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Examination of the Psychometric Properties of Marwit-Meuser Caregiver Grief Inventory-Short Form

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SUMMARY

Objective: Alzheimer caregiving literature usually focuses on caregiver outcomes like burden, depression and anxiety from a stress-coping paradigm. Yet, this approach has been criticized as it doesn't capture pre-death grief symptoms emerged in response to the unique pathology of the disease. The aim of this study is to investigate the reliability and validity criteria of the Turkish version of the Marwit-Meuser Caregiver Grief Inventory-Short Form (MMCGI-SF) developed to evaluate pre-death grief reactions of adult offspring caring for a parent with AD.

Method: The Turkish version of MMCGI-SF was tested on 190 adults providing care to their parents with AD. Beck Depression Inventory, State-Trait Anxiety Inventory-State Form, Zarit Burden Inventory, Caregiving Well-Being Scale and Multidimensional Scale of Perceived Social Support were also completed by the participants to examine convergent and divergent validity of the scale.

Results: Results of the Confirmatory Factor Analysis showed a good fit between the Turkish version of the MMCGI-SF and the original 3-factor structure of the scale. Total score of the scale was found to have significant positive correlations with depression, anxiety and caregiver burden and significant negative correlations with caregiver well-being and perceived social support scores. The Cronbach Alpha value of the scale was 0.92 and the test re-test reliability was 0.80.

Conclusion: Results of the study have shown that Turkish version of the MMCGI-SF was a reliable and valid tool to assess the pre-death reactions of adult offspring caregivers of AD.

Keywords: Alzheimer's disease, caregiver burden, anticipatory grief, reliability, validity

INTRODUCTION

Alzheimer's disease (AD) is a progressive neurodegenerative disorder resulting in permanent cognitive, emotional and physical impairments (Alzheimer's Society 2017). Although its most commonly recognized symptom is memory loss, impairment in judgement and reasoning, communication difficulties, personality changes and behavioral problems are amongst other disabling symptoms of the disease (Alzheimer's Society 2017, World Health Organization 2018). As the symptoms become more severe, AD patients need constant assistance and supervision for daily living activities (e.g. eating, bathing, walking) and behavioral problems (e.g. wandering, anger outbursts). Particularly in developing countries the primary caregivers of AD patients are determined on the basis of kinship (Ginzler 2009, Schulz and Martire 2004). In Turkey, 85% of the AD patients are cared for at home by their spouses, adult children or daughters- in-law (Alzheimer's Europe 2013). These caregivers, who are regarded as the ''invisible patient group", mostly do not benefit from health care services due to the lack of targeted psycho-social intervention programs and the prevailing cultural belief that ''caregiving is the responsibility of the family" (Alzheimer's Europe 2013, Brodaty et al. 2005, Knight and Sayegh 2010).

Caregiving outcomes of AD have been mainly investigated from a stress-coping paradigm. Studies revealed that AD caregivers experience greater depression, anxiety, burden, life

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dissatisfaction and somatic symptoms when compared to other caregiver groups due to chronic and ambiguous nature of the disease (Brodaty et al. 2005, Ross and Dagley 2009, Smith et al. 2001). However, researchers have started to criticize stress-coping paradigm as it fails to capture pre-death grief experiences of informal caregivers, which is a hidden yet important component of AD caregiving (Chan et al. 2013, Doka 2010, Meuser and Marwit 2005, Ott et al. 2007). Consistently, it was demonstrated that approximately half of the variance in the depressive symptoms of the AD caregivers could have been explained by the pre-death grief symptoms, which might have been previously confused with the symptoms of depression (Ponder and Pomeroy 1996, Sanders and Adam 2005). Therefore, it is crucial to differentiate these similar but conceptually distinct mental states for this caregiver group in order to establish effective psycho-social intervention programs (Blandin and Pepin 2015, MacCourt et al. 2017, Marwit and Meuser 2005).

Grief is generally conceived as the emotional, cognitive and physical reactions given in response to the loss of a loved one (Zisook and Shear 2009). However it is known that grief symptoms sometimes emerges long before the physical death in chronic illnesses like cancer (Large and Slinger 2015, Rando 2000). This anticipatory grief process emerging before the physical death is known as 'pre-death or anticipatory grief' (Large and Slinger 2015, Lindauer and Harvath 2014). AD caregivers go through a complicated pre-death grief process known as 'ambiguous loss' due to the complications specific to the prognosis of AD (Boss 2000, Large and Slinger 2015, Lindauer and Harvath 2014). Family members observe 'psycho-social death' of their loved ones due to profound cognitive destruction and personality changes of the AD patient (Diwan et al. 2009, Doka 2010). Despite being physically present, AD patient is not the person ''previously known" by the family members. This vacillating situation triggers sadness, anger and longing for and creates role confusions among family members (Boss 2000). Family members regard this process of losing while the patient is still physically present as a 'never-ending funeral' (Doka 2010). AD caregivers grieve for many small and major losses at a daily basis. They lose the past relationship they had with the patient, reciprocal sharing, previous family roles and quality of past relationship (Diwan et al. 2009, Lindauer and Harvath 2014, Shuter et al. 2014). The lack of closure in this process is thought to impede adaptation of caregivers to the disease process and caregiving responsibilities (Boss 2000, Doka 2010). Also, cognitive destruction nearly bars the reciprocity between the patient and caregiver which complicates the reconciliation of past confrontations (Blandin and Pepin 2016, Lindauer and Harvath 2014). In addition to those primary losses, caregivers also simultaneously experience secondary subjective losses (e.g. loss of social and public roles) due to extended caregiving responsibilities (Meuser and Marwit 2005). These secondary losses further complicate the pre-death grief reactions of AD family members (Loos and Bowd 1997, Meuser and Marwit 2005, Sanders and Corley 2003).

Continuation of sadness, anger, guilt, longing, burden and withdrawal of the caregivers even after hospitalization or physical loss of the AD patient have lead researchers to look beyond stress-coping paradigm and to investigate the pre-death grief concept. Research indicated that prevalence of pre-death grief symptoms among AD caregivers ranged between 47% and 71% (Chan et al. 2013, Collins et al. 1993, Sanders and Corley 2003, Walker and Pomeroy 1996) and these symptoms were associated with caregiver burden, depression, negative evaluations of caregiving and chronic grief symptoms after physical death (Gataric et al. 2010, Givens et al. 2011, Kiely et al. 2008, Schulz et al. 2006). If left untreated, pre-death grief symptoms were also found to predict poorer caregiving quality, as well (Kim et al. 2012, Mittelman et al. 2006, Pinquart and Sörensen 2003).

There are well-established scales in literature measuring grief reactions of bereaved individuals. However, these scales aim to measure normal and complicated grief reactions after the physical death of a loved one (Ayaz et al. 2014, Balcı Çelik 2006, Selvi et al. 2011, Tomita and Kitamura 2002). In Turkey, Gökler-Danışman and her colleagues adapted the Turkish version of Prolonged Grief Disorder Scale-Patient Form that is used to measure anticipatory grief responses of cancer patients (2017). Still, this measure is not specific enough to capture particular grief reactions of AD caregivers which result from unique pathology of the disease. As mentioned above, AD family members experience a complicated form of pre-death grief process due to ongoing losses that are extended over long periods of time. Two psychological measurement tools had been particularly developed the in international literature to fill this gap (Theut et al. 1991, Marwit and Meuser 2005). Yet, it is evident that Marwit-Meuser Caregiver Grief Inventory-Short Form (MMCGI-SF) is usually preferred by the researchers because of its strong theoretical and methodological background.

Urgency for intervening with the immediate needs of AD patients, difficulty of differentiating pre-death grief reactions from depressive symptoms and cultural beliefs emphasizing ''inappropriateness of grieving for an alive person" usually lead pre-death grief symptoms of AD caregivers to be overlooked by the society (Lindauer and Harvath 2014, McEvoy 2007). Consequently, using psychometric tools that specifically evaluate pre-death grief experiences of AD caregivers is important for the wholistic assessment of these complaints. Therefore, this study aims to investigate psyhometric

properties of the Turkish version of MMCGI-SF among adult children caregivers of AD.

METHOD

Participants

The current sample consisted of 190 adult children who still provided care for a parent with AD. Inclusion criteria were as follows: (1) providing at least 4 hours of assistance for the parent and defining oneself as a 'primary caregiver' (Alzheimer's Association, 2018), (2) the diagnosis of the patient was given by a neurologist. Only adult offspring caregivers were recruited for the study since caregiving outcomes differed depending on type of the relationship between the caregiver and patient (Meuser and Marwit, 2001). The mean age of the participants were 51.14 (*range*=26-77, *SD*=±8.68). Majority of the caregivers were female (89.5%), while more than half of them were co-residing with the patient (*N*=129, 67.9%). Disease and caregiving- related characteristics are presented in Table 1.

Table 1. Socio-Demographic Characteristics and Disease-Related Characteristics of AD Caregivers

Variables	N	%	M	SD	Range
Gender	190				
Female	170	89.5			
Male	20	10.5			
Age			51.41	8.68	26-77
Education					
Primary School	5	2.6			
Secondary School	13	6.8			
High School	63	33.2			
University and Beyond	109	54.7			
Working Status					
Employed	73	38.43			
Unemployed	102	53.68			
Retired	15	7.89			
Time Since Diagnosis (years)			5.6	3.48	1-19
Length of Caregiving (years)			5.23	3.46	1-15
Caregiving per Week (hours)			103.57	65.91	4-168
Co-residence					
Yes	129	67.9			
No	61	32.1			
Type of Relationship					
Mother	144	75.8			
Father	46	24.2			
Stage of Disease					
Mild	20	10.5			
Moderate	75	39.5			
Severe	95	50			

Instruments

Demographic Information Form: A demographic information form was developed by the researchers to obtain information regarding socio-demographic details and caregiving characteristics of the participants.

Marwit-Meuser Caregiver Grief Inventory-Short Form (MMCGI-SF): MMCGI was developed to measure pre-death grief reactions particular to family caregivers of AD. Item pool was generated through comprehensive focus groups conducted with spousal and adult children caregivers of patients with dementia. (Marwit and Meuser 2002, Meuser and Marwit 2001). The initial scale consisted of 50 items answered on a 5-point Likert type format (1 = *strongly disagree*, 5 = *strongly agree*). Increased scores obtained from the total scale indicated increased severity of pre-death grief reactions. Principal component analyses revealed a 3-factor structure comprising (1) Personal Sacrifice Burden, (2) Heartfelt Sadness and Longing, and (3) Worry and Felt Isolation. The first factor, *Personal Sacrifice Burden*, aims to measure secondary personal losses of family members (e.g. loss of freedom, loss of social interest) due to extensive caregiving responsibilities (i.e. *"I've had to give up a great deal to be a caregiver"*). The second factor, *Heartfelt Sadness and Longing*, assess pre-death grief symptoms resembling traditional grief reactions observed after physical death. This factor aims to measure sadness and longing felt in response to the changes in personality, loss of roles and quality of past relationship (i.e. *"It hurts to put her/him to bed at night and realize that s/he is gone*"). Items 4, 8, 9, 11, 12 and 15 compromised this sub-factor. The third factor, *Worry and Felt Isolation*, aims to measure perceived worry due to unpredictable nature of AD (i.e. *"I spend a lot of time worrying about bad things to come"*) and felt isolation due to lack of understanding from others (i.e. "*My friends simply don't understand what I'm going through*"). Items 3, 5, 6, 7, 13 and 14 were included in this sub-factor.

The final version of the MMCGI-SF was developed by reducing item numbers to 18 while preserving the 3-factor structure of the original scale in order to ease the administration process in larger samples. Through examination of the total and inter-item correlations, 6 items for each factor had been chosen which were thought to represent the corresponding factor best. Consequently, MMCGI-SF was developed (Marwit and Meuser 2005). To establish convergent validity of the shorter version, correlation coefficients were calculated between scores obtained from MMCGI with 50 items and MMCGI-SF with 18 items. The correlation coefficients were 0.92 for Personal Sacrifice Burden, 0.93 for both Heartfelt Sadness and Longing and Worry and Felt Isolation subscales (p<0.01). Cronbach alpha values were reported as 0.88, 0.82 and 0.82 for each sub-factor, respectively. Consistent with the psychometric characteristics of the original version, MMCGI-SF had

significant positive correlations with two different depression scales and Anticipatory Grief Scale. Correlation coefficients were 0.71, 0.69 and 0.76, respectively (p<0.01). Besides, Zarit Burden Inventory had the highest correlation with the scores of Personal Sacrifice Burden, among other subscales. Lastly, MMCGI-SF had significant negative correlations with perceived social support and caregiving well-being scores

Beck Depression Inventory (BDI): Beck and his colleagues (1961) originally developed BDI to assess cognitive, emotional, behavioral and physical symptoms of depression. The scale consists of 21 items answered on a 3-point Likert type scale. Higher total scores indicate increased severity of depressive symptoms. BDI was adapted to the Turkish by Hisli (1989). The Cronbach Alpha value was 0.80, while the split-half reliability was computed as 0.74. A moderate positive correlation was reported between Minnesota Multiphasic Personality Inventory (MMPI) Depression Subscale and BDI providing support for concurrent validity (r=0.50, p<0.01). BDI was used to establish convergent validity of MMCGI-SF in the current study. The Cronbach Alpha value was 0.88 for this sample.

Zarit Burden Inventory (ZBI): ZBI was developed by Zarit and his colleagues in 1980 to measure physical, emotional and social burden resulting from caregiving duties. The scale consists of 22 items which were answered on a 5 point Likert type format (1 = *Never,* 5 = *Always*). Higher scores indicate greater caregiver burden. ZBI was adapted to the Turkish by Özlü and her colleagues in 2009. The Cronbach alpha value of the total scale was 0.83. Convergent validity of the scale was investigated through calculating correlation coefficient between ZBI and Maslach Burnout Inventory; and a significant moderate correlation was found (r=0.61, p<0.01). ZBI was used to establish convergent validity of MMCGI-SF in the current study. The Cronbach Alpha value was 0.91.

Caregiver Well-Being Scale (CWS): CWS was developed by Berg-Weger and his colleagues (2000) in order to investigate the extent to which caregivers fulfill their physical, emotional and social needs while carrying out caregiving duties. The scale consists of 22 items answered on a 5 point Likert type scale. Higher scores indicate greater well-being among caregivers. Adaptation of the CWS to the Turkish language was made by Demirtepe-Saygılı and Bozo in 2009. The Cronbach alpha value was 0.93 for the Basic Needs subscale and 0.89 for the Activities of Daily Living subscale. The correlation between Basic Needs subscale and BDI was -0.71, while it was -0.69 between Activities of Daily Living subscale and BDI indicating evidence for convergent validity. Further evidence for convergent validity comes from the positive correlations between two subscales of CWS and general well-being scores (r=0.54, r=0.55, respectively). The CWS was used to establish divergent validity of the MMCGI-SF in the current study. The Cronbach Alpha value of the total scale was 0.93.

Multidimensional Scale of Perceived Social Support (MSPSS): MSPSS was developed by Zimmet and his colleagues (1988) to measure perceived social support from family, friends and significant others. The scale consists of 12 items answered on a 7 point Likert type scale. Increased scores indicated greater perceived social support. Adaptation of MSPSS to the Turkish language was made in two separate studies by Eker and his colleagues in 1995 and 2001. Cronbach alpha values were reported as 0.85 and 0.91, respectively. The criteria validity of MSPSS was tested through establishing its correlations with the UCLA Loneliness Scale (LS) and Brief Symptom Inventory (BSI). The correlations of MSPSS with UCLA LS and BSI scores were -0.63, and -0.58, respectively (p<0.01). MSPSS was used to provide evidence for divergent validity of MMCGI-SF in the current study. The Cronbach alpha coefficient was 0.90.

State-Trait Anxiety Inventory-State Form (STAI-S): STAI-S was developed by Spielberger and his colleagues in 1970. The state form includes 20 items answered on a 4 point Likert type format. State form measures transient anxiety felt in response to stressful life situations. Increased total scores indicated greater worry and anxiety. Adaptation of the scale to the Turkish language was performed by Öner ve Le Compte in 1985. The Cronbach alpha values ranged from 0.83 to 0.87 for the state form. STAI-S had significant positive correlations with various anxiety measures and the correlations were found to be ranging from 0.52 to 0.80 indicating good convergent validity. STAI-S was used to establish divergent validity of the MMCGI-SF in the current study. The Cronbach alpha value was 0.94.

Procedure

Initially, written permission was obtained from the developers of the original MMCGI-SF. The original version in English was translated to the Turkish independently by three academicians who were fluent both in Turkish and in English. Three sets of translations were then rated by two different clinical psychologists, and items with the highest scores were kept for the final version. Turkish version of MMCGI-SF was then back-translated to English by an academician from the Department of English Literature. Examination of corresponding items in Turkish and in English revealed excellent conceptual convergence. Finally, wording, grammar and comprehensibility of the Turkish items were inspected by a lecturer in Literary Studies and, the final version was formed based on the suggestions and feedbacks received.

Ethical permission for data collection was obtained from METU Human Subjects Ethics Committee. All the scales were uploaded to an online data collection platform, called Qualtrics. Data of the study were collected from three separate social media groups established to enhance psycho-social support among family members of AD patients. Before recruiting participants, written permission was taken

from the administrators of each of the 3 groups. A written informed consent form including information on the principles of volunteer participation and confidentiality was presented to each participant. Also, an informative brochure about functional caregiving coping strategies were sent to participants via e-mail. For the test-retest reliability analysis, the MMCGI-SF was tested on the same social media groups 2 months later. To match subjects for the examination of test-retest reliability, a nickname was created by the participants who accepted to fulfill the scale after 2 months.

RESULTS

Validity

Construct Validity: Confirmatory Factor Analysis (CFA) is known to provide more detailed and sophisticated information regarding factor structure of the previously validated scales. Thus, CFA was preferred over Exploratory Factor Analysis (EFA) in the current study to establish construct validity of the MMCGI-SF (Kellowey 1995, Kline 2015). The original version of MMCGI-SF consists of 18 items with 3 subscales each containing 6 items. Firstly, confirmatory factor analysis (CFA) was carried out using EQS program by keeping the item counts and distribution of the scale, thus testing the match between the current data and 3-factor model of the original scale. When the original scale was entered in the analysis, moderate fit indices were obtained ($\chi^2(132)=411.416$, $p<0.000$, *RMSEA*=0.10, *CFI*=0.84, GFI=0.79). Subsequently, 3 error covariance suggested by the Lagrange Multiplier (LM) test were added to the model. The first error covariance was added between two items of Worry and Felt Isolation (item 7: '*my friends simply don't understand what I'm going through*' and item 14: *'the people closest to me do not understand what I'm going through*'). The second error covariance was added between two items of Personal Sacrifice Burden (item 1: *'I've had to give up a great deal to be a caregiver'* and item 2: '*I feel I am losing my freedom*'). Final error covariance was added between two items of Heartfelt Sadness and Longing (item 11: '*It hurts to put her/him to bed at night and realize that she/he is gone*' and item 12: '*I feel very sad about what this disease has done*'). All of the suggested modifications were performed since correlated item pairs were theoretically similar and loaded to the same sub-factor (respectively, χ^2dif (1)=61.63, $p<0.001$; χ^2dif (1)=24.15, $p<0.001$ and χ^2dif (1)=22.15, $p<0.001$). Suggested modifications significantly improved the model and final model showed satisfactory goodness of fit with the original 3- factor structure of the scale ($\chi^2(129)=303.681$, $p<0.000$, *RMSEA*=0.08, *CFI*=0.91, *GFI*=0.85). Additionally, the ratio of chi square to df was found to be lower than 3 which also indicated a good fit between the current data and the original factor structure (Tabachnick and Fidell 2001). The factor structure and items of the final version are presented in Table 2.

Table 2. Items and Factor Loadings of the Turkish version of MMCGI-SF

Factor Explained	Item-Total Correlation	Factor Loadings
Personal Sacrifice Burden α = 0.88		
1. I've had to give up a great deal to be a caregiver.	0.56	0.66
2. I feel I am losing my freedom.	0.68	0.84
10. I will be tied up with this for who knows how long.	0.65	0.64
16. Independence is what I've lost... I don't have the freedom to go and do what I want.	0.80	0.87
17. I wish I had an hour or two to myself each day to pursue personal interests.	0.60	0.69
18. I'm stuck in this caregiving world and there's nothing I can do about it.	0.69	0.77
Heartfelt Sadness and Longing α = 0.82		
4. I have this empty, sick feeling knowing that my loved one is "gone".	0.64	0.73
8. I long for what was, what we had and shared in the past.	0.47	0.62
9. I could deal with other serious disabilities better than with this.	0.59	0.56
11. It hurts to put her/him to bed at night and realize that she/he is "gone".	0.57	0.76
12. I feel very sad about what this disease has done.	0.43	0.64
15. I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	0.70	0.73
Worry and Felt Isolation α = 0.82		
3. I have nobody to communicate with.	0.52	0.56
5. I spend a lot of time worrying about the bad things to come.	0.58	0.62
6. Dementia is like a double loss… I've lost the closeness with my loved one and connectedness with my family.	0.71	0.79
7. My friends simply don't understand what I'm going through.	0.48	0.51
13. I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	0.70	0.74
14. The people closest to me do not understand what I'm going through.	0.64	0.69
Total Internal Consistency Value: 0.92		

Table3. Correlation Coefficients between the MMCGI-SF, BDI, ZBI, STAI-S, CWS and the MSPSS

	1	2	3	4	5	6	7	8	9
1. MMCGI-SF Total	1	0.87**	0.84**	0.90**	0.52**	0.78**	0.48**	-0.38**	-0.26**
2. Personal Sacrifice Burden		1	0.57**	0.68**	0.40**	0.76**	0.39**	-0.35**	-0.094
3. Heartfelt Sadness and Longing			1	0.67**	0.56**	0.56**	0.39**	-0.21**	-0.04
4. Worry and Felt Isolation				1	0.56**	0.71**	0.48**	-0.41**	-0.26**
5. BDI					1	0.47**	0.62**	-0.57**	-0.29
6. ZBI						1	0.48**	-0.31**	-0.12
7. STAI-S							1	-0.47**	-0.22
8. CWS								1	0.34**
9. MSPSS									1

**p<0.01
MMCGI-SF: Marwit-Meuser Caregiver Grief Inventory- Short Form; BDI: Beck Depression Inventory; ZBI: Zarit Burden Inventory; STAI-S: State-Trait Anxiety Inventory-State Form; CWS: The Caregiver Well-Being Scale; MSPSS: Multidimensional Scale of Perceived Social Support

Convergent and Divergent Validity: Correlation coefficients were computed between MMCGI-SF, BDI, ZBI, STAI-S, CWS and MSPSS to evaluate convergent and divergent validity of the Turkish version of the MMCGI-SF. Total MMCGI-SF scores were positively correlated with BDI scores (r=0.52, p<0.001), ZBI scores (r=0.78, p<0.001), and STAI-S scores (r=0.48, p<0.001). In consistent with the original study, Personal Sacrifice Burden had the strongest correlation with caregiver burden scores (r = 0.76, p<0.001) among other sub-factors. Worry and Felt Isolation aiming to assess anxiety regarding unpredictable losses in AD had a slightly higher correlation coefficient with the anxiety scores. Also, total MMCGI-SF scores were negatively correlated with perceived social support level (r=-0.38, p<0.001), and caregiver well-being scores (r=-0.26, p<0.001). Worry and Felt Isolation was the only sub-factor which had a significant correlation with perceived social support scores (r=-0.26, p<0.001). The correlation coefficients among variables are presented in Table 3.

Reliability

Internal consistency reliability was 0.92 for the total scale, 0.88 for Personal Sacrifice Burden, and 0.82 for both Heartfelt Sadness and Longing and Worry and Felt Isolation subscales. Test-retest reliability with a 2-month time interval was 0.80, 0.77, 0.73 and 0.74, respectively (N=57, M=42, SD±8.28). Item-total correlations ranged from 0.47 to 0.80 for the total scale, from 0.56 to 0.80 for Personal Sacrifice Burden, from 0.47 to 0.70 for Heartfelt Sadness and Longing, and from 0.48 to 0.71 for Worry and Felt Isolation. Deletion of any items did not increase the Cronbach alpha values of the total scale or subscales. Split half reliability calculated through odd-even numbers method was 0.90.

DISCUSSION

To the researchers' knowledge, this is the third study outside USA context examining the psychometric properties of MMCGI-SF (Chan et al. 2017, Liew et al. 2017). Cultural factors have been known to influence grief-related experiences of AD caregivers (Chan et al. 2013). Thus, adaptation of MMCGI-SF to populations with different socio-cultural values is instrumental to our understanding of the unique and common needs of AD caregivers from different socio-cultural backgrounds.

Current study indicated that Turkish version of the MMCGI-SF also has a 3-factor structure (Marwit and Meuser 2005) and the scale is a reliable and valid psychometric tool for assessing pre-death grief reactions of AD caregivers in Turkey. Consistent with the original studies, a moderate positive correlation was observed between MMCGI-SF and depression scores of adult offspring caregivers (Marwit and Meuser 2002, Marwit and Meuser 2005). A much debated question in AD caregiving literature is whether pre-death grief reactions were confused with caregiver depression due to common symptoms shared by both mental states (Sanders and Adams 2005, Ott et al. 2007, Kiely et al. 2008). Although some symptoms, such as sadness and hopelessness, are manifested in both conditions, pre-death grief and depression are conceptually different phenomena with different predictors and outcomes. Whereas depression refers to a more general mood state associated with low self-worth, grief is more internally oriented and emerges in response to a loss (Boelen and van den Bout 2005, Shear et al. 2005). Also, separation anxiety and longing for are more likely to be manifested in grief-related reactions (Shear et al. 2005). Due to the similarity of the symptoms and grief reactions being associated with physical loss, pre-death grief reactions of AD caregivers might have been misinterpreted as caregiver depression (Ponder and Pomeroy 1996, Sanders and Adam 2005, Walker and Pomeroy 1996). In this respect, the moderately positive correlation between MMCGI-SF scores and depression scores provided further evidence that despite the similarity of these two psychological states, they are qualitatively different and might necessitate different intervention strategies.

As expected, a significant positive correlation was found between total MMCGI-SF scores and caregiver burden. Consistent with the original studies, Personal Sacrifice Burden had the highest correlation with subjective burden as this sub-factor aims to measure secondary losses (e.g. loss of freedom, loss of social interest and loss of psychological health) associated with caregiving responsibilities. Hence, it is theoretically sensible that Personal Sacrifice Burden had a relatively higher association with caregiver burden scale that measures psycho-social impacts of caregiving process (Chan et al. 2017, Marwit and Meuser 2002, Marwit and Meuser 2005, Meuser and Marwit 2001). On the other hand, Worry and Felt Isolation subscale had a relatively stronger association with caregiver burden scores when compared to previous studies. While the correlation coefficient was 0.71 for the current study, it ranged from 0.46 to 0.58 in other studies (Chan et al. 2017, Marwit and Meuser 2002, Marwit and Meuser 2005). This difference might be attributed to the different interpretation of the items of Worry and Felt Isolation subscale by Turkish caregivers. This subscale aims to measure anxiety provoked by future losses and felt isolation due to invalidation of pre-death grief experiences. From this perspective, it is probable that Turkish caregivers conceptualize social isolation as a secondary loss. Interpersonal relations have a profound importance in the daily living practices of Turkish people (Kağıtçıbaşı 1994, Lai 2009). Hence, social isolation might just create a unique relational burden for the Turkish adult offspring as AD caregivers (Ar and Karanci 2017, Lai 2009).

Finally, the positive correlation between MMCGI-SF and anxiety scores, and negative correlations with caregiver well-being scores and the perceived social support scores provide further evidence for the convergent and divergent validity of the Turkish version of MMCGI-SF (Chan et al. 2017, Liew et al. 2017, Marwit and Meuser 2002, Marwit and Meuser 2005). Particularly, the strong correlation between the Worry and Felt Isolation subscale and anxiety symptoms indicated that this subscale measures the anxiety and worry emerging due to anticipation of possible future losses. Consistently, previous studies also indicated that implicit losses such as those of future plans and past relationships, and explicit losses such as the patient's inability to recognize the caregiver result in a state of continuous anxiety among AD caregivers (Frank 2008, Holley and Mast 2009). Besides, Worry and Felt Isolation was the only subscale having a significant association with perceived social support levels in the current study. Existing literature indicated that pre-death grief reactions of AD caregivers usually remain unnoticed by society due to absence of a physical loss. Accordingly, many caregivers felt that their grief reactions are invalidated which further increases their social withdrawal and loneliness (Doka 2010). Caregiver burden and ambiguous losses associated with disease progression were regarded as unalterable aspects of AD caregiving process. Hence, external sources like social support usually had relatively limited impact on these aspects of pre-death grief reactions (Marwit and Meuser 2005, Shear and Shair 2005). By contrast, Worry and Felt Isolation component was more open to change through use of external resources like social support which might explain the significant association of Worry and Felt Isolation with perceived social support scores in the current study (Marwit and Meuser 2005).

While there are many psycho-social intervention programs to alleviate depression, anxiety and burden levels of dementia caregivers (Cooke et al. 2001, Liew et al. 2017), lack of a systematic intervention program targeting pre-death grief reactions of AD caregivers is noteworthy. Still, pre-death grief is an inherent part of AD caregiving process which might have differential impacts on other caregiver outcomes (Boss 2000, Doka 2010). Therefore, it seems crucial to develop psycho-social intervention strategies aiming to process grief-related experiences (e.g. loss of past relationship, role confusions, loss of reciprocal communication) and aiming to create a new normal to fulfill multidimensional needs of AD caregivers (Liew et al. 2017). In this respect, Turkish adaptation of MMCGI-SF is thought to be an important step to identify and fulfill grief-related needs of informal family caregivers in Turkey.

One of the limitations of the current study is the inclusion of only adult offspring of AD patients as caregivers. This limits the use of scale with spousal caregivers since spouses and adult children differed in their pre-death grief reactions due to nature of the relationship they had with the patient (Marwit and Meuser 2005). Additionally, lack of another psychometrically sound instrument assessing unique grief reactions of AD family caregivers might have created a disadvantage while establishing concurrent validity of the scale. Finally, these findings may be somewhat limited by the fact that data were collected from internet users who might have greater educational backgrounds than non-internet user caregivers.

In conclusion, AD family caregivers experience a unique form of pre-death grief experience due to distinct nature of the disease pathology. In this respect, it is crucial to assess caregivers' pre-death grief reactions with psychometrically sound measurement tools designed to capture this different form of pre-death grief experience. Therefore, the current study contributed to the existing literature by providing a reliable and valid instrument capturing grief-related needs of Turkish caregivers. Besides, use of this instrument might help to carry the concept of the pre-death grief to the agenda of the mental health professionals.

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