

# Research Paper: Contribution of Time Since Diagnosis in Anticipatory Grief of Mothers of Children Diagnosed With Cancer: A Descriptive Study in Iran



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## ABSTRACT

**Objective:** Anticipatory grief is one of the most prominent psychological phenomena in mothers of children diagnosed with cancer. The aim of present study was to compare anticipatory grief of mothers of children diagnosed with cancer within the previous 1 month and those whose children were diagnosed 6-12 months earlier.

**Methods:** This was a cross-sectional study. The sample consisted of 70 mothers living in Mashhad; the children of 35 mothers were diagnosed with cancer within the previous 1 month, and the children of 35 mothers were diagnosed with cancer 6 to 12 months earlier. The instrument was Marwit and Meuser Caregiver Inventory: Childhood Cancer. For data analysis in addition to the procedures of descriptive statistics (mean, standard deviation), inferential statistics (MANOVA) has been used.

**Results:** The results of MANOVA revealed that there is a significant difference between the anticipatory grief of mothers of children diagnosed with cancer within the previous 1 month and those diagnosed 6-12 months earlier.

**Conclusion:** Mothers of children recently diagnosed with cancer need to receive adequate support interventions.

## 1. Introduction

Pediatric cancer has risen dramatically in recent years and has become the second most common cause of death in children (Kazak & Noll, 2015). The annual incidence rate of pediatric cancer is approximately 150 cases per one million children in the age

group 0-14 years (Hile, Erickson, Agee, & Annett, 2014; Matzioua et al., 2008). Fortunately, in many parts of the world, treating children with cancer has been successful, so that more patients can expect a long recovery and full cure (Govender, Bowen, German, Bulaj, & Bruggers, 2015). Currently, approximately 80% of children with cancer in the UK survived for at least 5 years after diagnosis (Childhood Cancer Research Group, 2016), and

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the survival rate in Western Europe and America were found to be the same (Steele, Mullins, Mullins, & Muiriel, 2015). Thus, pediatric cancer is now recognized as a chronic and life-threatening; however, a curable disease in early diagnosis (Kazak & Noll, 2015). Parents have threatened fear for years relating to the return of illness and even death of their children (Hocking et al., 2014).

Traditionally, research on children with cancer focused on parents' pathological symptoms and mental health, which was considered synonymous with the absence of objective symptoms. In the research literature, little attention has been paid to the intrapsychic variables. Anticipatory grief is one of these intrapsychic factors that underlie the problems in the adaptation of parents of children with cancer (AL-Gamal & Long, 2010). Anticipatory grief is defined as the phenomenon that involves the process of mourning, coping, reacting, planning and psychological reorganization that begins and stimulates in response to the imminent loss of a beloved person (Rando, 2000). In a comprehensive review of anticipatory grief, Fulton (2003) concluded that the most practical value of this concept is to warn physicians and other health care providers about the effects of relatives' anticipatory grief on the patient's emotional states.

Empirical studies on anticipatory grief have suffered from the lack of consensus about the definition of this variable (AL-Gamal & Long, 2010). Worden (2018) defines anticipatory grief as an active process of being sad that occur prior to the actual loss; in this course of waiting for death, a caregiver starts to mourn and experiences diverse grief responses. Conceptual analysis shows that anticipatory grief is a multidimensional phenomenon (Rando, 2000). This phenomenon has been formulated in Meuser and Marwit (2001) caregiver predeath grief conceptual model. This model suggested that the caregiver grief before death of loved ones oscillates between personal responsibilities, emotional and social domains depending on the expectations and demands of current health care.

Parental reactions to their child's diagnosis of a chronic and potentially fatal illness can include denial, confusion, fear, feelings of inability to cope, anger and tension (Patištea, 2005). Childhood cancer creates an emotional crisis for the whole family and affects the quality of family reactions and adjustment to the diagnosis, which fosters an impact on child and family health (Vespa, Jacobsen, Spazzafumo & Balducci, 2011). When a child is diagnosed with a life-threatening illness, parents use long-term strategies for coping with emotional distress due to the uncertainty. They try to be consistent with the shock and disappointment and help their child to have

the best chance for cure while preparing themselves for the likely death of their child. In this situation, the incidence of anticipatory grief leads to confusion and sense of lack of future in parents (AL-Gamal & Long, 2010).

For most parents of children with cancer, recurrence of illness is accompanied by doubt, anxiety, grief, fear and lack of normal family life (AL-Gamal & Long, 2010). Mu et al. (2001) found that during the treatment, parents consider the return of cancer and vague symptoms as a sign of impending death. On the other hand, childhood cancer creates cognitive, emotional and physical polygonal needs for the whole family (Young, et al., 2002). All of these are influenced by anticipatory grief phenomenon (Rando, 2000; AL-Gamal & Long, 2010); thus, studying anticipatory grief of parents of children with cancer is very important. Despite the fact that childhood cancer has a significant negative effect on the mental status of the parents and may lead to mental disorders in them, adequate attention has not been paid to anticipatory grief of parents in previous literature studies. There is evidence of significant negative effects on parents that their children have been diagnosed with cancer, but diversity of definition, lack of focus on cultural issues, and limitations in instruments led to the contradictory findings. The present study is an attempt to overcome some of these problems through a clear definition of the concept, using a multidimensional instrument, and determining the effect of time on the diagnosis of anticipatory grief symptoms.

## 2. Methods

The study had a post-facto descriptive, comparative, and cross-sectional design. All mothers of children with cancer living in Mashhad in the last year and those who have transferred their children to one of the Mashhad hospitals constitute the samples of the current study. In collaboration with the hospital nursing department a list of mothers of children with cancer was prepared, and from the list, 70 mothers with random sampling were selected considering the time since diagnosis. Among them, child of 35 mothers were diagnosed with cancer within the previous 1 month, and child of rest 35 mothers were diagnosed with cancer 6 to 12 months earlier. Exclusion criteria included diagnosis of axis 1 disorder and a history of drug addiction, physical illness, and neurological disorders such as epilepsy, any type of brain injury, and mental illness. After the members were selected, each member visited the researcher at a time when she was able to dedicate at least 20 minutes for the research. Then, to get the subjects' anticipatory grief scores, the MM-CGI Childhood Cancer questionnaire were administered on them. Each subject usually

had 10 to 20 minutes to respond to the questionnaire. The questionnaires were performed individually and the subjects were informed to answer the questions by taking into account the knowledge of their personality and their psychological state. All participants were approved by an appropriate ethics committee. According to the ethical standards of the American Psychiatric Association and the ethics code of Iranian Organization of Psychology and Counseling (2006), in this research, the participants were informed about the research and its conditions, such as the timing of the evaluation, random selection, the confidentiality of their personal information and the right to withdraw from the research at any time they wish, and their informed consent was obtained. Mothers were living with a child with cancer in the same home (to reflect the actual experience of living and caring for a child with cancer). Two groups were considered to determine anticipatory grief in these mothers. Therefore, there was realization of need to support mothers, and notice the changes from the time of initial shock of diagnosis of their child with cancer to sometimes after they had experienced a complete cycle of treatment and factors related to their child's illness.

Anticipatory grief was assessed using the MM-CGI Childhood Cancer (Al-Gamal, Long, & Livesley, 2009). This inventory measures physical, emotional and social responses among parents of children who have been diagnosed with cancer. MM-CGI Childhood Cancer (Al-Gamal et al. 2009) is the only instrument that considers anticipatory grief as a multifaceted phenomenon. This test consists of three subscales: "personal sacrifice burden," "heartfelt sadness and longing" and "worry and felt isolation." All 50 questions of this test are equally weighted and are scored in a Likert spectrum from strongly disagree to strongly agree.

In the study by Al-Gamal et al. (2009), the Cronbach coefficient for the total instrument was 0.95, and for the subscales was 0.91 for personal sacrifice burden, 0.90 for heartfelt sadness and longing, and 0.86 for worry and felt isolation. Also, the instrument was positively and statistically significantly correlated ( $r=0.91$ ,  $P<0.001$ ) with the Anticipatory Grief Scale, demonstrating good convergent validity. In the current study, the Cronbach coefficient for the total instrument was 0.93, and for the subscales was 0.89 for personal sacrifice burden, 0.91 for heartfelt sadness and longing, and 0.88 for worry and felt isolation.

Data analysis was performed using SPSS version 19. To clarify the results of the implementation of questionnaires on sample members, descriptive statistics (frequency, percentage, mean, mean, and standard deviation) were

used. Since the data were distributed normally; we used the MANOVA to examine the mean differences between the total score of anticipatory grief and subscales of the questionnaire between mothers of newly diagnosed children and those who were diagnosed 6-12 months ago. The Pearson correlation coefficient was used to determine the correlation between anticipatory grief scores in the sample and age of the mother and child. To compare anticipatory grief scores of subjects with different demographic characteristics, ANOVA was used.

### 3. Results

Demographic information related to sample members has been reported in Table 1. Mean and standard deviation of anticipatory grief scores in two groups are presented in Table 2.

To find whether there is a significant difference between the mean total anticipatory grief scores and subscales among the mothers of newly diagnosed children and those diagnosed 6-12 months previously MANOVA was conducted. Results of MANOVA are presented in Table 2.

Results of Table 3 demonstrate that value of F related to Wilks' Lambda is 10.409 ( $P<0.0005$ ). Therefore, difference of at least one dependent variable (total anticipatory grief scores and subscales) among the mothers of newly diagnosed children and those diagnosed 6-12 months previously can be considered significant. Therefore, each of the dependent variables was compared among the mothers of newly diagnosed children and those diagnosed 6-12 months earlier. The results are presented in Table 4.

MANOVA results in Table 4 indicates that there is a significant difference between the mothers of newly diagnosed children and those diagnosed 6-12 months earlier in terms of personal sacrifice burden subscale ( $F_{(1, 68)}=21.118$ ,  $P<0.0005$ ), heartfelt sadness and longing subscale ( $F_{(1, 68)}=13.744$ ,  $P<0.0005$ ), worry and felt isolation subscale ( $F_{(1, 68)}=27.184$ ,  $P<0.0005$ ) and total MM-CGI childhood cancer ( $F_{(1, 68)}=27.181$ ,  $P<0.0005$ ), so that the total anticipatory grief scores and subscales are greater in mothers of newly diagnosed children than those diagnosed 6-12 months earlier.

### 4. Discussion

The aim of present study was to compare anticipatory grief of mothers of children recently diagnosed with cancer and those whose children were diagnosed 6-12 months earlier. Results showed that mothers of children

**Table 1.** Frequency distribution of mothers' gender education level, children's type of cancer and mean and range of age.

Variables		6 to 12 Months Earlier Diagnosed Group	Newly Diagnosed Group
Age of mother	Mean	33.12	32.27
	SD	6.68	6.23
	Range	23-56	22-52
Age of child	Mean	7.48	8.59
	SD	2.76	3.12
	Range	2-11	2-12
Level of education	Primary education	14.3	17.1
	Junior	22.9	22.9
	Diploma	22.9	25.7
	Associate	14.3	11.4
	Bachelor	20	14.3
	Master	5.6	8.6
Children's type of cancer	ALL	37.1	40
	AML	22.9	25.7
	Neuroblastoma	11.4	5.7
	Medulloblastomas	2.9	8.6
	Wilms tumor	5.7	5.7
	Hodgkin	8.6	2.9
	Non Hodgkin	5.7	5.7
	Rhabdomyosarcoma	5.7	5.7

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diagnosed with cancer within the previous 1 month reported a higher level of anticipatory grief and its components in comparison to those whose children were diagnosed 6-12 months earlier. It means that cancer diagnosis in children has an acute and intensive effect on the psychological state of mothers, and over time, this ef-

fect becomes milder. When mothers confront the cancer diagnosis in their child, they experience a wide range of negative emotions, such as confusion, denial, anger, and helplessness that find expression in anticipatory grief (Al-Gamal and Long, 2010).

**Table 2.** Mean and standard deviation of anticipatory grief scores considering diagnosis time

Variables	6 to 12 Months Earlier Diagnosed Group		Newly Diagnosed Group	
	Mean	SD	Mean	SD
Personal sacrifice burden	52.65	7.14	60.40	6.94
Heartfelt sadness and longing	44.62	6.57	50.74	7.21
Worry and felt isolation	53.45	4.85	60.80	6.76
Total MM-CGI childhood cancer	150.74	15.39	171.94	18.48

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**Table 3.** Multivariate tests of anticipatory grief scores and subscales among the mothers of newly diagnosed children and those diagnosed 6-12 months earlier

Effect	Value	F	Hypothesis df	Error df	Sig.
Pillai's trace	0.321	10.409 <sup>a</sup>	3.000	66.000	0.000
Wilks' lambda	0.679	10.409 <sup>a</sup>	3.000	66.000	0.000
Hotelling's trace	0.473	10.409 <sup>a</sup>	3.000	66.000	0.000
Roy's largest root	0.473	10.409 <sup>a</sup>	3.000	66.000	0.000

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**Table 4.** Univariate test of anticipatory grief scores and subscales among the mothers of newly diagnosed children and those diagnosed 6-12 months earlier

Source	Dependent Variable	df	Mean Square	F	Sig.	Partial Eta Squared	Observed Power
Group	Personal sacrifice burden	1	1049.157	21.118	0.000	0.237	0.995
	Heartfelt sadness and longing	1	654.229	13.744	0.000	0.168	0.955
	Worry and felt isolation	1	943.557	27.184	0.000	0.286	0.999
	Total MM-CGI childhood cancer	1	7865.200	27.181	0.000	0.286	0.999

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The findings on the acute and intensive effect of child cancer diagnosis on mothers are consistent with the findings of Wong and Chan (2006), Moore, Talwar and Moxley-Haegert (2015) and Al-Gamal and Long (2010). These researchers concluded that anticipatory grief in the early stage of confronting to child cancer diagnosis is at the maximum level and over time the intensity reduces.

In explaining the difference between anticipatory grief of mothers of children recently diagnosed with cancer and those whose children diagnosed 6-12 months earlier, should note to difficulties in regulating emotions and dysfunctional coping styles of mothers at the time they encountered to cancer diagnosis in their child. Rafii, Oskouie and Shoghi (2014) showed that shortly after child's cancer diagnosis, mothers showed a severe weakness in emotional regulation, which again improved over time. Also, Nikfarid, Rassouli, Borimnejad and Alavimajd (2015) reported that with passing time the parents would be consistent with the fear of losing their child with cancer and try to give this experience another meaning. According to Peek and Melnyk (2014), parent adoption with childhood cancer pressures over time, which is due to the support of surrounding people and supportive institutions that is absent in diagnosis time.

Mothers of cancer children have mental problems resulting from changes in their relationships with their

families and friends. In some cases, Mothers of cancer children have no time for social relationships because they are captive of caring the child. After a while of time of diagnosis, they adapt child's illness problems and anticipatory grief reduces.

Reactions of mothers to the child's cancer diagnosis can be denial. Worden (2018) noted that the first step to healing anticipatory grief is to accept the reality of loss to go on successfully to other steps. In our study, most mothers of children recently diagnosed with cancer reported difficulties in accepting child's illness; however, less than one-third in the other group felt this way. Accordingly, we inferred that specialists who worked with mothers of children recently diagnosed with cancer, need to support them in accepting their child's diagnosis and treatment in order to advance effectively to other tasks of anticipatory grief. In summary, the results of this study revealed that mothers of children recently diagnosed with cancer reported more anticipatory grief of those whose children were diagnosed 6-12 months earlier. Due to the heavy pressure they bear, mothers of children recently diagnosed with cancer need to receive adequate support interventions at the time they faced while the children were diagnosed with cancer.

Anticipatory grief is a subjective concept that can be assessed by the individual himself. Therefore, the re-



researcher's confidence in the accuracy of the responses on behalf of the research units and also lack of strong literature about anticipatory grief in Iran are among the limitations of the research. Given the importance of the psychological state of mothers of cancer children, it is highly recommended to carry out other studies in this regard for more generalization.

As reported, the results of this study indicate the acute effects of cancer diagnosis in children as anticipatory grief and a wider range of mental health problems for parents and caretakers of cancer children. In summary, the present study showed that for parents, one of the most difficult stages of adaptation to childhood cancer is tolerance of emotional disturbances at the time of diagnosis. Regarding the critical role of mothers of cancer children in the continuous care of their child, especially at the time of cancer diagnosis, their psychological status is of utmost importance; therefore, using interventions that target anticipatory grief at the time of diagnosis can be promising to increase their mental health.

## Ethical Considerations

### Compliance with ethical guidelines

All participants were approved by an appropriate ethics committee. According to the ethical standards of the American Psychiatric Association (APA) and the ethics code of Iranian Organization of Psychology and Counseling (2006), in this research, the participants were informed about the research and its conditions, such as the timing of the evaluation, random selection, the confidentiality of their personal information and the right to withdraw from the research at any time they wish, and their informed consent was obtained.

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### Conflict of interest

The authors declared no conflict of interest.

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