OMEGA, Vol. 67(3) 291-303, 2013

COMPLICATED GRIEF IN CHILDREN—THE PERSPECTIVES OF EXPERIENCED PROFESSIONALS*

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ABSTRACT

A total of 39 very experienced clinicians and researchers worldwide responded to a survey consisting of both structured and open-ended questions on complicated grief in children. The questions assessed their opinion on: a) what constitutes complicated grief in children; b) whether to develop a diagnosis for children as suggested for adults and, if so, would adult criteria be sufficient for children; and c) other aspects of normal and complicated grief in children. The analyses showed that the professionals struggled with defining complicated grief in children, although they agreed that the major defining aspects were intensity, duration, and longevity of reactions. They identified traumatic and delayed or inhibited grief as major types, and also agreed that adult criteria were inappropriate for children.

INTRODUCTION

It is estimated that around 4% of young people in Western countries experience the death of a parent before the age of 18 (Kaplow, Saunders, Angold, & Costello, 2010). In the United States alone, approximately 1 in 20 children and adolescents

*This work was funded by the Egmont Foundation.

doi: http://dx.doi.org/10.2190/OM.67.3.c
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experience such a loss before age 18 years (Melhem, Porta, Shamsedden, Payne, & Brent, 2011). In addition, an unknown number of children experience the death of a close friend or classmate. Deaths that affect children the hardest often happen unexpectedly, involve traumatic aspects, and affect both parental and societal caring capacity. Various health consequences can result that have far reaching consequences, including premature death (Dyregrov & Dyregrov, 2012; Rostila & Saarela, 2011).

There is of yet no clear definition of what is normal and complicated grief in children. Since the pioneering work of John Bowlby (1963) back in the 1960s, where he outlined several types of what he called pathological mourning, there have been few attempts to further delineate what constitutes different types of complicated grief in young people. Bowlby described the following subtypes of pathological mourning:

1. Persistent and unconscious yearning to recover the lost object;
2. Intense and persistent anger and reproach expressed toward various objects, including the self;
3. Absorbed in caring for someone else who has also been bereaved, amounting to compulsion; and
4. Denial that the object is permanently lost—absence of grief (here the death is not acknowledged, but there is some awareness of it) (Bowlby, 1963).

However, Bowlby made no mention of traumatic grief, the subject of studies and descriptions in recent years. Mannarino and Cohen (2011), in the tradition of Worden (1996), wrote about certain tasks that young people have to undergo as part of a reconciliation process. This includes accepting the reality of the loss, experiencing the emotional distress, adjusting to the new situation without the loved one, finding meaning, and becoming engaged with other adults who can provide the nurturing care needed. In complicated traumatic grief (CTG) children are unable to complete the tasks of reconciliation, as remembering the lost one serves as a trauma reminder. These children are "stuck" on the traumatic aspects of the death. Such complications are caused by the nature of the death, most often sudden and unexpected, be that by accident, murder, or sudden medical conditions (heart attacks or strokes). The presence of posttraumatic stress disorder (PTSD) symptoms is high in CTG, but a majority do not develop PTSD. However, the trauma symptoms preclude the child's ability to reminisce about the loved one. Layne et al. (2008) note that in traumatic grief the distress reactions to the circumstances of the death interfere with adaptive grief processes. They differentiate this from complicated grief that involves prolonged or ineffective grieving. While trauma did not enter into Bowlby's (1963) thinking, it is dominating present thinking about childhood complicated grief.

In the lead up to the proposal of a new grief disorder for adults for the inclusion in DSM-5, the first of Bowlby's types was most prominently promulgated (Prigerson, Horowitz, Jacobs, Parkes, Aslan, Goodkin, et al., 2009), while in

the current proposal for DSM-5, now termed "complex bereavement related disorder," separation distress has been somewhat downplayed. In the proposal, no mention of children is made. Following the introduction of PTSD as a diagnosis into the DSM system in 1980, the adult diagnosis was adjusted and applied to children. Thus, a parallel development where the proposed grief diagnosis will be adapted to children is possible. This constitutes a risk of imposing adult conceptions on children and overlooks the fact that children are undergoing development of important brain areas involved in emotion and cognition, as well as rapidly experiencing new life events (Gunnar & Quevedo, 2007). The development of these brain areas forms the basis for regulating emotions and understanding loss and its long-term consequences. The intensity and duration of children's reactions are also influenced by parental reactions and different family practice regarding communication of facts, the parents' expressed feelings and thoughts, the family support network, etc. The presentation of complex reactions following a loss may therefore be different in children than in adults, thus making the differentiation of complicated from normal grief more difficult in children.

Given the many adverse health consequences of parental or sibling loss on children (Dyregrov & Dyregrov, 2012) it is important to be able to differentiate complicated from normal grief, as well as looking into possible subtypes of grief. On the basis of the suggested inclusion of an adult grief diagnosis in upcoming revisions of classification systems, it is also opportune to ask if it would be helpful with a parallel development of a grief diagnosis for children. In addition to empirical studies of how grief reactions in children develop over time, another small step in illuminating normal and complicated grief in children would be to ask experienced clinicians and researchers about their views on this topic. Therefore, in this exploratory study, experienced clinicians worldwide were asked about their views on different aspects of complicated grief in children and how they view the possible development of a grief diagnosis for children.

METHOD

Procedure and Sample

A survey was e-mailed to clinicians and researchers in the field of child bereavement. The names and addresses of these professionals were accessed through the first author's extensive experience and contacts from working in the child bereavement field, as well as using a "snow-ball" method for collecting e-mail addresses. In addition, a search for articles published on child bereavement in the last 10 years (including December 2010) about grief and bereavement in children cited on PubMed.gov (the U.S. National Library of Medicine) was conducted. Where e-mail addresses could be found, the first author of the publication was included. The majority of the e-mail addresses were to professionals in the United States, many from Europe, some from Australia, and

a few from Africa, Asia, and the Middle East. Early in January 2011 an e-mail was sent to all the gathered e-mail addresses informing about the study and asking them to help in collecting other names/e-mail addresses of professionals who worked with bereaved children. In late February 2011, an e-mail with a link to the survey (on SurveyMonkey) was sent to all the collected addresses. A reminder was sent in late March 2011. The collection of surveys included in the study was finished by May 31, 2011.

The Sample

A total of 39 professionals filled in the questionnaire (response rate = 24%). Most responders were women (87%) and those who participated had extensive experience gained from working with bereaved children. Their mean age was 49 years (range 28 to 70). Around 79% had worked more than 10 years in the area, while 11% had worked in the field of child bereavement between 4 and 10 years, and the rest (10%) between 1 and 3 years. Psychologists (59%) were the largest professional group, followed by social workers (25%), nurses (12%), and others (4%). Most had their primary role in relation to bereaved children as clinicians (46%), while researchers (30%) and half researcher/half clinician (30%) comprised the other two main groups. Almost all respondents were from the United States and Europe.

The Survey

The survey that was used was drafted on the basis of the authors' extensive knowledge and experience from working in the child bereavement field. Thereafter, it was further developed by the input from five professionals from three different countries with great knowledge from the grief field.

The survey contained both closed and open-ended questions to be filled in by written statements. It started with the following questions: "In your opinion what constitutes complicated grief in children?" and "What differentiates it from normal grief?" The professionals were also asked if normal and complicated grief in children could be differentiated by the types of reactions to and the intensity and duration of grief. Also, questions about the presence of different subtypes, about manifestations at different age levels and whether they favored the development of a diagnostic category for children were asked. Moreover, some questions focused on whether the proposed adult criteria were appropriate for children and, if developed, what criteria they would like to see included, as well as what advantages and disadvantages they found with a grief diagnosis for children. Lastly, before demographic questions, the professionals were asked for how long a child should evidence problems before a diagnosis should be considered. Included in the survey were questions regarding their profession, their primary role in the field, years of experience, age, and gender.

Analyses

All relevant written statements from the questionnaires were collected in a matrix for each question to be explored and analyzed according to Kvale's (1996) phenomenological and thematic mode of analysis. First, this involved condensing the expressed meanings of relevant meaning units. Secondly, the condensed material was sorted on dimensions in such a way that repeated evidence of similar descriptions resulted in the identification of major categories.

RESULTS

What Constitutes Complicated Grief in Children?

This open question revealed three very common categories. Participants first of all pointed to the intensity and duration of reactions, then at the functional impairment that the reactions resulted in. Although many pointed to duration of reactions as important, few mentioned how long these reactions would have to last before indicating complicated grief. The interplay between several of these categories was mentioned by many, "Prolonged and intense grief that affects how the children function emotionally, cognitively, physically, and socially. Their prolonged inability to manage their day to day lives and to engage in the life they had known prior to the death."

However, these categories were often supplemented by other factors that complicated the loss. One respondent formulated this in the following way: "Bereavement responses which last longer than we would normally expect, and/or which are compounded by other factors in children's lives or related to the parental death—for example, AIDS-related deaths associated with stigma, or parental suicide."

What Differentiates Complicated from Normal Grief?

When asked what differentiates complicated grief from normal grief, the respondents emphasized the same aspects as above, but mentioned nuances in the reaction patterns with a special emphasis on traumatic aspects:

> In complicated grief the child is usually preoccupied with the traumatic memories about what happened. The child can have difficulties in accepting the death; she/he may have feelings of self-blame, anger, and lack of sense of safety. Concentration problems are common as well as difficulties in academic performances. The future may seem empty or the child cannot make plans for the future. Nightmares and other sleeping difficulties may occur as well as overall regression. Complicated grief does not allow many comfortable or happy memories to exist until the traumatic memories have been processed.

Overall, traumatic aspects (sudden, unexpected, murder, suicide) were often referred to under both questions. Also, the complexity of drawing a line between what is normal and complicated was a returning issue, with respondents referring to the process and consequences over time, more than very definite markers for complicated grief. In addition, the complex, multidimensional nature of complicated grief was mentioned with disruption in attachment and fantasies and bonds to the deceased as constituent parts. Some also mentioned the hindrance/lack of growth and change as being central in the complicated forms:

> Normal grief, especially the loss of a parent or sibling, is reworked in ways which represent developmental growth and change. It is "dynamic" in the sense that it grows and changes as the child does, whereas complicated grief remains more "static." Everything about normal grief changes over time: the intensity of affect, verbalizations about the deceased, focus of life from bereavement to living, one's role, and so forth. Normal grief has many "incidents" which are not patterns, an important distinction.

Respondents also pointed to the lack of flexibility, variation, and oscillation between feeling states, as well as lack of participation in pre-loss activities in complicated versus normal grief. The inflexibility in grief is reflected in various expressions by the professionals such as "frozen" grief, being trapped or arrested in development. The developmental integration of the loss (or lack of it) is reflected in the view above and further elaborated by another respondent:

> I think those in complicated grief have the same type of reactions as those in normal grief, but the differentiating factor is that the individual is unable to integrate the death into their life and is not able to move on. In normal grief, the bereaved person reaches a "turning point" where they accept the death and can then have positive growth again. Complicated grievers don't reach the turning point.

When asked whether the type of reactions differentiates normal and complicated grief in children, 83% answered affirmatively. The respective percentages for whether intensity or duration differentiated between normal and complicated grief in children were 86% and 97%.

Different Subtypes of Grief

Ninety percent answered that there were different subtypes of grief. When asked to describe these types, in the main, two types were mentioned. One was traumatic grief, either just named so or described more specifically as loss by accident or natural disaster, homicide, being present or involved in the death, missing not found, etc. The other was delayed or inhibited grief, also mentioned in relation to concepts such as dissociation, grief with delayed onset, masked grief, and suppression of grief. Avoidance of grief was also mentioned and could reflect both subtypes categorized above. Although not frequently mentioned,

five other subtypes were also listed: disorganized attachment, conduct problems and risk taking, generalized anxiety, somatization, and depression.

Different Manifestations at Different Age Levels

Ninety percent of the participants affirmed that grief manifested itself differently at different age levels; however, the written responses varied greatly. One professional (psychologist) was very detailed:

> Preschoolers and school-aged children:
> 1. exaggerated fears;
> 2. major disruptions in attachment with care taker(s);
> 3. traumatic play; and
> 4. persistent regression.
>
> Pre-adolescents and adolescents:
> 1. risk behaviors;
> 2. suicidal ideation;
> 3. inability to create a story about the loss event; and
> 4. disinvestment in or negative view of the future, inability to set goals.

Several of the other responses echoed the above citation in describing more fear and disruption of the attachment relationship in younger children and more risk taking behaviors in older children. A changed view of the future was mentioned by several for older children. Also, several mentioned the lack of expressive ability in younger children, while others reported little growth in normal maturational development. Repetitive play was also connected to younger children, while adolescents were seen as showing more adult-like reactions (like disruption of relations to peers).

The ever changing nature of the developmental process was mentioned by several:

> Some feelings could be classed as being "universal" for all children experiencing complicated grief. For example, being intensely sad, angry, depressed, or fearful. However, how these are manifested is likely to be dependent on the age and development of the child. For example, older children are more likely to have access to opportunities for more risk taking behavior—using this as a way of blocking the emotional pain they are feeling. How children manage cognitively will also depend on their age and development and thus can be manifested differently.

A Diagnostic Category for Complicated Grief in Children?

The survey informed that there was a proposal for a diagnostic disorder for complicated grief in adults for DSM V and participants were asked if they favored a similar development of a diagnostic category in children. Most (79%) were in favor of this, while 21% were not. When looking at their comments it was obvious

that there is much ambivalence around this. On the one hand, the respondents were positive because a diagnosis can help in recognizing children's needs, as well as trigger more research. On the other hand, they are concerned about the stigmatization it could instigate. The dilemmas are clearly illustrated by the following comment:

> This is a very difficult question. Because on one hand it could help to identify the relevant group for intervention, if we develop relevant criteria, and it could politically and financially give way to research and also approval of relevant treatment-plans. But on the other hand, there is the risk of stigmas. Psychologically we can generate a lot of other dimensions in which we can secure a helping, comforting, and development-supportive intervention. But I don't think it is possible not to develop a unique category for children. Otherwise we'll once again see (as we did with the PTSD) that the adult criteria sink into the children's area.

When asked what the *disadvantage* of developing a grief disorder for children would be, the most common answer was labeling, medicalization, and stigmatization. Two respondents put it like this, "It may lead to normal grief being seen as pathology or issues which are not grief related being dismissed as grief." It is always difficult to tease out issues the child may have struggled with even without the loss.

> May put a "label" on these kids that implies negative stereotypes. Could be harmful to kids/teens, as their self-image is so important to them developmentally. It's also hard to put them in a "box" of a diagnosis, when grief is so personal and individual.

Also, some were concerned that children not qualifying for the diagnosis would not receive adequate help.

When asked about possible advantages of developing a grief disorder for children, the main category that emerged was that it would allow better or more targeted services and help for the children. One respondent voiced her concern over how at present children were not seen:

> I have seen children where the parents and other adults have totally disregarded their grief mainly because they failed to recognize the signs. The poor child has been ignored, punished and tormented by this lack of attention. I think that the idea that children don't understand what has happened and therefore they don't need any special support is harming these young minds. If there was a diagnosis at least then clinicians would have to at least think about this possibility.

In addition, others pointed out how consciousness about grief in children would be raised, how children in need would be more easily identified and referred for treatment, and that treatment costs would be reimbursed. Finally, it was mentioned how a diagnosis, would increase our understanding of the impact of complicated grief and crystallize our thinking in this area.

To the question if the suggested criteria for the adult grief disorder were appropriate for children (a link was provided to the then latest proposed DSM V criteria, March 2011), three quarters answered "no" (73%).

What Criteria Should be Included for Children?

There was great variation concerning the criteria suggested for inclusion if a diagnosis of complicated grief was developed for children. The most mentioned aspect was that the criteria should be related to a child's development (i.e., that there should be age appropriate criteria). Many respondents referred back to their description under what constituted grief in children. Here the participants pointed to the intensity and duration of reactions, and at the functional impairment that the reactions resulted in. In addition, three aspects were frequently mentioned by participants: inhibited (delayed onset), masked, and traumatic grief. A few mentioned the child's capacity to relate to new attachment figures, such as a new partner for his/her parent, as well as the relationship to the deceased. Although not mentioned as a criterion, several respondents pointed out the importance of including family relationships. An example was the following:

> I would much prefer to see a move toward criteria that indicate a healthy non-pathological response . . . parental warmth and their capacity to facilitate clear boundaries in the home have also shown to be a key predictor of outcome for bereaved children . . . so it would be useful to develop ways of identifying those parents who are at risk of increasing the likelihood of complicated grief in their children. I would also like to see criteria around a child's capacity to adapt to a new parental figure (step parent) or new siblings . . . as these transitions and new family relationships after a family bereavement are often precursors to significant complicated grief in children and adolescents.

Others mentioned the need for more studies of specific behavioral and emotional responses such as fear that other family members might die, guilt, being ashamed of feeling happy, somatic symptoms, sleep disturbances, or concentration difficulties. Some pointed out that the criteria should be kept very similar to the adult criteria. Figure 1 shows how respondents answered regarding how long they thought a child should evidence problems before a diagnosis should be considered. As seen from the figure most respondents (48%) indicated 6 months, while 40% wanted this before 6 months. Only 16% of the professionals indicated that children should wait for 12 months before a diagnosis should be considered.

DISCUSSION

The professionals who answered the questionnaire were an extraordinarily experienced group with a large majority having worked for more than 10 years in the child bereavement field. The group contained professionals known and chosen

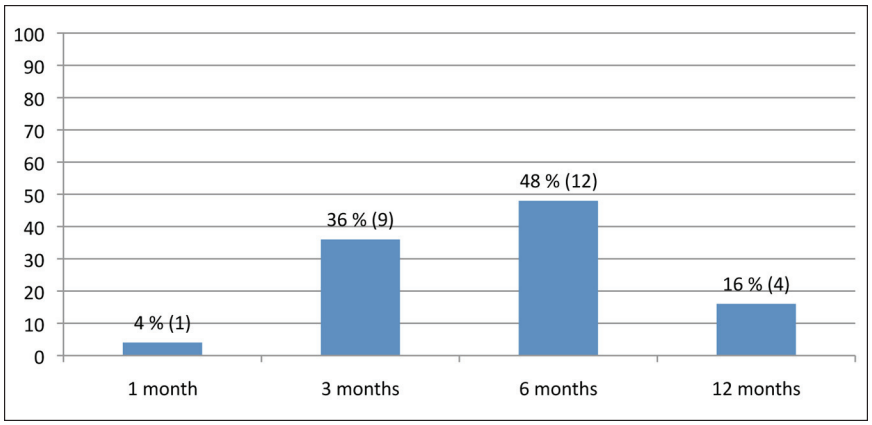

Figure 1. If a diagnosis for children is to be developed, how long do you think a child should evidence problems before a diagnosis should be considered?

for their clinical and/or research contribution to the area. This may partly explain the fairly diverse conceptualizations and lack of unity regarding what constitutes complicated grief in children. It may also reflect the fact that it is difficult to draw a clear line between what is normal grief and what is complicated grief. However, there was some agreement that the distinction between normal and complicated grief was related to the intensity and duration of the grief, and to the reactions having a negative functional impact on the child. More than 80% of the professionals agreed that intensity, duration, and type of reactions differentiated between normal grief and complicated grief. However, the complexity in drawing the line was mentioned by the respondents and few delineated which type of reactions differentiated the two aspects of grief. The complex, multidimensionality of grief was another returning issue, making the demarcation difficult. Longitudinal research designs that measure (complicated) grief symptoms at various intervals following the death will allow us to better understand which symptoms represent a clinical disorder.

Almost all respondents agreed that there were different subtypes in grief. In the main two types were mentioned. Traumatic grief was one and this concerned losses due to suicide, murder, or accident, as well as the child having witnessed the death. Such situation characteristics were mentioned as defining aspects of traumatic or complicated grief. The other was delayed or inhibited grief, also mentioned as masked or suppressed grief. Complicated grief was related to the child's development becoming frozen or inflexible. While normal grief allowed growth and change, complicated grief had the child remain in a more static state. Several respondents pointed out the emotional inflexibility resulting from what

they called the lack of developmental integration of the loss. The children did not proceed and became arrested in their development. In many respects these findings mimic the literature referred to in the introduction, as well as the debate leading up to the proposal for a new grief diagnosis. Here the Horowitz group (Horowitz, Siegel, Holen, Bonanno, Milbrath, & Stinson, 1997) laid more emphasis on the traumatic aspects of the disorder, while the Prigerson group (Prigerson & Jacobs, 2001) emphasized separation distress. These two types, traumatic and prolonged, are the same two types that have been emphasized by Nader and Layne (2009).

Almost all of the respondents also agreed that grief manifested itself differently at different age levels, but few provided accurate descriptions of such differences. Broadly, more fear and attachment problems were mentioned for younger children while adolescents evidenced a change in future perspective and more risk taking.

Although almost 80% were in favor of developing a diagnostic category for complicated grief in children, the written responses obviously demonstrated great ambivalence concerning this. Many wanted a diagnosis because they believed it would help recognize children's needs, as well as target services, instigate research, and allow for reimbursement of treatment costs, while labeling, medicalization, and stigmatization were noted as possible negative consequences. These arguments are perfectly in line with those discussed in relation to the adult diagnosis (Prigerson, Vanderwerker, & Maciejewski, 2008). The skepticism to applying adult criteria was very evident in that three-quarters of the professionals answered "no" when asked if the suggested criteria were appropriate for children.

At the time of the data gathering, the proposal for a new grief disorder for adults suggested that at least 6 months should have passed since the death (later changed to 12 months). Around half of the respondents in this study also indicated that a child should evidence problems for 6 months before a diagnosis was set. However, 40% wanted a shorter period and only 16% indicated 12 months. It is obvious that the professionals do not want problems to become too entrenched and therefore opt for earlier rather than later intervention.

Only 24% answered the survey. This is a low response rate but still adequate if one considers how e-mail addresses were collected. All first authors of written articles were contacted. Many of these authors conducted their study as part of their PhDs or other academic studies without working primarily with children and grief. Others were contacted to achieve a snowball effect where, on the basis of their network, they could put us in contact with other clinicians and researchers in the child bereavement field. Thus, many of the e-mails were received by professionals not dedicated to the child bereavement area. Although this reduces the response rate, we do know that the participants that filled in the survey reflect extensive experience and varied knowledge in the field of childhood bereavement.

CONCLUSION

Our explorative study shows that an experienced group of child researchers and clinicians struggle with defining complicated grief in children. There is, however, consensus about the main aspects concerning intensity, duration, and longevity of reactions, that traumatic and delayed or inhibited grief are the major types, and that adult criteria are not appropriate for children. We need empirical studies that can help us to better define different subtypes and dynamics of complicated grief in children, lay the ground for appropriate measures to identify them, and provide the background for appropriate interventions that offer specific help for various manifestations of complicated grief.

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