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Effects of Illness Representation, Perceived Quality of Information Provided by the Health-Care Professional, and Perceived Social Support on Depressive Symptoms of the Caregivers of Children with Leukemia

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Abstract The present study examined the effects of illness representation, perceived quality of information provided by the health-care professional, and perceived social support on the depressive symptoms of the caregivers of children with leukemia. The sample was composed of 71 caregivers of children with leukemia living in Turkey. The obtained data were analyzed by path analysis. The results show that caregivers of children with leukemia experience higher levels of depressive symptoms when they have negative illness representation and lower levels of depressive symptoms when they perceive higher levels of social support. Moreover, they perceive higher social support when they perceive high quality of information provided by health-care professionals. It can be suggested that intervention programs which aim to increase caregivers' social support and change their illness representation in a positive way would be helpful for the caregivers showing depressive symptoms.

Keywords Caregiver · Leukemia · Depression · Perceived social support · Illness representation

Leukemia is the invasion of bone marrow by abnormal white blood cells so that the production of red blood cells stagnates. Thirty-five percent of all cancer types seen during childhood are leukemia cases (Lösev, 2007). Every year 1200–1500 children under the age of 16 are diagnosed with leukemia in Turkey. Although leukemia is seen approximately 10 times more in adults than in children, it is the most common kind of cancer among children (Lösev, 2007).

Parents of children with leukemia have to deal with the emotional tension of caregiving for their children through diagnosis, treatment, and sometimes relapse or death (Eiser, Eiser, & Greco, 2002). Patistea (2005) revealed that nearly all parents have reported their child's leukemia as a threatening situation. It was also found that fathers and mothers do not differ in their perceptions of the seriousness of the illness significantly, since they all agreed that leukemia is a threat to the child's life. This high level of perceived seriousness towards leukemia and regard of it as a threat indicate that childhood cancer might cause a considerable amount of stress among parents (Patistea, 2005). Other research related to parents' emotional and social responses to leukemia has revealed similar results. For instance, parents of children with leukemia usually report high level of distress, depression, loneliness, feelings of lost, role strain, helplessness, and uncertainty (cited in Patistea, 2005). In addition, parents of children with leukemia experience a dilemma; although they wish to continue their child's daily routine of life, they also need to avoid risks of injury and infection (Eiser et al., 2002).

For parents to make informed decisions, it is necessary for health-care professionals to inform the parents about pediatric cancers. For example, family members of patients with esophageal cancer, who are found to be more worried than the patient after the diagnosis, need more information from health-care professionals about treatment, testing, and caring compared to the patients themselves (cited in Andreassen, Randers, Naslund, Stockeld, & Mattiasson, 2007). In the study of Atkin and Ahmad (2000) parents reported two difficulties they experienced, which were lack

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of information and impotence, and unsympathetic approach of health-care professional. Also, these parents considered health-care professionals as being disinterested in their child's suffering. For this reason, as it was stated in study of Patistea (2005), nurses and doctors should support parents of children with leukemia and provide them essential knowledge and competence, which in turn might help them to adapt to the new situation more easily. This adaptation process corresponds to maintaining their daily routine lives. However, it is not an easy process for families of children with leukemia. Beginning from the diagnostic phase, Earle, Clarke, Eiser, and Sheppard (2006) emphasize the role of providing concrete and realistic information by health-care professionals in order to guide families to continue their normal lives. This guidance prevents families from being disappointed in the later phases of illness and lets them acquire effective coping strategies (Earle et al., 2006). Similarly, Katz (2002) stated that parents of children with a severe disease like cancer use health-care professionals as a coping source during the frequent hospital visits.

Swallow and Jacoby (2001) emphasize the influence of the relationship between ill children and health-care professionals on the relationship between mothers and health-care professionals. In the study of McGrath, Paton, and Huff (2005), it was concluded that returning home during the treatment is also a stressful event for parents of children with leukemia. For the parents, returning home sometimes means getting far away from the security of helpful health-care professionals, and this leads to high levels of anxiety among parents. According to Patistea and Babatsikou (2003), parents who had higher education and have had previous experience with cancer would like to gain much more information about the illness of their children. Being informed about the illness reduces parental stress and uncertainty. Therefore, health-care professionals should provide adequate information to the parents of children with leukemia. However, it is not always possible for all parents of children with leukemia to gain adequate information. For example, parents living in large cities are better informed than the ones living in smaller cities (Patistea & Babatsikou, 2003).

In childhood cancer, parents experience both emotional and physical problems related to their child's illness. The psychological adjustment phase of mothers is especially important to the illness of their children. Hans (2003) indicates that the higher levels of stress the mothers experience, the more frustration they feel during their adjustment period. In order to deal with these stressors, they develop various coping behaviors (Patistea, 2005). One of the most effective sources of coping is seeking social support. Parents look for support from various sources such as friends, relatives, religion, and elders in order to find the best treatment; as a result, they learn both standard and alternative treatments (Yeh, 2003). Based on the interviews they made with parents of children with leukemia, McGrath et al. (2005) concluded that the support the parents received from their family made the situation easier for them. However, in order to cope with emotional problems, being too optimistic is not appropriate because parents who are too optimistic may reject the warning signs of illness of their children (Yeh, 2003). Moreover, in the study of Pinquart and Sörensen (2007) it was found that emotional and physical problems that parents experienced were associated with each other. That is, higher levels of depressive symptoms of the caregivers predicted lower levels of physical well being. As it was suggested in the stress buffering hypothesis (Cohen & Willis, 1985), social support decreases the negative effects of stressors in people's life, which in turn positively affects their health and well being. According to the stress buffering model, people with strong social support tend to have better health than those with weak social support, but only with respect to exposure to stressors (Cohen & Willis, 1985). In other words, support protects individuals from the potentially negative influence of stressful events (Dalgard, Bjork, & Tambs, 1995). To conclude, present literature shows that parents of children with leukemia suffer from this illness as if they are the patients themselves. In order to deal with this stress, they need support from medical professionals, spouses, and relatives. The ones who receive support, experience less psychological problems and overcome these problems more easily.

In the light of the literature mentioned above, the purpose of this study was to examine the effects of illness representation, perceived quality of information provided by the health-care professional and perceived social support on depression of the caregivers of children with leukemia. Please note that this study emphasized effects of leukemia on the caregivers of children with leukemia in Turkey. It was hypothesized that (1) negative illness representation would predict higher depressive symptoms; (2) higher perceived quality of information would predict higher perceived social support, (3) higher perceived quality of information would predict lower depressive symptoms, (4) higher perceived social support would predict lower depressive symptoms, (5) social support perceived by the caregivers would mediate the relationship between the perceived quality of information provided by health-care professionals and depressive symptoms, and (6) social support perceived by the caregivers would mediate the relationship between illness representation and depressive symptoms.

Method

Participants

The data of the present study was collected from 71 caregivers between the ages of 17 and 52 ($M = 34.57$, $SD = 7.54$) from hospitals from 3 different cities, namely; Ankara, Bursa, and Trabzon located in Turkey. While 60 of the participants were women (84.5%, mean age = 34.19, $SD = 7.86$), 11 of the participants were male (15.5%, mean age = 36.64, $SD = 5.33$). Participants were selected through ad hoc sampling. While 55 of the caregivers were mothers (77.5%), the rest were fathers ($N = 11$, 15.5%), sisters ($N = 3$, 4.2%), and aunts ($N = 2$, 2.8%). Based on a question on the participants' monthly income, the participants were categorized into lower (less than 500 YTL), middle (between 500 and 1500), and upper classes (more than 1500 YTL).[1] Approximately one half of the sample consisted of lower class ($n = 33$, 46.5%) and the other half consisted of members of middle class ($n = 33$, 46.5%). Only 4 (5.6%) participants were members of high class, and 1 participant did not provide any information (1.4%) about SES. By using one-way ANOVA, the participants were compared across the SES groups on the measures and it was found that SES groups were not significantly different from each other on any of the variables.

Approximately half of the sample was composed of primary school graduates ($n = 33$, 46.5%) and the remaining participants were either illiterate ($n = 11$, 15.5%), or high school ($n = 10$, 14.1%), secondary school ($n = 8$, 11.3%), or college/graduate school ($n = 7$, 9.9%) graduates. Only 2 (2.8%) of the participants were literate with no official education. Participants were compared across the educational level on measures of the current study. The comparison of participants across education levels was only significant for perceived quality of information provided by the health-care professional ($F(5, 65) = 4.02$, $p < .01$). Post hoc analysis using Tukey post hoc criterion for significance indicated that perceived quality of information provided by the health-care professional was significantly lower in college/graduate school graduates ($M = 104.14$, $SD = 9.03$) than in illiterate participants ($M = 124.91$, $SD = 7.79$) and literate participants with no official education ($M = 122.97$, $SD = 11.54$).

Measures

The Illness Representation Scale

The Illness Representation Scale consists of 15 items about illness severity, emotional response to illness, vulnerability to illness, controllability of illness, time appraisal, and self-reflectance. It is a 5-point Likert type scale that was originally developed by Prohaska, Leventhal, Leventhal, and Keller (1985). It was adapted to Turkish culture by Bozo (2001). The scale has 3 factors, namely severity and emotional response, vulnerability and controllability, and self-effectance with moderate reliability values; .74, .69, and .58, respectively. The scale's validity was examined with university students with respect to cancer by correlating it with the Beck Depression Inventory ($r = .25$, $p < .05$) and the Langner Psychiatric Impairment Scale ($r = .50$, $p < .01$), indicating an acceptable validity. In the present study, 11 out of 15 items with a 7-point Likert type scale ranging from 1 (totally disagree) to 7 (totally agree) was used. The internal consistency reliability of the scale in the present study was .68 (see Table 1).

Quality of Information Provided by Health-Care Professional Index

Quality of information provided by health-care professional was measured by an index established by the present authors. The index consisted of 20 items that are rated on a 7-point Likert type scale ranging from 1 (totally disagree) to 7 (totally agree). The index was found to be highly reliable ($\alpha = .84$) (see Table 1). Higher scores on this index indicated greater quality of information provided by health-care professional perceived by caregivers.

Multidimensional Scale of Perceived Social Support

Multidimensional Scale of Perceived Social Support consisted of 12 items about the source and level of social support provided by a significant other, family, and friends. It is a 7-point Likert type scale that ranged from 1 (totally disagree) to 7 (totally agree). It was originally developed by Zimet, Dahlem, Zimet, and Farley in 1988. Cronbach alphas were .91 for special person, .87 for family support, .85 for friend, and .88 for the whole scale. The reliability of the Turkish version was calculated by Cronbach's alpha and was found to be between .80 and .95 (Eker, Arkar, & Yaldız, 2001). The correlational analyses between MSPSS, and the Beck Depression Inventory, and Spielberger State Trait Anxiety Scale revealed that MSPSS is significantly and negatively correlated with the BDI and Spielberger State Trait Anxiety Scale, suggesting that the MSPSS is a valid scale (Eker & Arkar, 1995). In the present study, the

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[1] YTL is the abbreviation for the New Turkish Lira that became the new currency unit in January 1, 2005 (Central Bank of the Republic of Turkey, 2008).

Table 1 Intercorrelations among measures: illness representation, perceived quality of information provided by the health-care professional, perceived social support, and depressive symptoms

Measure	Correlations			
	1	2	3	4
1. Illness representation	(.68)			
2. Perceived quality of information provided by the health-care professional	−.10	(.84)		
3. Perceived social support	−.19	.33*	(.93)	
4. Depressive symptoms	.47*	−.18	−.36*	(.79)

Scores shown in parentheses on diagonal are alpha internal consistency reliabilities

* Correlation is significant at $p < .01$

internal consistency reliability of the scale was .93 (see Table 1). Higher scores on this scale indicated higher perceived social support.

Beck Depression Inventory (BDI)

In the present study the Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) was used to assess the level of depressive symptoms of the participants. The BDI consists of 21 items about somatic, emotional, cognitive, and motivational symptoms that are seen in depression. Each item includes four choices being rated on a 0 to 3 scale, and a lower overall score (out of 63) refers to a lower level of depression (Beck, Steer, & Brown, 1996). The internal consistency reliability of the original scale was .86 for psychiatric patients, and .81 for nonpsychiatric patients. The BDI was translated into Turkish both by Tegin (1980) with Cronbach alpha value of .65 and Hisli (1989) with Cronbach alpha value of .74. Test–retest reliability for the Turkish version of the BDI was calculated as .65, whereas the split-half reliability was .78 for students and .61 for depressive patients. By looking at the correlation between the BDI and Hamilton Depression Rating Scale, criterion related validity of the scale was calculated as .75. In the present study, the internal consistency reliability of the scale was .79 (see Table 1).

Procedure

The necessary permissions were received from Ankara Provincial Directorate of Health and the head of the pediatric oncology or hematology departments of the participating hospitals. The participants of the present study were recruited by convenience sampling. There was no payment for participation. After a brief explanation, the participants were requested to fill out the questionnaires by themselves. Informed consent forms, which described the aim of the study and assured confidentiality, were obtained from the participants before they filled in the questionnaires. The participants were also told that they were free to leave the study at any time. Once they accepted participation subjects were administered the questionnaires including four different instruments, completed by the caregivers of children with leukemia. Except for the demographic information sheet, the order of all measures used in the present study was counterbalanced. Thus, the informants for each of the instruments were the same. It took the participants about 30 min to complete the questionnaires. To test the mediation model, obtained data was analyzed by path analysis, which was done by using SPSS (Statistical Package for Social Sciences) (Green, Salkind, & Akey, 1997).

Results

Table 1 shows the correlation coefficients among the measures used in this study. As expected, these correlations suggested that illness representation is significantly related to the level of caregivers' depressive symptoms ($r = .47$, $p < .01$), indicating that the more negative the illness representation of the caregivers, the higher the level of their depressive symptoms. Moreover, the quality of information provided by the health-care professional and perceived social support were positively related ($r = .33$, $p < .01$) indicating that the higher the quality of information provided by the health-care professional, the higher the social support perceived by the caregivers. It was also found that there is a significant correlation between perceived social support and depressive symptoms ($r = -.36$, $p < .01$), indicating that the higher the social support perceived by the caregivers, the lower the caregivers' level of depressive symptoms.

In order to test the mediation model, two path analyses were performed (see Table 2). Using perceived social support as the mediator, the model included illness representation and perceived quality of information provided by the health-care professional as independent variables; and depressive symptoms as the dependent variable. Thus, to

Table 2 Path analyses for the mediation model

Variable	*B*	*SE B*	*β*	R^2	*F*	*df*
Illness representation						
Step 1 (regressing on perceived social support)						
Education	−1.09	1.36	-1.00^{ns}	.01	$.65^{ns}$	1, 69
Illness representation	−.29	.18	$-.19^{ns}$	.05	1.66^{ns}	1, 68
Step 2 (regressing on depressive symptoms)						
Education	−.31	.69	$-.05^{ns}$	.00	$.21^{ns}$	1, 69
Illness representation	.36	.08	.47***	.22	9.58***	1, 68
Step 3 (regressing on depressive symptoms)						
Education	−.31	.69	$-.05^{ns}$	.00	$.21^{ns}$	1, 69
Illness representation	.32	.08	.41***	.30	9.60***	2, 67
Perceived social support	−.15	.05	−.29**			
Perceived quality of information provided by health-care professional						
Step 1 (regressing on perceived social support)						
Education	−1.09	1.36	-1.00^{ns}	.01	$.65^{ns}$	1, 69
Perceived quality of information Provided by health-care professional	.37	.13	.34**	.11	4.18**	1, 68
Step 2 (regressing on depressive symptoms)						
Education	−.31	.69	$-.05^{ns}$	.00	$.21^{ns}$	1, 69
Perceived quality of information Provided by health-care professional	−.12	.07	$-.22^{ns}$	.05	1.69^{ns}	1, 68
Step 3 (regressing on depressive symptoms)						
Education	−.31	.69	$-.05^{ns}$	.00	$.21^{ns}$	1, 69
Perceived quality of information Provided by health-care Professional	−.06	.07	$-.11^{ns}$	.15	3.91*	2, 67
Perceived social support	−.17	.06	−.34**			

* $p < .05$; ** $p < .01$; *** $p < .001$

test the mediation model proposed by the current study two path analyses for each independent variable were conducted, and at each step of mediation analyses, the effect of education level was controlled. According to Baron and Kenny (1986) the conditions necessary for the mediation relation to exist are (1) variations in the independent variables account for variations in the mediator, (2) variations in the mediator account for variations in the dependent variables, and (3) when the effect of second condition is controlled, the previously significant relation between independent and dependent variables are lessened or disappears fully. Accordingly, two regression analyses were performed for the mediation model by using standard multiple regression analysis.

According to the first step of the first path analysis conducted for the first independent variable (illness representation), illness representation explained only 5% of the variance in perceived social support ($R^2 = .05$, $F(1, 68) = 1.66$, $p > .05$). Illness representation was not found to be related to perceived social support of the caregivers ($\beta = -.19$, $p > .05$). Thus, the first condition for the mediation was not met. In the second step of the path analysis illness representation was regressed on the depressive symptoms of the caregivers ($R^2 = .22$, $F(1, 68) = 9.58$, $p < .001$). Accordingly, illness representation of the caregivers was positively related to their depressive symptoms ($\beta = .47$, $p < .001$). In the third and the final step of the path analysis, illness representation ($\beta = .41$, $p < .001$) and perceived social support ($\beta = -.29$, $p < .01$) were regressed on the depressive symptoms of the caregivers ($R^2 = .30$, $F(2, 67) = 9.60$, $p < .001$). The standardized regression coefficient between illness representation and depressive symptoms decreased when controlling for perceived social support (from $\beta = .47$, $p < .001$ to $\beta = .41$, $p < .001$). However, since the first condition for the mediation was not met (illness representation was not a significant predictor of perceived social support), the relationship between illness representation and depressive symptoms was not mediated by perceived social support. The estimated path coefficients for the model are displayed in Fig. 1.

Another path analysis was performed for the second independent variable, perceived quality of information provided by the health-care professional. According to the

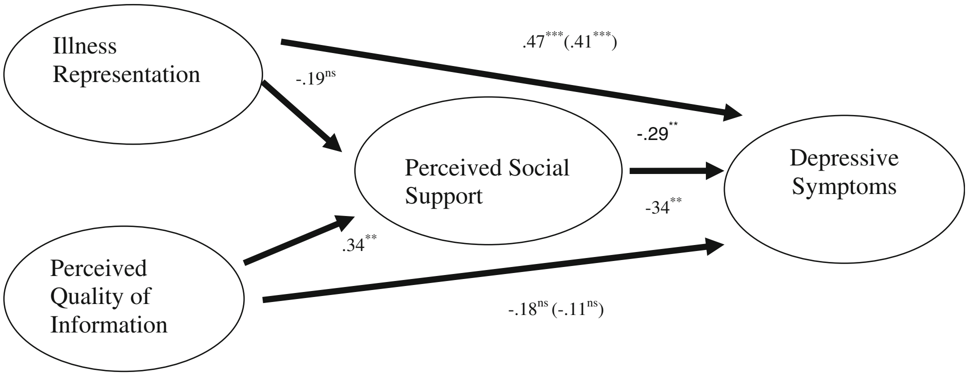

Fig. 1 Path model showing the relations among illness representation, perceived quality of information, perceived social support, and depressive symptoms

first step of this second path analysis, perceived quality of information provided by the health-care professional explained 11% of the variance in perceived social support ($R^2 = .11$, $F(1, 68) = 4.18$, $p < .01$). Perceived quality of information provided by the health-care professional was found to be positively related to perceived social support of the caregivers ($\beta = .34$, $p < .01$). Thus, the first condition for the mediation was met. In the second step of the path analysis, perceived quality of information provided by the health-care professional was regressed on the depressive symptoms of the caregivers ($R^2 = .05$, $F(1, 68) = 1.69$, $p > .05$). Accordingly, perceived quality of information provided by the health-care professional was not related to the caregivers' level of depressive symptoms ($\beta = -.22$, $p > .05$). In the third and the final step of the path analysis, perceived quality of information provided by the health-care professional ($\beta = -.11$, $p > .05$) and perceived social support ($\beta = -.34$, $p < .01$) were regressed on the depressive symptoms of the caregivers ($R^2 = .15$, $F(2, 67) = 3.91$, $p < .05$). Since perceived quality of information provided by the health-care professional was not a significant predictor of depressive symptoms of the caregivers, the third condition of the mediation was not met, and it was concluded that the relationship between perceived quality of information provided by the health-care professional and depressive symptoms was not mediated by perceived social support.

Discussion

In the present study, it was found that caregivers of children with leukemia are likely to experience more depressive symptoms when they have negative illness representation, and when they perceive lower levels of social support. Moreover, they were likely to perceive higher social support when they think that they received satisfactory information from health-care professionals. However, contrary to the expectations, the perceived quality of information provided by health-care professionals did not predict the level of depressive symptoms in the caregivers of children with leukemia. In addition, perceived social support did not mediate illness representation-depressive symptoms, and perceived quality of information provided by health-care professional-depressive symptoms relationships.

Consistent with the study of Patistea (2005), in the present study it was found that higher levels of perceived social support predicted lower levels of depressive symptoms. Although perceived quality of information provided by the health-care professional and depressive symptoms of caregivers did not have a significant relationship; social support perceived by caregivers had a positive relation with perceived quality of information provided by health-care professionals and a negative relation with depressive symptoms of caregivers. Thus, parallel to the stress-buffering model of Cohen and Willis (1985) it can be suggested that perceived social support has a buffering effect between perceived quality of information provided by health-care professionals and depressive symptoms of the caregivers.

Perceived quality of information provided by health-care professionals was also positively associated with perceived social support of the caregivers. This finding is supported by Patistea and Babatsikou (2003), who concluded that gaining more qualitative information about illness reduces parental stress. In addition, in another study, Patistea (2005) found that health-care professionals also provide social support to the caregivers by giving qualitative information about illness and the sick child. This finding of Patistea does also support the positive relation between perceived quality of information provided by health-care professionals and perceived social support of the caregivers in the present study.

The found association between illness representation and depressive symptoms is consistent with the finding of the study of Patistea (2005). A large number of parents of children with leukemia become disappointed with the situation that requires they have to cope with leukemia, which is a life-threatening illness. Therefore, it is inevitable to experience stress and higher levels of depressive symptoms among parents.

There are some limitations of the current study. Since this study is cross-sectional cause-effect relations cannot be concluded. The small sample size is another limitation. A larger sample size might provide more powerful results. There were only 71 participants in the present study and this might have resulted in Type II errors. In other words, the null hypotheses might have been erroneously accepted. Having closed-ended questions could also have limited the answers of the caregivers and lessened their ability to reflect their thoughts thoroughly. Moreover, only 10% of the sample had either a university or a graduate degree; and almost all of the participants (93%) were in low or middle-income groups. Thus, caregivers from high-income groups and caregivers with higher education levels are not represented in this study and this limits the generalizability of the findings. Furthermore, the informants for each of the instruments were the same, and this is a major methodological limitation of the current study. A caregiver who was exhibiting depressive symptoms might be prone to complete each of the instruments in a particular manner, and this limits any particular conclusion that otherwise might be gleaned from this particular investigation. Some of the measures used in the current study were problematic, too. By looking at the correlation of the Illness Representation Scale with the Beck Depression Inventory ($r = .25$, $p < .05$), which is marginally significant, one would say that this validity value is hardly acceptable. However, the correlation of the same measure with the Langner Psychiatric Impairment Scale ($r = .50$, $p < .01$) indicated an acceptable validity. One final limitation is about the specificity of the social support measure employed in this investigation. The Multidimensional Scale of Perceived Social Support is a general scale that measures the source and level of social support provided by a significant other, family, and friends. In other words, it does not relate specifically to social support as related to having a family member with a chronic illness. All in all, this particular study tested important research questions and set the stage for preliminary findings. However, due to the limitations mentioned above, the study needs to be replicated with a more complete design prior to developing any definitive conclusions.

It is a well-known fact that having a child with leukemia is a very difficult situation for caregivers to cope with and it is inevitable that they experience some adjustment problems. However, these problems may be lightened by qualitative information provided by health-care professionals and social support from family, friends, and spouses. Intervention programs that aim to increase individuals' social support and change their illness representation in a positive way may be helpful for caregivers showing depressive symptoms. It might also be suggested that education programs that aim to increase health-care professionals' sensitivity towards caregivers would be helpful to increase the perceived social support of caregivers of children with leukemia, and as a result, to decrease their depressive symptoms.

In conclusion, there are at least 1200–1500 children with leukemia and there are at least many as caregivers in Turkey. If intervention programs that are aiming to ease the adjustment of caregivers in this stressful situation would use the findings of the present study, they are expected to influence their lives in a more positive way.

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