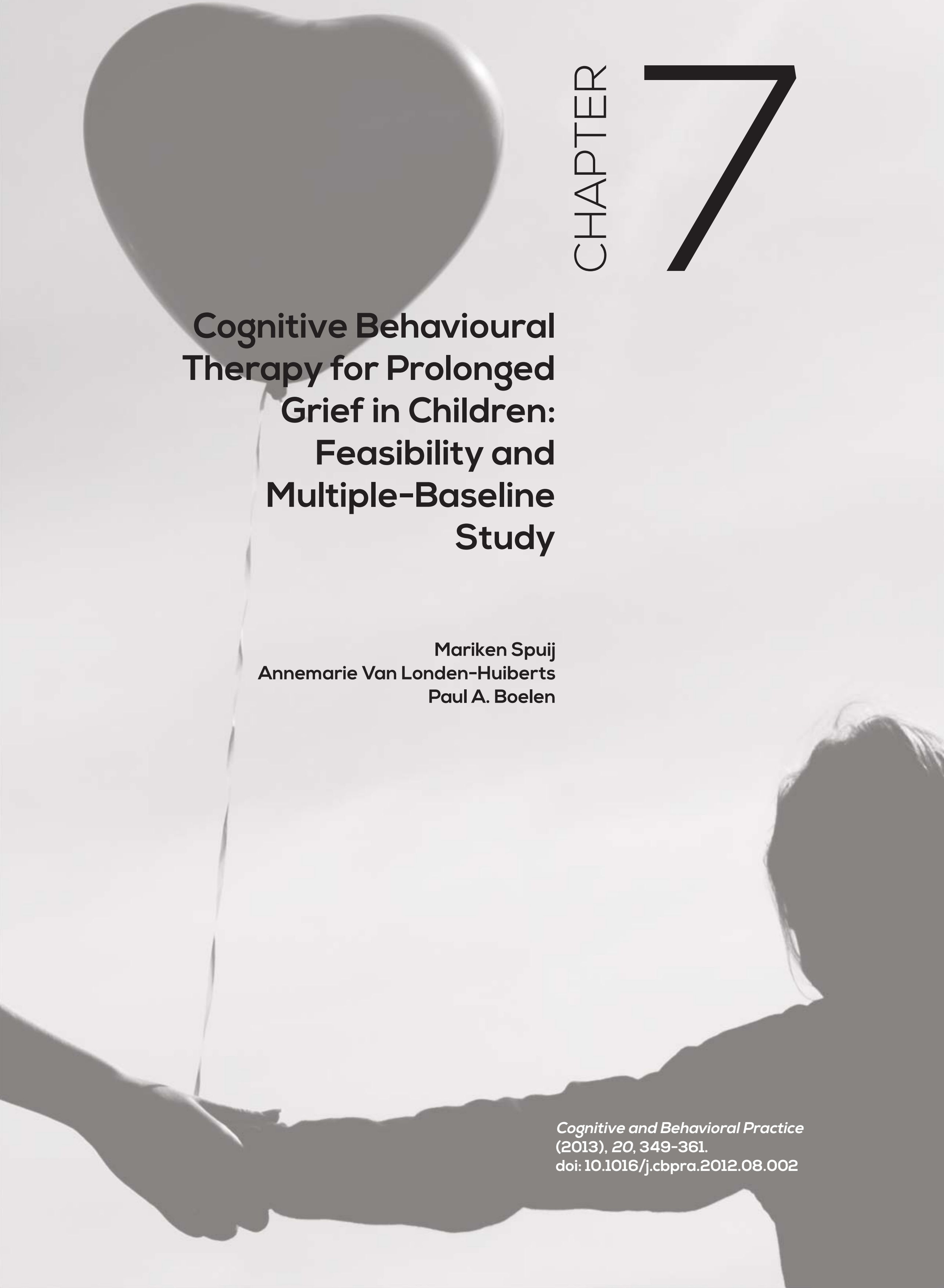

CHAPTER 7

Cognitive Behavioural Therapy for Prolonged Grief in Children: Feasibility and Multiple-Baseline Study

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ABSTRACT

There is growing recognition of a syndrome of disturbed grief referred to as Prolonged Grief Disorder (PGD). Although mostly studied in adults, clinically significant PGD symptoms have also been observed in children and adolescents. To date, no effective treatment for childhood PGD yet exists. We developed a nine-session cognitive behavioural treatment for childhood PGD, combined with five sessions of parental counselling. In the present article, the content of this treatment is described. We also describe findings of a multiple baseline study among six bereaved children and adolescents. This study showed that the intervention coincided with reductions in symptoms of PGD and other self-rated and parent-rated symptoms. All participating children and parents gave favourable scores to their satisfaction about each session, the contact with their therapist, and the information they received, attesting to the feasibility of this treatment approach.

INTRODUCTION

The past years have shown a growing recognition of a syndrome in adults referred to as Prolonged Grief Disorder (PGD; also termed Complicated Grief). PGD encompasses several symptoms, including separation distress, preoccupation with thoughts about the lost person, a sense of purposelessness about the future, numbness, bitterness, difficulties accepting the loss, and difficulty moving on with life without the lost person (Prigerson et al., 2009; Shear et al., 2011). Symptoms of PGD have been found to be distinct from depression and Posttraumatic Stress Disorder (PTSD) and to be associated with persistent mental and physical health complaints and reduced quality of life (Bonanno et al., 2007; Prigerson et al., 2009). PGD is also different from normal grief in that people with PGD are essentially stuck in a state of chronic mourning in which symptoms of acute grief do not subside, but continue to interfere with normal functioning far beyond the first half year of bereavement (Boelen & Van den Bout, 2008; Prigerson, 2004). Given that PGD is a distinct and debilitating condition, researchers have pleaded for inclusion of a specific grief disorder in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (Prigerson et al., 2009; Shear et al., 2011). Accordingly, inclusion of a formal disorder of grief in DSM is now being considered (APA, 2012; for a discussion, see Boelen & Prigerson, 2012).

Research has shown that PGD can also occur in children and adolescents confronted with loss. For instance, in a study among 11- to 23-year-old friends and acquaintances of suicide victims, Melhem et al., (2004) found that adolescents can experience a traumatic grief reaction that is similar to that of adults and that is associated with increased suicidal ideation, depression, and PTSD. Melhem, Moritz, Walker, Shear, and Brent (2007) studied the phenomenology and correlates of PGD among parentally bereaved children, aged 7 to 18, and found that PGD severity was significantly correlated with suicidal ideation and functional impairments, even when controlling concomitant depression and PTSD. Other studies have also provided evidence that childhood PGD is distinct from depression, anxiety, and normal grief (Dillen, Fontaine, & Verhofstadt-Denève, 2008, 2009) and is associated with impairments in health and quality of life (e.g., Brown & Goodman, 2005; Cohen & Mannarino, 2004; Spuij et al., 2012).

Despite these facts, effective interventions for bereaved children and adolescents are hardly available. In a meta-analytic review Currier, Holland, and Neimeyer (2007) examined the effectiveness of bereavement interventions with children. Based on 13 controlled studies, it was found that that the overall weighted effect size, representing the benefit of bereavement interventions compared to no-intervention at post-test, was $d = 0.14$ and did not differ significantly from zero. Fortunately, more recent research has countered some of the pessimism about the efficacy of interventions for bereaved children that has arisen from earlier studies (cf. Larson & Hoyt, 2007). Most important in this respect is the work of Sandler and colleagues in the family bereavement program (FBP). The FBP is a 14-session (12 group, 2 individual) program that targets family level (e.g., parenting skills) and child level (e.g., coping skills) variables that promote resilient outcomes. This program has been found to reduce immediate as well as long term grief problems in children confronted with parental loss (Sandler et al., 2003, Sandler, Ayers et al., 2010; Sandler, Ma et al., 2010). Despite these positive findings, more work on the development and evaluation of grief interventions for children and adolescents is still needed. For instance, the FBP is focused on parentally bereaved children and no effective treatments have yet been developed for bereaved children confronted with other losses. Moreover, the FBP uses a group based format and the effects of individual treatments are still understudied. Finally, the degree to which the FBP (or any other bereavement intervention) alleviates or prevents symptoms of PGD has not been investigated yet.

In light of the clinical significance of childhood PGD and associated problems that may emerge following loss and limited knowledge about effective interventions, it is important to further develop and test psychotherapeutic interventions for childhood PGD. As part of a larger project on childhood PGD, we developed a nine-session manualised cognitive behavioural treatment for children with elevated levels of PGD. In the present article, the content and theoretical background of this treatment are introduced. In addition, we present the findings of a multiple-baseline study among six bereaved children with elevated PGD, designed to explore the feasibility and potential efficacy of this new treatment.

Cognitive Behavioural Therapy (CBT) for Childhood PGD: Theoretical Basis

CBT for childhood PGD is based on a cognitive behavioural model of adult PGD (Boelen, Van den Hout, & Van den Bout, 2006, 2012). This model postulates that PGD-symptoms develop under the influence of three interrelated processes. The first process is *insufficient integration* of explicit knowledge about the irreversibility of the separation with preexisting knowledge about the self and the relationship with the lost person, stored in autobiographical memory. This lack of integration maintains a sense of shock about the loss and a sense that the separation is reversible, causing yearning and a persistent urge to restore proximity to the lost person. The second process is a propensity to engage in *persistent negative thinking*. Negative cognitions about the self, life, and the future, and catastrophic misinterpretations of one's grief reactions as signaling loss of control or insanity are assumed to be particularly detrimental. Specifically, it is assumed that negative thoughts about the self, life, and the future directly contribute to a persistent preoccupation with what went lost, whereas catastrophic misinterpretations of one's grief reactions (e.g., "*If I would allow my feelings to run loose, I would go crazy*") fuel avoidant tendencies and emotional distress (Spuij & Boelen, 2012). The third of these processes encompasses 'anxious' and 'depressive avoidance'. Anxious avoidance refers to fear-driven avoidance of stimuli that remind of the loss, whereas depressive avoidance encompasses avoidance of activities that could foster adjustment, driven by pessimistic cognitions that one is unable to carry out and/or to enjoy such activities. Anxious avoidance maintains PGD by blocking elaboration and integration of the loss. Depressive avoidance is detrimental because it maintains negative cognitions, alienation and isolation, and interferes with constructive action that could foster adjustment.

Based on this framework, alleviation of PGD can be achieved by targeting these processes using conventional CBT interventions. Thus, first, therapy aims to promote integration of the loss with preexisting knowledge. To this end, different interventions can be applied including *imagery exposure* (telling the story of the loss-event, zooming in on the most painful aspects), *in vivo exposure* (visiting the scene of the death), and *confrontational writing* (writing a letter to the lost person, explaining what is missed most). Second, negative cognitions are altered, using cognitive restructuring techniques. Examples of these include *Socratic questioning* (i.e., identifying, discussing the validity and utility of, and altering maladaptive cognitions) and *behavioural experiments* (i.e., using specific behavioural assignments to test the validity of cognitions). Third, maladaptive avoidance behaviours are replaced by more helpful ways of coping. For instance, *exposure to avoided stimuli* can be used to target anxious avoidance, and *behavioural activation* to turn the vicious cycle of depressive avoidance. In a controlled trial with bereaved adults, this CBT approach was found to be significantly more effective for reducing PGD symptoms than nondirective supportive counselling (Boelen, De Keijser, Van den Hout, & Van den Bout, 2007).

CBT for Childhood PGD: Treatment Protocol

CBT for childhood PGD is based on the same principles and uses the same interventions as does the adult version, albeit that these are simplified to accord with the developmental level and intellectual and cognitive abilities of children.

The treatment consists of nine 45-minutes sessions planned with 1- or 2-week intervals. The treatment is described in a therapist manual and in an illustrated workbook for the children. Treatment starts with the formulation of specific goals for the treatment ("*What is it that you want to achieve over the next sessions?*", "*After our ninth meeting, how would you* *notice that you profited from this treatment?*"). Each treatment session contains the same elements: completion of the Grief Checklist (described below), setting an agenda, evaluation of the homework assignments, discussion of new topics and interventions, and setting new homework assignments. Table 7.1 summarises the content of treatment.

The treatment is divided into five main parts, all described in the children's workbook. In the first part of treatment (titled '*Who Died?*'), the child is invited to talk about facts of the loss and things he or she misses and wished he or she could still share with the lost person. The accompanying chapter in the workbook includes verbal assignments (e.g., space to describe recollections of the funeral and unanswered questions for the lost person) as well as creative assignment (e.g., space to make a drawing of the funeral) that can be used to promote expression of thoughts and feelings. A key aim of this part is to encourage confrontation with the reality and pain of the loss and, for the therapist, to gather information about maladaptive thinking and behavioral patterns to be addressed later on in treatment.

In the second part of treatment (titled '*What Is Grief?*'), a task model of grief is introduced. The model is comparable to Worden's (1996) task model of grief and explains tasks that bereaved children are faced with and processes that may block achievement of these tasks. The model provides a framework for interventions applied in subsequent sessions. Task 1 ('Facing the Reality and Pain of the Loss') describes that reviewing the implications of the loss is crucial for adjustment and that some children avoid doing so because they fear the intensity of the pain that this may evoke. As such, in terms of the CBT model, the importance of integrating the loss and how anxious avoidance can interfere with this process is addressed in this first task. Task 2 ('Regaining Confidence in Yourself, Other People, Life, and the Future') describes how a loss can shatter positive thoughts and induce negative thinking. Although this is not abnormal in itself, persistent negative thinking maintains negative feelings and blocks adjustment. Accordingly, regaining a positive outlook on oneself, other people, life, and the future is important for recovery. This task introduces the role of negative cognitions in maintaining PGD symptoms. Task 3 ('Focusing on Your Own Problems and Not Only Those of Others') describes that, after a loss, some children are inclined to focus on the problems of others more than on their own problems and needs. It also explains how to distinguish between problems that children can and cannot solve and what skills are useful in solving the former ones. Task 4 ('Continuing Activities That You Used to Enjoy') describes that discontinuing particular social, recreational, and school-related activities is an understandable response to loss but, at the same time, can block adjustment. As such, this task explains how depressive avoidance blocks recovery from loss and that actively continuing valued activities fosters recovery.

Table 7.1 Summarised Content of Sessions

Sessions with child			Session with parent(s)	
Session	Treatment part	Content	Session	Content
1 - 2	*'Who Died?'*	Encouragement of expression of thought and feelings about the loss using verbal and creative assignments; therapist gathers information about maladaptive thinking and behavioural patterns.	1-2	Psycho-education using part 2, 3, and 4 of treatment workbook focused on tasks of grief and maladaptive thinking and behavioural patterns that could block achievement of tasks. Increasing the positive quality of parent-child relationship. Discussing and practicing specific assignments focused on spending more quality time with the child (doing things together), improving communication skills (e.g., active listening), and sharing thoughts and feelings about the loss within the parent-child relationship.
2 - 3	*'What Is Grief?'*	Psycho-education about tasks of grief and processes (specifically maladaptive thinking and behavioural patterns) that may block achievement of tasks. Homework: writing first letter, inviting child to write about thoughts and feelings about loss.		
4-5	*'Cognitive Restructuring'*	Explanation of how persistent negative thoughts block achievement of tasks of grief; identification of idiosyncratic maladaptive thoughts; modification of thoughts using Socratic questioning and behavioural experiments. Homework: cognitive diaries, behavioural experiments, and writing second letter, articulating positive thoughts about the self, life, and one's grief that foster adjustment.	3-4	Teaching ways to support children in achieving tasks of grief (e.g., by supporting them with cognitive diaries and with exposure, problem solving, and behavioral activation assignments, and by providing rewards).
6-7-8	*'Maladaptive Behaviours'*	Targeting "anxious avoidance" through social sharing of emotions and (in vivo or imagery) exposure; targeting poor problem solving by distinguishing between problems one can vs. cannot solve, addressing maladaptive responsibility thoughts, and teaching problem solving skills; targeting depressive avoidance using behavioural activation. Homework: behavioural assignments promoting healthy coping.		
9	*'Moving Forward After Loss'*	Summarising skills learned, making plans for continued practice, and trouble shooting. Homework: writing third letter with summary of behaviours and activities that foster coping.	5	Summarising skills learned, making plans for continued practice in maintaining the positive quality of parent–child relationship.

Cognitive restructuring is introduced in the third part. Negative cognitions that are central to the child's problems are identified using information from the intake interview, a brief questionnaire, and analyses of recent emotional episodes. Next, the validity (e.g., "*How do I know that what I think is true?*") and utility (e.g., "*What will be the effect if I continue thinking this way?*") of these cognitions are examined using Socratic questioning and completion of cognitive diaries. In addition, behavioural experiments are applied to examine the validity of particular negative predictions of the child, using specified assignments. Based on the information gathered, the initial negative cognitions and their more positive and rational counterparts are summarised on flashcards (Spuij & Boelen, 2012).

The fourth part of treatment (titled '*Maladaptive Behaviours*') targets maladaptive coping behaviors. The first subsection of this part addresses *anxious avoidance*. The child is encouraged to speak with others about the loss. In addition, exposure to reminders of the loss is applied encompassing identification of avoided stimuli (e.g., places, people, pictures, thoughts) and gradual confrontation with these stimuli. In the second subsection of this part, *problem solving* (linked with Task 3 of the task model) is addressed. The child is helped to distinguish between problems that he or she *can* solve (e.g., "*I spend too little time with friends*") and those that he or she *cannot* solve (e.g., "*Dad is having trouble at work, since mum died*"). Maladaptive thoughts about responsibility (e.g., "*I should take every effort to help my father as good as I can*") and one's own problems (e.g., "*My own problems can wait, those of others can't*") are targeted using cognitive restructuring. Problem-solving skills are taught to help the child deal with his/her own problems. The third subsection of this part targets 'depressive avoidance' using behavioural activation. This includes a 2-week daily registration of activities and mood (to experience how activity improves mood), making a list of potentially pleasant and meaningful activities, and gradually planning and conducting such activities (cf. Stark & Kendall, 1996; Weersing, Gonzalez, Campo, & Lucas, 2008).

The fifth and final part of treatment ('*Moving Forward After Loss*') entails reviewing skills learned during treatment and planning for continued practice of skills, including what the child should do if his or her emotional problems increase.

As an additional component of treatment, the child writes three letters to an imaginary or real friend. The first letter follows part 2 of the treatment and invites the child to write about the loss-event and his/her thoughts and feelings about the loss. The second letter follows Part 3 and instructs the child to write down positive thoughts about the self, life, and one's grief that foster adjustment. The third letter asks the child to report about behaviors and activities that help him/her to better cope with the loss. These writing assignments are meant to facilitate consolidation of the learning process and to make a document of skills learned that can be consulted after treatment.

The modular format of the treatment, with different interventions being described in distinct parts of the workbook makes it possible for therapists to address some parts of the treatment in more detail than others and to flexibly move back and forth through the workbook. Three interrelated points guide decisions about parts of the treatment that are emphasised. First, choices are based on hypotheses about the most important obstacles for recovery. Thus, for instance, relatively much attention is paid to exposure exercise if the child experiences greater anxious avoidance, whereas greater depressive feelings and inactivity would recommend more behavioural activation. Second, the child's treatment goals guide decisions about interventions that are emphasised (e.g., more attention for problem-solving skills if the child reports having difficulty dealing with particular social problems or problems at school). Third, decisions about parts that are emphasised are based on intellectual and developmental differences. Notably, our treatment uses a single workbook for all children aged 8 to 18 years. Yet, the variety of verbal, creative, and behavioural assignments allows adjusting interventions to intellectual ability. For example, in the first part of the treatment and workbook (titled '*Who Died?*'), the use of creative, non-verbal assignments is recommendable for children with lower cognitive abilities, whereas verbal assignments (writing about thoughts and feelings) are recommendable for children with stronger cognitive abilities.

The present approach differs from adult CBT for PGD in a number of ways. Generally, adult CBT relies more strongly on verbal methods (e.g., Socratic dialoguing), whereas CBT for children and adolescents uses more creative methods and play. Application of interventions may also differ between children and adolescents. Some adolescents grasp adult-type CBT principles very rapidly, whereas children sometimes need more emotional education focused on learning to distinguish different emotional states and link emotions with thoughts, events, and behaviours. Important also is that the family context influences grief expression and interventions applied. For instance, younger children may experience intense separation anxiety and a tendency to cling on available loved ones following a loss because they are generally more dependent on caregivers, whereas adolescents may feel obliged to take on new roles and responsibilities after parental or sibling death, which may interfere with the process of individuation (cf. Dowdney, 2008).

The nine individual sessions with the children are paralleled by five counselling sessions with the parents (or other caretakers of the child). These sessions are not meant to target parents' emotional problems; instead, the aim of these sessions is to help the parents in dealing with their children's grief and the therapeutic process their child is undergoing. To this end, parents receive the children's treatment workbook that is reviewed in the first two parent counselling sessions. Specifically, based on the chapters '*What Is Grief?*', '*Cognitive Restructuring*', and '*Maladaptive Behaviours*' therapist and parents discuss the tasks of grief children are faced with and maladaptive thinking and behavioural patterns that possibly block this process. Parents are given assignments focused on spending more quality time with their child, improving communication skills, and sharing thoughts and feelings about the loss, in order to improve the parent-child relationship. In Session 3 and 4, improvement of the parent-child relationship is further discussed and parents are taught what they can do to support their children in altering maladaptive thoughts and behaviours (e.g., by helping their children making cognitive diaries, supporting them during their exposure, problem solving, and behavioural activation, and providing rewards). In Session 5, relapse prevention is discussed, with a specific focus on signs of the child that should signal parents that their child might experience increased problems. Attention is also paid to how to maintain a good parent-child relationship.

Below, findings of our feasibility and multiple-baseline study are presented.

METHOD

Design

We used a nonconcurrent multiple-baseline design to evaluate the efficacy of the current approach in decreasing grief symptoms in a small sample of bereaved children. This design controls for potential confounds including maturation, exposure to the clinical setting, repeated testing and regression to the mean, increasing confidence that any observable changes are attributable to the intervention. Six patients were randomly assigned to three predetermined baseline lengths of 3, 5, or 7 weeks. It was our intention to start treatment at the designated time if the baseline was stable, otherwise extension of the baseline was deemed necessary. Stability was defined as an absence of a decreasing trend in PGD symptoms assessed with the Grief Checklist (described below) of at least two consecutive data-points prior to the start of treatment. Following the baseline assessment, patients completed the Grief Checklist at the start of each session in order to monitor PGD symptom levels.

Participants

Children included in this study were six consecutively assessed bereaved children applying for help at the outpatient clinic of Utrecht University.[1] They met the following criteria: (1)

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[1] Names and other identifying information were altered to protect confidentiality. All participants were Caucasian, except Eva who had a Hindustan background.

aged 8 through 18 years, (2) having suffered the loss of a parent or sibling between 6 and 12 months earlier, (3) suffering from symptoms of PGD as primary problem and reason to seek therapy, (4) no retardation, (5) absence of severe conduct disorder and developmental disorders, (6) not receiving concurrent psychological or psychopharmacological treatment, and (7) no current substance abuse or dependence, psychotic symptoms, severe depression with risk of suicide in participating children or their parents. A further inclusion criterion was a score of ≥ 40 on the Inventory of Prolonged Grief for Children (IPG-C, described below). This cutoff score represented a score in the top 75% of summed IPG-C score in a representative group of bereaved children from the general population (Spuij et al., 2012). These criteria were determined through assessment by the three therapists who also conducted the subsequent treatments.

Participant 1, Debby (3-week baseline)

Debby (10 years old) had been confronted with the sudden death of her father seven months earlier due to surgical complications. She experienced anger about possible medical failures made by doctors that had caused her father's death. Furthermore, she felt responsible for her mother's wellbeing and was worried that her mother would die too. She tended to stay close to her mother as often as she could to make sure that mother was okay.

Participant 2, Eva (3-week baseline)

Eva (9 years old) had been confronted with the death of a father seven months earlier, due to heart failure. Yearning for father's presence was central to her problems. In addition, she experienced PTSD-symptoms as she feared and tended to suppress memories of moments surrounding her father's death. Eva was afraid that she would 'go mad' if she would confront these memories. Coming from a Hindustan family, Eva's social context prescribed her to engage in active mourning for at least one year. Because of these social rules, Eva refrained from engaging in rewarding and pleasant activities

Participant 3, Ed (5-week baseline)

Ed was 9 years old and his older sister had died eight months before treatment. She was physically and mentally handicapped and died due to an epileptic episode. Ed did not want to talk about the loss. During the intake-interview, he seemed annoyed whenever the therapist asked about his thoughts and feelings. It was hypothesised that, because taking care of his sister had always provided Ed with a sense of fulfillment and pride, he now experienced a sense of purposelessness, that contributed to his difficulty accepting the loss.

Participant 4, Mike (5-week baseline)

Mike, 17 years old, was confronted with the loss of his older mentally retarded brother who died due to pneumonia, 11 months before treatment. Mike appeared numb and said that life felt meaningless since his brother died. He was pessimistic about his future and saw no need in continuing education after high-school. These negative thoughts led to depressive avoidance and prevented him from making plans for the future.

Participant 5, Anna (7-week baseline)

Anna was aged 13. Her father had died seven months before treatment. She considered his death as 'too painful to bear' and avoided different stimuli that confronted her with his death. For instance, father had been a professional violin player and Anna put a lot of effort in avoiding places where classical music was played, because this music reminded her too much of the painful loss. Father's death had led to financial problems. Anna worried about these problems and did her best not to spend too much money.

Participant 6, Yolanda (7-week baseline)

Yolanda was also aged 13 years and, six months before treatment, her father died after a long-term illness. She thought a lot about ways that she could have prevented his death, blaming herself that she had been unable to do so. Depressive avoidance was central to her problems. Yolanda felt unable to enjoy activities that she used to enjoy before father's death. She also felt unable to continue doing things that she used to do together with her father.

Children's Measures

Grief Checklist

This is a 12-item measure that taps criteria for PGD outlined by Prigerson et al. (2009). Participants rated how often they experienced symptoms in the preceding week on 5-point scales ranging from 0 = *almost never* to 4 = *almost all the time* (e.g., "*I long and yearn for the person who died*", "*I experience pangs of grief*"). Participants completed the Grief Checklist on a weekly basis during the baseline period, at the start of every treatment session, and after the ninth session. Its total score served as the primary dependent variable to evaluate the efficacy of treatment.

Inventory of Prolonged Grief for Children (IPG-C)

The IPG-C is a 30 item measure of PGD symptoms. It is an adapted version of the Inventory of Complicated Grief developed to assess adult PGD (Prigerson et al., 1995). It differs from the Grief Checklist in that it includes several additional markers of dysfunctional grief, apart from those tapped by the Grief Checklist. Moreover, the Grief Checklist asks respondents to rate symptom-frequency in the preceding week, whereas the IPG-C rates symptom-frequency in the last month, on 3-point scales ranging from 1 (*almost never*) to 3 (*always*). The measure has been found to have good internal consistency, stability and concurrent validity (e.g., high correlations with other measures of grief; Spuij et al., 2012).

Child PTSD Symptom Scale (CPSS)

The CPSS is a 17-item questionnaire for the assessment of PTSD symptoms as defined in the DSM-IV (APA, 2000) constructed by Foa, Johnson, Feeny, and Treadwell (2001). Respondents rate the occurrence of symptoms on 4-point scales (0 = *not at all/only once a week*, 3 = *almost always/five or more times a week*). Research has shown that the CPSS has good reliability and convergent and discriminant validity (Foa et al., 2001).

Children's Depression Inventory (CDI)

The CDI is a well-validated 27-item measure of depression symptoms (Kovacs, 2003, Dutch version, Timbremont, Braet, & Roelofs, 2008). Each item contains three statements representing depressive symptoms at increasing levels of severity from which respondents select the one statement that best describes how they felt in the preceding week.

Parent Measures

Child Behaviour Checklist (CBCL)

The CBCL (Achenbach & Rescorla, 2001) is a 118-item measure of emotional and behavioural problems of children aged 6 to 18 years that is completed by parents. Items are rated on 3-point scales with anchors 0 = *not true* to 2 = *very true/often true*. Scores can be used to obtain indices of Internalising Problems and Externalising Problems. The summed score of all items represents a Total Problem score. Psychometric properties of the original (Achenbach & Rescorla, 2001) and Dutch version (Verhulst, Van der Ende, & Koot, 1996) are adequate.

Feasibility measure

Children and parents evaluated each meeting on four items (1) "*I am satisfied about this session*", (2) "*I felt my therapist understood me*", (3) "*I understood the information that I received*", and (4) "*The workbook was handy to work with*". These items were rated on 5-point scales with anchors 1 = *totally disagree* to 5 = *totally agree*. Moreover, as a fifth item of the feasibility measure, they rated their overall satisfaction on a scale ranging from 0 (lowest) to 10 (highest).

Procedure

Potentially eligible patients (referred to the clinic by their GP) and their parent(s) received oral and written information about the current study. Those willing to participate were then invited for an interview in which inclusion criteria were assessed. Children then completed baseline measures (Grief Checklist, IPG-C, CPSS, and CDI) accompanied by a therapist. Parents completed the CBCL. For children aged < 12 years, written informed consent was obtained from the parents and oral consent from themselves. For children aged ≥ 12 years, written informed consent was obtained. All participants were informed that treatment would start after three to seven weeks but were not informed about the exact length of the baseline period. The Grief Checklist was administered over the telephone on a weekly basis, during the predetermined baseline period, and completed at the beginning of each treatment session. All self-report questionnaires were readministered at post-treatment.

Treatment was applied as described earlier. For Participants 1, 2, 5, and 6 parent sessions took place with the mother, as all these participants lost a father. Both parents were involved in the parent counseling for Participants 3 and 4. Approval for this research study was obtained from the local Institutional Review Board.

Treatments were conducted by the present authors, all licensed (post-master level) cognitive behavioural therapists. Adherence to the treatment-protocol was promoted by regular therapist meetings. Therapy sessions were audio-taped. Selected tapes were discussed to ensure that therapists adhered to the protocols.

RESULTS

Summary of Clinical Outcomes

Pre-treatment and post-treatment scores on the measures used are shown in Table 7.2 (CBCL scores are raw scores). Looking at pretreatment functioning, Participant 4 and 5 were at risk

Table 7.2 Scores on Symptom Measures at Pre-treatment and Post-treatment Per Child

	P1: Debby			P2: Eva			P3: Ed			P4: Mike			P5: Anna			P6: Yolanda		
	Pre	Post	RCI	Pre	Post	RCI	Pre	Post	RCI	Pre	Post	RCI	Pre	Post	RCI	Pre	Post	RCI
Grief Checklist	13	2	-	18	2	-	10	3	-	15	0	-	6	2	-	16	4	-
IPG-C	56	38	3.19	57	39	3.19	40	32	1.42	55	36	3.36	43	36	1.23	51	39	2.12
CPSS	6	2	0.88	8	1	1.53	6	5	0.22	13	4	1.96	10	3	1.53	12	6	1.31
CDI	5	1	0.94	1	2	-0.23	9	5	0.88	27	11	3.51	16	5	2.57	11	5	1.40
CBCL internalising	25	12	6.02	8	4	1.85	21	6	6.67	32	10	10.38	22	0	9.33	12	3	3.82
CBCL externalising	12	3	4.59	8	2	3.06	8	5	1.51	5	4	0.51	8	0	3.85	12	2	4.81
CBCL total	61	26	11.36	45	14	10.06	41	19	8.94	58	22	15.33	49	2	19.54	42	8	14.14

Note. CBCL scores are raw scores. CDI = Children's Depression Inventory. CBCL Child Behaviour Checklist. CPSS = Child Posttraumatic Stress-Disorder Symptom Scale. IPG-C = Inventory of Prolonged Grief for Children. RCI = Reliable Change Index.

for clinical depression, considering the > 13 cutoff proposed by Kovacs (1992). Compared with a Dutch reference group (Verhulst et al., 1996), scores on the CBCL Internalising scale of the CBCL of Participant 1, 3, 4 and 5 fell within the clinical range, whereas scores of Participant 6 fell in the subclinical (borderline) range. Scores of Participants 1 and 6 on the CBCL Externalising scale fell in the subclinical range, whereas scores of other participants fell in the normal range. CBCL Total scores of Participant 1, 4, and 5 fell within the clinical range. CBCL total scores of Participant 2, 3 and 6 fell in the subclinical range. Thus, although distress levels varied, participants all experienced moderate to severe levels of distress at pretreatment.

Pre-treatment and post-treatment scores averaged across participants are shown in Table 7.3. As shown, across participants, there was a 77% decline in scores on the Grief Checklist, a 27% decline in IPG-C scores, and ≥ 58% declines in CDI, CPSS, and CBCL scores. Paired sample t-tests showed that reductions in symptom measures from pre-treatment to post-treatment were all statistically significant. In terms of pre-treatment to post-treatment effect sizes (Cohen's *d*) symptom reductions were large (Table 7.3).

Summary of Feasibility Outcomes

On average, the nine treatment sessions were delivered over a period of 12.5 weeks (*SD* = 2.1 weeks). Scheduling of the sessions was conducted such that children could attend all nine therapy sessions and parents all five parent counselling sessions. For each participant, scores on the five feasibility items administered at the end of each session were averaged.

Table 7.3 Scores on Symptom Measures at Pre-treatment and Post-treatment for All Six Participants

	Mean scores (*SD*) at pre-treatment	Mean scores (*SD*) at post-treatment	Paired sample *t*-value	Cohen's *d*	% reduction from pre-treatment to post-treatment
Grief Checklist	13.0 (4.4)	2.2 (1.3)	5.7***	3.3	77%
IPG-C	50.3 (7.2)	36.7 (2.6)	6.2***	2.5	27%
CPSS	9.3 (3.0)	3.5 (1.9)	2.7***	1.0	62%
CDI	11.5 (9.2)	4.8 (3.5)	4.9*	2.3	58%
CBCL internalising	20.0 (8.7)	5.8 (4.5)	4.7***	2.0	71%
CBCL externalising	8.3 (2.7)	2.7 (1.7)	4.3**	2.5	68%
CBCL total score	49.3 (8.4)	15.2 (9.0)	10.4***	3.9	69%

Note. CDI = Children's Depression Inventory. CBCL = Child Behaviour Checklist. CPSS = Child Posttraumatic Stress Disorder Symptom Scale. IPG-C = Inventory of Prolonged Grief for Children.
* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

These are shown in Table 7.4. Children were generally positive about their overall satisfaction with each session, the understanding of their therapist, the information they received, and the workbook. The averaged ratings across sessions all approached the maximum score of 5.0. Moreover, ratings of overall satisfaction were high, with the exception of the rating from Participants 3 (Ed) who gave a zero rating in session 3. At this point in treatment, Ed reported feeling very angry about everything that was happening in his life at that moment. Nevertheless, feasibility scores averaged across sessions and children (shown in the last row in Table 7.4) indicated that, overall, children evaluated the program favourably.

Parents rated the same items as did their children. Mean scores across sessions are also shown in Table 7.4. For Participant 3 and 4, ratings from both parents were available. These were averaged for each session, before the overall averages across sessions, and across sessions and participants were calculated. The parents provided favourable evaluations of the program, with all scores approaching the maximum scores on the feasibility items.

Individual Outcomes

A key aim of multiple baseline studies is to determine if there is a clear treatment effect, after the introduction of the treatment, following the no-treatment baseline period. Accordingly, visual examination of graphed data provides a stringent test of the treatment efficacy as only unambiguous effects will become apparent (Parsonson & Baer, 1992). Weekly total ratings on the Grief Checklist across the (3, 5, or 7-week) baseline period and the treatment period are shown in Figure 7.1. With all six participants, treatment was started at the predetermined time, because stable trends in Grief Checklist scores were observed at the end of the baseline period.

Importantly, all participants showed stability in PGD scores (Grief Checklist) across the baseline period and these scores declined rapidly and substantially with the introduction of the treatment. The combination of stable scores during the baseline periods and declines in grief severity during treatment suggests that the reduction in PGD symptoms from pre-treatment to post-treatment was associated with the treatment interventions offered, rather due to spontaneous recovery.

Participant 1, Debby

Debby's Grief Checklist scores changed from 14 to 13 (-7%) during the 3-week baseline period and reduced to 2 (-85%) over the period of treatment. Cognitive restructuring focused on cognitions underlying Debby's anger towards doctors who had not prevented

Table 7.4 Summary of Feasibility Data

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6	All participants
Mean child ratings averaged across nine sessions							
1. I am satisfied about this session.	5.0	5.0	2.3	4.0	4.0	5.0	4.2
2. I felt my therapist understood me.	5.0	5.0	2.8	4.0	4.1	5.0	4.3
3. I understood the information that I received.	5.0	5.0	3.0	4.0	4.1	4.4	4.3
4. The workbook was handy to work with.	5.0	5.0	1.7	3.1	4.2	4.7	3.9
5. Overall satisfaction.	10.0	10.0	4.0	7.6	7.4	8.0	7.8
Mean parent ratings averaged across five sessions							
1. I am satisfied about this session.	4.8	4.8	4.0	4.0	5.0	5.0	4.6
2. I felt my therapist understood me.	4.5	4.5	4.3	4.3	5.0	5.0	4.6
3. I understood the information that I received.	4.3	4.3	4.3	4.1	5.0	5.0	4.5
4. The workbook was handy to work with.	4.0	4.0	3.9	3.3	4.5	4.5	4.0
5. Overall satisfaction.	8.0	8.0	8.0	7.5	8.4	8.4	8.0

Note. Scores on items 1 through 4 range from 1 (totally disagree) to 5 (totally agree); scores on item 5 range from 0 (lowest) to 10 (highest).

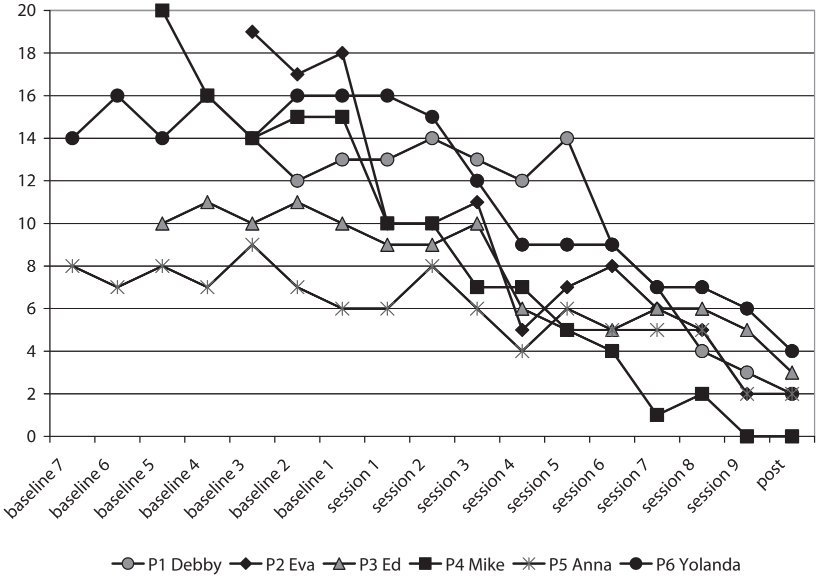

Figure 7.1 Weekly scores on the Grief Checklist for the six patients for baseline and treatment phases.

her father's death. Exploring the immediate effects of these cognitions helped Debby to see that ruminating about other's being to blame did not relieve her pain. The fear that mother would die too was targeted by calculating the chance that this would happen. Discussing that Debby could live with her favorite aunt if this disaster would in fact happen brought further relief to this fear. Problem solving skills were taught to help Debby provide support to her mother in other ways than constantly staying close to her (e.g., by phoning mother instead or staying physically close and by encouraging mother to make use of support that was offered by friends). According to RCIs (Table 7.2), Debby improved significantly (i.e. RCIs > 1.96; Jacobson & Truax, 1991) on the IPG and CBCL.

Participant 2, Eva

PGD scores of Eva declined from 19 at the start of the three-week baseline period to 18 upon implementation of the intervention (-5%) and further decreased to 2 (-89%) at post-treatment. Imaginal exposure to memories of moments surrounding her father's death was central to Eva's treatment. Experiencing that she could bear confronting the memories altered her catastrophic misinterpretations and reduced anxious avoidance. It was also discussed how Eva could gradually reengage in pleasant activities, while respecting the

Hindustan rule of mourning. Eva believed that during the first year following the loss, her father was still present as a ghost and she felt that she would 'betray' him if she would go out of the house and have fun again. Discussing that father would probably prefer Eva to experience joy rather than to stay at home feeling sad, helped her to reengage in some of the activities that she used to enjoy before father died, including dancing. According to RCIs (Table 7.2), Eva improved significantly on the IPG and CBCL.

Participant 3, Ed

PGD scores of Ed remained a stable 10 during the 7-week baseline period and declined to 3 (-70%) at the end of treatment. Therapy did not go smoothly. He continued to be hesitant to confront the reality of his sister's death. The therapist gradually gained Ed's trust using play and creative methods. Discussing the many good things Ed had done for his sister made him aware of how important she had been for him and, consequently, also seemed to help him to confront the reality and pain of the loss. Realising that the many good things he had done for his sister were not made undone by her death made him feel proud. However, although all this promoted achievement of Tasks 1 and 2, the nine sessions turned out to be too short to work on Tasks 3 and 4. For instance, little time was left to help Ed to share his feelings with his family and friends and to practice other positive coping skills. According to RCIs (Table 7.2), Ed only improved significantly on the CBCL; changes on the IPG (RCI = 1.42) represented a trend toward significant improvement.

Participant 4, Mike

Mike's PGD scores declined from 20 at the start of 5-week baseline period to 15 upon implementation of the intervention (-25%) and further reduced to 0 (-100%) after the ninth session. Cognitive restructuring was used to help Mike to alter his negative views of life and future. For instance, discussing the impact of his negative view of the future on his emotions and his motivation to prepare for his exams helped him to alter these negative beliefs. A behavioural experiment was used to test the prediction that friends would not respond supportive if he would share the story of his loss with them. Writing about his thoughts and feeling in a letter to an imaginary friend helped him to gain a more positive outlook on his future and to experience further benefits of emotional expression. Looking at the RCIs (Table 7.2), Mike improved significantly on all measures that were administered, including measures of PTSD and depression.

Participant 5, Anna

With Anna, PGD scores changed from 8 to 6 (-25%) during the six-week baseline period and to 2 (-67%) at post-treatment. Treatment included a detailed review of the implications of father's death using the verbal and creative assignments from the first part of the workbook. This helped her to achieve Task 1. Avoidance of violin music was targeted using exposure to classical music (during therapy session) and gradually going to public places were such music was played (e.g., shopping centers). Problem solving skills and cognitive restructuring were used to help Anna to better deal with her feelings of responsibility for the financial problems within the family. According to RCIs (Table 7.2) Anna improved significantly on the CDI and CBCL and to a lesser extent on the IPG and CPSS.

Participant 6, Yolanda

PGD scores of Yolanda increased from 14 to 16 (+14%) during the seven-week baseline period and declined to 2 (-88%) after the ninth session. Cognitive restructuring was used to alter cognitions underlying guilt and self blame. Specifically, the pie-chart technique helped her to see that there were many different unfortunate events that eventually led to her father's death and that there was no reason for blaming herself. The prediction that she was unable to enjoy activities that she used to enjoy before the loss was tested using behavioral assignments in which she tested the effects of picking up ice skating which was her favorite hobby. Getting more active also helped her to achieve Task 4. Achievement of this task was further promoted with gradual activation. According to RCIs (Table 7.1), Yolanda improved significantly on the IPG and CBCL.

DISCUSSION

There is evidence that childhood PGD is a clinical significant condition (Melhem et al., 2007; Spuij et al., 2012). However, there is limited knowledge about effective treatment interventions for children confronted with loss (Currier et al., 2007). We described and evaluated a newly developed nine-session manualised CBT treatment for children aged 8 to18 years, who suffer from PGD symptoms and other emotional problems following the death of a loved one. This approach is based on a CBT program developed for adult-PGD (Boelen et al., 2006; Boelen et al., 2007; Boelen et al., 2012) and also draws from existing treatments for childhood depression and anxiety (Weersing et al., 2008) and literature on childhood grief (Christ, 2000; Worden, 1996). In addition, our CBT-approach has similarities with the Family Bereavement Program (Sandler et al., 2003; Sandler, Ayers et al., 2010;

Sandler, Ma et al., 2010) that also includes CBT interventions to promote effective coping and a parenting component that is focused on the parent-child interactions.

With respect to the feasibility, children and their parents evaluated the treatment favorably. Five of six participating children gave very positive ratings to their overall satisfaction with each session, the degree to which they felt that their therapist understood their problems, the information that they received in the treatment session, and the content of the workbook. Averaged across the sessions, their ratings all approached maximum scores on the items that were used. Parents also rated the treatment favourably. One participant, Ed, was less positive about the treatment and profited least in terms of reduction in emotional problems. Ed's hesitance to confront the reality, pain, and consequences of his sister's death likely reflected his more generalised indignation and anger over this loss experience. Methods in the workbook (e.g., working through the '*Who Died?*' section), were perhaps too challenging to reduce this resistance. It seems likely that with clients like Ed, more than nine sessions are needed to gain trust and build a good working alliance. Instead, therapy should start slow (e.g., by taking more time to discuss neutral issues, bringing the therapy into an informal setting, relying more strongly on creative methods, or utilising play).

As a preliminary evaluation of the potential efficacy of our treatment approach, pre-treatment and post-treatment scores on measures of PGD, depression, and PTSD, and parent-rated problem behaviour of the six participants were evaluated. Averaged across the six participants, reductions in scores on the outcome measures were all statistically significant and pre-treatment to post-treatment effect sizes were all large ($d > 0.8$). Further information about the potential efficacy of this approach was obtained from analyses of the changes on the Grief Checklist that was administered weekly during the baseline and treatment phase. Scores on the Grief Checklist for the six participants showed a change of -7%, -5%, 0%, -25%, -25%, and +14% during the baseline period, and -85%, -89%, -70%, -100%, -67%, and -88% over the course of treatment, respectively. These substantial declines in grief symptoms during treatment relative to the stability of grief symptoms during the baseline intervals, suggests that the intervention contributed to the alleviation of symptoms.

Changes in scores on the Grief Checklist were complemented by substantial reductions in scores on the IPG-C, a validated measure of childhood PGD (Spuij et al., 2012). Notably, the 77% pre-treatment to post-treatment decline in scores on the Grief Checklist was discrepant with the considerably smaller 27% decline in IPG-C scores. These findings could indicate that the 12 symptoms tapped by the Grief Checklist are more amenable to change than the symptoms tapped with the 30-item IPG-C. However, this discrepancy could also reflect a practice effect, due to the fact that the Grief Checklist was administered repeatedly.

Symptoms of depression and PTSD decreased as well, although the magnitude of these changes differed between participants. For instance, with Participant 2, Eva, exposure to feared memories was a core component of treatment, the usefulness of which was suggested by significant RCI on the CPSS. With Participant 4, Mike, much attention was paid to depressive cognitions and the change in CDI scores suggests that this was useful. Notably, RCIs on for parent-rated Internalising were all significant, indicating that parents also observed significant improvements in functioning over the course of treatment.

Several limitations should be taken into account when interpreting the present findings. First and foremost, this study is limited by its small sample and absence of a no-treatment control group. Thus, although the findings suggests preliminary efficacy of CBT for childhood PGD, the multiple-baseline design does not rule out a number of other possible explanations for treatment effects, such as placebo or expectancy effects. Second, caution should be applied in generalising the present findings. For instance, four participants had lost a father within the past year. Future studies are needed to examine the effectiveness of CBT for more remotely bereaved children who lost other relatives or friends. Also of note is that the level of participants' distress was relatively modest. Thus, the applicability of our approach to more severely distressed cases requires further study. Future research could also address the moderating role of intellectual ability and developmental differences. For instance, it is possible that intellectual ability moderates treatment effects, such that younger children and those with intellectual disabilities profit less from CBT. However, prior studies have shown that it is not necessary to have mature, adult cognitive abilities to profit from CBT (Taylor, Lindsay, & Willner, 2008). Moreover, one of the strengths of the current program is that its inclusion of a variety of verbal, creative, and behavioural assignments seems to make it potential suitable for children of varying intellectual ability and distress severity. Further limitations are that there was no quantitative assessment of adherence to the treatment manual and that no follow-up assessments were included.

Notable also is that, because different interventions were employed, the relative importance of distinct interventions remains to be examined. In a related vein, CBT is theorised to produce changes in PGD by enhancing integration of the loss and reducing negative cognitions and avoidance (cf. Boelen et al., 2006). However, future research is needed to examine to what extent the present interventions produce such changes. It would also be relevant for future studies to examine the added value of parent counselling, something that we cannot draw conclusions about based on the present design. It was our impression that parent counselling indeed had such value. For instance, in talking with Anna's mother, it became clear that she (mother) feared confronting the loss. Discussing the impact of mother's own fear on Anna's recovery motivated mother to gradually lessen her own avoidant tendencies, which helped both herself and Anna to move forward. The sessions with Ed's parents brought to light that they did not know how to communicate about their daughter's death at home. Improving their communication skills helped them to talk about the loss at home with each other and with Ed.

Notwithstanding these considerations, the results of this study are encouraging and suggest that CBT is a well-received and potentially efficacious treatment for childhood PGD and associated symptoms. The present findings converge with growing evidence that such interventions are effective in the treatment of adult PGD (e.g., Boelen et al., 2007). Randomised clinical trials are needed to further examine the program's efficacy. It could be useful for such trails to compare the present approach with a no-treatment control group (in order to compare the program's efficacy with the natural course of grief), with supportive treatment in which no specific theory-based interventions are applied (to investigate the added value of CBT interventions over therapeutic support), or with mutual self-help group. A controlled study is currently being conducted at our institution. We present these results to draw attention to the need for treatment targeting childhood PGD and to provide information about strategies that may be effective in doing so.

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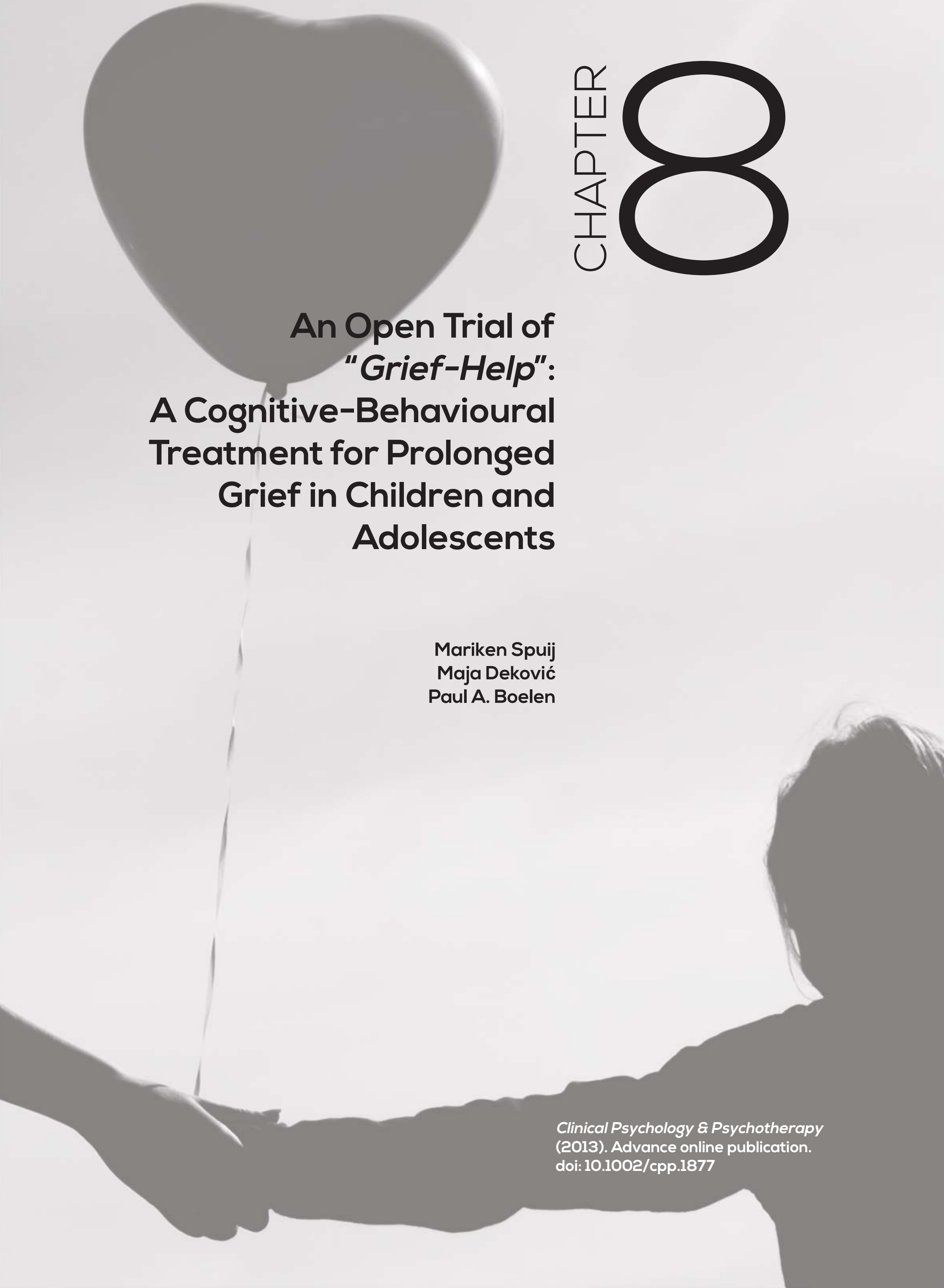

CHAPTER 8

An Open Trial of *"Grief-Help"*: A Cognitive-Behavioural Treatment for Prolonged Grief in Children and Adolescents

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ABSTRACT

In the past years, there is growing recognition of a syndrome of disturbed grief referred to as Prolonged Grief Disorder (PGD). Although mostly studied in adults, clinically significant PGD symptoms have also been observed in children and adolescents. To date, no effective treatment for childhood PGD yet exists. We recently developed a nine-session cognitive-behavioural treatment for childhood PGD combined with five sessions of parental counselling. In the current article we present outcomes of treatment of ten consecutive children and adolescents turning to our university clinic with elevated PGD symptoms as their primary problem and main reason to seek therapy. Patients were significantly improved at post-treatment, with large improvements in self-rated PGD and posttraumatic stress (effect sizes > 0.8) and small to moderate improvement in depression and parent-rated Internalising and Externalising Problems (0.2 < effect sizes < 0.8). Additional predictor analysis of outcomes suggested that, among other things, this treatment approach is less efficacious for children and adolescents further removed from loss and those confronted with suicidal loss. That said, the treatment appears promising, and controlled evaluation is clearly indicated.

INTRODUCTION

The death of a loved one in childhood and adolescence is a risk factor for distress and dysfunction. This event has been associated with increased emotional problems including elevated depression, anxiety, and posttraumatic stress, as well as somatic complaints and behavioural problems (Dowdney, 2008; Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012). An estimated 5% to 10% of children experience clinically significant psychiatric problems following loss including major depression, Posttraumatic Stress Disorder (PTSD), and Prolonged Grief Disorder (PGD) (Melhem, Moritz, Walker, Shear, & Brent, 2007; Melhem, Porta, Shamseddeen, Walker, & Brent, 2011).

PGD encompasses several symptoms including separation distress, preoccupation with thoughts about the lost person, a sense of purposelessness about the future, numbness, bitterness, difficulties accepting the loss and difficulty moving on with life without the lost person (Prigerson et al., 2009; Shear et al., 2011). Although PGD has mostly been studied among adults, a growing body of empirical studies has shown that children and adolescents can develop PGD symptoms that can be reliably assessed, are distinct from normal grief, depression and anxiety, including PTSD, and are predictive of significant concomitant Internalising and Externalising Problems (Brown & Goodman, 2005; Dillen, Fontaine, & Verhofstadt-Denève, 2008; Spuij, Prinzie et al., 2012; Spuij, Reitz et al., 2012). The evidence that, in a small percentage of people, acute grief reactions turn into chronic debilitating distress, blocking reestablishment of normal routines, has led to the inclusion of Persistent Complex Bereavement Disorder in the appendix of DSM-5 (American Psychiatric Association [APA], 2013; for discussions, see Boelen & Prigerson, 2012; Kaplow et al., 2012; Wakefield, 2012).

Despite these facts, no effective treatment for childhood PGD yet exists. Based on a meta-analysis of 13 controlled studies examining the effectiveness of bereavement interventions with children, Currier, Holland, and Neimeyer (2007) concluded that bereavement interventions for children are no more useful than undergoing no intervention. More recently, two research lines stem more optimistic about the usefulness of bereavement interventions for children. The first, by Sandler et al. (2003), Family Bereavement Program (FBP), a group based program that targets family-level (e.g., parenting skills) and child-level (e.g., coping skills) variables that promote resilient outcomes. The FBP has been found to reduce immediate as well as long-term grief-problems in children confronted with parental loss (Sandler et al., 2003, 2010). The second, by Layne et al. (2008), is a group treatment of adolescents confronted with loss in the context of a civil war conflict. This latter treatment has proven to be effective in terms of reducing grief, depression, and anxiety symptoms (see also Kaplow et al., 2012). However, both approaches are limited in their reliance on a group-based format (which may yield practical problems and may be less effective because it is less well adjusted to the individual child's circumstances) and their focus on restricted groups (parentally bereaved children in the FBP and children exposed to traumatic deaths, in Layne et al.'s treatment). Moreover, the impact of these treatments on PGD, as currently defined (Prigerson et al., 2009), is unknown.

Given the need for effective treatments for PGD symptoms in children and adolescents, we developed '*Grief-Help*', a nine-session manualised cognitive behavioural treatment, administered in combination with five sessions of parental counselling. We recently conducted a multiple-baseline study among six bereaved children and adolescents who were all confronted with the death of a parent or sibling, relatively recently (i.e., 6-12 months earlier) (Spuij, Van Londen-Huiberts, & Boelen, 2013). That study showed that the intervention coincided with reductions in symptoms of PGD, depression, PTSD, and (parent-rated) Internalising and Externalising Problems. All participating children and parents evaluated the treatment positively, attesting to its feasibility. The current study was conducted to provide a further evaluation of our treatment approach, with a focus on its potential efficacy in alleviating symptoms of PGD and associated symptoms in a more heterogeneous and more remotely bereaved group of children and adolescents. The evaluation of '*Grief-Help*' reported in this paper relies on data from ten consecutive children and adolescents turning to our university clinic with elevated PGD symptoms as their primary problem and main reason to seek therapy. Before we turn to the study, more information about the content and background of our approach are provided.

'*Grief-Help*': Cognitive Behavioural Therapy for Childhood PGD

'*Grief-Help*' is based on a cognitive behavioural theory of PGD. This theory proposes that, in people with PGD, symptoms of acute grief persist and exacerbate to the point of impairment under the influence of three process: (a) insufficient integration of knowledge about the irreversibility of the separation into representational knowledge about the self and the relationship with the lost person, maintaining separation distress and proximity seeking responses; (b) a propensity to engage in persistent negative thinking about oneself, life, and one's ability to deal with the pain and grief; and (c) a propensity to fear and avoid external and internal reminders of the loss (termed 'anxious avoidance') and to withdraw from normal routines and valued activities that could foster adjustment, driven by pessimistic cognitions that one is unable to carry out and/or to enjoy such activities (termed 'depressive avoidance') (Boelen, Van den Hout, & Van den Bout, 2006). Alleviation of PGD symptoms can be achieved by targeting these processes using conventional CBT interventions. That is, *imaginary exposure* (telling the story of the loss event, zooming in on the most painful aspects), *in vivo exposure* (visiting the scene of the death), and *confrontational writing* (writing a letter to the lost person, explaining what is missed most) are used to promote integration of the irreversibility of the loss with other knowledge. *Socratic questioning* (i.e., identifying, discussing the validity and utility of, and altering maladaptive cognitions) and *behavioural experiments* (i.e., using specific behavioural assignments to test the validity of cognitions) are used to curb maladaptive thinking (Spuij & Boelen, 2012). Finally, behavioural assignments and skill training are applied to replace maladaptive coping by more helpful ways of coping. For instance, *exposure to avoided stimuli* can be used to target anxious avoidance, and *behavioural activation* to stop the vicious cycle of depressive avoidance. In our treatment, these interventions are delivered in a simplified manner to accord with the developmental level and intellectual and cognitive abilities of children. For instance, therapists can use a variety of verbal, creative, and behavioural assignments throughout treatment, allowing them to focus more strongly on the use of creative, non-verbal assignments for children with lower cognitive abilities (e.g., drawing pictures as a means to express ones feelings) and verbal assignments (e.g., using Socratic questioning to identify and discuss maladaptive cognitions) with children with stronger cognitive abilities.

The treatment is divided into five main parts that are described in a workbook the child uses throughout treatment. These five main parts include an introduction part, focused on getting to know the child and his/her loss, a second part focused on psycho-education about loss, two further parts addressing cognitive restructuring and maladaptive behaviours respectively, and a final part focused on ending therapy and looking at the future; we distinguished these particular parts because they reflect a logical content and order. Specifically, in the first part of treatment (titled '*Who Died?*'), the child is invited to talk about facts of the loss and things she/he misses and wished he/she could still share with the lost person. A key aim of this part is to encourage confrontation with the reality and pain of the loss and, for the therapist, to gather information about maladaptive thinking and behavioural patterns to be addressed later on in treatment. In the second part of treatment (titled '*What Is Grief?*') a task model is introduced that explains four tasks that bereaved children are faced with in coming to terms with loss and the processes that may block achievement of these tasks (i.e., Task 1: *Facing the reality and pain of the loss*; Task 2: *Regaining confidence in yourself, other people, life, and the future*; Task 3: *Focusing on your own problems and not only those of others*; Task 4: *Continuing activities that you used to enjoy*). The model provides a framework for interventions applied in the next stages of the treatment.[1] For instance, in the third part

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[1] The notion that bereaved individuals have to work through several tasks to recover is based on Worden's task model of grief (e.g., Worden, 1996). Yet, although the first of our tasks overlaps with Task 1 of Worden's model, our task model is different from Worden's in its focus on specific thinking patterns and coping styles that foster recovery, based on a cognitive-behavioural perspective on disturbed grief; cf. Boelen et al., 2006.

(‘*Cognitive Restructuring*’) cognitive restructuring is used to work on Task 2. The fourth part of treatment (titled ‘*Maladaptive Behaviours*’) targets maladaptive coping behaviours. Graded exposure interventions are used to work on Task 1, problem-solving skills are taught to address Task 3, and behavioural activation is used to help achievement of Task 4. In the fifth and final part of treatment (‘*Moving Forward After Loss*’) skills learned during treatment are reviewed, summarised, and written down. As an additional component of treatment, the child writes three letters to an imaginary or real friend as a means to facilitate consolidation of the learning process and to make a document of skills learned that can be consulted after treatment.

The treatment is delivered in nine individual sessions with the children which are paralleled by five counselling sessions with the (surviving) parent(s) or other caretaker(s). These numbers of sessions were chosen because we strove to develop a relatively brief intervention (to reduce its costs and enhance its eventual dissemination) and pilot work revealed that these numbers were sufficient to bring across the intervention to children and parents. The aim of the sessions with parents is to support the parent(s)/caretaker(s) in coaching their child during his/her therapeutic process. To this end, the workbook that guides treatment is reviewed, and maladaptive thinking and behavioural patterns that may block the child’s grieving process are discussed. Parents are given assignments focused on spending more quality time with their child, improving communication skills, and sharing thoughts and feelings about the loss, in order to improve the parent-child relationship. In what follows, a further evaluation of ‘*Grief-Help*’ is described, using data from ten bereaved children and adolescents.

METHOD

Participants

Participants were ten consecutively assessed bereaved children and adolescents, applying for help at the outpatient clinic of Utrecht University. They met the following criteria: (1) aged 8 through 18 years, (2) having suffered the loss of a close relative, (3) having symptoms of PGD as primary problem and reason to seek therapy, (4) no retardation, (5) absence of severe conduct disorder and developmental disorders, (6) not receiving concurrent psychological or psychopharmacological treatment, and (7) no current substance abuse or dependence, psychotic symptoms, severe depression with risk of suicide in participating children or their parents. All ten patients were Caucasian. There were four boys and six girls with ages ranging between 10 and 18 ($M = 13.90$, $SD = 2.9$). Four had lost their mother, four their father, one had lost an aunt, and one other had lost a sister. Losses occurred 6 to 181 months ago ($M = 49.4$, $SD = 60.2$, Median = 16 months) and were due to an illness, suicide, or unexpected medical cause (e.g., cardiovascular attack) in 2, 6, and 2 cases, respectively.[2]

Measures

The following outcome measures were administered at the beginning and end of treatment; the Child Behaviour Checklist (CBCL) was completed by (one of) the surviving parent(s), the other measures by the children and adolescents.

Inventory of Prolonged Grief for Children

The Inventory of Prolonged Grief for Children (IPG-C) is a 30-item measure of PGD symptoms. It is an adapted version of the Inventory of Complicated Grief developed to assess adult PGD (Prigerson et al., 1995) tapping all symptoms listed in proposed criteria for PGD as well as additional markers of dysfunctional grief. The IPG-C rates symptom-frequency in the last month, on 3-point scales ranging from 1 (*almost never*) to 3 (*always*). The measure has good internal consistency, stability and concurrent validity (e.g., high correlations with other measures of grief; see Spuij, Prinzie, et al., 2012).

Child PTSD Symptom Scale

The Child PTSD Symptom Scale (CPSS) is a 17-item questionnaire for the assessment of PTSD symptoms as defined in the DSM-IV (APA, 2000) constructed and validated by Foa, Johnson, Feeny, and Treadwell (2001). Respondents rate the occurrence of symptoms on 4-point scales ranging from 0 (*not at all/only once a week*) to 3 (*almost always/five or more times a week*). The index event was defined as "the death of your loved one".

Children's Depression Inventory

The Children's Depression Inventory (CDI) is a well-validated 27-item measure of depression symptoms (Kovacs, 2003, Dutch version, Timbremont, Braet, & Roelofs, 2008). Each item contains three statements representing depressive symptoms at increasing levels of severity from which respondents select the one statement that best describes how the felt in the preceding week.

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[2] Because we were interested in the potential efficacy of our treatment for a diverse group of bereaved children and adolescents, we set no limit to the time since loss, resulting in this wide range in time since loss.

Child Behaviour Checklist

The CBCL (Achenbach & Rescorla, 2001) is a 118-item measure of emotional and behavioural problems of children aged 6-18 years that is completed by parents. Items are rated on 3-point scales with anchors 0 = *not true* to 2 = *very true/often true*. Scores can be used to obtain indices of Internalising Problems and Externalising Problems. The summed score of all items represents a Total Problem score. Psychometric properties of the original (Achenbach & Rescorla, 2001) and Dutch version (Verhulst, Van der Ende, & Koot, 1996) are adequate.

Procedure

Potentially eligible patients (referred to the clinic by their general practioner) and their parent(s) received oral and written information about the research program. Surviving parents' consent was obtained for their children to participate. Assent or consent was obtained from the children, depending on their age. Children then completed baseline measures (IPG-C, CPSS, and CDI) accompanied by a therapist. Parents completed the CBCL. Patients received nine individual 45 minutes sessions of CBT for childhood PGD, planned once every one or two weeks. Five 45 minute sessions with one or two of the parents were planned parallel to these nine sessions.[3] The treatment followed the format described by Spuij et al. (2013). The present project was approved by a local ethical review board. Treatments were all conducted by licensed (post-master level) cognitive behavioural therapists. Adherence to the treatment protocol was promoted by regular therapist-meetings.[4]

RESULTS

Summary of Clinical Outcomes

Mean pre-treatment and post-treatment scores on the measures used are shown in Table 8.1. Examination of pre-treatment scores showed that IPG-C scores were similar to the score of *M* = 50.6 (*SD* = 12.2) of a reference group of outpatient children and adolescents

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[3] It was strived for to have weekly therapy sessions. Yet, this was not always feasibly, for instance because there was not always an adult available to accompany the child.

[4] It turned out that the treatment workbook provided sufficient guidelines to deliver the treatment to participating children and their parent(s). Therapist meetings were mostly spent on discussions of how best to implement a particular intervention included in the work-book and what particular parts should possibly be emphasised with a particular child. No systematic changes were made to the treatment protocol based on these meetings.

Table 8.1 Means, Standard Deviations and *Z* Statistics (Wilcoxon Signed-Rank Tests) for Outcome Measures at Pre-Treatment and Post-Treatment

Measure	Pre-treatment, *M* (*SD*)	Post-treatment, *M* (*SD*)	*Z*	*p*	Cohen's *d*	% reduction
IPG-C	51.50 (11.76)	38.70 (10.08)	-2.81	0.005	1.17	24.8%
CPSS	16.50 (12.29)	6.30 (10.04)	-2.65	0.008	0.90	61.8%
CDI	12.95 (6.88)	10.10 (5.66)	-2.04	0.041	0.45	22%
CBCL Internalising	15.90 (7.30)	10.40 (7.44)	-1.89	0.059	0.74	34.5%
CBCL Externalising	8.62 (6.64)	7.13 (5.61)	-1.64	0.100	0.24	17.2%
CBCL total	41.99 (23.22)	35.06 (18.55)	-1.58	0.114	0.33	16.5%

Note. CBCL scores are raw scores. CDI = Children's Depression Inventory. CBCL = Child Behaviour Checklist. CPSS = Child Posttraumatic Stress-Disorder Symptom Scale. IPG-C = Inventory of Prolonged Grief for Children.

seeking help following bereavement reported by Spuij, Prinzie et al. (2012). On the CDI, six participants scored above the > 13 cut-off indicative of clinical depression (Kovacs, 1992). Compared with a Dutch reference group (Verhulst et al., 1996), scores on the CBCL Internalizing scale of six participants fell within the subclinical or clinical range; scores on the CBCL Externalising scale of four participants fell within the subclinical or clinical range; and scores on the CBCL total scale of four participants fell within the clinical range. Thus, although distress levels varied, participants all experienced moderate to severe levels of distress at pre-treatment.

In all participants, PGD severity (IPG-C) declined during the course of treatment. Table 8.1 presents mean scores on each outcome measure at pre-treatment and post-treatment. Wilcoxon signed-rank tests showed significant improvements on self-rated PGD (IPG-C), depression (CDI), and PTSD (CPSS). The decline in parent-rated Internalising (CBCL) was marginally significant ($p < 0.10$). Parent-rated Externalising (CBCL) and Total Problem behaviour (CBCL) did not decline significantly. In terms of pre-treatment to post-treatment effect sizes (Cohen's *d*, Cohen, 1988), reduction in symptom levels of PGD and bereavement related PTSD were large ($d > 0.8$) and all other reductions were small to medium ($0.2 < d < 0.8$).

Individual Outcomes

To further examine changes in symptoms among the participants, we calculated reliable change indices (RCIs) for all 10 participants, on all six outcome measures. These are shown in Table 8.2. The RCI indicates whether a change in an individual's score (in this case before and after '*Grief-Help*') is statistically significant or not (based on how reliable the measure

Table 8.2 Reliable Change Indices for Changes in Symptoms from Pre-Treatment to Post-Treatment for all 10 Patients

	Participant number									
	1	2	3	4	5	6	7	8	9	10
IPG-C	1.24	2.30*	1.59	5.31*	1.42	1.59	5.65*	1.24	4.25*	2.48*
CPSS	1.53	5.24*	1.09	2.84*	0.22	3.06*	0.22	1.31	5.23*	1.96*
CDI	0.70	0.23	1.31	1.40	0.70	1.64	0.93	0.22	1.10	0.43
CBCL Internalising	4.67*	10.19*	3.30*	2.55*	2.55*	2.31*	6.79*	0.47	2.22*	3.30*
CBCL Externalising	1.44	13.96*	1.02	0.48	1.41	0.51	0.96	0.51	1.00	0.51
CBCL Total	7.48*	4.08*	2.55*	4.99*	0.41	0.62	8.32*	1.31	2.84*	1.70

Note. CDI = Children's Depression Inventory. CBCL = Child Behaviour Checklist. CPSS = Child Posttraumatic Stress-Disorder Symptom Scale. IPG-C = Inventory of Prolonged Grief for Children. * $p < 0.05$.

is), with value of RCI > 1.96 pointing at a statistically significant difference (Jacobson & Truax, 1991).

Table 8.2 shows that, according to the RCIs, five participants improved significantly on the IPG-C; five improved significantly on the CPSS; none improved on the CDI; nine participant improved on the CBCL Internalising scale and only one on the CBCL Externalising scale; and six improved significantly on the CBCL Total scale.

Additional Analyses: Predictors of Outcomes

Changes in symptom scores observed from pre-treatment to post-treatment in the current sample were smaller than those found in our prior multiple baseline study among six children/adolescents (Spuij et al., 2013). To obtain possible explanations for these differences, we decided to conduct a predictor analysis of treatment outcome, based on 16 participants included in the prior study ($N = 6$) and present study ($N = 10$). We calculated residual gain scores on the IPG-C, CDI, CPSS, and Internalising, Externalising, Total Problem scores from the CBCL (from the regression of the pre-treatment scores on the post-treatment scores) as indices of treatment outcome. These were calculated as the standardised symptom score at post-treatment minus the standardised symptom score at pre-treatment multiplied by the correlation between standardised scores at pre-treatment and post-treatment and, thus, represented post-treatment symptom scores adjusted for pre-treatment scores, calculated such that lower scores represented better treatment outcome (cf. Steketee & Chambless, 1992).

First, we tested whether treatment outcomes differed significantly between the current and the prior sample. These analyses showed that the present sample had significantly worse outcomes in terms of scores on the CDI (Mann-Whitney $U = 6.00$, $p = 0.009$), the CBCL Externalising scale ($U = 6.00$, $p = 0.012$), and the CBCL Total Problem scores ($U = 0.00$, $p = 0.001$).

Second, we examined the impact of gender and age on outcomes. Boys profited equally in terms of PGD, depression, PTSD, Internalising, and Total Problem scores, but improved less than girls in terms of parent-rated Externalising scores ($U = 10.00$, $p = 0.03$). In addition, at a trend level, children that were older had worse outcomes in terms of CBCL Internalising scores ($\rho = 0.47$, $p = 0.07$) and Externalising scores ($\rho = 0.49$, $p = 0.05$).

Third, we examined the impact of time since loss, kinship (i.e., loss of mother, father, or other relative), and cause of loss (i.e., loss due to suicide, illness, or unexpected medical cause). At a trend level, a greater amount of time elapsed since loss, was associated with worse outcomes in terms of CDI scores ($\rho = 0.46$, $p = 0.07$). Treatment outcome did not vary between children who lost a mother, a father, or some other relative. CBCL Externalising scores varied as a function of cause of loss (Kruskal-Wallis $\chi^2 = 6.86$, $p = 0.03$), such that children confronted with suicidal loss had worse outcomes compared to those whose loved one died to illness ($p < 0.05$) or an unexpected medical cause ($p = 0.05$).

DISCUSSION

The present study aimed to enhance knowledge about the potential efficacy of our recently developed treatment protocol for CBT for childhood PGD (Spuij et al., 2013), named "*Grief-Help*", using data from 10 consecutive children and adolescent seeking help for emotional problems following the death of a close relative. Outcomes showed that, averaged across participants, the treatment coincided with statistically significant reductions in self-rated symptom levels of PGD (IPG-C), depression (CDI), and PTSD (CPSS). Reductions in parent-rated Internalising, Externalising, and Total Problem behaviour tapped with the CBCL were observed, but these changes did not reach statistical significance. In terms of Cohen's *d* effect size (Cohen, 1988), pre-treatment to post-treatment effect sizes for self-rated PGD and PTSD were large ($d > 0.8$) and effect sizes for depression and parent-rated Internalising, Externalising, and Total Problem behaviour were low to moderate. Evaluation of RCIs of changes in symptom scores for individual participants showed that all participants except one showed significant improvement on at least one of the outcome measures.

The current findings add to findings from our prior feasibility and multiple baseline study among six consecutive patients (Spuij et al., 2013); that study also showed that our CBT protocol "*Grief-Help*" for childhood PGD coincides with a considerable reduction in PGD and other forms of loss-related psychopathology. The degree of improvement across self-rated indices of PGD, depression, and PTSD suggests that our treatment was efficacious and probably more efficacious than many bereavement interventions studied before (Currier et al., 2007). The fact that this treatment had a relatively larger effect on PGD symptoms than on concomitant symptoms of depression, posttraumatic stress, and Internalising and Externalising Problems (see Table 8.1) is not unexpected, given the treatment's focus on the processing of the loss. However, this finding may indicate that the current treatment approach should perhaps be complemented with additional interventions (e.g., learning skills to handle aggression in case of severe externalising tendencies) if other problems instead of PGD symptoms are the key problems of the bereaved child.

Outcomes of this study support the continued evaluation of our CBT protocol. That said, findings in the current sample were less positive compared to those observed in our previous sample of six children/adolescents included in our feasibility study (Spuij et al., 2013), e.g., Cohen's *d* effect sizes were higher in that prior sample and, different from the current study, CBCL-scores declined significantly in that prior sample. This may be due to differences in the composition of this prior sample and the previous sample. For instance, children in the previous study were all in their first year of bereavement, whereas some of the participants in the current study were further removed from their loss. Moreover, the current sample included six participants confronted with suicidal loss, compared to none in our previous study. To gain some hints of variables moderating the outcome of our treatment, we conducted additional analyses using the combined consecutive cases included in our prior and the current studies ($N = 16$) to examine whether outcomes varied as a function of different background and loss related variables. These analyses confirmed that participants in the current study had worse outcomes compared with participants in the prior study. In addition, outcomes varied as a function of several demographic and loss related variables. That is, in accord with evidence that externalising disorders show more continuity for boys (McGee, Feehan, Williams, & Anderson, 1992), boys had worse outcomes on Externalising compared to girls. In addition, at a trend level, older children showed less positive outcomes on parent-rated internalising and externalising behaviour. This finding raises the possibility that our treatment protocol is suitable for younger children more than for older children. In addition, also at a trend level, more time elapsed since loss was associated with worse outcomes in terms of depression symptoms and suicidal losses coincided with worse treatment outcomes in terms of Externalising scores. These particular findings confirm our impression that differences between outcomes of this study and our prior study (Spuij et al., 2013) may be due to the fact that the current sample was further removed from loss and included more (i.e., a notable six out of ten) children/adolescents confronted with suicidal loss. Interestingly, the current findings suggest that parent-rated problems (i.e., CBCL scores) are affected by these variables more strongly than self-rated problems. In fact, PGD scores were unrelated to any of the predictor variables; this is encouraging as it suggests that PGD severity decreases quite consistently, independent of characteristics of the person or the loss she/he suffered. However, as these predictor's analyses are based on a small sample, conclusions must remain tentative.

Several other limitations should be kept in mind when interpreting the current findings. First, the absence of a no-treatment control group means that spontaneous fluctuation in symptoms cannot be ruled out. A second limitation, related to the first one, is that, because we did not include a no-treatment control group, the effect sizes reported in this study are uncontrolled pre-post effect sizes; because these tend to run larger than controlled effects between the post test scores of treated and untreated clients (cf. Lipsey & Wilson, 1996), the effect sizes of our treatment will likely turn out to be smaller when compared to a no-treatment control group. Thirdly, caution should be applied in generalising the present findings. For instance, it is unknown to what extent this treatment is effective for non-assessed groups (e.g., children confronted with loss during war, multiple loss, or motor vehicle accidents). Fourthly, the amount of time passed since the loss varied widely between participants and it is possible that life events experienced since the loss occurred exerted an influence on the present problems. It would be relevant for future studies to systematically register such life events, in order to examine their possible moderating effects on treatment outcome. Finally, we did not examine other factors that possibly affected the children's grief and their responses to treatment, such as the grief of the (surviving) parents or distress seen in other relatives and this would also be important to address in future studies.

Notwithstanding these considerations, the results of this open trial complement prior findings from our multiple baseline study in showing that CBT is a well-received and potentially efficacious treatment for childhood PGD and associated symptoms. The current findings compare favourably to prior effects of interventions for childhood grief (Currier et al., 2007) and add to other more recently developed treatment programs to help children and adolescent stuck in their process of grief (Layne et al., 2008; Sandler et al., 2010b). The present findings converge with growing evidence that CBT interventions targeting unhelpful thinking and behavioural patterns are effective in the treatment of adult PGD (e.g., Boelen et al., 2007) and indicate that it is important to subject this cognitive behavioural treatment for childhood-PGD to further investigation. For instance, randomised clinical trials are needed to further examine the efficacy of this treatment, in comparison with no-treatment control groups, or in comparison with supportive treatment in which no specific theory-based interventions are applied, in order to be able to investigate the added value of CBT interventions over therapeutic support. Such a controlled study is currently being conducted at our institution. At a later stage, it would be interesting to identify predictors and moderators of treatment effects and to use this information to refine the interventions for subgroups of bereaved children.

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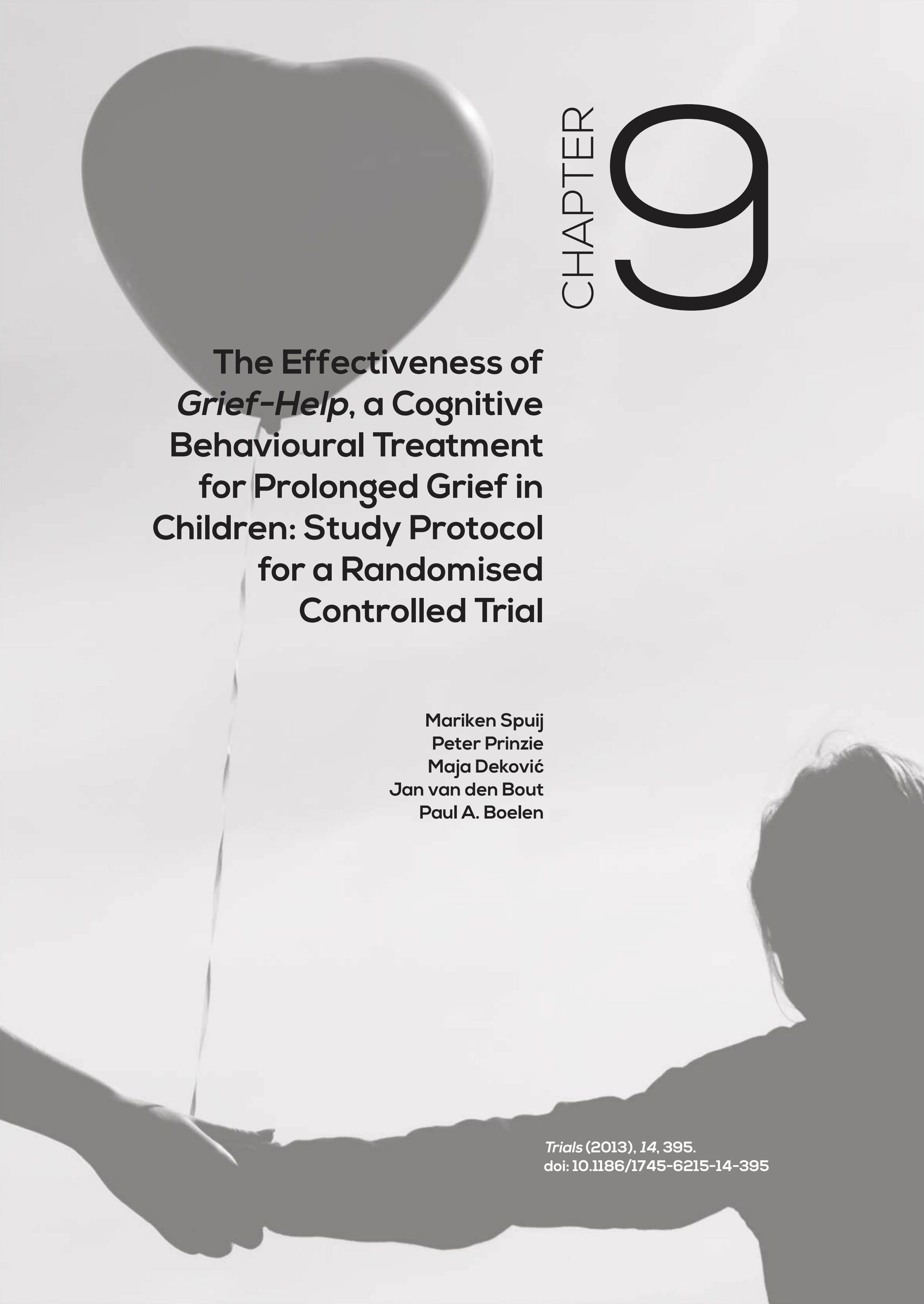

CHAPTER 9

The Effectiveness of *Grief-Help*, a Cognitive Behavioural Treatment for Prolonged Grief in Children: Study Protocol for a Randomised Controlled Trial

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ABSTRACT

Background

There is growing recognition of a syndrome of disturbed grief referred to as Prolonged Grief Disorder (PGD). PGD is mostly studied in adults, but clinically significant PGD symptoms have also been observed in children and adolescents. Yet, to date no effective treatment for childhood PGD exists. The aims of this study are: (1) to investigate the effectiveness of *Grief-Help*, a nine-session cognitive behavioural treatment for childhood PGD, combined with five sessions of parental counselling, immediately after the treatment and at three, six and twelve months follow-up; (2) to examine tentative mediators of the effects of *Grief-Help*, (i.e, maladaptive cognitions and behaviours and positive parenting), and (3) to determine whether demographic variables, child personality, as well as symptoms of PGD, anxiety, and depression in parents moderate the treatment effectiveness.

Methods

We will conduct a Randomised Controlled Trial in which 160 children and adolescents aged 8 to 18 years are randomly allocated to cognitive behavioural *Grief-Help* or to a *supportive counselling* intervention; both treatments are combined with five sessions of parental counselling. We will recruit participants from clinics for mental health in the Netherlands. The primary outcome measure will be the severity of PGD symptoms according to the Inventory of Prolonged Grief for Children (IPG-C). Secondary outcomes will include Posttraumatic Stress Disorder (PTSD), depression and parent-rated Internalising and Externalising Problems. Mediators like positive parenting and maladaptive cognitions and behaviours will be identified. We will also examine possible moderators including demographic variables (e.g., time since loss, cause of death), psychopathology symptoms in parents (PGD, anxiety and depression) and child personality. Assessments will take place in both groups at baseline, after the treatment-phase and three, six and twelve months after the post-treatment assessment.

Discussion

We aim to contribute to the improvement of mental health care for children and adolescents suffering from loss. By comparing *Grief-Help* with *supportive counselling*, and by investigating mediators and moderators of its effectiveness, we hope to provide new insights in the effects of interventions for bereaved children and their mechanisms of change.

BACKGROUND

The death of a loved one in childhood and adolescence is associated with increased emotional problems including elevated depression, anxiety and posttraumatic stress, as well as somatic complaints and behavioural problems (Dowdney, 2000; Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012). From among all children who experience such a loss, an estimated 5% to 10% go on to experience clinically significant psychiatric problems. Such problems include major depression, Posttraumatic Stress Disorder (PTSD), and Prolonged Grief Disorder (PGD) (Melhem, Moritz, Walker, Shear, & Brent, 2007; Melhem, Porta, Shamseddeen, Walker, & Brent, 2011).

PGD encompasses several symptoms including separation distress, preoccupation with thoughts about the lost person, a sense of purposelessness about the future, numbness, bitterness, difficulty accepting the loss, and difficulty moving on with life without the lost person (Prigerson et al., 2009; Shear et al., 2011). Empirical studies have shown that PGD symptoms can be reliably assessed in children and adolescents (e.g., Spuij, Prinzie et al., 2012) PGD symptoms can be distinguished from normal grief, depression and anxiety, including PTSD, and are associated with significant concomitant internalising and externalising problems (Brown & Goodman, 2005; Dillen, Fontaine, & Verhofstadt-Denève, 2008; Spuij, Prinzie et al., 2012; Spuij, Reitz et al., 2012).

Few effective interventions for bereaved children and adolescents are available. On the basis of a meta-analysis of 13 controlled studies examining the effectiveness of bereavement interventions with children, Currier, Holland and Neimeyer (2007) concluded that interventions available at the time were not more useful than undergoing no intervention. Indeed, a number of controlled studies have been conducted on the treatment of bereaved children, including studies examining family interventions for bereaved children (Black & Urbanowicz, 1987), music therapy in groups (Hilliard, 2001), group therapy for children (Tonkins & Lambert, 1996), and group therapy for children bereaved by the suicide of a relative (Pfeffer, Jiang, Kakuma, Hwang, & Metsch, 2002). These studies are limited by the fact that they did not articulate the theoretical basis of the intervention tested (Currier et al., 2007), focused on generic indices of distress rather than on symptoms of grief (Black & Urbanowicz, 1987; Pfeffer et al., 2002) or did not randomly allocate participants to treatment and control groups (Hilliard, 2001; Tonkins & Lambert, 1996).

In the past decade, several promising lines of research have greatly advanced our understanding of bereavement interventions for children. The first and most extensive line of research concerns the family bereavement program (FBP), developed by Sandler and colleagues (Sandler et al., 2003; Sandler et al., 2010). The FBP is a group-based program that targets family-level variables (for example, parenting skills) and child-level variables (for example, coping skills) that promote resilience. The FBP was found to reduce immediate and long-term emotional problems in children confronted with parental loss. A second promising intervention is the trauma and grief component therapy (TGCT) developed by Layne et al. (2008). TGCT is a group treatment for adolescents confronted with loss in the context of a civil war. This treatment proved to be effective in terms of reducing grief, depression, and anxiety symptoms (Layne et al., 2008; see also Kaplow et al., 2012). A third important line of research concerns the work of Cohen and colleagues (Cohen, Mannarino, & Knudsen, 2004; Cohen, Mannarino, & Staron, 2006) on cognitive behavioural therapy for Childhood Traumatic Grief (CBT-CTG). This treatment approach explicitly focuses on the alleviation of the emotional condition termed Childhood Traumatic Grief (CTG), which is defined as a combination of traumatic and grief stress reaction, among children exposed to deaths that occurred under traumatic circumstances (for example, motor vehicle accidents, suicide, homicide). Two uncontrolled studies showed that children who underwent CBT-CTG reported significant improvement in CTG and PTSD symptoms (Cohen et al., 2004, 2006)

Notwithstanding the importance of these three research lines, they still leave room for further study and refinement of treatment options for children confronted with the death of a loved one. For instance, the FBP and TGCT are limited to a group-based format, which may yield practical problems; for example, clients may have to wait until there are enough children for a group and may be less effective because it is less well- adjusted to an individual child's circumstances. In addition, all three approaches are limited by their focus on restricted groups, such as parentally bereaved children (FBP) or children exposed to traumatic deaths (TGCT and CBT-CTG), making these approaches less suitable for use with other groups of bereaved children. The impact of these treatments on PGD symptoms, as currently defined (Prigerson et al., 2009; Shear et al., 2011), is unknown.

Given the need for effective therapy for PGD symptoms in children and adolescents, we developed a nine-session protocolized cognitive behavioural treatment that is administered in combination with five sessions of parental counselling. This treatment is called *Grief-Help*. It is based on a cognitive behavioural model of processes that interfere with adjustment to loss. Two pilot studies of this treatment have been done.

The first was a multiple-baseline study of six bereaved children and adolescents, which showed that the intervention coincided with reductions in symptoms of PGD, depression, PTSD, and (parent-rated) Internalising and Externalising Problems (Spuij, Van Londen-Huiberts, & Boelen, 2013). The intervention proved to be feasible, as both children and parents evaluated the treatment positively. That is, all participating children and parents gave favourable scores regarding their satisfaction with each session, the contact with their therapist and the information they received, attesting to the feasibility of this treatment approach. Results showed that after treatment there were reductions in symptoms of PGD, depression, posttraumatic stress and parent-rated Internalising and Externalising Problems. Averaged across the six participants, reductions in scores on the outcome measures were all statistically significant, and all pre-treatment to post-treatment effect sizes were large (Cohen's $d > 0.8$).

The second pilot study was an open trial conducted with ten children and adolescents (Spuij, Deković, & Boelen, 2013). We conducted this study to evaluate the potential effectiveness of *Grief-Help* therapy among children confronted with losses other than the loss of a parent or sibling and to investigate whether the program is effective when the loss occurred more than 12 months prior to initiation of treatment. In this study, patients significantly improved from pre-treatment to post-treatment, with large improvements observed in self-rated PGD and bereavement related posttraumatic stress (effect size (ES) > 0.8) and small to moderate improvements in depression and parent-rated Internalising and Externalising Problems ($0.2 < ES < 0.8$). Additional analyses focused on predictors of treatment outcomes suggested that *Grief-Help* therapy might be less effective for children and adolescents who are further removed in time from the loss and for those confronted with loss due to suicide. Taken together, *Grief-Help* therapy appears to be a promising treatment, and controlled evaluation is clearly indicated.

TRIAL OBJECTIVE

This randomised controlled trial seeks to examine the effect of cognitive behavioural *Grief-Help* therapy for children with emotional problems following the death of a loved one. Participants are randomly assigned to one of two treatment conditions: (1) cognitive behavioural *Grief-Help* therapy combined with parental support, *or* (2) a control treatment consisting of nondirective *supportive counselling* combined with parental support. Participants are asked to complete questionnaires before and after treatment and at three follow-up assessment points.

This treatment trial has three goals. First, we want to compare the effects of cognitive behavioural *Grief-Help* therapy with the effects of *supportive counselling* by measuring the reduction of PGD symptoms and other emotional problems, including depression and PTSD. Our second goal is to gain knowledge about variables that are expected to mediate the effects of *Grief-Help* therapy, such as maladaptive cognition, avoidance behaviours and positive parenting (warmth, involvement and autonomy-granting). We also want to generate knowledge about variables that moderate the effectiveness of *Grief-Help* therapy.

We hypothesise that the *Grief-Help* group will show a greater reduction of PGD-symptoms and other emotional problems (for example, depression, PTSD symptoms) than the supportive counselling group immediately after treatment and at each follow-up point (three, six, and twelve months later). Furthermore, we expect that this reduction will be mediated by a change in maladaptive cognitions and behaviours as well as by increases in positive parenting. We consider the following factors to be possible moderators: demographic variables, severity of symptoms before treatment, time since loss, cause of death, child personality and psychopathology symptoms in parents. We will use state-of-the-art statistical techniques to analyse temporality, causality and mechanisms of change.

METHOD

Study Design

We will conduct a randomised controlled trial with two intervention groups: *Grief-Help* therapy versus supportive counselling (Figure 9.1). Ethical approval was granted by an independent medical ethics committee (Central Committee on Research Involving Human Subjects NL30528.041.09).

Participants

Participants will be bereaved children and adolescents (and their parents) who apply for help in outpatient mental health care clinics in the Netherlands. The following inclusion criteria will be used: (1) ages 8 through 18 years, (2) loss of a close relative, (3) symptoms of PGD as the primary problem and reason for seeking therapy, (4) absence of mental retardation, (5) absence of severe conduct disorder and developmental disorders, (6) not concurrent psychological or psychopharmacological treatment, and (7) no current substance abuse or dependence, no psychotic symptoms, and no severe depression with risk of suicide in participating children or their parents.

Procedure and Randomisation

Potentially eligible participants (and their parents) referred to the participating clinics by their general practitioners will receive oral and written information about the research program. (Surviving) parents' consent will be obtained for their children to participate. Assent or consent will be obtained from the children, depending on their age. Children

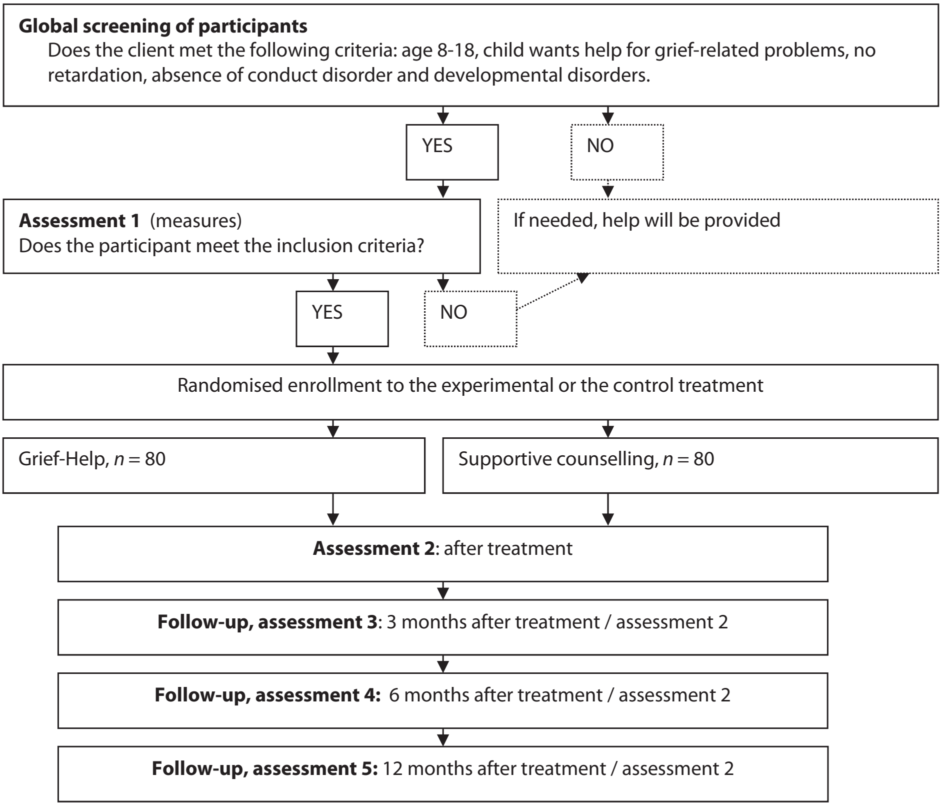

Figure 9.1 Diagram Showing Flow of Participants Through the Study.

will then complete baseline measures (assessment 1 (A1)) in the presence of a therapist. Parents will also complete baseline measures at A1.

Randomisation will take place after informed consent is obtained and after completion of the baseline measures (A1). Participants will be randomly allocated to one of two treatment conditions. Both treatments will be introduced to participants as potentially useful interventions for bereaved children. Four follow-up assessments will be conducted: directly after completion of the treatment (A2) and three, six, and twelve months later (A3, A4 and A5, respectively).

Measures

All measures, time points and informants are summarised in the assessment schedule (Table 9.1).

Table 9.1 Assessment Schedule

Variable	Concept	Measure	Informant	Assessment	Goal
Primary outcome measure	PGD symptoms	IPG-C	Child	A1, A2, A3, A4, A5	1,2,3
Secondary outcome measures	PTSD symptoms	CPSS	Child	A1, A2, A3, A4, A5	1,2,3
	Depression symptoms	CDI	Child	A1, A2, A3, A4, A5	1,2,3
	Behaviour problems	CBCL	Child	A1, A2, A3, A4, A5	1,2,3
Mediator	Positive parenting	PPQ, MFP	Parent and Child	A1, A2, A3, A4, A5	2
	Maladaptive cognitions and behaviours	GCQ-C, GBQ-C	Child	A1, A2, A3, A4, A5	2
Moderator	Demographic variables	Demographic questions	Parent and Child	A1	3
	PGD symptoms (parents)	ICG-R	Parent	A1	3
	Anxiety and depression (parents)	HADS	Parent	A1	3
	Child personality	H*i*PIC	Parent	A1	3

CBCL = Child Behaviour Checklist. CDI = Children's Depression Inventory. CPSS = Child Posttraumatic Stress-Disorder Symptom Scale. GBQ-C = Grief Behaviour Questionnaire for Children. GCQ-C = Grief Cognition Questionnaire for Children. HADS = Hospital Anxiety and Depression Scale. H*i*PIC = Hierarchical Personality Inventory for Children. ICG-r = Inventory of Prolonged Grief-revised. IPG-C = Inventory of Prolonged Grief for Children. MFP = Mother-Father-Peer Scale. PPQ = Parenting Practices Questionnaire.

Primary Outcome Measure

Inventory of Prolonged Grief for Children

The Inventory of Prolonged Grief for Children (IPG-C) is a 30-item measure of PGD symptoms. It is an adapted version of the Inventory of Complicated Grief developed to assess adult PGD (Prigerson & Jacobs, 2001) that taps all symptoms listed in the PGD criteria proposed for the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) and the International Classification of Diseases, 11th Revision (ICD-11) (Prigerson et al., 2009), as well as several additional markers of dysfunctional grief. The IPG-C rates symptom-frequency in the past month on three-point scales ranging from 1 (*almost never*) to 3 (*always*). The measure has good internal consistency, stability and concurrent validity (for example, high correlations with other measures of grief) (see Spuij, Reitz et al., 2012).

Secondary Outcome Measures

Child PTSD Symptom Scale

The Child PTSD Symptom Scale (CPSS) is a 17-item questionnaire for the assessment of PTSD symptoms, as defined in the DSM-IV (APA, 2000), constructed by Foa, Johnson, Feeny and Treadwell (2001). Respondents rate the occurrence of symptoms on four-point scales ranging from 0 (*not at all/only once a week*) to 3 (*almost always/five or more times a week*). The index event is defined as "*the death of your loved one*". Research has shown that the CPSS has good reliability and convergent and discriminant validity (Boelen & Spuij, 2013; Foa et al., 2001; Nixon et al., 2013).

Children's Depression Inventory

The Children's Depression Inventory (CDI) is a well-validated 27-item measure of depression symptoms (Kovacs, 1992, 2003; Timbremont, Braet, & Roelofs, 2008). Each item contains three statements representing depressive symptoms at increasing levels of severity, from among which respondents select the one statement that best describes how he or she felt during the preceding week.

Child Behaviour Checklist

The Child Behaviour Checklist (CBCL) (Achenbach & Rescorla, 2001) is a 118-item measure of emotional and behavioural problems of children 6 to 18 years that is completed by parents. Items are rated on three-point scales with the anchors being 0 (*not true*) and 2(*very true/ often true*). Scores can be used to obtain indices of Internalising Problems and Externalising

Problems. The summed score of all items represents a Total Problem score. The psychometric properties of the original version (Achenbach & Rescorla, 2001) and Dutch version (Verhulst, Van der Ende, & Koot, 1996) are adequate.

Potential Mediators

Positive Parenting

Parenting Practices Questionnaire (PPQ)

Two scales of the PPQ (Robinson, Mandleco, Olsen, & Hart, 1995) are used: warmth and involvement (11 items) and reasoning/induction (7 items). According to Locke and Prinz (2002), the PPQ has adequate psychometric characteristics. The items are rated on a 5-point scale ranging from 1 (*never*) to 5 (*always*).

Mother- Father-Peer Scale

The Mother-Father-Peer Scale (MFP) is administered to assess psychological autonomy-granting, an aspect of positive parenting (Gray & Steinberg, 1999). Only the mother and father parts of the scale are included. Because of time constraints, a slightly shorter version of the scale from the original inventory will be used (nine of the original thirteen items). Using a Likert scale ranging from 1 (*not at all*) to 5 (*very much*), each of the parents fills out the scales with regard to his or her relationship with their child. The inventory has good reliability and has been validated against several other measures of parenting (Crowell, Treboux, & Waters, 1999).

Maladaptive Cognitions and Behaviours

Grief Cognition Questionnaire for Children

The Grief Cognition Questionnaire for Children (GCQ-C) is a 20-item measure of maladaptive grief cognitions and is based on the Grief Cognitions Questionnaire for adults (Boelen & Lensvelt-Mulders, 2005). The CGQ-C rates the frequency of maladaptive cognitions during the past 2 weeks on four-point scales ranging from 1 (*never*) to 4 (*very often*). The internal consistency, temporal stability, and concurrent and construct validity of the questionnaire are adequate (Spuij, Prinzie, & Boelen, submitted for publication).

Grief Behaviour Questionnaire for Children

The Grief Behaviour Questionnaire for Children (GBQ-C) was specifically designed for this study to assess strategies to avoid confrontation with the reality of the loss (called "anxious avoidance") and a tendency to refrain from activities that could foster adjustment (called "depressive avoidance"). Its 12 items are based on items from the Depressive and Anxious Avoidance in Prolonged Grief Questionnaire (DAAPGQ), developed by Boelen, Van den Bout and colleagues (Boelen & Van den Bout, 2010; see also Eisma et al., 2013).

Potential Moderators

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale HADS (Zigmond & Snaith, 1983) is a 14-item measure of anxiety and depression symptoms in adults. The Dutch version of the HADS has been validated (Spinhoven et al., 1997). Items are rated on a four-point Likert scale, with higher ratings indicating higher states of anxiety or depression.

Inventory of Complicated Grief-revised

The Inventory of Complicated Grief-Revised (ICG-R) was developed by Prigerson and Jacobs (Prigerson & Jacobs, 2001) as a 30-items measure of PGD symptoms in adults. The Dutch version of the measure has good internal consistency, stability and concurrent validity (Boelen, Van den Bout, De Keijser, & Hoijtink, 2003). Respondents rate the occurrence of these symptoms during the past month on five-point scales ranging from 'never' to 'all the time'.

Hierarchical Personality Inventory for Children

The Hierarchical Personality Inventory for Children (H*i*PIC) is a 144-item personality inventory that assesses individual differences between children within the framework of the Big Five that is completed by parents. Dimensions that can be identified are Extraversion (32 items), Benevolence (40 items), Conscientiousness (32 items), Emotional Stability (16 items) and Imagination (24 items). It has been shown to have high convergent and discriminant validity as well as temporal stability (Mervielde & De Fruyt, 2002; Shiner & Caspi, 2003). The items are on a five-point scale, ranging from 1 (*hardly characteristic*) to 5 (*very characteristic*).

Other Information

Demographic information will be assessed at baseline. Treatment adherence will be measured in terms of the number of sessions attended and completion of homework assignments. Adherence to both treatment-protocols will be promoted by regular meetings with the therapist. Therapy sessions will be audio-taped, and randomly selected tapes will be discussed to ensure that therapists adhere to the protocols.

Sample Size

Our sample size calculation is based on the conventional significance (α) and power (1-β) levels of 0.05 and 0.80 respectively, planning one-sided testing. The sample size of this study is based on the expected difference on the primary outcome variable (that is, PGD symptoms) between the two conditions. On the basis of a power of 0.80, and α of 0.05 and an expected dropout percentage of 20%, we will need 80 participants for each condition to show an effect size of 0.50 (Boelen, De Keijser, Van den Hout, & Van den Bout, 2007). Therefore, we have determined the total sample size to be 160.

EXPERIMENTAL AND CONTROL TREATMENT

Clients will receive nine individual 45-minute sessions of therapy for childhood PGD, which are planned to occur once every 1 or 2 weeks. Five 45-minute sessions with one or two of the parents will be planned to be conducted in parallel with these nine sessions. Both treatments will follow the format described by Spuij et al. (2013). Treatments will be conducted by licensed (post-master's degree level) therapists.

Grief-Help Therapy

Grief-Help therapy for childhood PGD is based on a cognitive-behavioural framework that postulates that symptoms of acute grief persist and exacerbate to the point of impairment in people with PGD (Boelen, Van den Hout, & Van den Bout, 2006). At least three processes influence this: (1) knowledge about the irreversibility of the separation is insufficiently integrated into representational knowledge about the self and the relationship with the lost person, which maintain separation distress and proximity-seeking responses; (2) a propensity to engage in persistent negative thinking about oneself, life and in one's ability to deal with the pain and grief; and (3) a propensity toward fear and avoidance of external and internal reminders of the loss (termed 'anxious avoidance') and to withdraw from normal routines and valued activities driven by thoughts that one is unable to carry out and/or to enjoy such activities (termed 'depressive avoidance'). Alleviation of PGD can be achieved by targeting these processes, using conventional cognitive-behavioural interventions. *Imagery exposure* (telling the story of the loss event, zooming in on the most painful aspects), *in vivo exposure* (visiting the scene of the death) and *confrontational writing* (writing a letter to the lost person, explaining what is missed most) are used to promote integration of the irreversibility of the loss with other knowledge. *Socratic questioning* (identifying and discussing the validity and utility of maladaptive thoughts, and altering those) and *behavioural experiments* (specific assignments to test the validity of cognitions) are used to mitigate maladaptive thinking (Spuij & Boelen, 2012). Behavioural assignments and skill-training are applied to replace maladaptive coping with more helpful ways of coping; for instance, *exposure to avoided stimuli* is used to target anxious avoidance, and *behavioural activation* is employed to interrupt the vicious cycle of depressive avoidance. Cognitive-behavioural *Grief-Help* therapy includes all these interventions, which are used in a simplified manner in accordance with the developmental level and cognitive abilities of the children.

The treatment is divided into five main parts, all of which are described in a workbook children use throughout treatment. In the first part of treatment (titled '*Who Died?*'), the child is invited to talk about facts of the loss and things she or he misses and wished she or he could still share with the lost person. An important aim of this part is to encourage confrontation with the reality and pain of the loss for the client, as well as for the therapist to gather information about maladaptive thinking and behavioural patterns that are to be addressed later on in treatment. In the second part of the treatment (titled '*What Is Grief?*') a task model (comparable to Worden's (1996) task model of grief) is introduced. The model explains four tasks bereaved children faced in coming to terms with loss and the processes that may block achievement of these tasks (Task 1: *Facing the reality and pain of the loss*; Task 2: *Regaining confidence in yourself, other people, life, and the future*; Task 3: *Focusing on your own problems and not only those of others*; and Task 4: *Continuing activities that you used to enjoy*). The task model provides a framework for interventions applied in the next stages of the treatment. For instance, in the third part ('*Cognitive Restructuring*') cognitive restructuring is used to work on Task 2. In the fourth part of the treatment (titled '*Maladaptive Behaviours*'), graded exposure is used to work on Task 1, problem-solving skills are taught to address Task 3 and behavioural activation is used to help achievement of Task 4. In the fifth and final part of treatment ('*Moving Forward After Loss*'), the skills that are learned during the treatment are reviewed, summarised and written down. Additionally, a plan is discussed for continued practice of learned skills. Specific attention is paid to what the child could do, should his or her emotional problems become exacerbated. Moreover, during the course of treatment, the child writes three letters to an imaginary or real friend as a means by which to facilitate consolidation of the learning process and form a document of learned skills that can be consulted after treatment.

Children receive nine individual sessions. Surviving parents or caregivers receive five parental counselling sessions that are planned in parallel and aimed at supporting them in coaching their child during therapy. Therefore, the emotional problems of the parents are not the specific focus of these sessions.

The therapist reviews the child's workbook together with the parents during the first two parental counselling sessions. The therapist and parents discuss the grief tasks the child is facing, based on the workbook parts '*What Is Grief?*', '*Cognitive Restructuring*' and '*Maladaptive Behaviours*'. They do this in a general manner, but also focus specifically on patterns of behaviour and maladaptive thinking that may block the child's grieving process.

To promote positive parenting skills and to strengthen the parent-child relationship, parents are given assignments to spend more quality time with their child and to improve communication skills. In session 3 and 4, there is a further focus on what parents can do to support their children in their grieving process by helping them to change maladaptive thoughts and behaviours (for example, by helping their children write cognitive diaries, supporting them during their exposure (i.e., to situations, persons and/or memories related to the deceased), solving problems, activating behaviours and providing rewards), and improvement of the parent-child relationship is further discussed. Session 5 is centered on relapse prevention, specifically focusing on signs that could signal to parents that their child might be experiencing new or increased intensity of problems. Parents are then encouraged to make a relapse prevention plan and attention is again paid to maintaining a good parent-child relationship after the completion of treatment.

Supportive Counselling

Supportive counselling for childhood PGD is based on nondirective treatments for bereaved children (Bluestone, 1999; Webb, 2010) and adults (Boelen et al., 2007; De Keijser & Schut, 1991) and on treatments for children with PTSD (Cohen & Mannarino, 1996). As a rationale for *supportive counselling*, it is explained to children that PGD coincides mostly with various emotional, social and practical difficulties, and that discussing these could bring relief from the emotional burden of bereavement. Children are encouraged to express all their feelings and thoughts about the loss. The rationale for this encouragement of children to express their feelings is that bereaved children can experience many intense and different feelings and thoughts about the loss and that they can learn to cope with those feelings by expressing them. Expressing feelings of grief can take the form of talking, playing or making a memory box or book. Therapists are unconditionally supportive of issues children bring up and their attempts at problem solving. They do not address cognitions and give no instructions for exposure.

As in *Grief-Help* therapy, supportive counselling includes nine individual sessions with the child, and five counselling sessions with the parents or other caregivers. The treatment is divided into three parts. The first sessions are devoted to identifying difficulties children experience in their everyday lives. Children are encouraged to express all their feelings and thoughts about the loss in any way they like. As a second step, the therapist and child review all themes that have been identified in the first phase of therapy in more detail. The child decides if she or he prefers to talk, play or express their feelings in any other possible way. In the last phase the therapist and child speak about or play saying goodbye to each other.

Counselling sessions with parents are planned every 2 weeks. In the first session, a plan is made about which themes parents want to discuss and in which order they should be talked about. The therapist helps the parents to think about solutions to problems that they encounter in supporting their child. The therapist can also suggest themes. Examples include (1) the grieving process; that is, "*What does the parent think about the grieving process, how do parents support their child, what are the main problems for the child?*" (2) feelings and thoughts the child expresses about the loss and the reactions of the parents to these expressions; (3) coping behaviours of the child related to the loss; that is, "*In what ways does the child cope with his or her feelings and thoughts?*", "*What do parents think helps the child and what does not?*" (4) the development of the child in the near future; that is, "*What are potential problems, given the loss and the development of the child thus far?*", "*How do the parents cope with those ideas about the future of the child?*" There are no homework assignments for children and parents in the supportive counselling sessions.

STATISTICAL ANALYSES

Most analyses will be conducted using the software program SPSS (SPSS, Inc, Chigago, IL, USA). Descriptive analyses will be carried out using standard methods. For analysis of the primary and secondary outcome measures, we will use analysis of covariance with the outcome measures post-treatment or at follow-up sessions as dependent variables, treatment condition as a factor and pre-intervention scores of the outcome variables as covariates. We will compare the scores of children in both groups with their own scores on previous assessments by using regression analysis and/or structural equation modelling. Mediator and moderator models will be tested. Analysis and reporting of the results will be carried out according to the CONsolidated Standards of reporting Trials (CONSORT 2010) Statement guidelines (Schultz, Altman, & Moher, 2010).

Protection of Data Privacy

Children and parents participating in this study will be assigned a number. This number will be used in the data set. Key lists of participants' names and assigned numbers will be stored separately from the data, in lockable cabinets and rooms, and will be deleted after final data analyses. No conclusions will be drawn from the data on individual clients.

Publication Policy

We plan to publish the results of this study in peer-reviewed national and international journals. The results will be presented at national and international scientific conferences.

DISCUSSION

There is growing evidence that childhood PGD is a clinically significant condition (Melhem et al., 2007; Spuij, Prinzie et al., 2012). However, there is limited knowledge about effective treatment interventions for children confronted with loss (Currier et al., 2007). Given the lack of effective treatments for childhood PGD, research is urgently needed. Herein we have presented the protocol of a study designed to investigate the effectiveness of a novel cognitive-behavioural treatment called *Grief-Help* in comparison with supportive counselling for childhood PGD and to enhance knowledge about the variables mediating and moderating the effects of *Grief-Help* therapy. The current study is a randomised controlled trial among bereaved children and adolescents (ages 8 to18 years) with elevated PGD who will be randomly allocated to one of the intervention groups. To the best of our knowledge, we are the first researchers to compare *Grief-Help* therapy with *supportive counselling* in bereaved children. In this study, we hope to contribute to the treatment of childhood PGD as well as to knowledge about mediators and moderators of change.

This study has several strengths. First, we will compare two different treatment conditions instead of a treatment and a waiting list condition. Both treatments are similar in certain aspects. Both treatments comprise nine sessions for the children and five sessions for the parents, and, in both conditions, children and parents will get the same psycho-education. This will make it possible to evaluate different outcomes in terms of specific interventions, such as cognitive restructuring, exposure (both imaginary and in vivo), behavioural activation and confrontational writing. The second strength of this study is the fact that we will use validated measures. A third strength is that there will be multiple sources of information, because, both parents and children will be administered multiple measures. Another strength is that, in this study, we will go beyond simple effectiveness questions and examine mechanisms that can explain the effects (for example, positive parenting, maladaptive cognitions and behaviours) and possibly moderate them (for example, demographic variables, time since loss, cause of death). By doing this, we will gain better insight into what works for whom.

The study also has potential weaknesses. First, it is possible that therapists (or someone else who does the intake interview in a specific setting) will be biased toward selecting children who are likely to benefit from treatment instead of including in A1 all children who meet the inclusion criteria. Second, only family members who are participants and receivers of treatment will be used as informants, without including more objective persons such as teachers.

TRIAL STATUS

Ethical approval for this study has been obtained from a medical ethics committee (Central Committee on Research Involving Human Subjects NL30528.041.09). All therapists have been trained at the different participating sites. Patient recruitment is on-going and will continue until mid-2014.

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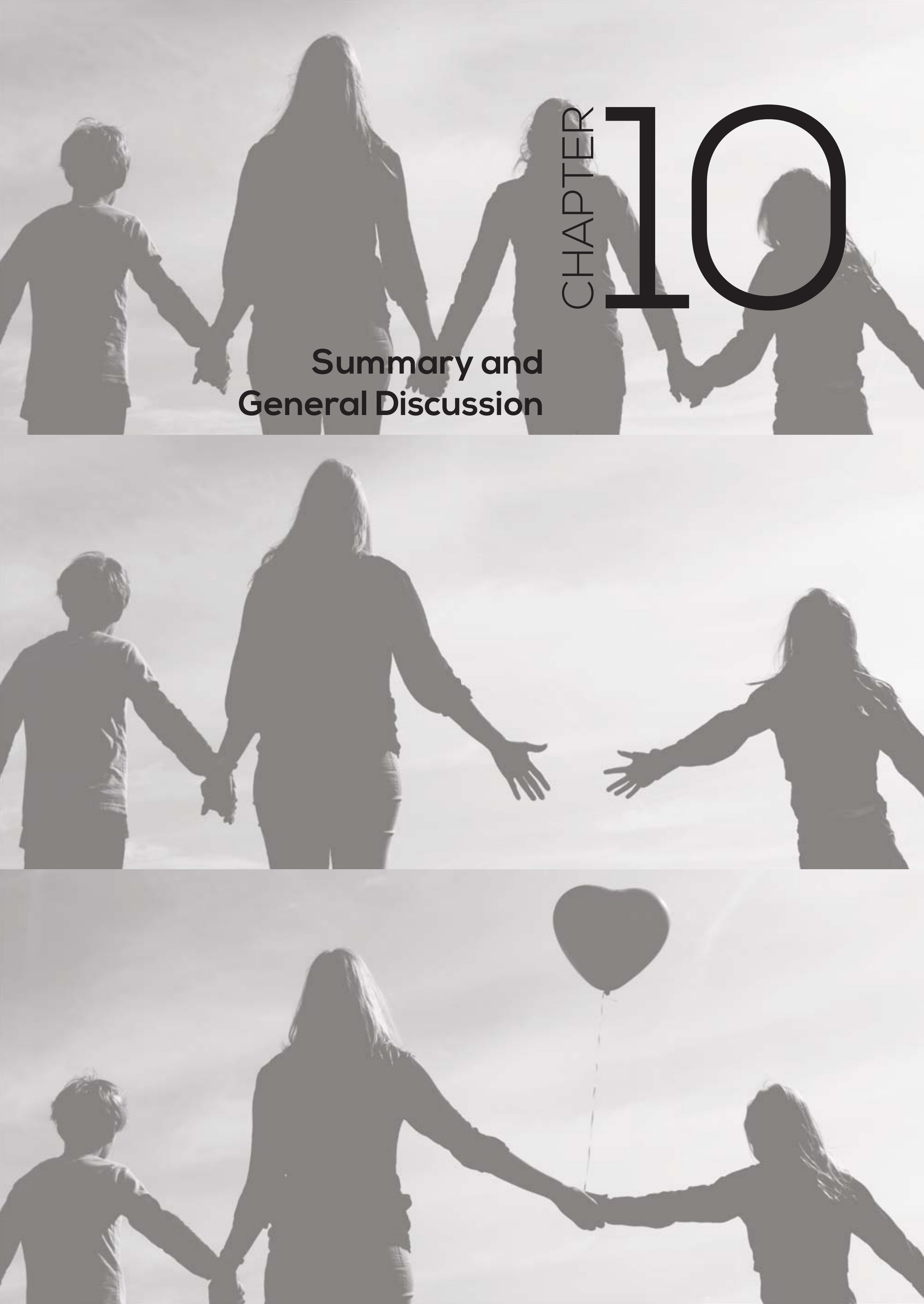
CHAPTER 10

Summary and General Discussion



INTRODUCTION

The death of a loved one is one of the most devastating events that can occur in children's[1] lives. There is growing recognition of a syndrome that children can develop post loss, referred to as Prolonged Grief Disorder (PGD; Prigerson et al., 2009). This chapter starts with a summary of the previous chapters, in wich we follow th structure of this dissertation i.e., the three aims: (I) to increase our understanding of the phenomenology and correlates of PGD, (II) to enhance knowledge on the role of negative thinking in the development of PGD in children and (III) to develop an intervention for children who suffer from loss and to examine its potential efficacy in two pilot studies. Next, a general discussion of the studies in this dissertation and directions for future research are given. Finally, implications of this project for practitioners are described.

SUMMARY OF FINDINGS

Part I Phenomenology and Correlates of Prolonged Grief Disorder

With respect to the phenomenology and correlates of childhood PGD three studies were conducted and described in ***chapter 2***, ***3*** and ***4***.

Chapter 2 of this dissertation describes the development of the Inventory of Prolonged Grief for Children (IPG-C) and the Inventory of Prolonged Grief for Adolescents (IPG-A). Findings suggested that the IPG-C and the IPG-A represent one underlying dimension of PGD-symptoms severity. Crohnbach's alphas of both questionnaires were high and test-retest analyses showed high stability across a 6-week period. The findings also supported the concurrent validity, convergent and divergent validity and incremental validity of the IPG-C and IPG-A. These findings suggest that the IPG-C and IPG-A can be used for the assessment of PGD in children and adolescents who suffer from loss and for treatment studies among bereaved children. The results also give some important suggestions for both researchers and professionals about the informant to choose when PGD is considered. We found that parent's estimates of loss related problems of their children are more in line with their child's own ratings when their children are older (i.e., > 12 years). This indicates that it is important that children under the age of 13 report about their own grief instead of solely relying on their parents' observations of the suffering following a loss.

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[1] In this summary and discussion the term children is used to refer to children and adolescents.

Next, we wanted to shed a light on whether PGD, depression and Posttraumatic Stress Disorder (PTSD) are distinct constructs in children who suffer from bereavement, like they were found to be distinct constructs in adults. This was the aim of ***chapter 3***. Confirmatory factor analysis (CFA) was used to compare the fit of a one-factor model with the fit of a three-factor model in which symptoms formed three distinct, yet correlated factors. Both in children and adolescents CFA showed that a model in which symptoms of PGD, depression, and PTSD loaded on three factors had excellent fit estimates and was superior to a unitary model. Correlations between factors were moderate, indicating that the symptom clusters represent distinguishable, but related constructs. The second main finding of this study was that the concurrent validity of the three factors is attested by the fact that scores of the PGD, PTSD and depression items were *all* significantly associated with a measure of functional impairment. However, we found differences between children and adolescents. In the children sample, PGD, depression and PTSD all predicted unique variance in functional impairment when controlling for the shared variance between symptom clusters. In the adolescent sample, the PTSD factor was the single factor explaining unique variance in functional impairment. These findings could indicate that symptoms of PGD have a more specific debilitating impact in children compared to adolescents, and that symptoms of PTSD are relatively more debilitating in this latter group. This conclusion, however, should be considered tentative as our analyses relied on a single index of functional impairment, which was part of the PTSD measures, and that the size of the adolescent sample may have been too small to detect unique significant associations between PGD and functional impairment.

As mentioned before, many, but not all, bereaved children experience symptoms of PTSD. In ***chapter 4*** the factor structure and correlates of PTSD symptoms among 332 bereaved children (8 to 18 years) were investigated. To this aim, we used CFA. Data showed that approximately half of the participants (51.5%) met the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria for PTSD. This high rate may be a consequence of our recruitment strategy. All children were recruited via a grief support group or from outpatient clinics. This means that PTSD is highly prevalent among those who seek help, but this result cannot be generalised to the whole population of bereaved children. Our second finding was that PTSD status and scores on the PTSD factors varied as a function of age and gender (e.g., girls scores higher than boys on the total PTSD severity score), but were unrelated to other demographic and loss related variables, including relation to the deceased and time since loss. Third, outcomes showed that the four-factor numbing model from King, Leskin, King, and Weathers (1998) fit the data best with distinct factors of reexperiencing, avoidance of activities and thoughts, emotional numbing (i.e., passive avoidance in the form of, e.g., loss of interest, detachment and restricted affect), and hyperarousal. This study suggests that the DSM-IV conceptualisation of PTSD might not be the best description of PTSD symptoms and that avoidance symptoms may better be conceived as separate clusters of effortful avoidance and emotional numbing symptoms. This is in line with recent changes in the description of PTSD in the DSM-5 (American Psychiatric Association [APA], 2013) where, other than in DSM-IV, persistent avoidance and numbing symptoms are categorised under two separate criteria. Finally, findings of the study provide further evidence of the clinical significance of childhood PTSD; children who met DSM-IV criteria for PTSD scored higher on self-report measures of depression, PGD, and functional impairment compared to participants who did not meet these criteria. Parent-rated Internalising Problems, but not parent-rated Externalising Problems, were also higher among participants meeting the criteria for PTSD. An important finding for clinicians is that the correlations between scores on the PTSD factors, on the one hand, and self-rated symptoms of PGD and depression on the other hand, seemed considerably stronger than the associations between scores on the PTSD factors and parent-rated Internalising and Externalising scores. In line with the findings presented in ***chapter 2*** where we found that parents seemed to underestimate the suffering following a loss of their child under the age of 13, this finding underscores that clinicians should ask the child directly about their loss. We will return to this issue in the section called 'General conclusion and implications for practitioners'.

Part II The Role of Negative Thinking in Psychological Functioning after Bereavement

In order to understand why some children cope with loss more easily than others, it is important to study the role of negative thinking among bereaved children. Cognitive behavioural conceptualisations of PGD propose that negative thinking and avoidance behaviours play a significant role in the development and maintenance of the disorder (e.g., Boelen, Van den Hout, & Van den Bout, 2006). Very limited research is available among bereaved children on negative thinking. An important reason is the lack of a measure for negative thinking among bereaved children. ***Chapter 5*** describes the development and psychometric properties of the Grief Cognition Questionnaire for Children (GCQ-C). The GCQ-C is tailored to assess grief cognitions in children. Exploratory factor analysis (EFA) suggested that the GCQ-C items are best characterised as one factor. Furthermore, Crohnbach's alpha was high. Test-retest correlation showed high stability over time. Findings supported the concurrent validity, concurrent and divergent validity and incremental validity. Altogether, our findings suggest that the GCQ-C is a reliable and valid tool to examine negative grief related cognitions in children and adolescents. Therefore, it can be used in future research examining PGD and its correlates in children.

Part III Development and Examination of *Grief-Help*

Despite the fact that there is growing recognition of PGD, hardly any effective treatments are available. That is why we developed *Grief-Help*, a cognitive behavioural treatment that consists of nine (weekly) sessions for the child and five separate (two-weekly) sessions for their parent(s). We tested *Grief-Help* in two separate pilot studies before subjecting this treatment to a Randomised Controlled Trial (RCT). Accordingly, we first conducted a feasibility study with a multiple-baseline design among six children who were bereaved six to twelve months before the treatment started. This study is described in ***chapter 7***. The main finding of this pilot study was that children and their parents evaluated the treatment favourably; all participating children and parents gave favourable scores to their satisfaction with each session, their contact with the therapist, and the information they received. Moreover, *Grief-Help* coincided with reductions in self-rated symptoms of childhood PGD, PTSD and depression and parent rated behaviour problems. The magnitude of these changes differed between participants. On the basis of these findings, we decided to do a second pilot study with *Grief-Help*, with a focus on its potential efficacy in alleviating symptoms of PGD and associated symptoms in a more heterogeneous and more remotely bereaved group of children. That study, described in ***chapter 8***, showed that *Grief-Help* is potentially efficacious for children who suffer from PGD. Moderator analysis suggested that this treatment is probably less effective for children and adolescents further removed from loss and those confronted with suicidal loss. Based on both pilot studies, the treatment appears promising enough to warrant a controlled evaluation. A multicentre Randomised Controlled Trial is therefore being conducted in the Netherlands. The study design of this trial was described in ***chapter 9***. In this study 160 children (aged 8 to 18 years) will be randomly allocated to cognitive behavioural *Grief-Help* or to a *supportive counselling* intervention and both treatments are combined with five sessions of parental counselling. Participants will be recruited from mental health clinics and assessments will take place in both groups at baseline, after the treatment-phase and three, six and twelve months after the post-treatment assessment.

GENERAL DISCUSSION AND DIRECTIONS FOR FURTHER RESEARCH

Several conclusions were presented throughout this dissertation. Knowledge gained from studies in this dissertation can be very helpful for the assessment and treatment of bereaved children with elevated distress following loss. We should also take note of some limitations. Some of those are more of a methodological nature, whereas others are a consequence of theoretical decisions we made. These are discussed below.

Methodological Considerations

There are several methodological limitations to each study, which have already been discussed in the previous chapters. Some more general limitations that touch upon more studies are discussed below.

First, our studies are based on relatively small sample sizes which has limitations for the statistical analyses we could conduct. For instance, we had to select a limited set items of depression, PTSD and PGD measures in ***chapter 3*** to conduct a CFA, and in ***chapter 2*** and ***5*** we used Exploratory Factor Analysis (EFA) instead of conducting a CFA due to power problems. Our samples in both pilot studies, ***chapter 7*** and ***8***, were very small, so we could do only limited analyses on moderating variables on the effect of *Grief-Help*.

Secondly, data of the Dutch subjects were used in the studies in ***chapter 2***, ***3***, ***4*** and ***5***. ***Chapter 2*** and ***5*** have 23 participants (all children) in common. After conducting the study described in ***chapter 2*** we continued collecting data for the study described in ***chapter 5***. ***Chapter 3*** and ***4*** were based on the same data set. This fact imposes limits on the interpretation of the results, as there is a risk of a certain (atypical) bias being present in this study group that would in this way pervade in several conclusions. Replication of findings in independent samples is therefore desirable.

Thirdly, demographic and loss related characteristics of participants of studies described in ***chapter 2***, ***3***, ***4*** and ***5*** were heterogeneous. Where, on the one hand, our results are more representative for the whole population of bereaved children due to the greater variability within our study groups, the lack of homogeneity also led to power problems when we wanted to distinguish within the group of bereaved children. For instance, we did not include enough children bereaved from a specific cause of death (e.g., bereavement after murder, suicide, traffic accidents and sudden medical causes) or with a specific relationship to the deceased (e.g., parent, sibling or other). Therefore we were not able to make meaningful comparisons of for instance the severity of PGD between subgroups.

Larger datasets or datasets with more homogeneous participants raise the opportunity to get more detailed information about the influence of specific moderating and mediating variables on the development of PGD. For instance, findings from Brent, Melhem, Donohoe and Walker (2009) suggest that children who are bereaved by suicide or murder are especially at risk. It may be that they have more maladaptive thoughts or that their thoughts are more intense about the loss or deceased loved one, but, to our knowledge, no data are available about specific mediators for the development of PGD in those groups. Findings of Brent et al. (2009) suggest that in suddenly bereaved children blaming others, low-self esteem, negative coping and complicated grief were associated with depression in the second year after loss.

A fourth issue is that longitudinal data are needed if we really want to understand the course of normal and pathological bereavement. After all, to some extent symptoms of PGD are normal for all children, but in most children they vanish after some time. Those children do not need help from a professional; they need a supportive environment and trust in the future. However, a significant minority of children do need help and we have to identify them as soon as possible after they were confronted with their loss. Longitudinal studies (preferably prospective, starting before someone died) can shed light on moderators and mediators in the development of PGD and help to identify persons at risk. Prospective studies among bereaved children are very rare. Worden and Silverman (1996) followed 125 children up to two years after the loss of a parent. They found that many problems did not emerge before two years after bereavement. After two years significantly more bereaved children, compared to non-bereaved children, developed psychopathology. Brent and colleagues (2009) studied the incidence and course of depression among 176 suddenly bereaved children (aged 7 to 25 years). A comparison with 168 non-bereaved participants was made. Major depression and alcohol and/or substance abuse were more common in the bereaved group. Recently, Brent, Melhem, Masten, Porta and Walker-Payne (2012) assessed the impact of sudden parental death on the subsequent attainment of developmental competencies among 242 children (126 bereaved and 116 non-bereaved) at 9, 21, 33 and 62 months after parental death. The bereaved children showed lower competency in work, peer relations, career planning and educational aspirations. There was no relation between developmental competencies on the one hand, and age at the time of parental death, gender of the deceased parent or the cause of death on the other hand. Their findings suggest that the effects of bereavement on developmental competencies are mostly mediated via offspring- and caregiver functioning and family climate. Although this study controlled for psychiatric problems, they did not control for PGD. Thus, it was not clear which children develop PGD and how PGD is related to their development in different competence areas.

Theoretical Considerations

A central starting point of this dissertation was that we based our studies on the criteria for complicated grief, later described by Prigerson and colleagues (2009) as PGD. Another set of criteria for complicated grief was formulated by Shear and colleagues (2011) and since May 2013 a hybrid of both sets is included in DSM-5 as Persistent Complex Bereavement Disorder (PCBD). Importantly, both criteria sets for problematic grief were not developed from a developmental perspective. In a preliminary version of the DSM-5 criteria set (cf., Boelen & Prigerson, 2012), there was also no specific focus on children's grief. Kaplow, Layne, Pynoos, Cohen and Lieberman (2012), however, proposed developmental modifications. Almost all of these were included in the final criteria set (see Table S.1 in the next section). Furthermore, we too used a theoretical conceptualisation of PGD that was primarily developed for adults (Boelen et al., 2006). These choices can be debated for both issues on assessment and treatment.

Assessment of Childhood PGD

Since PGD criteria were not developed from a developmental perspective, it is not certain that these symptoms and criteria can be readily applied to children and adolescents.

As mentioned before, Kaplow et al. (2012) made developmental modifications to the criteria (see Table S.1). They recommended supplemental wording for some symptoms, e.g., the fact that young children express their feelings through play and behaviour. More fundamental was their consideration about the first criterion (A): the time between the loved person died and the moment that PCBD can be diagnosed. In adults this period is twelve months, while Kaplow et al. (2012) proposed that this should be six months in children. With respect to the lack of prospective research among bereaved children, we agree with Kaplow et al. (2012) that there are four reasons for this. Except for the study of Worden and Silverman (1996), who found that approximately 19% of the bereaved children develop emotional problems two years after loss according to parental ratings on the CBCL, most findings showed that children who are likely to exhibit the most severe reactions would do so within the first several months after a death (Brent et al., 2009; Brown et al., 2008; Melhem, Moritz, Walker, Shear, & Brent, 2007). Those latter studies asked children directly instead of asking their parents alone. So, these different findings underscore the importance of asking children themselves about their grief related feelings and not to rely on parental ratings. Second, research among adolescents who lost a peer due to suicide showed that PGD reactions at six months predict the onset and course of depression and PTSD at later assessment points (Melhem et al., 2004). In addition, research among adults underscores the

Table S.1 DSM-5 Bereavement-Related Disorder Criteria and Proposed (Developmental) Modifications

Bereavement related disorder criteria DSM-5 (APA, 2013)	Proposed developmental modifications (Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012)	Proposed modifications (Melhem, Porta, Walker-Payne, & Brent, 2013)
A. The individual experienced the death of someone with whom he or she had a close relationship.	The person experienced the death of a close relative or friend at least 6 months earlier.	Not subject of the study.
B. Since the death, at least one of the following symptoms is experienced on more days that not and to a clinically significant degree and has persisted for at least 12 months after the death in the case of bereaved adults and 6 months for bereaved children:		
1. Persistent yearning/longing for the deceased. In young children, yearning may be expressed in play and behaviours that reflect being separated from, and also reuniting with, a caregiver or other attachment figure.		
2. Intense sorrow and emotional pain in response to the death.	Supplemental wording is recommended: In young children, B1 and B2 may be expressed in play and behaviour, including separation-reunion behaviour with caregivers.	
3. Preoccupation with the deceased.		
4. Preoccupation with the circumstances of the death. In children, this preoccupation with the deceased may be expressed through the themes of play and behaviour and may extend to preoccupation with possible death of others close to them.	Supplemental wording is recommended: In children, B4 may be expressed through play themes related to the circumstances of the death, as well as fearful preoccupation that others close to them may also die.	
C. Since the death at least 6 of the following symptoms are experienced on more days than not and to a clinically significant degree, and have persisted for at least 12 months after the death in the case of bereaved adults and 6 months for bereaved children:		Since the death at least 2 of the following symptoms are experienced on more days than not and to a clinically significant degree.

Table S.1 continues on next page

Table S.1 *Continued*

Bereavement related disorder criteria DSM-5 (APA, 2013)	Proposed developmental modifications (Kaplow, Layne, Pynoos, Cohen, & Lieberman, 2012)	Proposed modifications (Melhem, Porta, Walker-Payne, & Brent, 2013)
Reactive distress to the death		
1. Marked difficulty accepting the death. In children this is dependent on the child's capacity to comprehend the meaning and permanence of death.	Supplemental wording is recommended: In children, C1 depends on the capacity to understand the nature and permanence of death.	
2. Experiencing disbelief or emotional numbness over the loss.		
3. Difficulty in positive reminiscing about the deceased.		
4. Bitterness or anger related to the loss.		
5. Maladaptive appraisals about oneself in relation to the deceased or the death (e.g., self blame).		
6. Excessive avoidance of reminders of the loss (e.g., avoidance of individuals, places or situations associated with the deceased; in children this may include avoidance of thoughts and feelings regarding to the deceased).	Supplemental wording of C6 is recommended: (e.g., avoidance of people, places, or situations associated with the deceased, and in children, including avoidance of thoughts and feelings regarding the deceased).	
Social/identity disruption		
7. A desire to die in order to be with the deceased.		
8. Difficulty trusting other individuals since the death.		
9. Feeling alone or detached from other people since the death.		
10. Feeling that life is meaningless or empty without the deceased, or the belief that one cannot function without the deceased.		

11. Confusing about one’s role in life, or a diminished sense of one’s identity (e.g., feeling that a part of oneself died with the deceased).		
12. Difficulty of reluctance to pursue interests since the loss or to plan for the future (e.g., friendships, activities).		
	Additional criterion suggestion specific to children:	
	13. Excessive worry about surviving caregivers’ welfare, safety, and/or health.	
D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.		Note: Findings suggest that the sensitivity of this criterion increases over time. Children who did not meet criteria for CGAS ≤ 70 at 9 months became functionally impaired with time (Melhem et al., 2013).
E. The bereavement reaction is out of proportion to or inconsistent with cultural, religious, or age-appropriate norms.	Mourning shows substantial cultural and developmental variation: the bereavement reaction must be out of proportion or inconsistent with cultural, religious, or age-appropriate norms.	Not subject of the study.
Specify if: **With traumatic bereavement:** Bereavement due to homicide or suicide with persistent distressing preoccupations regarding the traumatic nature of the death (often in response to loss reminders), including the deceased’s last moments, degree of suffering and mutilating injury, or the malicious or intentional nature of the death.		

importance of the first six months, see for instance the proposed criteria of both Prigerson et al. (2009) and Shear et al. (2011). It seems that in an attempt to avoid false positives (i.e., adults with normal grief being categorised as disturbed grievers) a period of twelve months is defined in adults. Third, one year in a young child's life can be very long, especially when it is a major developmental period. Finally, early focus on maladaptive adjustment to the loss may permit more timely intervention, focused on promoting effective facilitation of the adaptation to the death.

Furthermore, the usefulness of three out of five of the new DSM-5 criteria (B, C, D) have already been subject of a study conducted by Melhem, Porta, Walker-Payne, and Brent (2013). Notwithstanding some limitations (e.g., small sample and only children aged 8 to 17 years bereaved from a sudden parental death), they found that longing and yearning for the deceased, inability to accept death, shock, disbelief, loneliness and changed worldview are the core symptoms of PGD. Findings suggest DSM-5 to be insensitive to PGD symptoms among children. They suggest making two modifications for children. Their first suggestion was a modification of criterion C such that it requires at least two symptoms instead of six. In addition they concluded that criterion D is not sensitive enough at 9 months after bereavement. In other words, both criteria are too stringent for children who suffer from bereavement and who are in need for help. According to Melhem et al. (2013) six items of their interview could be used as a screening of PCBD among children: "*I feel that I cannot accept the death*", "*I very much miss […]*", "*I feel that I cannot believe the death*", "*I feel shocked about the death*", "*I feel lonely ever since the death*", "*I feel that the death made me see the world differently*". In our versions of the IPG-C and IPG-A these are, in slightly different wording, item 4, 5, 8, 9, 22 and 25.

In order to refine the DSM-5 criteria for children, we suggest to broaden the way data is collected in both research and clinical practice. Most studies done so far used questionnaires, which implies several problems. First, using only questionnaires may lead to method bias. We suggest using other methods for data collection such as observations, diagnostic interviews or day-to-day diaries. Secondly, most questionnaires are developed for children older than 8 years. Other methods would enable to study grief and bereavement in children, younger than 8 years, a group that is not included in systematic bereavement research yet. The development of validated measures or observation methods for this age group is very much needed. Research in different age groups and with different measures would probably lead to a refinement of the symptoms and criteria of childhood PGD in younger children; for instance, the expression of feelings in behaviour or typical play themes, the amount of symptoms needed for a diagnosis in childhood, the time between loss and onset of problematic grief. Finally, in other problem areas (for instance PTSD), there are indications that questionnaires may overestimate distress, leading to over diagnosis (Griffin, Uhlmansiek, Resick, & Mechanic, 2004). In line with this finding, Hukkelberg, Ormhau, Holt, Wentzel-Larsen and Jensen (2014) found that the CPSS, a questionnaire for PTSD, is a good tool for screening purposes, but an interview is needed for diagnostic purposes.

A cognitive behavioural framework for the treatment of childhood PGD

Given the lack of a theoretical framework for childhood PGD, we used a conceptualisation of PGD for this dissertation that was originally developed for adults (Boelen et al., 2006). In summary, this model proposes that three interrelated processes account for symptoms that can be described as PGD: (1) insufficient elaboration and integration of the loss within autobiographical memory; (2) persistent negative thinking; and (3) anxious and depressive avoidance behaviours. It is proposed that the three processes are mediating mechanisms that explain why some people have an elevated chance of developing PGD. The model is described in the introduction of this dissertation. Below we discuss the applicability of this model in children and adolescents.

Autobiographical memory is the part of our memory that is concerned with the recollection of personally experienced events. It plays a core role in the development of an individual's sense of self, the relation with the world and future. To our knowledge, no research of autobiographical memory is done among (bereaved) children. In other words, we do not know how autobiographical memory in bereaved children (with and without PGD) is organised and why some children experience the loss as an unreal event or are easily reminded of the deceased.

Linked to the lack of research on the autobiographical memory among bereaved children is the potential role of overgeneral memory. Overgeneral memory refers to the tendency to recall past events in a broad, vague manner. In both adults (e.g., Williams et al., 2007) and children (Kuyken, Howell, & Dalgleish, 2006; Park, Goodyer, & Teasdale, 2002, 2004), an overgeneral autobiographical memory is associated with emotional problems like for instance depression and PTSD. It is hypothesised that this process also has an important role in the development and maintenance of childhood PGD and its treatment. For instance, according to our clinical observations, children with PGD tend to remain stuck in general memories associated with feeling of missing and yearning. They thereby seem to avoid confrontation with the reality of the loss, which blocks the integration of the loss in their autobiographical memory. In therapy they receive help with focusing on specific memories and thoughts associated with the deceased person and the irreversibility of the separation.

Persistent negative thinking, another component of the model we used, was studied in this dissertation. In ***chapter 5*** we examined negative thinking among bereaved children. More research in larger samples and with additional measures of negative thinking is needed to get a more detailed understanding of negative thinking in bereaved children. As suggested earlier, this should be done in close relation to autobiographical memory and avoidance behaviour. In this light, research on rumination, is very interesting. Rumination is defined as a recurrent, self-focused negative thinking about experiences and mood, and in adults it is related to depression (Nolen-Hoeksema, 2001; Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008) and PGD (Boelen, Van den Bout, & Van den Hout, 2003; Stroebe, Schut, & Stroebe, 2007). Rumination is an important focus of future research for at least two reasons. Findings among adults suggest that rumination during bereavement increases symptoms of PGD (Eisma, Stroebe, Schut, Stroebe, Boelen, & Van den Bout, 2013; Van der Houwen, Stroebe, Schut, Stroebe, & Van der Bout, 2010). Rumination has not yet been studied in bereaved children yet. However, studies among depressed children (Gibb, Grassia, Stone, Uhrlass, & McGeary, 2012) and adolescents (Kuyken, Watkins, Holden, & Cook, 2006; Peled & Moretti, 2007) suggest that they tend to report more rumination, that this increases the risk for depression and that it is related to overgeneral autobiographical memory (Park et al., 2004). Moreover, there is a relation between rumination, psychopathology and sleeping problems. Sleeping problems are common in children with PTSD (APA, DSM-5), depression (Van Lang, Ferdinand, & Verhulst, 2007) and in children suffering from loss (cf., Dowdney, 2000), and they are associated with concentration problems and academic problems (Dewald, Meijer, Oort, Kerkhof, & Bögels, 2010). Rood, Roelofs, Bögels, Nolen-Hoeksema and Schouten (2009) showed that rumination was significantly associated with depression and that girls tend to ruminate more than boys. Van Lang, Ferdinand and Verhulst (2007) found that rumination, sleeping problems and depression are related and suggested that these variables amplify each other. No research has been done to examine sleeping problems in bereaved children. Research on rumination and sleeping problems in bereaved children could potentially be used to refine existing interventions for this group.

Next to the three processes that we have described, characteristics of the loss, characteristics the bereaved child and characteristics of his/her environment may have an influence on the grief process. More research should be done to get a full understanding of factors that influence grief in children. Despite our findings suggesting that there is considerable overlap in grief manifestations in children and adults, there are two important differences between childhood and adulthood that we want to discuss here.

First, there is the developmental context of the child. In ***chapter 1*** we described the influence of developmental tasks on the grieving process. We illustrated this with the case of Bas who lost his mother when he was only three years old. His problems developed many years later and he came to see a therapist at the age of twelve. It is hypothesised that he did not understand the irreversibility of the death when he lost his mother. Understanding of the concept of death develops when a child gets older (cf., Worden, 2009) and this was probably also the case with Bas. Furthermore, when he reached the age of twelve he could understand that the death of his mother also had an impact on his father. Because he did not want to upset his father, Bas decided not to talk about his mother. This thought may have blocked further processing of the loss and meaning making, resulting in PGD symptoms in Bas. Future research should examine developmental aspects (e.g., cognitive, social and emotional development) of grief.

Another important difference between a grieving child and grieving adult is the role of the environment on the grieving process. In adults the environment plays a significantly less prominent role than in children. Some time ago, Dowdney (2000) conducted a systematic review of the literature among bereaved children. She concluded that there are many inconsistencies in mediating and moderating factors, but that the risk of disturbance following parental bereavement is heightened when children show a psychiatric disorder prior to parental death and when the surviving parent suffers from psychopathology. Among boys externalising behavior problems are more common, while in girls internalising problems are more likely. Children who are survivors of traumatic parental death are particularly at risk. More recently Carr (2006) suggested the importance of the family system for bereaved children. In addition, findings among traumatised children (Ellis, Nixon, & Williamson, 2009) also underscore the effect of the child's perception of social support on acute stress symptoms and depression in children who were confronted with a single-incident trauma. This is supported by a number of findings on the effect of family functioning on the resilience of parentally bereaved children (e.g., Haine, Wolchik, Sandler, Millsap, & Ayers, 2006; Kwok et al., 2005; Sandler et al., 2002, 2003; Sandler, Ayers et al., 2010; Sandler Ma, et al., 2010; Schmiege, Khoo, Sandler, Ayers, & Wolchik, 2006). In summary, those studies showed that positive parenting (defined as parental warmth, open communication and effective discipline) was associated with fewer mental health problems in bereaved children. In addition, in a literature review on evidence-based practice for parentally bereaved children, Haine, Sandler and Wolchick (2008) recommended to promote positive parenting practices and to create a safe environment for bereaved children. Given the importance of positive parenting on bereavement outcomes, we have included this in *Grief-Help*.

GENERAL CONCLUSION AND IMPLICATIONS FOR PRACTITIONERS

This dissertation holds several suggestions and implications for practitioners who work with bereaved children.

First, the findings of ***chapter 2*** suggest that some children suffer from bereavement, but others seem to cope (very) well with this devastating circumstance. Some children develop a syndrome that is called Prolonged Grief disorder (PGD). PGD can be measured with the Inventory for Prolonged Grief for Children (IPG-C; aged 8 to 12 years) or the Inventory of Prolonged Grief for Adolescents (IPG-A; aged 13 to 18). However, evidence presented in ***chapter 2*** and ***4*** showed that parents (primarily caregivers of the child) are probably not the best informants about the degree of suffering of their child. Professionals who see children on a regular basis (for instance general practitioners, teachers or school counselors) should help to select the children who will probably need professional help. We think that it is worthwhile to screen parentally bereaved young children (i.e., < 13 years), in order to identify children at risk for PGD at an early stage. In addition, the findings of our studies suggest that it is important to obtain information about the degree of suffering from the children themselves. Practitioners can use the IPG-C or IPG-A for measuring PGD symptoms in children (aged 8 to 18 years) to get a quick first impression.

Our studies in ***chapters 2***, ***3*** and ***4*** showed that PGD, depression and PTSD are distinguishable constructs in children and adolescents. In addition to these results ***chapter 5*** gave preliminary insights into specific grief related cognitions in children. Sometimes children suffer from PGD and another form of psychopathology, but this is not the case in all children. Although PGD is not at all included in DSM-IV-TR and in DSM-5 only in section III (that includes provisional syndromes, in need of further investigation), we are of the opinion that children suffering from PGD should have access to some form of professional help. Our review described in ***chapter 6*** showed that interventions for grief are understudied. It is suggested in ***chapter 7***, ***8*** and ***9*** that specific treatments may be required for the various syndromes that may be developed post loss in children and adolescents. For instance, IPT-A or CBT-techniques for behavioural activation may be indicated for children who can be diagnosed with serious depressive symptoms. For PTSD symptoms in children a trauma-focused treatment with exposure (imaginary and in vivo) may be useful. And techniques used in *Grief-Help*, like cognitive restructuring targeted at dysfunctional meanings assigned to the loss and maladaptive coping, may be indicated for typical grief related symptoms. In all cases, regardless of the symptoms of an individual child, the resilience of the family should also be a focus of attention.

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Samenvatting in het Nederlands

INLEIDING

Het verliezen van een dierbare wordt doorgaans gezien als een van de meest ingrijpende gebeurtenissen die kinderen kunnen meemaken in hun leven. Uit recente gegevens van het Centraal Bureau voor de Statistiek blijkt dat jaarlijks 6400 minderjarige kinderen een ouder verliezen. Er is in toenemende mate bewijs dat een (klein) deel van deze kinderen een stoornis ontwikkelt dat in de Engelstalige literatuur *Prolonged Grief Disorder* (PGD) wordt genoemd en in het Nederlands beter bekend is onder de naam Gecompliceerde Rouw. Gecompliceerde Rouw kenmerkt zich door een aanhoudende separatie-pijn; een gevoel van onthechting, ofwel een verscheurend verlangen naar de overledene. Bij mensen met Gecompliceerde Rouw blijft deze pijn langdurig aanwezig en vormt het een belemmering voor het functioneren op diverse gebieden. In de inleiding van dit proefschrift wordt een cognitief gedragsmatig model geschetst waarmee het ontstaan en voortbestaan van de klachten (bij volwassenen) wordt verklaard. In dit model staan negatief denken en vermijdingsgedrag centraal. Deze processen belemmeren de verwerking van het verlies, wat betekent dat het kind het verlies niet integreert in zijn of haar autobiografisch geheugen. De vooronderstelling in dit proefschrift was dat dit model ook toepasbaar zou kunnen zijn op kinderen en jongeren die lijden aan de gevolgen van een ingrijpend verlies.

Dit proefschrift gaat over kinderen als Bas en Eva, twee kinderen die, onder andere in de inleiding, kort besproken worden. Bas heeft zijn moeder verloren toen hij drie jaar oud was. Op zijn twaalfde komt hij bij een psycholoog omdat hij slecht slaapt en zijn schoolprestaties achterblijven. Het blijkt dat Bas veel negatieve gedachten heeft die betrekking hebben op zijn moeder, vader, zichzelf en zijn toekomst. 's Nachts moet hij sterk denken aan zijn moeder en ligt hij vaak te huilen en piekeren in bed. De negenjarige Hindoestaanse Eva werd verwezen naar een psycholoog in verband met een stagnerend verliesverwerkingsproces. Eva had haar vader zeven maanden daarvoor plotseling verloren aan de gevolgen van een hartaanval. Ze had symptomen die passen binnen een Post Traumatische Stress Stoornis (PTSS), maar bovenal miste Eva haar vader enorm maar vermeed ze om aan hem te denken. Ze dacht namelijk dat ze 'gek' zou worden als ze dat zou doen. Het lastige was dat vanuit haar Hindoestaanse geloof juist werd voorgeschreven dat ze actief moest rouwen, omdat de geest van vader nog gedurende een jaar aanwezig was in het huis. Naast dat Eva probeerde om gedachten aan haar vader te onderdrukken, had ze de overtuiging dat ze geen leuke dingen mocht doen, omdat ze haar vader dan zou 'verraden'. In hoofdstuk 7 wordt besproken hoe de behandeling van Eva met behulp van het *RouwHulp* protocol is vormgegeven.

In de context van dit dissertatie-project zijn drie onderwerpen onderzocht. Op de eerste plaats wilden we meer zicht krijgen op hoe Gecompliceerde Rouw zich bij kinderen en jongeren manifesteert. Bovendien wilden we weten of Gecompliceerde Rouw, net als bij volwassenen, kan worden onderscheiden van verwante stoornissen zoals depressie en PTSS. Deze vragen zijn uitgewerkt in het drie studies die opgenomen zijn in het eerste deel van deze dit proefschrift. Vervolgens wilden we zicht krijgen op de vraag welke rol 'negatief denken' speelt in de ontwikkeling van Gecompliceerde Rouw bij jeugdigen. Dit is onderzocht in de studie die beschreven is in hoofdstuk 5. Het derde en laatste deel van dit proefschrift heeft betrekking op ons laatste doel, namelijk om een behandeling te ontwikkelen voor kinderen en jongeren met (dreigende) gecompliceerde rouw en deze te toetsen op haar (potentiële) effectiviteit. Dit doel is uitgewerkt in hoofdstuk 6 tot en met 9 waarin we allereerst een overzicht geven van behandelingen voor rouwende kinderen en jongeren en vervolgens de ontwikkeling van en het onderzoek naar *RouwHulp* beschrijven.

Deel I Gecompliceerde Rouw bij Kinderen en Jongeren

Zoals gezegd, wilden we allereerst zicht krijgen op de manifestatie van Gecompliceerde Rouw bij kinderen en jongeren. Omdat een vragenlijst om Gecompliceerde Rouw bij kinderen en jeugdigen te meten nog niet beschikbaar was, hebben we deze eerst ontwikkeld. In ***hoofdstuk 2*** beschrijven hoe we de Rouw VragenLijst voor Kinderen (RVL-K) voor kinderen in de leeftijd van 8 tot en met 12 jaar en de Rouw VragenLijst voor Jongeren (RVL-J) voor adolescenten tussen de 13 en 18 jaar hebben ontwikkeld. Vervolgens hebben we de psychometrische kwaliteiten van deze vragenlijsten onderzocht. Uit de studie bleek dat voor beide leeftijdscategorieën de vragenlijsten uit één dimensie bestond, beiden beschikten over een goede betrouwbaarheid en er werd voor beide instrumenten ondersteuning gevonden voor de concurrente, convergente en divergente validiteit. Beide vragenlijsten kunnen gebruikt worden door professionals om een indruk te krijgen van de mate waarin kinderen en jongeren last hebben van rouwreacties. Beide vragenlijsten zijn daarnaast geschikt om bijvoorbeeld effectiviteitsonderzoek uit te voeren bij interventies gericht op rouw. Een belangrijke bevinding voor professionals, die voortvloeit uit dit onderzoek, is dat de resultaten suggereren dat het belangrijk is kinderen zelf te bevragen over hoe ze zich voelen over het verlies en niet (alleen) af te gaan op wat ouders aangeven over de toestand van hun kinderen op bijvoorbeeld de Child Behaviour CheckList (CBCL).

Vervolgens onderzochten we in ***hoofdstuk 3*** of Gecompliceerde Rouw, depressie en PTSS te onderscheiden 'constructen' zijn bij rouwende kinderen, met andere woorden, of het gaat om duidelijk te onderscheiden stoornissen. Uit de resultaten bleek dat de drie constructen weliswaar deels samenhangen, maar dat ze ook verschillen. Depressieve symptomen worden vooral gekenmerkt door somberheid, PTSS door angst en Gecompliceerde Rouw door gemis. Bovendien bleek dat Gecompliceerde Rouw, depressie en PTSS allemaal samenhangen met de mate waarin kinderen beperkingen in hun dagelijks functioneren ervaren. Bij de groep adolescenten (13 tot 18 jaar) bleken PTSS-symptomen de meeste samenhang te vertonen met beperkingen in het dagelijks functioneren, terwijl dit bij kinderen de symptomen van Gecompliceerde Rouw waren. Op basis hiervan wordt, met enige voorzichtigheid vanwege het gebruikte meetinstrument voor PTSS en de beperkte omvang van de steekproef, geconcludeerd dat Gecompliceerde Rouw-symptomen een grotere impact hebben op het leven van de respondent als deze jonger is, terwijl dit bij oudere respondenten juist meer de PTSS-symptomen betreft.

In ***hoofdstuk 4*** is de factor-structuur van PTSS-symptomen bij rouwende kinderen onderzocht. In de steekproef van dit onderzoek bleek dat iets meer dan de helft van de kinderen voldeed aan de criteria van PTSS volgens de criteria die beschreven staan in de DSM-IV-TR. Dat zoveel kinderen van de steekproef mogelijk voldeden aan deze stoornis wordt toegeschreven aan de wervingsstrategie die gebruikt is; de kinderen waren deelnemers aan een lotgenotengroep of ze waren aangemeld bij instellingen voor geestelijke gezondheidszorg. Met andere woorden, deze resultaten zijn niet zonder meer te generaliseren naar andere groepen rouwende kinderen. Een ander belangrijk resultaat van deze studie was dat meisjes hoger scoorden op de PTSS-schaal dan jongens. Bovendien bleek dat de kinderen die voldeden aan de PTSS-criteria tevens hoger scoorden op zelf-rapportage vragenlijsten voor depressie, Gecompliceerde Rouw en functionele beperkingen en dat de ouders van deze kinderen ook hogere scores rapporteerden op de ‘Internaliserende problemen’ schaal van de CBCL. Verder bleek dat de samenhang tussen zelfrapportage vragenlijsten voor PTSS, depressie en Gecompliceerde Rouw hoger was dan de samenhang tussen PTSS-symptomen (gemeten door middel van zelfrapportage) en de internaliserende en externaliserende problemen die door ouders gerapporteerd worden door middel van de CBCL. Dit laatste is voor professionals die werken met kinderen en jongeren in rouw een relevante bevinding, omdat het aansluit bij de resultaten in ***hoofdstuk 2***, waarin benadrukt wordt dat het belangrijk is om kinderen zelf te bevragen over hun beleving van het verlies. Ten aanzien van de belangrijkste onderzoeksvraag van deze studie werden zes theoretische modellen van PTSS getoetst. De modellen verschillen in het aantal symptoomclusters waar PTSS uit bestaat. De modellen variëren van één tot twaalf symptoomclusters van PTSS. Het bleek dat een 4-factoren-model de data het best representeerde. Met andere woorden, volgens ons onderzoek bestaan de PTSS-klachten van rouwende kinderen uit vier factoren: ‘herbeleving’, ‘vermijding van activiteiten en gedachten’, ‘emotionele afstomping’ en 'prikkelbaarheid'. Geconcludeerd werd dat de conceptualisatie van PTSS in de DSM-IV-TR mogelijk niet de beste beschrijving van PTSS is, omdat hetgeen in de DSM-IV-TR als één cluster wordt gezien, beter gecategoriseerd kan worden in twee aparte symptoomclusters ('hardnekkig vermijdingsgedrag' en 'emotionele afstomping').

Deel II De Rol van Negatieve Gedachten op het Functioneren na een Ingrijpend Verlies

Zoals gezegd veronderstelt de cognitief gedragsmatige conceptualisatie van Gecompliceerde Rouw dat negatieve gedachten een belangrijke rol spelen in het ontstaan en voortbestaan van de stoornis. Bij rouwende kinderen is echter nog erg weinig onderzoek gedaan naar de rol die negatief denken kan spelen. Dit komt onder meer doordat er geen goed meetinstrument beschikbaar is. In ***hoofdstuk 5*** wordt de ontwikkeling van en het onderzoek naar de Rouw Cognitie Vragenlijst voor kinderen (RCV-K) besproken. Uit een exploratieve factoranalyse (EFA) blijkt bleek dat de RCV-K items één factor representeren. Bovendien bleek dat zowel de betrouwbaarheid hoog is als dat de test-hertest betrouwbaarheid hoge stabiliteit vertoont over de duur van enkele weken ($r = 0.84$,) tot enkele maanden ($r = 0.73$). De resultaten bevestigden de hoge betrouwbaarheid, en de concurrente, convergente en divergente validiteit van de RCV-K. De studie onderstreept het belang om meer onderzoek te doen naar de rol van negatieve gedachten in de ontwikkeling en het voortduren van Gecompliceerde Rouw. Bovendien is de RCV-K voor professionals een waardevolle aanvulling op bijvoorbeeld de RVL-K en RVL-J om meer zicht te krijgen op verwerkingsprocessen bij een kind. Ook is het een waardevol instrument voor onderzoekers die zicht willen krijgen op de mediatoren van behandeleffecten.

Deel III De Ontwikkeling van en het Onderzoek naar *RouwHulp*

Het laatste doel van dit project was het ontwikkelen van een behandeling voor kinderen die lijden aan de gevolgen van een ingrijpend verlies. Opmerkelijk genoeg zijn er, ondanks het feit dat er in toenemende mate bewijs is voor het bestaan van Gecompliceerde Rouw bij kinderen en jongeren, nog nauwelijks effectieve interventies voorhanden voor deze groep kinderen. ***Hoofdstuk 6*** bevat een overzicht van gepubliceerde behandelingen voor rouw en aanverwante emotionele problemen. Al deze studies waren betrokken in één van de vier meta-analyses over rouwinterventies die besproken zijn in de introductie. Concluderend kan worden gezegd dat er maar weinig interventies voor rouwende kinderen empirisch zijn onderzocht, dat veel studies beperkingen hebben omdat ze geen controlegroep gebruikten, geen follow-up-metingen verrichtten en vaak toepasbaar waren voor een kleine groep kinderen (bijvoorbeeld alleen voor kinderen en niet voor adolescenten of voor kinderen die getraumatiseerd waren door een burgeroorlog of natuurgeweld). Bovendien waren de gemiddeld gewogen effectscores gering (zie hoofdstuk 1).

Als onderdeel van dit promotieproject is mede daarom *RouwHulp* ontwikkeld. *RouwHulp* is een cognitief gedragstherapeutische behandeling die bestaat uit negen (wekelijkse) sessies voor het kind en vijf separate (tweewekelijkse) sessies voor de ouder(s). *RouwHulp* werd in twee pilotstudies onderzocht. In ***hoofdstuk 7*** wordt beschreven dat we allereerst de uitvoerbaarheid van het behandelprogramma onderzochten en tevens een eerste indruk verkregen van de mogelijke effectiviteit. Deze eerste studie had een 'multiple-baseline-design' en werd uitgevoerd bij zes kinderen en hun ouders die allemaal recent (6 tot 12 maanden geleden) het verlies van een gezinslid hadden meegemaakt. Uit de resultaten bleek dat ouders en kinderen tevreden waren over de sessies, het contact met hun therapeut en de informatie die ze kregen tijdens de behandeling. Bovendien bleek dat *RouwHulp* gepaard ging met een vermindering van Gecompliceerde Rouw-symptomen (gemeten door middel van de RVL-K of J), depressie en PTSS-symptomen en door ouders gerapporteerde internaliserende en externaliserende problemen. Aan een tweede pilotstudie, beschreven in ***hoofdstuk 8***, deed een heterogene groep kinderen mee die bovendien verlieservaringen hadden die langer geleden hadden plaatsgevonden. Er werd, opnieuw, ondersteuning gevonden voor de potentiële effectiviteit van *RouwHulp*. Deelnemende kinderen rapporteerden significante vermindering van symptomen van depressie, PTSS en Gecompliceerde Rouw. Ouders rapporteerden bovendien een vermindering van internaliserende en externaliserende problemen bij hun deelnemende kinderen, maar deze waren niet significant. Verder bleek dat kinderen die een dierbare hadden verloren aan de gevolgen van suïcide en/of waarbij het verlies langer geleden was, mogelijk minder van de behandeling zullen profiteren. Beide pilotstudies vormen de basis voor een gerandomiseerde gecontroleerde trial (RCT) die momenteel in samenwerking met diverse instellingen in Nederland wordt uitgevoerd. De onderzoeksopzet voor deze studie wordt besproken in ***hoofdstuk 9***. In deze studie zullen 160 kinderen worden geïncludeerd die ofwel *RouwHulp* krijgen ofwel *ondersteunende counseling*. Deelnemende kinderen en hun ouder(s) zullen voorafgaand aan de behandeling, na afloop en drie, zes en twaalf maanden na afloop van de behandeling vragenlijsten invullen.

BESLUIT EN AANBEVELINGEN VOOR PROFESSIONALS

Het proefschrift sluit in ***hoofdstuk 10*** af met een algemene discussie over de uitgevoerde studies. Samengevat kan gezegd worden dat de studies in dit proefschrift bijdragen aan de theorievorming rondom de stoornis Gecompliceerde Rouw. Er is meer zicht gekomen op de meting, de onderliggende mechanismen en de behandeling. Hoewel met de studies in dit proefschrift een aantal vragen is beantwoord, worden minstens evenveel nieuwe vragen opgeroepen. Beantwoording van deze nieuwe vragen is niet alleen theoretisch interessant. Het is vooral relevant, omdat het tot een verbetering van de identificatie van en hulp aan kinderen die (mogelijk) lijden aan Gecompliceerde Rouw zal kunnen leiden. Ten aanzien van toekomstig onderzoek wordt gesuggereerd om in de toekomst ook andere manieren van dataverzameling te gebruiken, te denken valt bijvoorbeeld aan observaties, dagboekstudies of diagnostische interviews. Daarnaast is de suggestie gedaan om onderzoek te doen naar de manier waarop rouwende kinderen herinneringen opslaan in hun geheugen; mogelijk slaan sommige kinderen hun herinneringen erg algemeen op in hun geheugen en lijken zij de confrontatie met de werkelijkheid van het verlies te vermijden hetgeen zorgt voor de ontwikkeling en het voortbestaan van Gecompliceerde Rouw. Tot slot is gesuggereerd de relatie tussen rumineren, slaapproblemen en Gecompliceerde Rouw bij kinderen te onderzoeken. Slaapproblemen komen veelvuldig voor bij kinderen en jongeren in rouw. Bovendien worden slaapproblemen vaak in verband gebracht met rumineren (een langdurig ‘herkauwen’ van negatieve gedachten over gevoelens en problemen) en leiden ze tot bijvoorbeeld concentratieproblemen overdag. Onderzoek naar de relatie tussen deze processen kan de behandeling van kinderen en jongeren in rouw verder verfijnen.

Tot slot worden er een aantal aanbevelingen gegeven voor professionals die werken met kinderen en jongeren in rouw. Deze aanbevelingen sluiten aan bij de eerder genoemde doelen van dit project. Ten eerste, in dit onderzoek wordt ondersteuning gevonden voor het bestaan van Gecompliceerde Rouw bij kinderen en jongeren en blijkt dat dit in kaart gebracht kan worden met behulp van de RVL-K en RVL-J. Een belangrijke vondst was dat ouders mogelijk niet de beste informanten zijn voor rouwreacties bij hun kind. Geadviseerd wordt om kinderen, met behulp van de RVL-K of RVL-J zelf ook te vragen hoe het met hen gaat. Op de tweede plaats lijken negatieve gedachten een rol te spelen bij kinderen die lijden aan Gecompliceerde Rouw. Professionals wordt geadviseerd deze negatieve gedachten te onderzoeken bij hun cliënten, bijvoorbeeld door gebruik te maken van de RCV-K. De laatste belangrijke aanbeveling is dat kinderen en jongeren in rouw behoefte hebben aan een specifieke aanpak die aansluit bij de klachten die ze hebben.

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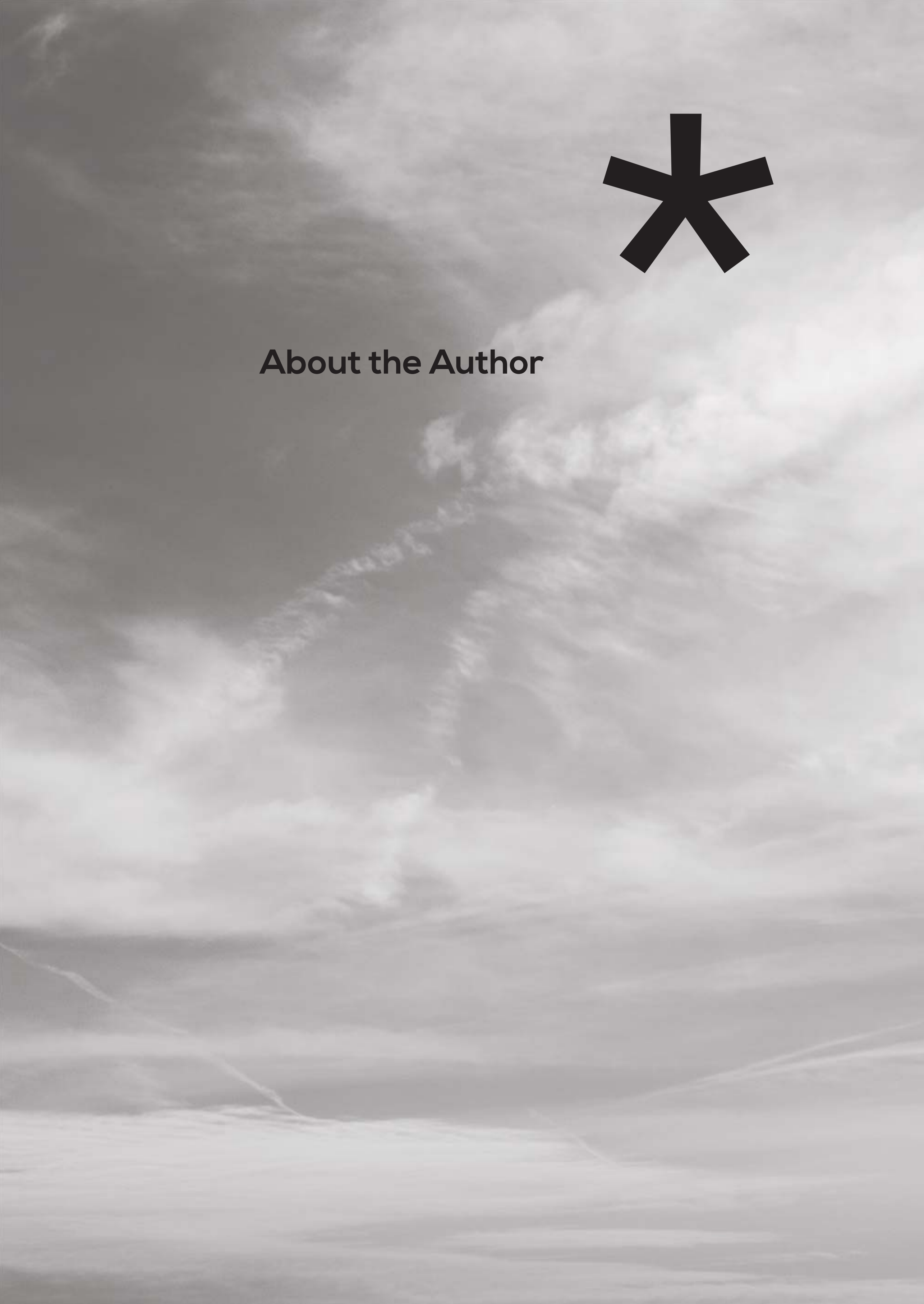

About the Author

CURRICULUM VITAE

Mariken Spuij (1970) was born in Maassluis, The Netherlands. After she graduated from High School (Florens Radewijns College) in Raalte, she studied Speech Therapy at Hogeschool Enschede in Hengelo. From 1991-1995 she studied Pedagogical Sciences at Utrecht University and finished two tracks ("Psychosocial problems in childhood" and "Cognitive and learning problems in childhood"). During her final two years she worked as a student assistant.

From the start of her career, Mariken wanted to combine lecturing and work as a professional in mental health care. In 1995 Mariken started working part-time as an Assistant Professor at the department of Pedagogical Sciences and as mental health care psychologist at the outpatient clinic of the Utrecht University (Ambulatorium). From 1996-1998 she combined her work at Utrecht University with work at two subsequent High Schools for adolescents with special needs (VSO-LOM De Sprong, Gouda and VSO-LOM De Linie, Nieuwegein). Since then, Mariken is an Assistant Professor and she lectures and coordinates mainly courses on clinical skills, assessment and treatment of psychological problems in childhood. She works with students on Bachelor and Master level.

From 1995-2008 Mariken was a mental health care professional in the Ambulatorium. Since 2008 she is also the section manager of a small but great team that focuses on psychosocial problems in childhood and adolescence. In 2008 she also started this research project with a grant from ZonMw under supervision of prof. dr. Paul A. Boelen, prof. dr. Maja Deković and dr. Peter Prinzie.

From 1995 until 1997 Mariken specialised in the assessment of children with psychosocial problems. This resulted in a license as a mental health care specialist (GZ-psycholoog). In the years that followed she expanded her professional training. From 1998-2004 she studied play therapy ("Beeldcommunicatie") in Leiden, cognitive behavioural therapy and child and adolescent psychotherapy. She is now licenced as a Clinical Psychologist (Klinisch Psycholoog-BIG), Orthopedagoog-Generalist (NVO), Cognitive Behavioural Therapist (VGCt) and Child and Adolescent Psychotherapist (VKJP) and also licensed as a supervisor for professionals who receive training for a post-academic licence as a mental health care professional. Besides that, she occasionally teaches on Post-Master level for the Centrale RINO-Groep, RINO-Noord Holland and Landelijk Steunpunt Rouw (for instance, about grief and bereavement or play therapy). Finally, she got both University Teaching Qualifications (BKO and SKO).

Beyond work Mariken is married to Marco and mother of Marleen (12), Rogier (10) and Jildau (7). She likes coffee, Sigmund, Fokke and Sukke, rollercoasters, film editing, funky music, North Sea Jazz, the Taj Mahal, more coffee, (talking about drinking) wine ☺, Wordfeud, Ruzzle and reading.

PUBLICATIONS

Academic Publications in English Refereed Journals

Boelen, P. A., & Spuij, M. (2008). Negative cognitions in loss related emotional distress in adolescent girls: A preliminary study. *Journal of Loss and Trauma*, *13*, 441-449.

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Spuij, M., Van Londen-Huiberts, A., & Boelen, P. A. (2011). Rouw en verliesverwerking. In M. Taal & C. Poleij (Red.), *Interventies in het onderwijs: Werken aan goede verhoudingen* (pp. 177-201). Den Haag: Boom Lemma Uitgevers.

Professional Publications

Spuij, M., & Boelen, P. A. (2006). *RouwHulp: Werkboek voor kinderen*. Utrecht: Universiteit Utrecht.

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PRESENTATIONS

Spuij, M. (2009, November). *Normale en gecompliceerde rouw*. Paper presented at Symposium: 'Verdriet is drie sokken' (SCEM), Amersfoort, the Netherlands.

Spuij, M. (2009, November). *De korte en lange termijn gevolgen van ingrijpende verliezen*. Paper presented at Symposium: 'Verdriet is drie sokken' (SCEM), Amersfoort, the Netherlands.

Spuij, M. (2010, November). *Kinderen: Praten of Laten*. Paper presented at Symposium 'Rouwzorg in de toekomst' van het Landelijk Steunpunt Rouw, Amersfoort, the Netherlands.

Spuij, M. (2011, March). *RouwHulp*. Paper presented at 'Interventies in het onderwijs, werken aan goede verhoudingen', Amsterdam, the Netherlands.

Spuij, M. (2011, October). *Rouw en verliesverwerking bij kinderen en jongeren*. Paper presented at 'Netwerkleden van de NVO', Utrecht, the Netherlands.

Spuij, M. (2012, January). *Rouw en verliesverwerking in de schoolcontext*. Paper presented at 'Rebound levert kwaliteit. Kwaliteitsbepaling en Borging', Amersfoort, the Netherlands.

Spuij, M. (2012, April). *Rouw en verliesverwerking. Wat kan de schoolpsycholoog doen?* Paper presented at 'Regionaal netwerk van Schoolpsychologen stad Utrecht en omstreken', Utrecht, the Netherlands.

Spuij, M. (2012, May). *Diagnostiek en behandeling van rouwspecifieke klachten bij kinderen en jongeren*. Paper presented at 'Rouw bij kinderen en jongeren na plotseling verlies van een ouder', Landelijk Psychotraumacentrum Wilhelmia Kinderziekenhuis, Utrecht, the Netherlands.

Spuij, M. (2012, December). *Verliesverwerken in de spelkamer*. Paper presented at 'Spel werkt!', Utrecht, the Netherlands.

Spuij, M. (2013, May). *Psychotherapie bij kinderen met verlieservaringen*. Paper presented at 'Niemand is geboren om alleen te zijn', Zeist, the Netherlands.

Spuij, M. (2013, May). *Verstrikt in rouw*. Paper presented at 'Kleine mensen, groot verdriet', Utrecht, the Netherlands.

Spuij, M. (2013, December). *RouwHulp. Een cognitief gedragstherapeutische behandeling voor kinderen waarbij de verliesverwerking stagneert*. Paper presented at 'Professioneel omgaan met gecompliceerde rouw', Eindhoven, the Netherlands.

OTHER EXPERT MEETINGS

2004	Invited by Universiteit van Gent (Mw L. Dillen and prof. dr. L. Verhofstadt-Denève): 'Expertmeeting Rouw en Verliesverwerking door Kinderen en Jeugdigen'.
2007	Invited by the board of Stichting Achter de Regenboog to give advise on the development of a protocol for bereaved children.
2009	Invited by the board of NVO to give advise on the multi-disciplinary guidelines 'Depressie, Addendum Kinderen en Jeugdigen'.
2011	Invited by the Nederlands Jeugd Institituut (NJI) to comment as a consultant on the dossier 'Overleden Ouder'.

www.rouwhulp.nl
www.marikenspuij.nl