Assessing Grief in Family Caregivers of Individuals With Alcohol Use Disorder or Substance Use Disorder using the Marwit-Meuser Caregiver Grief Inventory Short Form (MM-CGI-SF)

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ABSTRACT: This study assessed grief in caregivers of family members with alcohol use disorder (AUD) and substance use disorder (SUD) using the Marwit-Meuser Caregiver Grief Inventory Short Form (MM-CGI-SF). We used snowball sampling to recruit participants who had family members with AUD and SUD. The sample was comprised of 100 caregivers of family members with AUD and 75 caregivers of family members with SUD. The original MM-CFI-SF was modified by changing the wording to reflect those with AUD and SUD. The 18-item instrument consisted of 3 factors: personal sacrifice burden, sadness and longing, and worry and felt isolation. The professional care of caregivers with family members with AUD and SUD should be addressed by health professionals in the same manner as dementia caregivers. AUD and SUD caregivers may also downplay the distress, require social support, or have a common reaction to the stress and grief encountered. The correlations were moderate to strong and significant between each of the factors for both AUD and SUD caregiver scale.

KEYWORDS: Alcohol use disorder, substance use disorder, Marwit-Meuser Caregiver Grief Inventory, caregiver, grief, social support, coping, burden, family members

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Alcohol use disorder (AUD) continues to be an epidemic in the United States, accounting for 6 deaths a day and 40% of hospital beds nationwide.[1] Not only does AUD impact the individual but also the immediate family.[2,3] AUD is considered a disease, and spouses, children, and parents often take the role of caregiver for the individual with AUD.[4] Lipari and VanHorn[5] reported that approximately 1 in 10 children lived in households with at least 1 parent with an alcohol use disorder.

Likewise, substance use disorder (SUD), is also a chronic illness that affects the brain function and behavior of a family member.[6–8] Family members of individuals with SUD, often women, also take the role of caregiver to the SUD family member.[6,9,10] Children can also have a negative impact from parent SUDs, such as being a caregiver to a parent and increased risk of also developing an SUD. Approximately 1 in 35 children lived in households with at least 1 parent with an illicit drug use disorder.[5]

Existing research of family members of individuals with alcohol and substance use disorders includes variables such as social support,[9–15] stigma,[16–18] conflict,[2,4,19] and family rituals and rules.[13,20,21]

However, a variable that is often overlooked in these studies is grief. Instead, current research discusses grief primarily regarding caregiver depression, burden, stress, and coping.[22]

Yet, research on grief recognizes that it is a "uniquely important and measurable variable among family caregivers with chronic and terminal illness" (p. 191).[23] AUD and SUD are considered chronic illnesses,[3,6-8] and family members often experience grief regarding these chronic conditions.[24,25]

Because grief can be experienced by the family of those with chronic conditions, it should follow that those who are caretakers of family members with AUD and SUD would also experience grief, as AUD and SUD are also considered chronic conditions. Thus, the purpose of this study was to examine the psychometric properties of the Marwit-Meuser Caregiver Grief Inventory Short Form (MM-CGI-SF) to see if it could also be applied to people taking care of family members with AUD and SUD.

Caregiver Grief

Grief is defined as a response to any loss and it is also considered "the price we pay for love" (p. 4).[26] Caregivers can experience grief from loss of personal freedom, loss of familiar communication, loss of future planning, and loss of their mental capacities.[22] While grief research is often associated with death, grief is also experienced as emotional reactions prior to a loss, or pre-death or anticipatory grief, especially among caregivers of persons with chronic illnesses such as cancer and brain injuries.[27,28] Caretakers and families of those with AUD and SUD experience grief due to the condition.[24,25] Thus, we hypothesized that the grief that AUD and SUD families experience will have the same psychometric properties of the

MM-CGI-SF scale, when modified to reflect the context of AUD and SUD family members.

Method

Participants

Snowball sampling was used to recruit eligible participants in 1 of 2 separate IRB approved Qualtrics surveys: (1) family affected by alcohol and (2) families affected by substance dependence. Participants were recruited through the researchers' network of friends and associates requesting participants that have a family member with alcohol or substance use disorder. The researcher indicated the role of grief and social support in this relationship was the focus of the survey. Participants were solicited through social media notifications and through emails to potentially eligible participants. Participants were also recruited through the researcher's professional connections of Alcohol and Other Drug Addiction (AODA) professionals. Participant eligibility was determined by the first 3 questions in the Qualtrics survey: (1) are you over the age of 18 years old, (2) do you have a family member with hazardous alcohol/substance use, and (3) is the family member with hazardous alcohol/substance use currently living. If the 3 questions were not answered "Yes," the survey terminated for the ineligible participant.

Participants for the AUD family study consisted of 100 individuals with an AUD family member. The AUD family members reported the family members with AUD consisted of 44 spouses, 38 adult children, 11 siblings, 4 parents, and 3 others. The family members with AUD included 69 males and 31 females, of which 50% have had past treatment for their harmful drinking.

There were 75 participant caregivers of family members with SUD in the study. The participants reported that their family member with SUD included 24 spouses, 19 adult children and 2 children under 18 years of age, 14 siblings, 11 parents, and 5 others. The family members with SUD included 56 males and 19 females, of which 81.3% have had past treatment for their harmful drug use. Similar to the AUD survey, the most common relationship the family member with AUD/SUD is in most to least order is spouse, adult children, siblings, and then parents. In addition, a majority of the family member with SUD or AUD was reported as male.

Surveys

Two IRB approved online surveys were constructed using Qualtrics that maintained confidentiality for participants. This research is part of two larger studies used to determine the impact of a family member's substance use disorder on other family members. The MM-CGI-SF tool has been modified in the two studies to adapt to (1) individuals with a family member with AUD, and (2) individuals with a family member with SUD. The original MM-CGI-SF inventory form was used to measure caregiver grief. For example, the original scale had items Likert-style items (1 = Strongly Disagree to 5 = Strongly Agree) that said, "Dementia is a double loss. . .I've lost the closeness with my loved one and connectiveness with my family." The AUD version was modified to read, "Family alcoholism is a double loss. . .I've lost the closeness with my loved one and connectiveness with my family," and the SUD version was modified to read, "Family addiction is a double loss. . .I've lost the closeness with my loved one and connectiveness with my family."

Measure

The MM-CGI-SF was developed to replace the prior 50-item measure (MM-CGI) for caregiver grief in 2005.[22,29,30] The 18-item MM-CGI-SF is used for caregivers to measure and identify the impact of pre-death grief-related losses in various areas of life. The loss, pain, burden, and lack of social support often creates a substantial strain on the family member that is now in the new role of caretaker. This loss can be referred to as grief, anticipatory grief, or disenfranchised grief.[22,23,26,29]

The current self-scoring inventory measures the grief experience of family caregivers of persons living with progressive dementia.[23] Like the full form, the grief scores were calculated for caregivers on this self-scoring 18-item measure in three subscales of six items each (1) personal sacrifice burden, (2) heartfelt sadness and longing, and (3) worry and felt isolation. The overall 18-item measure then addresses the total grief level of the caregiver using the Likert scale from 1-strongly disagree to 5-strongly agree.[23]

The correlations were similar in both versions of the measure for the three factors. The long form was .89, .83, and .85, while the short form was .85, .76, and .82. Therefore, Marwit and Meuser[23] have determined that the short version of the measure presents reliability and validity use the measure to measure grief in caregivers. The three factors will be defined next.

The first factor in the scale is *personal sacrifice burden*. The caregiver is often forced to prioritize caregiving to the family member before taking care of oneself.[23] The family member may feel the burden of postponed or missed opportunities for oneself, in place of taking care of the family member with AUD or SUD.[30] For example, one may be unable to go see a movie because of the fear the family member with AUD may come home drunk and wake the landlord.

The second factor in the inventory is *heartfelt sadness and longing*. The intrapersonal sadness that accompanies the feeling of powerlessness and emotional sadness related to the changes that are occurring within the family member while still being unable to accept these changes.[23] The caregiver may be longing for how the relationship previously was or returning to the role they had before caregiver.

The final factor in the scale is *worry and felt isolation*. The caregiver often will spend more time attempting to provide the social support to the family member, without getting the social support required for oneself. Caregivers have already given up

Table 1. Scale reliability: consistencies between applications.

SCALES (SUBSCALES)	PROGRESSIVE DEMENTIA (N=292)	AUD (N=100)	SUD (N=75)
Personal Sacrifice Burden (k=6)	M=20.2, SD=5.3, α=.83	M=16.7, SD=6.5, α=.87	M=18.4, SD=6.3, α=.86
Heartfelt Sadness & Longing (k=6)	M=20.2, SD=5.0, α=.80	M=22.6, SD=4.8, α=.77	M=23.95, SD=4.4, α=.71
Worry & Isolation (k=6)	M=16.6, SD=5.2, α=.80	M=20.8, SD=5.9, α=.81	M=22.3, SD=5.1, α=.73
Total Grief Level (k=18)	M=57, SD=12.9, α=.90	M=59.3, SD=14.8, α=.91	M=64.7, SD=13.4, α=.89

Table 2. Correlation of MM-CGI-SF Factor scores for AUD caregivers.

FACTOR	MM-CGI-SF FACTOR 1	MM-CGI-SF FACTOR 2	MM-CGI-SF FACTOR 3
MM-CGI-SF Factor 1	1.000	.487**	.634**
MM-CGI-SF Factor 2	.487**	1.000	.676**
MM-CGI-SF Factor 3	.634**	.676**	1.000

Table 3. Correlation of MM-CGI-SF Factor scores for SUD caregivers.

FACTOR	MM-CGI-SF FACTOR 1	MM-CGI-SF FACTOR 2	MM-CGI-SF FACTOR 3
MM-CGI-SF Factor 1	1.000	.598**	.540**
MM-CGI-SF Factor 2	.598**	1.000	.590**
MM-CGI-SF Factor 3	.540**	.590**	1.000

**Correlation is significant at the 0.01 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

connection to things and outside relationships important to them in order to dedicate themselves to the caregiver role.[23,30]

All three factors are grief related and put a strain on the caregiver while providing the support to the family member. Although the family member is still alive, the grief process has already begun for the caregiver, and the caregiver may experience a feeling of being caught in the grief process. The overarching purpose of this study was to determine if the caregiver grief scale, MM-CGI-SF[23] would apply to individuals with an AUD or SUD family member.

Results

Cronbach's alpha was calculated for each of the factors with the scale for caregivers of family members with AUD and SUD and compared with the original MM-CGI-SF scale for caregivers of family members with dementia (α=.90). Results indicated that the complete MM-CGI-SF scale for caregivers of AUD (α=.91) and SUD (α=.89) were reliable (see Table 1). Furthermore, the correlations for the three 6 item subscales were consistent with Marwit and Meuser.[23] Factor 1 of personal sacrifice burden subscale (a=83) was slightly higher for caregivers of AUD (α=.87) and SUD (α=.86). Factor 2 of heartfelt sadness and longing subscale (a=80) was slightly lower for caregivers of AUD (α=.77) and SUD (α=.71). Factor 3 of worry and isolation subscale (a=80) had a slight variation for caregivers of AUD (α=.81) and SUD (α=.73).

In addition, correlation coefficients were calculated in a factor analysis to compare the three subscales of the caregivers of family members with AUD caregiver scale. Results indicated that there were moderate to strong significant correlations between each of the variables in the AUD scale (see Table 2).

The resulting correlations to Factor 1 with Factor 2 and Factor 3 respectfully were .487 and .634. The resulting correlation to Factor 2 to Factor 3 was .676 (*P*<.01).

Moreover, correlation coefficients were calculated to compare the factors in the caregivers of family members with SUD scale. Results indicated that there were moderate, significant correlations between each of the variables in the SUD scale (see Table 3). The resulting correlations to Factor 1 with Factor 2 (.598) and Factor 3 (.540). The resulting correlation to Factor 2 to Factor 3 was .590 (*P*<.01).

Marwit and Meuser's[23] scale provided a way to interpret scores on each subscale. The means and standard deviations indicate various grief processes. For example, means 1 standard deviation higher than the overall mean indicate that an intervention is needed to help those process their grief more effectively; means near the standard deviation indicate "common reactions" to grief (p. 199); low means (eg, 1 standard deviation below the overall mean) can indicate a positive adaptation to the situation or can indicate "suppressed grief or psychological disturbance" (p. 199). The means for all three subscales (eg, personal sacrifice burden, heartfelt sadness and longing, and worry and felt isolations) were 1 standard deviation below the overall mean.

Discussion

This study sought examine if the Marwit-Meuser Caregiver Grief Inventory Short Form (MM-CGI-SF) would have similar psychometric properties when applied to caregivers of AUD or SUD family members (Figure 1). The results indicated that the MM-CGI-SF reliably measured grief among caregivers of AUD and SUD family members. In addition, this study demonstrated that grief is something that AUD and SUD

Instructions: This inventory is designed to measure the grief experience of <u>current</u> family caregivers of persons living with alcohol use disorder (AUD) or substance use disorder (SUD). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1-5 to the right using the answer key below (For example 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed below.

ANSWER KEY
1=Strongly Disagree 2=Disagree 3=Somewhat Agree 4=Agree 5= Strongly Agree

1	I've had to give up a great deal to be a caregiver.	1	2	3	4	5	A
2	I feel I am losing my freedom.	1	2	3	4	5	A
3	I have nobody to communicate with.	1	2	3	4	5	C
4	I have this empty sick feeling knowing my loved one is getting worse.	1	2	3	4	5	B
5	I spend a lot of time worrying about the bad things to come.	1	2	3	4	5	C
6	Family alcoholism (Family addiction) is a double loss. I have lost the closeness of my family AUD (SUD) member, and the feeling of connection with my family.	1	2	3	4	5	C
7	My friends simply don't understand what I am going through.	1	2	3	4	5	C
8	I long for what was, what we had and shared in the past.	1	2	3	4	5	B
9	I could deal with other serious disabilities better than with this.	1	2	3	4	5	B
10	I will be tied up with this for who knows how long.	1	2	3	4	5	A
11	It hurts to help my AUD (SUD) family member last time and know it will happen again.	1	2	3	4	5	B
12	I feel sad about what the harmful alcohol (drug) use has done.	1	2	3	4	5	B
13	I lay awake at night and worry about what's happening and how I'll manage tomorrow.	1	2	3	4	5	C
14	The people closest to me do not understand what I'm going through.	1	2	3	4	5	C
15	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5	B
16	Independence is what I've lost. I don't have the freedom to go and do what I want for myself.	1	2	3	4	5	A
17	I wish I had an hour or two to myself each day to pursue my personal interests.	1	2	3	4	5	A
18	I'm stuck in this caregiving world and there's nothing I can do about it.	1	2	3	4	5	A

Self-Scoring Procedure: Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you.
Personal Sacrifice Burden (A Items) = ___
(6 items, AUD: M = 16.7, SD = 6.5, α = .87, n = 100; SUD: M = 18.4, SD = 6.3, α = .86, n = 75)
Heartfelt /Sadness & Longing (B Items) = _____
(6 items, AUD: M = 22.6, SD = 4.8, α = .77, n = 100; SUD: M = 23.95, SD = 4.4, α = .71, n = 75)
Worry & Felt Isolation (C Items) = _____
(6 items, AUD: M = 20.8, SD = 5.9, α = .81, n = 100; SUD: M = 22.3, SD = 5.1, α = .73, n = 75)
Total Grief Level (Sum A+B+C Items) = _____
(18 items, AUD: M =59.3, SD = 14.8, α = .91, n = 100; SUD: M = <u>64.7, SD =13.4, α = .89, n = 75)</u>
Plot your scores using the grid to the right. Make an "X" nearest to your numeric score for each sub-scale heading. Connect the X's. This is your grief profile. Discuss this with your support group leader or counselor.

See Marwit & Meuser (2005) for copyright information and permissions

MM-CGI-SF Personal Grief Profile

30			**High**
25			
20			**Average**
15			
10			
5			**Low**
0			
	Personal Sacrifice Burden	**Heartfelt Sadness & Longing**	**Worry & Felt Isolation**

What do these scores mean? Scores in the top area are one standard deviation (SD) higher than average based on responses of other family caregivers (n = 100, n = 75). High scores may indicate a need for formal intervention or support assistance below the mean) may indicate denial or a downplaying of distress. Low scores may (one SD below the mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaption if the individual is not showing other signs of suppressed grief or psychological disturbance. Average scores in the center indicate common reactions. These are general guides for discussion and support only - more research is needed on specific interpretation issues.

Figure 1. Marwit-Meuser caregiver grief inventory short form (MMCGI-SF) for caregiver family members of individuals with alcohol use disorder and substance use disorder.

caregivers experience, despite not being examined as a separate variable in previous research.

Furthermore, the results of this study indicate that those experiencing grief may not be acknowledging it. The results note that they are experiencing grief, but it is perhaps not viewed as grief because it does not fit the traditional setting when grief occurs (eg, loss). This could point to several issues. First, it could mean that the individuals know how to deal with their grief. This could include having a good system of social support or knowing how to adjust and handle the AUD and SUD situations with their loved ones. This could also indicate that perhaps they are used to this type of behavior and have developed a system to deal with these issues. Alternatively, these lower scores could also reflect psychological distress and poor coping skills. As such, scores on the lower end could indicate a need for an intervention to help the family cope in dealing with a family member suffering from AUD or SUD. However, because the meaning of these scores can vary greatly, more research should be done to get a clearer picture of what lower scores indicate.

Practically, this scale is still a useful tool for AUD and SUD counselors. Although there could be confusion regarding what lower scores indicate, having a measure that can give counselors information about the system around the individual suffering from AUD and SUD will be helpful. Even if the lower scores point to good coping strategies of family members, this scale would help start a conversation with the family system to provide other resources and to understand the dynamics affecting AUD and SUD behaviors and the relationships with their caregivers.

Limitations and Future Research

One limitation with the study is the sample. While snowball sampling is purposive, it also has its own limitations, such as the possibility for the lack of representativeness in the sample and sampling bias. For example, multiple members of one family could possibly have taken the survey, which could have had an effect on the results. Future research should use random sampling and ensure that multiple people from one family are treated as a group and not as independent observations.

Moreover, this research shows that this scale can be useful for those caring for family members with AUD or SUD, but more research needs to be done regarding what the low scores indicate. Currently, low scores could indicate good coping strategies or psychological distress. These are two very different situations, and future research needs to examine how to distinguish between what the lower scores mean.

In addition, future research should examine communication as a variable in the scale. The current scale examines aspects of social support, which is defined as the "verbal and nonverbal communication between recipients and providers that reduces the uncertainty about the situation, self, the other, or the relationship that enhance a perception of personal control in one's life experiences" (p. 19).[31] The essence of social support is communicative, so future research should examine how communication functions in situations regarding caregivers of those suffering from AUD and

SUD. By examining that variable separately, perhaps it will be clearer what the lower scores indicate.

Overall, this study examined grief in a different population than previous studies, looking at the caregivers of AUD and SUD. Previous research has overlooked the role of grief in caregivers of AUD and SUD individuals, but it is a variable that should be addressed, as these caregivers do experience it. Overlooking the grief that caregivers of AUD and SUD individuals experience can lead to less effective healing for those suffering from AUD and SUD because the entire support system is not considered. Thus, it is important that counselors and support systems recognize caregivers' grief so that a situation is created that helps the individual stay sober long-term.

Author Contributions
DAP designed the project, collected and analyzed the data. MBA joined Priddis in the evaluation of the analysis and writing of the manuscript.

Ethical Approval
The research has been approved by the Institutional Review Board (IRB) at Middle Tennessee State University as Protocol ID 17-1226. All participants were 18 years of age or older and were provided a mandatory informed consent before completing the survey.

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