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“I Was Just Trying To Stick It Out Until I Realized That I Couldn't”: A Phenomenological Investigation of Support Seeking Among Older Adults With Complicated Grief*

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Abstract

Complicated Grief (CG) is a prolonged, impairing mental health condition affecting about 7% of the bereaved. CG may be especially prevalent in older adults. Though evidence-based treatments for CG have been developed, little is known about support-seeking in older adults with CG. This study used the descriptive phenomenological approach to explore the CG support-seeking process. In-depth interviews were conducted with 8 CG-positive older adults who had completed participation in a randomized clinical trial of CG treatment. Five primary themes arose: observing that grief was causing a great deal of distress and impairment; grief not meeting expectations of what grief “should be”; an important influence of social relationships on support-seeking; lack of effectiveness of grief support groups and/or care from mental health professionals prior to study enrollment; and strong reactions to the label of CG. Themes may help inform efforts to engage older adults with CG in effective care.

Introduction

Experiencing the death of a loved one is a near-universal part of human life, and, in the United States, is especially frequent among adults aged 65 and older (Federal Interagency on Aging Related Statistics, 2010). Strong emotional responses of sadness and yearning are also common, but longitudinal studies show that for the majority of bereaved older spouses, the frequency and intensity of these feelings attenuate considerably within the first year after the death (Bonanno, Moskowitz, Papa, & Folkman, 2005). Most mourners are also able to continue to function well in day-to-day activities shortly after the death (Chentsova, Dutton, & Zisook, 2005). Indeed, loss of loved ones tends to be an expected part of aging, which may reduce the stress associated with these events (Carr, Nesse, & Wortman, 2006). A minority, however, experience longer-term reactions to bereavement that can be classified as mental health disorders, including Major Depressive Disorder (MDD, or depression), posttraumatic stress disorder (APA, 2013) and Complicated Grief (CG); Prigerson, Maciejewski, Reynolds, Bierhals, Newsom, Fasiczka, et al. 1995). The recently released 5th

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edition of the American Psychiatric Association's (APA) Diagnostic and Statistical Manual (DSM-5) includes CG in Section III (Disorders Requiring Further Study) (APA, 2013). Here, CG is labeled "Persistent Complex Bereavement Disorder," but "complicated grief" will be used throughout this article because this term is more widely used in the existing research literature. The condition is characterized by intense yearning or longing for the deceased, intense sorrow and emotional pain regarding the death, and preoccupation with the deceased or the circumstances of the death. Other symptoms include difficulty accepting the death, intense anger or bitterness over the loss, a diminished sense of self without the loved one, a feeling that life is empty or meaningless, difficulty planning for the future, and disengagement in activities or relationships that were enjoyed before the loss (APA, 2013; Shear, Simon, Wall, Zisook, Neimeyer, Duan, et al., 2001).

The DSM-5 criteria also state that, in adults, the disorder not be diagnosed until 12 months after bereavement, and require that severity of symptoms are outside cultural, religious, or age-appropriate norms (APA, 2013). Though CG, depression, and other mental health disorders like anxiety often co-occur (Jacobs, Hansen, Kasl, Ostfeld, Berkman, & Kim, 1990; Simon, Shear, Thompson, Zalta, Perlman, Reynolds, et al., 2007), CG has been found to constitute a distinct cluster of symptoms which can be distinguished from anxiety and depression (Horowitz, Siegel, Holen, Bonanno, Milbrath, & Stinson, 1997; Prigerson, Frank, Kasl, Reynolds, Anderson, Zubenko, et al., 1995; Shear et al., 2011). A recent population-based survey found that 6.7% of those who lost a loved one developed CG, and that those who were 61 and older had a significantly higher risk of developing CG than younger bereaved (Kersting, Braehler, Glaesmer, & Wagner, 2011). A higher cumulative burden of losses, diminished coping capacity, and diminished social resources may all account for this difference.

Preliminary evidence indicates that adults with CG can benefit from mental health treatment which specifically focuses on their symptoms (Schut & Stroebe, 2005; Shear, Frank, Houck, & Reynolds, 2005), but little is known about support-seeking in this population. Across mental disorders, there is a well-documented gap between the number of people suffering from mental disorders and the use of mental health treatment. In a large U.S. representative sample of adults, only 5.8% received mental healthcare via a specialist mental healthcare professional, while 30.8% of those surveyed met diagnostic criteria for a psychiatric condition (Kessler, Zhao, Katz, Kouzis, Frank, Edlund, et al., 1999). Moreover, the gap between the need and mental health service use for older adults is even larger when compared to younger age groups (Bartels, 2002). For example, in one survey in Baltimore (Bogner, de Bries, Maulik, & Unützer, 2009), adults aged 60 years and older were only one-third as likely to consult a specialist in mental health compared to adults aged 40-59, even when controlling for type of disorder and past use of mental health services. The explanation for these differences is still being determined, and may be due either to cohort effects (e.g., different norms about the acceptability and perceived stigma of using mental health services) or to issues specific to chronological age (e.g., making physical health a priority over mental health, or mobility constraints; Bogner et al., 2009). Aspects of the U.S. mental healthcare system may also contribute to low mental health service utilization among older adults, including fragmentation of the system of care, lack of matching of services to the preferences and needs of older adults, limited Medicare coverage for care, low use of

evidence-based practices, a shortage of providers skilled in geriatric mental healthcare, and poor continuity of services (Bartels, 2003). The available literature suggests that a similar gap in service use could exist among those with CG. Analyzing a sample of 110 widowed adults interviewed about 4 months after their loss, Prigerson et al. (2001) found that only 33.3% of those with CG symptoms had used mental health services in the previous 2 months, though the study did not explore the reasons behind this finding. More data on bereavement service use among those with CG is needed.

The purpose of this study is to explore mental health support seeking for CG among older adults, using semi-structured in-depth interviews. The key research question is: *Among a group of adults aged 60 and over who enrolled in a therapy treatment study for Complicated Grief, what was the process by which they sought professional mental health support for their grief symptoms?* Qualitative research methods are appropriate because so little is known on this topic (Peters, 2010) and because qualitative data can reveal nuances in an individual's experience that are difficult to capture in quantitative data (Creswell, 2007; Peters, 2010). Preliminary findings can help inform future quantitative studies of factors influencing mental health service use in older adults with CG. Moreover, qualitative research may be especially useful in mental health research, which covers sensitive topics with a population which does not always have a voice (Peters, 2010). A few qualitative studies have been conducted on support seeking for bereavement more broadly, considering reasons for joining bereavement support groups (Picton, Cooper, Close, & Tobin, 2001) and preferences for support after the death of a loved one in palliative care (Benkel, Wijk, & Molander, 2009), but none have examined support-seeking specifically among older adults with CG.

Study Design and Method

The qualitative method used was Husserl's descriptive phenomenological approach (Husserl, 1931, 1970). Phenomenology seeks to identify the essence of an experience shared by participants (Creswell, 2007). Descriptive phenomenology focuses on a common lived, primarily internal, experience among participants, and differs from interpretive phenomenology, which emphasizes how narratives are shaped by larger historical, social, and political contexts (Lopez & Willis, 2004). Descriptive phenomenology may be most appropriate in studying aspects of experiences that have not been fully conceptualized in previous research (Creswell, 2007; Lopez & Willis, 2004). Phenomenology has been rather widely used previously as a method in qualitative data collection with older adults (e.g., McInnis & White, 2001).

Recruitment and Sampling Strategies

I conducted in-depth cross-sectional semi-structured interviews with older adults who completed participation in an NIMH-funded randomized clinical trial of a 16-session CG treatment, the Complicated Grief Treatment in Older Adults (CGTOA) study (RO1MH60783). Participants were recruited via radio and newspaper advertisement and from referrals from other mental health professionals. Eligibility criteria for enrollment in the CGTOA study were:

1. a death of a loved one had occurred at least 6 months previously;
2. aged 60 or older; and
3. a score on the Inventory of Complicated Grief (Prigerson, Maciejewski, et al., 1995) of 30 or greater.

Exclusion criteria were:

1. history of psychotic disorder or bipolar I disorder, as measured by the Structured Clinical Interview for DSM-IV (SCID) (First, Spitzer, Gibbon, & Williams, 2002); and
2. pending lawsuit or disability claim related to the death.

To avoid any contamination of activities on the treatment study, only those participants who had already completed all CGTOA study procedures were interviewed. Treatment study procedures end 1 year from the date of initial treatment study enrollment.

Sample Selection

Initial interviews began in May of 2010 and were completed in March of 2011. As of March 2011, approximately 45 people had completed all procedures on the CGTOA study. From this group, the purposeful sampling method (Creswell, 2007) was used to select a diverse, stratified group of 20 participants who varied by gender, type of loss (e.g., child, parent, partner), and race. Literature indicates that differences in the gender of participant, relationship to the deceased, and race or ethnicity may have an impact on grief symptoms (Stroebe, Schut, & Stroebe, 2007). Moreover, to be eligible, participants were required to be 60 and over. Some CGTOA participants under age 60 were enrolled as practice cases for training study therapists, but were not randomized to treatment. Participants who had conveyed to CGTOA study staff that they did not want any further contact from the study were also excluded from participation. Over a 4-month period, all potential participants were sent a letter describing the study, along with a card in a stamped, addressed envelope which they were asked to return if they were not interested in participating. CGTOA study participants had already provided contact information to that study. All those who did not return a card were then contacted by telephone and/or e-mail by the author. In both written and verbal descriptions, the qualitative study was presented as affiliated with, but separate from, the CGTOA study, and the voluntariness of participation was emphasized. Of the 20 individuals contacted, 7 were not reachable via telephone or e-mail and 4 returned the mailed card stating that they did not wish to participate. One participant who agreed to participate was misidentified as being over 60 years old in the initial review of eligible participants and was excluded from the study. Once participants were reached via e-mail or phone and agreed to participate, an initial interview was scheduled with the author at a time and location of their choosing. Participants did not receive compensation for participation.

All procedures were approved by the Institutional Review Board (IRB) of the New York State Psychiatric Institute, which has an authorization agreement with the Columbia University IRB. The IRB approved a waiver of signed consent for cases where participants preferred to do the interview over the telephone, but all participants reviewed a study consent form which described study procedures in detail.

Data Collection and Analysis

To obtain a detailed account of the professional mental health treatment-seeking process for CG, a semi-structured interview was developed, based on a review of literature on qualitative interviewing techniques and in consultation with other qualitative researchers. Questions included: “Do you remember when you first realized that you were having a hard time dealing with (LOVED ONE)’s loss?” “Was there a point at which you decided you wanted to get professional help with grief? Tell me more about that. Did any experience or event lead to that point?” and “Was there anything else you did that helped you cope after (LOVED ONE)’s loss?” The author conducted all interviews. While outlined topics were discussed in all interviews, the participant was given maximum flexibility to describe their own experience. The use of prompts enabled the interviewer to encourage participants to give more specific examples of their experiences, especially in cases where these examples were not offered immediately.

Interviews lasted, on average, 53 minutes, and ranged in length from 24 to 86 minutes. Six interviews were conducted in-person (four at the participant’s home, two in other quiet locations of the participants’ choosing) and two were held over the phone. Phone interviews were conducted when participants’ current location or schedule did not permit an in-person interview. Second interviews were conducted to ask follow-up questions and confirm preliminary findings with participants. Seven of the eight participants were reached for discussions of findings and follow-up questions; one had said that she did not wish to review findings.

All interviews were recorded digitally. Each interview was subsequently fully transcribed by the author using guidelines described by McLellan, MacQueen, and Neidig (2003). All interviews were analyzed by the author using qualitative data management software ATLAS.ti. Analysis by a single individual is common in the phenomenological approach, as it encourages immersion in the text (Giorgi, 2009). The analytic process described by Giorgi (1985, 2009) was used to create an in-depth description of the CG support-seeking experience. Giorgi’s method involves four steps: description, reduction, essences or structures, and intentionality. The process began with a reading of the entire transcript of each participant (description). The next step, reduction, involved reading each transcript closely to identify specific “meaning units” of the support-seeking experiences in participants’ own words. The third step involved reviewing each meaning unit to identify the psychological insights within them. Processes of reflection and imaginative variation allowed for categorizing the phenomenon’s essences or structures. Imaginative variation consists of seeking possible meanings through imagination, changing frames of references, and considering the phenomenon with different perspectives.

The fourth step involved synthesizing all meaning units into a consistent description of the participant’s experience of support seeking. Themes that were common across participants were then identified to create a general description of the grief support-seeking experience. Finally, the entire original transcripts were read again to ensure that final master themes accurately reflected the original material. Any quotations to be included for publication were shared with participants to confirm their accuracy, determine that the account resonated with their subjective experiences, and ensure that interviewees were comfortable with their

publication. Throughout the data collection and analysis process, as recommended by descriptive phenomenologists (Giorgi, 1985; Husserl, 1931; Lopez & Willis, 2004), I attempted to “bracket out” my own experiences and assumptions. Gearing (2004) has noted that bracketing can refer both to the process “setting aside, suspending, or holding in abeyance presuppositions surrounding a specific phenomenon” and “focusing in on the essences and structure of the phenomenon” (p. 1433). Both types were utilized.

Results

Sample Characteristics

Data from a total of eight participants, aged 62 to 88, was analyzed. This sample size falls within that generally suggested by researchers; Morse (1994) has recommended that phenomenological researchers interview about six people. Demographic and loss-related data are presented in Table 1. Six participants were White, one was African American, and one was Hispanic. six were women. The demographics of those interviewed roughly correspond to those of the larger CGTOA study sample, in which approximately 75% are White, 10% are Hispanic, 15% are African American, and 90% are female. All also had a history of major depressive disorder, and all but one had experienced a depressive episode after the death associated with their CG.

Time since the loss (at CGTOA study enrollment) ranged from .5 to 35.38 years. One participant lost his mother to a chronic illness in his mid-20s, but did not seek treatment for grief until his early 60s. Until then, no available treatments seemed like an appropriate fit to him. Two other female participants lost their male partners to chronic illnesses, both about 5 years before CGTOA study enrollment. A fourth participant lost her father to a chronic illness about 14 months before CGTOA study enrollment. Two female participants lost their adult sons in sudden deaths, one about 6 months before enrollment, another about 18 months before enrollment. Another participant lost his wife to chronic illness about 3 years before CGTOA study enrollment, while the final participant lost her close friend to chronic illness about a year before enrollment.

The study participants also entered the larger CGTOA study in divergent ways. Two participants had never sought any sort of mental health treatment, including any grief-specific treatment, at any point in their lives. They heard about the CGTOA study and felt that it was something that could benefit them. Two participants had sought counseling in the past (before the death), but had never sought specific grief counseling before enrolling in the CGTOA study. Another four participants sought professional treatment for grief after the death, both individual counseling and group support. Two of these participants had also sought counseling for other reasons before the death.

Several master themes arose in analyses, which were experienced by all participants in their support-seeking process:

1. observing that their grief was causing a great deal of emotional distress and role impairment;

2. a realization that grief was not meeting their own or others expectations of what grief “should be”;
3. the role of social support—both a failure of existing social support and being told by others that they needed help;
4. a lack of effectiveness of support groups and/or care from mental health professionals; and
5. reactions to the label of “complicated grief” and a sense that CG-specific treatment could be of help to them.

Grief Causing Distress

Many participants used very dire language to describe the level of suffering they experienced after their loss: terms like “enormously sad,” “despair,” “feeling lousy,” “awful,” a sense of “futility,” “[going] on the downhill,” “paralyzed,” “desperate,” “consumed in a negative way,” “no joy ... no optimism,” and “want[ing] the pain to end.” These feelings were seen as resulting directly from the death of their loved one, and were quite different from the participants' usual emotional experience. One participant said, for example, that her grief came over her suddenly, that “it just hit me.” Another said: “You go through life ... and it's just going along, and this was going to be it, and then all of a sudden you're on a totally, totally different climate, trapped beneath.” When these intense emotions arose, they felt out of participants' control or understanding. As one participant put it: “It was sort of free-fall. Going off the edge of the mountain and everything just going by you, and it's not really the end but it's having no control of anything. ... You don't really have that firm grip.” Another said, similarly: “It's just like the whole world was still going and I was in the woods. ... And ... I was frightened [by that].”

For most participants, the onset of symptoms seemed sudden and dramatic and occurred immediately after the death of their loved one. Yet for others, though they could see in retrospect that symptoms had been present for some time, they did not recognize them immediately. These participants tended to suppress or ignore their symptoms until some event forced them into awareness. As one participant said: “I wasn't aware of it at the time. I was just numb. ... I didn't realize. I thought I was doing fine.” Denying symptoms often acted as a sort of coping mechanism so that participants could continue to function. Denial was most common immediately after the loss. As one put it: “It was too much to sort through. So I wasn't sorting through it.” Many of these participants also tried to use self-reliance, believing that grief was something they had to deal with “on their own.” As one described it: “Well, I'm not a person who lies to go [for professional support]. ... It's not that I don't believe in it, but I think I can handle ... a lot of things.” Or, as another participant noted: “you just try to do the very best you can.” These participants ultimately found, though, that coping with grief on their own didn't make the symptoms diminish. In these cases, emotional distress was often brought into awareness through specific events, including difficulty functioning at work or in relationships and changes in health. For example, one participant started having marked physical health problems: “I fell. I'd never fallen [before] in my life. I wasn't paying attention to anything, I wasn't driving well. I was very sick over and over again. My hair turned grey in 6 weeks. I didn't have the first grey

hair, and [now] it was grey.” Finally, after many months, the participant “started putting the pieces together. And realizing that I was really in trouble.”

Not only intensity of symptoms, but their duration, played a significant role in symptom recognition. Many participants said that though they thought their symptoms would improve over time, instead grief remained and often even got worse. Getting better “seemed to be taking ... too long.” As one participant noted: “I was just trying to stick it out until I realized that I couldn't.” Indeed, the longer symptoms lasted, the longer they seemed to become part of the participants' way of being in the world. As one participant said: “Since I carried it so long, it's a little bit harder to cut loose from it. ... When it doesn't improve over time then it starts to feel like a problem. Because it interferes with other things, you know, defeatism, futility, and so on, starts to overshadow everything you do.” Notably, the average time between the loss and CGTOA-study treatment seeking was years 6.60 years (see Table 1), while the median time was 2.26 years.

Participants also expressed ambivalence about wanting to get better. For many, grief was a way of maintaining a link to the loved one. Lessening of grief was sometimes seen as indicating that the bereaved person would also lose a connection to the deceased, or a sign that the bereaved hadn't truly loved them. As one participant, who lost his wife, put it: “I ... felt ... ‘Am I doing the right thing? Should I really want to make myself feel better?’ ... [My wife] was worth so much, and how could I even entertain that?” For participants with this experience, a need to address their suffering ultimately outweighed this concern. The same participant added: “Yet, life is for the living.”

Grief Not Meeting Expectations of Self and Others

For all participants, the intensity of grief symptoms and their duration was different than what they, and other people in their lives, expected them to be. Many had lost other loved ones before the death that triggered their CG, and commented how much their CG varied from these other losses, that their CG was “not the customary thing.” In addition to comparing grief to their own experiences, participants told stories about others who had lost a similar relationship (e.g., also lost a partner or a child), and how different these others' reactions were to their own. One participant noted “I don't know anyone who has reacted like me.” Sometimes there was self-judgment in the comparison to others, that participants' grief reactions didn't “deserve” to be as strong as they were. One woman, who had lost a close friend, said: “I had the kind of foolish notion that I would hear somebody else who'd be talking about ... something so much worse. I mean, [loved one's name omitted] was 80 when he died. So it wasn't a tragedy, it wasn't premature. ... So it's not like someone whose child committed suicide or, you know, something like that.”

Many participants also found that friends, family members, and even professionals were surprised by the duration and intensity of their grief, which influenced their ability and continuing willingness to be supportive to the participants. One participant noted this explicitly: “I wasn't meeting anybody's expectations. And, you know, they were devising grief from their own experience or their own reading or their own whatever. And I wasn't meeting any of those criteria. ... And people just either ... got tired of it or ... they just, you know, didn't want to deal with it.” Several participants mentioned, as months and sometimes

years passed since the death, that friends and family told them “you should be over it by now.” As one participant described, friends and family would say: “You should be feeling better now. ... You should be moving on. You need to get out. You need to do this, you need to do that.” When, a year after her husband's death, one participant told acquaintances that she was still sad about it, they responded with “What do you mean [you're still grieving], after a [whole] year!?” These reactions often contributed to a feeling of being misunderstood, and also made participants feel even more concerned about their grief symptoms.

The Influence of Social Support

All participants relied on existing interpersonal supports to help them manage their grief symptoms, but this support was usually somehow insufficient. Though many participants wanted to maintain social relationships after the loss, all participants described experiences where this was difficult. Some participants experienced a marked withdrawal of certain close friends or relatives, who reduced communication soon after the loss. One participant described her friends' separation from her as “loss on loss” noting that this “made it harder for me, not only because I didn't have their support but also because it [became] another form of grieving for me. ... What I would have normally turned to wasn't there anymore.” Participants often felt disappointed and betrayed by these reactions.

In some cases, friends or family members remained in participants' lives, but the support and understanding they provided was poor. In addition to the experience of being told they “should be over it by now” noted above, lack of skill in discussing grief was the most common social interaction described by participants. Others often noticed that the participant wasn't doing well and wanted to be helpful but didn't know how. As one participant described: “They don't know what to say, [so] they feel uncomfortable ... and frustrated. You want to say or do the right thing, and you don't know what it is, and [so] you either back off or bumble.” A related unhelpful reaction was a sort of condescending, cheery reassurance. As one participant described: “A lot of people approached me with this false ‘you're going to be all right’ kind of thing. [A] pat on the head. It's almost patronizing. And at that time I was allergic to that.” Another noted, similarly: “What I felt more than anything else was a kind of pity.”

Feeling like others simply weren't open to discussing participants' feelings was also common. As one participant put it: “You just sort of try to sense it ... I don't want to just assume they're not going to understand, but if I toss out [deceased loved one's] name so many times and if they don't want to talk about it, you move on and talk about the weather.” Changing the subject when their loss arose in conversation was mentioned by most participants. Many felt that grief was more difficult for family and friends to discuss than other emotions.

The effect of social relationships was not uniformly negative, however. Many of those who remained in participants' lives influenced their support seeking. While two of the participants sought care for grief without any input from others (e.g., one heard a radio ad for the CGTOA study, felt it fit him, and scheduled an initial assessment), the remainder were told by others that they thought grief treatment would be useful. Three specific types of

input were offered. For two participants, people they knew (usually friends or family, but, in one case, a medical provider) noticed grief symptoms and expressed concern. They said things like “You know, you really should get counseling.” Three other participants entered grief treatment because friends who had also lost a loved one recommended it. One participant described how, very soon after her loss, a good friend called her: “She [said]: ‘Look. ... I’ve had losses too, but tomorrow you’re going to get out of bed, you’re going to take a shower, and you’re going to call this number [for a grief counselor].’” Finally, in one case, a participant was asked to enter her treatment because it was affecting her relationship with her partner. “He said to me one day ‘I don’t think this is going well. ... It’s taking a toll on me. ... Go ... to a psychologist.’ ... So I got scared. ... I thought ‘Well, [what if] he leaves? If he cannot take it any longer, [and] he decides ‘I’m leaving’? And I got petrified.’” She immediately started searching for grief treatment and came in for an initial interview with the CGTOA study a few days later. This participant noted that, if her partner hadn’t said anything, she probably would never have sought grief treatment. In general, then, recommendations from others, expressions of concern, and fear of a loss of the relationship all influenced support seeking for grief.

Ineffectiveness of Professional Treatment

While, as noted above, not all participants sought support from grief support groups or mental health professionals before enrolling in the CGTOA study, those who did so were often dissatisfied with what they received. Interestingly, none of the participants got ongoing support from a religious organization about their grief. As one explained “The pastor from my parents’ church said that I could talk to him. But I didn’t know him, he was my parents’ pastor, and I had no previous relationship with him, so I didn’t feel comfortable doing that. You know, he’s a clergyman, he’s not a psychiatrist, psychologist, anything like that, so I thought ‘Nah.’”

Participants who sought specialized mental healthcare often found the process challenging. Not being sure who to go to for grief treatment was a commonly cited problem. For those who did find mental health support, care was often ineffective. Some participants describe a lack of fit with their therapist, that “something wasn’t clicking.” Several others commented that care wasn’t specialized enough, that it was “garden variety” rather than focused on grief. Similar to family and friends’ discomfort or lack of familiarity with grief, many mental health professionals seen by participants had difficulty discussing grief. As one participant described his short-lived experience with a behavior therapist: “it really has very little to do with the grief itself, or understanding grief. ... All she seemed to be interested in was pulling me back in, without referring to grief at all.” Indeed, therapists rarely seemed comfortable talking about grief and very few specialized in it. One participant, while generally satisfied with her care, felt she got inaccurate information from her therapist (who provided Jungian analyses rather than grief-specific treatment): “Well, at the beginning he said things that were not true, but I guess they say that to everybody. Like ‘In 3 months you will feel better. In 1 year you will be better.’ And 3 months and a year went by and I felt worse.” Participants’ dissatisfaction seemed to be primarily with a lack of focus on grief in particular, rather than the specific treatment modality; participants were dissatisfied both when treatment was too structured and when it was not structured enough. Participants

expressed a great deal of frustration with not finding treatment when they needed it, fostering a feeling of hopelessness that actually enhanced their grief symptoms; one called this a “double negative.”

Some participants never tried grief groups, with two noting that they simply didn't like groups, in general. Those who did try grief groups sometimes found that hearing about others' losses seemed to add to their grief, rather than make them feel less alone. A related experience was a sense of comparison to others in the group that made their grief worse: “It was such a downer. These were people that were still years and years afterwards going to two and three meetings a week. And I couldn't process the fact that this would be it forever. ... And I couldn't go with that, that they were still in this after 7, 9 years.” Another had the opposite reaction, feeling that some of the other group members were not truly grieving: “Some of them were honestly sorrowful and felt that. ... Others it was kind of sub thing. The bereavement group was what they were looking for, that was a means of social contact which had very little to do actually with bereavement.” All these participants felt a lack of real connection to other members. Finally, some participants felt that the organization of the group impacted their interest in participating. Regularity of attendance was one issue. As one participant described: “I believe if there had been a little more continuity, if people had come more often. I don't think it was that comfortable.” None of the participants went to grief groups for more than a few sessions, and most went once and then stopped.

Reactions to Complicated Grief and Complicated Grief-Specific Treatment

The importance of labeling symptoms as CG varied significantly by participant. None had heard the term “complicated grief” until they heard about the CGTOA study. For some, having a name for symptoms was a powerful, important experience. These participants identified strongly with the label, making statement such as “It fit so well. It absolutely resonated.” These participants felt a huge sense of relief both that they were not alone in their symptoms and that treatment existed for their condition. As one participant described her first reading an article about CG:

It was almost like I was reading about that they'd discovered gold because it validated something [for] me that was ... just unnamed before. It told me that what I was experience A. Others experienced also, which really helped me. ... And ... it also told me that [my problem] has been recognized and it can be treated. ... [Because] I hd the key words, I had “complicated grief”. ... I mean it was “Eureka!”. ... It was so wonderful that it was recognized [because] validity was there. I had almost all the symptoms that the paper described. ... That was the key to everything, those two words.

Many of these participants expressed a wish that they'd known about CG sooner, so as to have better understood their symptoms.

For others, though, the label of CG was irrelevant. They didn't identify strongly with the term and instead their focus was on getting treatment that they felt would be helpful. As one participant said “[I thought] nothing special. It sounded like a term that's used, that I wasn't familiar with. That's all ... I really didn't think about the word.” Another said: “Whether they call it complicated grief or spaghetti sauce, it doesn't matter. As long as we had a well-

defined phenomenon here.” Another noted “Oh, I didn't really think much about it. I'm not sure that it's the right word that I would use. It doesn't really matter to me.” Another said, when asked if she identified with the term “complicated grief”: “Not at all. I felt I loved so much. And I got so much love from [deceased partner] that it was. ... I just, I wanted help. ... [I knew I was having a] hard time. And I knew that that's the place I needed to be. The title had nothing to do with it.” Some of these participants actually had a strong negative reaction to the label of CG. As one stated: “Well, that's not the appropriate term, but complicated almost makes it an accounting problem.” Another said: “I thought it was a little bit artsy, you know? I mean, sounded to me, like contrived or something ... like a given name in sort of an artificial way or something.” Suggestions for other names included “super grief,” “anxiety loss,” or a name with the word “disorder” or “reaction” in it.

However, regardless of their feelings about the CG label, the distinction between CG and “normal” grief was clear in participants' minds. As one stated: there is “normal grief [but] some people carry it all the time and some people never get over it.” Another said: “Complicated [grief], it's totally different. ... I don't even say apple and oranges or whatever. It just has to be handled differently.” Similarly, most participants felt a strong identification with CG-specific treatment. One noted that “what was appealing was that it was different from what I had done.” In all these cases, the identification of themselves as having CG seemed to result in a desire for CG-specific treatment.

Discussion

This study uses the descriptive phenomenological approach to explore the grief support-seeking process among a group of bereaved older adults who sought care from a CG treatment study. Participants described several core experiences in their process, including having grief symptoms that were severe, impairing, and long lasting, a sense that grief symptoms not meeting expectations, insufficient support from family and friends, encouragement to get care from family and friends, ineffective support from grief support groups and mental health professionals, and a positive view of CG-specific treatment. The final stage of phenomenological research is reintegration, which involves assimilating bracketed material (including both researcher interpretations and previously published literature) with the identified phenomena and providing some interpretation. Existing models and theories provide some context for results.

Pescosolido's Network-Episode Model (NEM; Pescosolido & Boyer, 1999; Pescosolido, Gardner, & Lubell, 1998), and Thoits' self-labeling theory (Thoits, 1985) may both enhance understanding of support seeking for CG. Both have been used to examine mental health support seeking in outpatient settings (Pescosolido, Wright, Alegria, & Vera, 1998; Thoits, 2011). Moreover, both view support-seeking as essentially a social process. The interaction between social relationships and professional support seeking may be especially salient in bereavement support-seeking, as evidence indicates that most bereaved individuals first seek support from family and friends, and then seek professional support when those resources are lacking in some way (Benkel, Wijk, & Molander, 2009).

The NEM (Pescosolido & Boyer, 1999; Pescosolido, Gardner, et al., 1998) is based on several assumptions. First, those with mental illness often consult with a range of individuals about their symptoms, including informal supports (like family members, friends, coworkers, religious leaders, and ethnic/traditional healers) and formal providers (like physicians and mental health professionals). Second, support-seeking is a dynamic process, involving a series of decisions, rather than a single event or choice. People experiencing mental health problems usually continue to seek advice regarding their concerns until the problems have reached a resolution. Finally, social network members play a key role in mental health service use. The availability of the social network (the number of people in the network and frequency of contact with them) determines the networks' potential influence on access to, volume, and types of services used. However, it is the content of the social network (including norms like the beliefs, experiences, values, and attitudes of those in the network about support-seeking), the sources of instrumental and emotional support provided in the network, information and coercion given that actually influences support-seeking behavior. In general, then, the NEM emphasizes the importance of how available social networks influence support seeking (Pescosolido, 1992).

In keeping with the NEM, participants did not seek treatment in a linear way. Rather, they tried to get help with their grief from a variety of individuals, including family, friends, physicians, grief groups, and a number of mental health professionals until they found a treatment (the CGTOA study) that they felt met their needs. Four of the eight participants had sought other professional support for grief before enrolling in the CGTOA study. The fact that many entered grief treatment because of input from friends or other providers also fits with the NEM, as these social network members helped shape support-seeking behavior. However, data is not available in the current study from those who did not seek treatment because their social ties provided sufficient support; both mechanisms may be operating for older adults with CG. The study also provides preliminary information on how exactly social network members might encourage support-seeking—some had received grief treatment themselves, and recommended it; some observed distress in participants and expressed concern; and, in one case a participant was told that her relationship might suffer if she did not seek care. Previous research revealed similar trends. Pescosolido, Gardner and colleagues (1998) have found, for example, that those with severe mental illness are often encouraged to go to treatment by others. research has also shown that having a relationship with someone who recommends seeking help, or who has themselves sought mental healthcare, was associated with positive expectations about mental health services and more positive attitudes to help seeking (Vogel, Wade, Wester, Larson, & Hackler, 2007).

Self-labeling theory focuses more specifically on internal recognition of having a mental health condition (Thoits, 1985). According to Thoits, self-labeling begins when distressed individuals notice that their reactions are intense, recurrent, or prolonged compared to cultural norms; she calls this recognition of “emotional deviance.” The theory assumes that the person who self-labels internalizes the norms for behavior and perspectives of their larger culture, and can recognize when they are violating those norms. Often, awareness of discrepancy arises through comparison to others who have had similar experiences. Thoits refers to differences between private emotional experiences and societal views of what emotional reactions one “should” have as a condition of “norm-state discrepancy.” Certain

categories of norms are given labels when norm-state discrepancy occurs, including the label of a mental illness. Thoits' theory also operates under the assumption that most social actors want to conform to social expectations. Thus, when they self-observe that they have violated social norms, either in thoughts or behavior, they make attempts to conform again. Mental health support-seeking offers one avenue to do so, as treatment can help alter feelings to fit norms.

Participants detailed a process of recognizing that grief was causing distress, similar to that proposed by Thoits' self-labeling theory (Thoits, 1985). As Thoits argues, situations where emotional reactions are prolonged and frequent tend to be labeled as a mental illness. All participants described their grief as both intense and long-lasting. Thoits also posited that mental illness labels are usually assigned as a result of social comparison. Study participants often engaged in a process of comparison to others who were grieving, noted that their grief was more severe than others' reactions or from their previous experiences, and then identified their grief as a different (or "deviant") response.

Also consistent with self-labeling theory, many participants noticed that family and friends viewed their reactions as unusual (or "socially undesirable") and withdrew. This sudden absence of, or judgment from, others who had previously supported them created a need to find support from other avenues. For study participants, and as hypothesized by Thoits, seeking professional support for grief often replaced lacking social support. The association between bereavement support-seeking and low family and friend support is also consistent with previous research. For example, in a qualitative study with 38 relatives of deceased cancer patients about their reasons for joining a bereavement support group, lack of support from family and friends was commonly identified (Picton et al., 2001).

Findings also parallel other qualitative research. Howard (2006) interviewed 29 adults with a variety of mental health conditions about the process of identifying (and later deidentifying) with their conditions. She found that finding a label for one's condition helped participants make sense of their experience and overcome feelings of being overwhelmed and out of control. Before finding the label, symptoms felt nebulous, while identification with labels provided a sense of order and presented a direction for treatment. Howard argues that the label allows for a creation of a cohesive narrative, where there is an explanation for past symptoms, an understanding of present experiences, and an idea of what to expect in the future. In the current study, the identification process was similar to that in Howard's sample, with the CG label providing a sense of comfort and order to many participants and allowing them to find effective CG-specific care.

The study has several limitations. I was an Independent Evaluator on the CGTOA study as part of my graduate research assistantship when interviews were conducted, and had already established a relationship with many participants in the CGTOA study through work conducting structured interviews with them. My pre-existing relationship with participants and participation as an interviewer on the CGTOA study may have reduced the ability to "bracket out" my perceptions and affected my interpretation of results. In cases where I had interacted previously with participants, I had information about their loss and their response to treatment which may have prevented me from asking relevant content-specific questions.

My previous role on the study may have also impacted what participants shared and what they omitted. Validity may also be a concern. Not all of those who were contacted about the qualitative study agreed to participate in it. Those who refused may have had very different treatment experiences than those who participated. In addition, because data were collected retrospectively (over a year since participant's enrollment in the CGTOA), their description of their experiences may have been altered by memory and experience.

Finally, though generalizability is not a goal of qualitative research, transferability can be (Seale, 1999). Transferability involves consideration of whether the data could be applied to other situations. The study sample was made up of a very distinct group, and their support seeking may not be easily transferred to other populations. Participants were seeking treatment in a large urban area in the northeastern United States. Most had a long history of treatment-seeking, which might speak to specific cultural norms about the acceptability of mental health help-seeking. Moreover, all participants had a history of depression. Though discussions of depression arose infrequently in the interviews, and all participants felt that grief (rather than depression) was their most important problem upon CGTOA study enrollment, history of depression may have accounted in part for the high rate of mental health treatment-seeking before study enrollment. Many participants' skepticism about using religious support may also reflect that most were from New York City, an urban, fairly secular part of the country. In addition, all were seeking treatment specifically through a research study; motivation to participate in research may be different than help seeking in a clinical setting (e.g., perhaps more motivated by altruism, or an interest in novel forms of care). All of these limitations may impact the transferability and credibility of the findings.

Future Directions

Study findings have several potential practical applications. First, increasing awareness of CG, both among mental health providers and the general public, may assist in detection of the disorder and also lessen the feelings of isolation and misunderstanding experienced by and about those with CG. Many participants experienced judgments of symptoms from family and friends, which negatively impacted these relationships. Many participants also interacted with several mental health providers before finding the study, including providers specializing in bereavement support, but only a few ever mentioned CG. While the importance of having a specific label for CG varied by participant, knowing that treatment was available for their condition was helpful for all of them. A few participants noted that the rejection or dismissal they received from friends and family about their condition was allayed once they shared knowledge of CG with them. If the sense of validation described is indeed important to recovery from CG, then greater community knowledge may be an important first step in engaging those with CG in care and in order to address their symptoms.

Participants suggested several ways to reach others in similar situations who had not yet sought care. These included a large-scale public relations effort, radio ads, newspaper ads and articles, television ads and news reports, information on websites, direct contact with bereaved individuals who may have CG through death certificate information or funeral homes, and making professionals more aware of CG and its treatment (including having a

CG checklist available at intake visits). Specific training in identifying CG among those who are most likely to come into contact with bereaved individuals, including hospice and palliative care workers and nurses at hospitals and nursing homes, seems especially needed. All of these methods may be effective in increasing public and professional awareness of CG.

More generally, participants' experience of "waiting it out"—expecting their distress to get better on its own—may be unique to grief, and may make both internal perceptions of and reactions of others to complicated bereavement reactions different than with other mental disorders. Because grief is a common human experience, and for most people does lessen naturally with time, knowing when to wait and when not to wait may be quite difficult to determine. Whether this experience of waiting is important in other mental health conditions, like depression or anxiety disorders, requires more empirical attention. Some participants sought treatment fairly quickly for grief, but many did not seek professional treatment for years; one waited almost 40 years. It should also be noted that all enrolled participants had symptoms continuously from the time of the loss, but Jacobs (1993) has written about delayed and absent grief, in which grief reactions do not appear for some time after a loss, if at all. The absence of pangs of grief is usually combined with severe emotional numbing and disbelief, severe symptomatology of other types (like pain syndromes), and virtually no other symptoms of disturbance. When there is a delay in the onset of grief symptoms, treatment seeking may also be delayed. In general, greater research attention to why some older adults seek grief treatment right away and others wait may contribute greatly to understanding of service utilization for grief.

The notion of wanting to cope with grief on one's own, expressed by many participants, may be specific to American culture, which tends to value autonomy more than other societies (Markus & Kitayama, 1991). In cultures outside of the United States, greater existing support, from family and friends or religious organizations, may be more available and widely utilized. There may also be variability within the United States; African Americans often utilize group activities at churches to assist with their grief and these services may take the place of mental health services (Clements, Vigil, Manno, Henry, Wilks, Das, et al., 2003). Though African Americans and Whites appear to have similar rates of CG (Stroebe et al., 2007) African Americans generally are less likely to seek mental health treatment than Whites (Neighbors, 1985). However, as this sample only included one African-American participant and African Americans make up less than 10% of the larger CGTOA study, data could not be gathered on unique aspects of support seeking. Expectations for how long grief should last and what it should entail may also be culture-specific (Clements et al., 2003). Interviews with grieving older adults in non-White, non-American cultures are needed. Participants also varied greatly in how much of their support seeking was motivated by internal perceptions of needing support and how much by information or encouragement from others. Greater exploration of the intersection of internal processes and external social or cultural influences on CG support-seeking, and when and how each mechanism may operate, would also be useful.

While more research remains to be done, the study results reveal new details about the process by which a group of older adults who enrolled in a CG treatment study sought care

for their grief. Findings draw attention to the role of social support and to the importance of labeling symptoms in support-seeking for CG. These preliminary findings may eventually be practically applied in order to increase the detection and effective treatment of CG.

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Table 1
Participant Demographics, Types of Loss, and Time Since Loss ($N = 8$)

Variable	Mean or n	SD or %
Age	72.6	7.9
Female gender	6	75.0
White race	6	75.0
Completed college	6	75.0
Lost a partner	3	37.5
Lost a child	2	25.0
Lost a parent	2	25.0
Lost a friend	1	12.5
Time since the loss (years)	6.6	11.8