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Effectiveness of a Lived-Experience-Based Educational Program on Distress Tolerance in Mothers of Children with Leukemia

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A B S T R A C T

Objective: This study aimed to determine the effectiveness of a lived-experience-based educational program in improving distress tolerance among mothers of children diagnosed with leukemia.

Methods and Materials: This quasi-experimental study employed a pretest–posttest design with a three-month follow-up and a control group. The statistical population consisted of mothers of children with leukemia who attended the Children's Medical Center Hospital in Tehran during the first half of 2025. Forty eligible mothers were selected through convenience sampling and randomly assigned to an experimental group or a control group, with 20 participants in each group. Data were collected using the Distress Tolerance Scale developed by Simons and Gaher. The experimental group participated in an 11-session lived-experience-based educational program developed according to Behfar's 2026 protocol. The intervention content was formulated from themes identified through a phenomenological investigation of the lived experiences of mothers caring for children with leukemia. The control group received no intervention during the study period. Data were analyzed using repeated-measures analysis of variance and Bonferroni post hoc comparisons.

Findings: The results demonstrated significant main effects of time and group on distress tolerance scores. A statistically significant interaction effect between time and group was also observed, indicating that changes in distress tolerance across the assessment stages differed significantly between the experimental and control groups ($p < .001$). Bonferroni post hoc comparisons showed that distress tolerance significantly improved from pretest to posttest and from pretest to the three-month follow-up in the experimental group. However, the difference between posttest and follow-up scores was not statistically significant, confirming that the intervention effects were maintained over the follow-up period. No significant changes were observed in the control group.

Conclusion: The lived-experience-based educational program was effective in enhancing and maintaining distress tolerance among mothers of children with leukemia. This culturally responsive and needs-based intervention may therefore be used as a practical psychological support program in pediatric oncology settings.

Keywords: *lived-experience-based educational program; distress tolerance; mothers; childhood leukemia; psychological intervention*

1. Introduction

Cancer remains one of the most consequential health challenges worldwide, imposing substantial burdens not only on affected individuals but also on families, healthcare systems, and communities. Although advances in screening, diagnosis, supportive care, and treatment have improved survival for many malignancies, cancer continues to account for a considerable proportion of global morbidity and mortality (Siegel et al., 2024; Sung et al., 2021). Childhood cancer constitutes a particularly distressing category because it affects children during sensitive developmental periods and abruptly transforms the emotional, relational, and practical functioning of the entire family. Among pediatric malignancies, leukemia is one of the most frequently diagnosed cancers and commonly requires intensive, prolonged, and complex courses of treatment. Hospitalization, chemotherapy, invasive procedures, uncertainty regarding treatment response, vulnerability to infection, and the possibility of relapse expose children and their families to repeated and often unpredictable sources of stress. Consequently, the diagnosis of leukemia cannot be regarded solely as a medical event affecting the child; rather, it is a family crisis that reorganizes parental roles, daily routines, financial priorities, interpersonal relationships, and perceptions of the future.

Parents are usually the principal source of emotional security, practical care, treatment adherence, and communication for children with cancer. Within many families, mothers assume the largest share of direct caregiving responsibilities and remain continuously involved in hospitalization, symptom monitoring, medication administration, nutritional care, communication with healthcare professionals, and the management of the child's emotional and behavioral reactions. This prolonged caregiving role can expose mothers to substantial psychological pressure, particularly when they must simultaneously manage fear about the child's survival, uncertainty about treatment outcomes, disruption of employment and family routines, concern for other children, financial strain, and changes in marital or social relationships. Research on parents of children with advanced cancer has shown that psychological distress may be persistent and clinically meaningful, especially when parents encounter uncertainty, perceived loss of control, and repeated threats to the child's life (Rosenberg et al., 2014). The emotional burden may also intensify when mothers feel responsible for maintaining hope and stability while concealing their own anxiety, sadness, exhaustion, or despair from the ill child and other family members.

Qualitative evidence indicates that mothers caring for children with leukemia experience a multidimensional form of suffering that extends beyond ordinary caregiver stress. Their experiences may include shock at diagnosis, fear of death or relapse, helplessness during painful medical procedures, sleep disturbances, social isolation, disruption of maternal identity, uncertainty regarding the future, and difficulty balancing caregiving with other personal and family responsibilities. A qualitative investigation of mothers parenting children with leukemia described their experiences as involving emotional turmoil, uncertainty, altered family functioning, and continuous adaptation to the demands of illness and treatment (Al Omari et al., 2023). Similarly, an Iranian qualitative study demonstrated that mothers of children with leukemia encounter profound psychological, interpersonal, spiritual, and practical challenges, while attempting to create meaning and maintain functioning under highly stressful conditions (Shaygani et al., 2024). More recent qualitative evidence has also characterized the transition into cancer caregiving as an experience immersed in fear and doubt, during which mothers must acquire new caregiving competencies while remaining uncertain about the child's prognosis and their own ability to cope effectively (Ghanbari et al., 2025). These findings indicate that mothers' psychological needs are rooted in their lived realities and cannot be fully addressed through generic psychoeducation alone.

The psychosocial consequences of childhood cancer can also affect the quality of care mothers provide. Mothers who experience severe anxiety, emotional exhaustion, or persistent distress may find it more difficult to communicate calmly with their children, regulate their own reactions, make treatment-related decisions, or maintain consistent parenting behavior. Maternal self-efficacy has been associated with caring behavior in mothers of children with cancer, suggesting that mothers who feel more capable of managing caregiving demands may engage in more effective and supportive care practices (Barani et al., 2019). Conversely, psychological overload may contribute to overprotection, inconsistency, irritability, withdrawal, or difficulty responding appropriately to the child's developmental needs. Distress tolerance is especially relevant in this context because mothers are repeatedly exposed to emotionally intense situations that cannot always be immediately resolved or avoided. Their ability to remain engaged, purposeful, and emotionally regulated in the

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presence of distress may therefore influence both their own psychological health and their caregiving behavior.

Distress tolerance refers to an individual's perceived or actual capacity to withstand aversive emotional states without resorting to maladaptive avoidance, impulsive behavior, cognitive disengagement, or ineffective attempts to eliminate distress. It involves the ability to experience emotional discomfort, evaluate it as manageable rather than intolerable, prevent it from completely absorbing attention, and regulate behavior despite the continued presence of unpleasant internal experiences. Low distress tolerance is not equivalent to merely experiencing high distress; rather, it reflects the belief that emotional discomfort is unbearable and must be escaped, suppressed, or controlled immediately. Such beliefs can intensify emotional reactivity and encourage avoidance-based coping strategies. Evidence suggests that distress tolerance is closely related to emotional disorders and may interact with anxiety sensitivity in predicting social anxiety and depressive symptoms (Paulus et al., 2019). In mothers of children with leukemia, low distress tolerance may be manifested through catastrophic thinking, persistent rumination, avoidance of difficult information, excessive reassurance seeking, emotional withdrawal, or difficulty remaining psychologically present during treatment-related crises.

The relevance of distress tolerance to parenting in pediatric oncology has been supported by empirical findings. In mothers of children with cancer, distress tolerance has been found to predict aspects of parenting style and children's attachment-related behaviors, indicating that mothers' capacity to tolerate emotional discomfort may have important implications for the parent–child relationship (Firoozi, 2020). A mother who is able to tolerate fear, uncertainty, sadness, and helplessness may be better prepared to respond sensitively to her child, communicate honestly in developmentally appropriate ways, and remain consistent during periods of medical crisis. In contrast, a mother who perceives emotional distress as intolerable may become overwhelmed by the child's suffering, avoid difficult conversations, respond inconsistently, or unintentionally communicate fear and insecurity. Therefore, strengthening distress tolerance can be conceptualized not only as a strategy for reducing maternal psychological distress but also as a means of improving parental functioning and the emotional climate surrounding the child.

Mothers' difficulties in tolerating distress are also closely linked to emotion regulation. Caring for a child with cancer requires repeated regulation of fear, grief, guilt, anger, uncertainty, and anticipatory anxiety. Mothers may attempt to control these experiences through suppression, denial, rumination, avoidance, or excessive vigilance, although such strategies can provide only temporary relief and may increase distress over time. The conceptualization of emotion regulation strategies among mothers of children with cancer has highlighted the complexity of their emotional responses and the need to distinguish between adaptive strategies, such as acceptance, cognitive reappraisal, support seeking, and purposeful action, and maladaptive strategies, such as self-blame, catastrophizing, rumination, and emotional suppression (Mohajeri Tehrani et al., 2024). Because distress tolerance supports the ability to remain in contact with difficult emotions without automatically reacting to them, it may provide a foundation for more adaptive emotion regulation and problem-solving.

At the same time, mothers' psychological adjustment should not be viewed solely in terms of reducing symptoms. Positive psychological resources, including hope, self-efficacy, meaning, resilience, compassion, and perceived competence, can help parents remain engaged with treatment and sustain caregiving under adversity. Positive psychotherapy emphasizes the systematic development of strengths, meaning, positive emotions, supportive relationships, and adaptive engagement rather than focusing exclusively on pathology and symptom reduction (Rashid & Seligman, 2018). In pediatric oncology, parental hope can influence communication and the ways in which families interpret illness-related information. Evidence from families of children with advanced cancer suggests that hope is associated with communication patterns and may shape how parents balance realism with emotional protection (Rosenberg et al., 2020). Interventions designed for mothers of children with leukemia may therefore benefit from combining distress-management strategies with strength-based components that reinforce self-efficacy, compassion, personal values, realistic hope, and constructive coping.

A growing body of evidence demonstrates that structured psychological and educational interventions can improve maternal adjustment in families affected by childhood illness. Problem-solving skills training has been shown to produce targeted benefits for mothers of children newly diagnosed with cancer by helping them define problems, generate alternative responses, evaluate solutions, and implement effective coping strategies (Sahler et al., 2013). Such training is particularly appropriate in pediatric oncology because mothers face both solvable practical problems and emotionally painful circumstances that cannot

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be immediately changed. Similarly, reality therapy has been found to improve resilience among mothers of children with cancer, suggesting that interventions emphasizing responsibility, choice, present-focused action, and effective need fulfillment can strengthen adaptation (Shamli & Hasani, 2017). These findings support the broader proposition that mothers' psychological functioning can be improved through systematic and skills-based interventions rather than relying only on informal support.

Other studies have demonstrated the value of empowerment and self-care frameworks for mothers caring for children with chronic or life-threatening conditions. An empowerment intervention based on the Gibson model improved self-efficacy and quality of life in mothers of children with thalassemia, indicating that increasing knowledge, participation, decision-making capacity, and perceived control can have meaningful psychological benefits (Shahsavari et al., 2022). Likewise, implementing Orem's self-care model improved health-promoting behaviors among mothers of children with leukemia, highlighting the importance of supporting mothers' own physical and psychological care while they focus on their ill children (Famili Khalili & Salehi, 2021). Mothers often deprioritize their personal needs because of the intensity of caregiving, yet prolonged neglect of sleep, nutrition, social support, emotional expression, and medical care may ultimately impair their caregiving capacity. Interventions that validate maternal needs and reinforce self-care can therefore contribute indirectly to the child's care environment.

More recent intervention studies have specifically targeted distress tolerance. Self-compassion training has been found to improve cognitive emotion regulation and distress tolerance in mothers of children with intellectual disabilities (Giahi et al., 2024). Self-compassion may be particularly beneficial for mothers who blame themselves for the child's illness, perceive themselves as inadequate caregivers, or hold unrealistic expectations regarding emotional control. By encouraging kindness toward oneself, recognition of shared human vulnerability, and balanced awareness of painful experiences, self-compassion may reduce self-criticism and allow distress to be experienced without escalation. Similarly, both solution-focused therapy and narrative therapy have demonstrated effectiveness in improving distress tolerance among mothers of children with celiac disease (Akafian et al., 2024). Although celiac disease differs from leukemia in severity and treatment demands, these findings suggest that approaches centered on personal resources, alternative narratives, exceptions to problems, and achievable change can strengthen mothers' capacity to manage ongoing emotional strain.

Acceptance-based interventions have also produced promising findings in mothers of children with cancer. Acceptance and commitment therapy has been shown to improve distress tolerance and reduce identity-related difficulties in this population (Golestan Kalateh et al., 2024). This approach may be effective because it teaches individuals to reduce experiential avoidance, observe difficult thoughts without becoming fused with them, clarify personal values, and take meaningful action despite emotional discomfort. A crisis intervention model enriched with acceptance and commitment therapy has likewise improved distress tolerance, resilience, and death anxiety among mothers of children with cancer (Jafarzadeh & Khaleghipour, 2025). These results indicate that increasing distress tolerance requires more than reassurance or positive thinking; mothers need practical methods for accepting uncertainty, distancing themselves from catastrophic thoughts, managing physiological arousal, and continuing value-consistent caregiving under conditions that cannot be fully controlled.

Educational interventions delivered through digital formats have also been explored. A web-based educational program reduced distress among parents of children with cancer, demonstrating that accessible, structured, and targeted information can support parental psychological adjustment (Wiener et al., 2020). Digital interventions may reduce barriers related to transportation, caregiving schedules, and geographical distance, but they may not fully address the interpersonal, emotional, and culturally specific dimensions of maternal experience. Mothers may require opportunities to discuss fears, hear similar experiences, practice skills, and receive feedback within a supportive group context. Therefore, while web-based education is valuable, face-to-face or interactive programs grounded in mothers' own experiences may offer additional benefits, particularly when the intervention addresses sensitive themes such as guilt, social isolation, marital conflict, fear of death, perceived incompetence, and the child's behavioral changes.

The importance of systematic psychosocial care in pediatric oncology has been emphasized in clinical guidelines. Evidence-based recommendations indicate that children with cancer and their families should receive routine psychosocial assessment, risk screening, and interventions matched to the severity and nature of their

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needs (Kazak et al., 2021). Family psychosocial risk screening can facilitate early identification of parents who may be vulnerable to persistent distress and guide the allocation of evidence-based services (Kazak et al., 2015). This stepped-care perspective recognizes that some families may benefit from basic information and support, whereas others require more intensive psychological intervention. It also reinforces the principle that parental distress should not be treated as a secondary or optional concern. Because maternal psychological functioning influences treatment participation, communication, family stability, and the child's adjustment, psychosocial care is an essential component of comprehensive pediatric oncology services.

Palliative and supportive care literature similarly underscores the necessity of family-centered, interdisciplinary services. Pediatric palliative care is not restricted to end-of-life treatment; rather, it includes symptom management, communication support, psychosocial assistance, decision-making, and quality-of-life enhancement from the point of diagnosis when appropriate (Jones et al., 2014). Mothers caring for children with leukemia may need support during diagnosis, active treatment, remission, relapse, or advanced illness. Their distress may fluctuate across these phases, and the skills required to cope with uncertainty may differ from those needed to manage behavioral problems, social isolation, or treatment-related exhaustion. Therefore, effective interventions should be sufficiently comprehensive to address emotional, cognitive, behavioral, interpersonal, and practical dimensions of caregiving.

Despite the growing evidence for psychological interventions, many existing programs are developed from general theoretical models and may not fully reflect the culturally situated realities of mothers caring for children with leukemia. Generic protocols can be beneficial, but their relevance may be limited when they do not directly incorporate mothers' language, priorities, fears, caregiving contexts, family expectations, or healthcare experiences. Lived-experience-based intervention design offers a way to bridge this gap. In this approach, qualitative findings derived from the narratives of the target population are translated into intervention goals, session themes, examples, exercises, and coping strategies. Such interventions may increase perceived relevance, engagement, emotional validation, and cultural responsiveness because participants encounter concerns that closely resemble their own experiences.

The protocol developed by Behfar was specifically derived from the lived experiences of mothers of children with leukemia and was designed to improve distress tolerance and empathy through an integrated educational framework (Behfar, 2026). The program addresses negative thoughts and emotions, cognitive distortions, rumination, self-blame, social isolation, interpersonal difficulties, uncertainty about the future, the child's behavioral problems, adjustment to disability or illness-related limitations, and mothers' perceived inability to manage themselves and their children. It combines cognitive-behavioral techniques, compassion-focused strategies, mindfulness exercises, behavioral activation, communication training, problem-solving, acceptance, and cognitive defusion. This integration is clinically relevant because the challenges reported by mothers are unlikely to be adequately addressed by a single technique. For example, catastrophic thinking may require cognitive restructuring, self-blame may respond to compassion-focused work, uncertainty may require acceptance and defusion, interpersonal conflict may require communication training, and caregiving difficulties may require behavioral problem-solving.

A lived-experience-based program may also strengthen intervention acceptability by validating mothers' suffering rather than framing their distress as an individual weakness. When mothers recognize that fear, exhaustion, ambivalence, and uncertainty are common responses to pediatric cancer, shame and self-criticism may decrease. Group-based discussion can additionally reduce social isolation and create opportunities for observational learning, emotional normalization, and mutual support. At the same time, a structured protocol ensures that the intervention moves beyond unstructured emotional disclosure and teaches transferable skills. This balance between experiential validation and evidence-informed techniques is particularly important in settings where formal psychological services may be limited or where mothers may be reluctant to seek individual psychotherapy.

Although previous studies have supported problem-solving training, acceptance and commitment therapy, self-compassion, reality therapy, empowerment, narrative therapy, solution-focused therapy, self-care education, and web-based psychoeducation, limited research has examined an integrated protocol developed directly from the lived experiences of mothers of children with leukemia. Moreover, many studies have assessed outcomes only immediately after treatment, making it difficult to determine whether observed gains remain stable over time. A three-month follow-up can provide stronger evidence regarding

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the durability of intervention effects. Evaluating distress tolerance is also important because it represents a transdiagnostic capacity that may influence emotional regulation, parenting behavior, treatment engagement, and adaptation to uncertainty. Accordingly, the present study aimed to determine the effectiveness of a lived-experience-based educational program in improving distress tolerance among mothers of children with leukemia.

2. Methods and Materials

2.1. Study design and Participant

This applied quantitative study used a quasi-experimental pretest–posttest design with a control group and a three-month follow-up to evaluate the effectiveness of a lived-experience-based educational program in improving distress tolerance among mothers of children diagnosed with leukemia. The statistical population comprised all mothers of children with a confirmed diagnosis of leukemia who attended the Children's Medical Center Hospital in Tehran, Iran, during the first half of 2025 and whose children were receiving medical care or treatment at the hospital. From this population, 40 eligible mothers were recruited through convenience sampling and subsequently assigned by simple random allocation to either the experimental group or the control group, with 20 participants in each group. The required sample size was estimated using Cohen's sample size guidelines, assuming a statistical power of .81, an effect size of .60, and a significance level of .05, resulting in a minimum requirement of 20 participants per group. The inclusion criteria were having a child with a confirmed diagnosis of leukemia, being between 25 and 50 years of age, having at least a high school diploma, providing informed and voluntary consent to participate in the study, not having received concurrent pharmacological or psychological treatment during the preceding six months, having no history of alcohol or substance misuse, and showing no evidence of an acute psychiatric disorder based on an initial diagnostic interview. Participants were excluded if they were absent from more than two intervention sessions, failed to complete the study questionnaires, withdrew their consent, or participated in another psychological or psychotherapeutic intervention during the study period. Before the intervention, both groups completed the pretest assessment. The experimental group then received the lived-experience-based educational program, whereas the control group remained on a waiting list and received no psychological intervention during the pretest-to-follow-up period. Immediately after completion of the intervention, both groups completed the posttest assessment, and the same measure was administered again three months later to assess the maintenance of the intervention effects. All procedures were conducted in accordance with research ethics principles. Written informed consent was obtained from all participants, the confidentiality of personal information and questionnaire responses was guaranteed, and participants were informed that they could withdraw from the study at any stage without negative consequences. After completion of the follow-up assessment, the educational program was provided to the control group in a condensed format to ensure equitable access to the intervention.

2.2. Measures

The Distress Tolerance Scale was developed by Simons and Gaher in 2005 to assess individuals' perceived capacity to experience, tolerate, evaluate, and regulate negative emotional states. The scale consists of 15 items distributed across four dimensions: tolerance, absorption, appraisal, and regulation. The tolerance dimension measures the perceived ability to endure emotional distress; the absorption dimension assesses the extent to which distress captures an individual's attention and disrupts functioning; the appraisal dimension evaluates personal judgments and attitudes toward distressing emotional experiences; and the regulation dimension assesses efforts to reduce, avoid, or control distress. Items are rated on a five-point Likert scale ranging from strongly disagree to strongly agree. After reverse-scored items are recoded in accordance with the original scoring instructions, item scores are summed to obtain a total distress tolerance score, with higher scores indicating a greater perceived capacity to tolerate psychological distress. The psychometric properties of the scale have been supported in Iranian samples. Azizi, Mirzaei, and Shams reported a Cronbach's alpha coefficient of .67 for the total scale and a test–retest reliability coefficient of .79. In another Iranian study, Esmaeilinasab reported a Cronbach's alpha coefficient of .86 for the total score, indicating satisfactory internal consistency. In the present study, the scale was administered at the pretest, posttest, and three-month follow-up stages to measure changes in distress tolerance and determine whether the effects of the educational intervention were maintained over time.

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2.3. Intervention

The intervention was a lived-experience-based educational program developed according to Behfar's 2026 protocol. The program included 11 core instructional sessions preceded by an orientation meeting and was designed using themes extracted from a phenomenological study of the lived experiences of mothers caring for children with leukemia. Its content integrated cognitive-behavioral principles, mindfulness-based exercises, compassion-focused techniques, behavioral activation, acceptance-based strategies, communication skills training, and problem-solving methods. During the orientation meeting, the facilitator introduced the program, explained the objectives, structure, group rules, confidentiality requirements, and expectations for participation, and invited the mothers to introduce themselves and discuss their principal concerns and expectations. The first three core sessions focused on negative thoughts and emotions. Participants were taught the relationship among thoughts, emotions, and behaviors through the activating event–belief–consequence model, the cognitive model of emotional distress, the cognitive triangle, mood-monitoring techniques, and methods for identifying automatic negative thoughts, intermediate beliefs, core beliefs, and cognitive distortions. Mindfulness exercises, including focused attention on a single object, attention-control training, and body scanning, were introduced to reduce cognitive absorption and rumination. Behavioral activation was taught as an alternative to withdrawal and inactivity, while techniques such as thought postponement, value clarification, cognitive distancing, and the two-chair exercise were used to help participants respond more flexibly to self-critical and distressing thoughts. The fourth core session addressed experiences of blame and self-blame through compassion-focused attention, emotions, behaviors, thoughts, and sensory imagery. Participants practiced writing a compassionate letter to themselves, engaging in three-position role-play involving the critical self, the criticized self, and the compassionate self, and using self-reinforcement and appropriate personal rewards. The fifth session addressed social isolation by teaching effective communication, unconditional self-acceptance, acceptance of others, acceptance of life circumstances, differentiation between thoughts and facts, recognition of irrational beliefs, and coping skills for loneliness, including conversational competence, social responsiveness, and active engagement with supportive individuals. The sixth session focused on interpersonal difficulties and included compassionate behavior toward oneself and others, ineffective communication patterns, principles of effective interaction, behavioral experiments, and strategies for managing marital disagreements. The seventh and eighth sessions addressed fear and worry about the future. Participants learned about the nature of worry, generalized anxiety, and the cognitive dimensions of anxiety, followed by an integrated seven-step cognitive intervention involving parasympathetic activation, differentiation between productive and unproductive worry, cognitive distancing, environmental description, scheduled worry, probability estimation, metaphor-based work, behavioral experiments, defense-attorney/prosecutor role-play, structured problem-solving, and imaginal exposure with audio recording. The ninth session focused on the child's behavioral difficulties and emphasized compassion toward the ill child, systematic problem-solving, appropriate use of reinforcement, punishment, extinction, and shaping, effective use of social support systems, and continuum techniques for modifying catastrophic interpretations. The tenth session addressed coping with the child's limitations and introduced stages of family adaptation to childhood illness, experiential avoidance, cognitive fusion, acceptance, and cognitive defusion. Metaphors such as the hole, the unwelcome guest, leaves floating on a stream, and the struggle between a lion and the hands were used to facilitate experiential understanding of acceptance-based concepts. The final session focused on mothers' perceived inability to manage themselves and their children. Participants practiced selecting effective solutions, examining evidence for and against distressing beliefs, using the Coach A and Coach B technique, recognizing and rewarding personal achievements, avoiding a victim role, assuming appropriate responsibility, understanding the child's physical and psychological condition, and developing realistic expectations regarding the child's functioning and treatment process. The control group received no intervention during the study period and remained on a waiting list until completion of the three-month follow-up.

2.4. Data Analysis

The collected data were analyzed using SPSS software, version 27. Descriptive statistics, including frequency, percentage, mean, and standard deviation, were used to summarize participants' demographic characteristics and distress tolerance scores at the pretest, posttest, and three-month follow-up stages. Repeated-measures analysis of variance was employed to examine within-group changes

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over time, between-group differences, and the interaction between time and group. Before conducting the main inferential analysis, the relevant statistical assumptions were evaluated. The normality of score distributions was assessed using the Kolmogorov–Smirnov test, the homogeneity of variances across the experimental and control groups was examined using Levene's test, and the sphericity assumption for the repeated measurements was evaluated using Mauchly's test. When the sphericity assumption was violated, an appropriate correction, such as the Greenhouse–Geisser adjustment, was applied to the degrees of freedom. The main effect of time was examined to determine whether distress tolerance scores changed across the pretest, posttest, and follow-up assessments, while the main effect of group was examined to determine whether the overall scores differed between the experimental and control groups. The time-by-group interaction was evaluated as the primary indicator of intervention effectiveness because it determined whether changes in distress tolerance across the three measurement stages differed significantly between the two groups. When a statistically significant time effect or time-by-group interaction was identified, Bonferroni-adjusted pairwise comparisons were conducted to compare pretest, posttest, and follow-up scores and to determine whether the intervention effects were maintained during the three-month follow-up period. All statistical tests were conducted using a two-tailed significance level of .05.

3. Findings and Results

The demographic characteristics of the participants indicated that the experimental and control groups were relatively comparable. In the experimental group, 8 mothers (40.0%) were between 25 and 35 years of age and 12 (60.0%) were between 35 and 45 years of age; in the control group, 9 mothers (45.0%) were between 25 and 35 years of age and 11 (55.0%) were between 35 and 45 years of age. Regarding educational attainment, 7 participants (35.0%) in the experimental group had a high school diploma, 8 (40.0%) held a bachelor's degree, and 5 (25.0%) held a master's degree. In the control group, 8 participants (40.0%) had a high school diploma, 6 (30.0%) held a bachelor's degree, and 6 (30.0%) held a master's degree. With respect to employment status, 9 mothers (45.0%) in the experimental group were employed and 11 (55.0%) were homemakers, whereas 8 mothers (40.0%) in the control group were employed and 12 (60.0%) were homemakers. Overall, the distributions of age, education, and employment status were similar across the two groups, suggesting satisfactory demographic comparability at baseline.

Table 1

Descriptive Statistics for Distress Tolerance Scores by Group and Measurement Stage

Group	Measurement Stage	Mean	Standard Deviation	Skewness	Kurtosis
Experimental	Pretest	71.80	12.20	0.55	1.73
Experimental	Posttest	91.20	14.97	−0.30	−0.29
Experimental	Three-month follow-up	93.00	16.81	−1.68	1.60
Control	Pretest	72.00	14.86	0.97	0.85
Control	Posttest	71.20	11.76	−0.16	−1.07
Control	Three-month follow-up	70.02	13.89	−0.56	−0.19

As shown in Table 1, the experimental and control groups had nearly identical mean distress tolerance scores at the pretest stage, with means of 71.80 and 72.00, respectively. Following the intervention, the mean distress tolerance score in the experimental group increased substantially to 91.20 at posttest and continued to rise slightly to 93.00 at the three-month follow-up. In contrast, the mean score in the control group decreased slightly from 72.00 at pretest to 71.20 at posttest and 70.02 at follow-up. Therefore, the descriptive findings revealed a clear improvement in distress tolerance among mothers who participated in the lived-experience-based educational program, whereas no comparable improvement was observed in the control group. Furthermore, the skewness and kurtosis values were within an acceptable range, providing preliminary support for the approximate normality of the distributions.

Before conducting the repeated-measures analysis of variance, the relevant statistical assumptions were examined. The Shapiro–Wilk test indicated that the distributions of distress tolerance scores did not significantly deviate from normality in either group at any of the three measurement stages, as all significance values were greater than .05. Levene's test was also nonsignificant at the pretest, posttest, and follow-up stages, supporting the assumption of homogeneity of variances between the groups. Box's M test was nonsignificant, p = .34, indicating that the variance–

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covariance matrices were homogeneous across the two groups. However, Mauchly's test of sphericity was statistically significant, p = .019, indicating that the assumption of sphericity had been violated. Consequently, the Greenhouse–Geisser correction was considered when interpreting the within-subject and time-by-group interaction effects.

Table 2

Repeated-Measures Analysis of Variance for Distress Tolerance Scores

Effect	Sum of Squares	df	Mean Square	F	p	Partial η²
Group	8410.00	1.00	8410.00	18.74	< .001	.40
Time	3459.80	2.00	1729.90	22.17	< .001	.44
Time × Group	4418.60	1.94	2274.25	28.31	< .001	.05

The results presented in Table 2 demonstrated a statistically significant main effect of group on distress tolerance, $F(1, 38) = 18.74$, $p < .001$, partial $\eta^2 = .40$. This result indicated that, when scores were considered across all measurement stages, the overall level of distress tolerance differed significantly between the experimental and control groups. The main effect of time was also statistically significant, $F = 22.17$, $p < .001$, partial $\eta^2 = .44$, showing that distress tolerance scores changed significantly across the pretest, posttest, and three-month follow-up assessments. More importantly, the interaction between time and group was statistically significant, $F = 28.31$, $p < .001$, partial $\eta^2 = .05$. The significant interaction indicated that the pattern of change in distress tolerance across the three measurement stages was different for the experimental and control groups. Specifically, the experimental group showed a substantial increase following the intervention, whereas the control group exhibited no meaningful improvement. These findings supported the effectiveness of the lived-experience-based educational program in increasing mothers' distress tolerance.

Table 3

Bonferroni-Adjusted Pairwise Comparisons of Distress Tolerance Scores

Comparison Type	Group or Stage	Comparison	Mean Difference	Standard Error	p
Within-group	Experimental	Pretest − Posttest	−19.40	3.86	< .001
Within-group	Experimental	Pretest − Follow-up	−21.20	4.12	< .001
Within-group	Experimental	Posttest − Follow-up	−1.80	3.28	1.000
Between-group	Pretest	Experimental − Control	−0.20	4.62	.970
Between-group	Posttest	Experimental − Control	20.00	5.07	< .001
Between-group	Follow-up	Experimental − Control	22.98	5.80	< .001

As shown in Table 3, the Bonferroni-adjusted within-group comparisons revealed that the experimental group's mean distress tolerance score increased significantly from pretest to posttest, with a mean difference of −19.40, $p < .001$. A significant difference was also found between the pretest and three-month follow-up scores, with a mean difference of −21.20, $p < .001$. In contrast, the difference between the posttest and follow-up scores was not statistically significant, with a mean difference of −1.80, $p = 1.000$. The absence of a significant decline from posttest to follow-up indicated that the improvement produced by the intervention was maintained for at least three months. The between-group comparisons further showed that there was no statistically significant difference between the experimental and control groups at pretest, with a mean difference of −0.20, $p = .970$, confirming their baseline comparability. However, the experimental group obtained significantly higher distress tolerance scores than the control group at posttest, with a mean difference of 20.00, $p < .001$, and at the three-month follow-up, with a mean difference of 22.98, $p < .001$. Collectively, these results demonstrated that the lived-experience-based educational program significantly increased distress tolerance among mothers of children with leukemia and that its beneficial effect remained stable throughout the three-month follow-up period.

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4. Discussion

The present study examined the effectiveness of a lived-experience-based educational program in improving distress tolerance among mothers of children with leukemia. The findings demonstrated that the experimental group experienced a substantial increase in distress tolerance from pretest to posttest, whereas the control group showed no meaningful improvement across the same period. The significant main effects of time and group indicated that distress tolerance changed across the three measurement stages and that the overall pattern of scores differed between the experimental and control groups. More importantly, the significant interaction between time and group showed that the observed improvement was specifically associated with participation in the educational program rather than with the passage of time or repeated assessment. Bonferroni-adjusted comparisons further revealed significant differences between the pretest and posttest scores and between the pretest and three-month follow-up scores in the experimental group. However, the difference between posttest and follow-up was not significant, indicating that the beneficial effect of the intervention was maintained for at least three months. In addition, the two groups did not differ significantly at baseline, whereas the experimental group obtained significantly higher distress tolerance scores than the control group at both posttest and follow-up. Collectively, these results support the effectiveness and short-term durability of the lived-experience-based educational program.

The principal finding of the study is consistent with previous research indicating that structured psychological and educational interventions can strengthen distress tolerance in mothers caring for children with serious or chronic medical conditions. For example, acceptance and commitment therapy has been shown to improve distress tolerance among mothers of children with cancer by reducing experiential avoidance and helping mothers respond more flexibly to painful thoughts and emotions (Golestan Kalateh et al., 2024). Similarly, a crisis intervention model enriched with acceptance and commitment therapy improved distress tolerance, resilience, and death anxiety in mothers of children with cancer (Jafarzadeh & Khaleghipour, 2025). The present program included several acceptance-based elements, such as distinguishing thoughts from facts, reducing cognitive fusion, accepting uncontrollable experiences, using metaphors to facilitate psychological distance, and encouraging action consistent with caregiving values. These components may have helped participants remain engaged with difficult emotions without interpreting them as intolerable or requiring immediate elimination.

The findings also align with evidence concerning the effectiveness of self-compassion interventions. Self-compassion training has been reported to improve both cognitive emotion regulation and distress tolerance among mothers of children with intellectual disabilities (Giahi et al., 2024). Mothers of children with leukemia may experience self-blame, guilt, inadequacy, and harsh self-judgment, particularly when they are unable to protect their child from pain or control the course of the disease. The present intervention directly addressed self-criticism through compassionate attention, compassionate imagery, self-directed letter writing, three-position role-play, and self-reinforcement. These techniques may have reduced the tendency to interpret distress as evidence of personal weakness or maternal failure. When distress is met with self-kindness rather than self-condemnation, its emotional intensity may decrease and the individual may become more capable of tolerating it without avoidance or behavioral dysregulation.

The effectiveness of the intervention can also be explained by its cognitive-behavioral components. Mothers were taught to identify automatic negative thoughts, cognitive distortions, intermediate assumptions, core beliefs, catastrophic interpretations, and unhelpful predictions about the future. They also learned to examine evidence for and against distressing thoughts, estimate probabilities, distinguish productive from unproductive worry, and conduct behavioral experiments. Such techniques may have weakened beliefs that uncertainty, fear, and helplessness were unbearable. Distress intolerance is often maintained by catastrophic appraisals of emotional states, such as believing that anxiety will become uncontrollable or that sadness will permanently impair functioning. Cognitive restructuring may help mothers reinterpret distress as painful but manageable. This explanation is compatible with evidence that distress tolerance is meaningfully associated with anxiety sensitivity, social anxiety, and depressive symptoms (Paulus et al., 2019). By reducing catastrophic interpretations of internal experiences, the program may have increased participants' perceived capacity to endure emotional discomfort.

The intervention's effect is also consistent with research supporting solution-focused and narrative approaches. Both solution-focused therapy and narrative therapy have been found to improve distress tolerance in mothers of children

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with celiac disease (Akafian et al., 2024). Although childhood leukemia involves different medical risks and caregiving demands, the underlying psychological mechanisms may overlap. Mothers may become absorbed in problem-saturated narratives involving helplessness, failure, danger, and an uncertain future. The lived-experience-based program helped participants identify personal values, recognize previous successes, generate alternative solutions, and challenge rigid interpretations of their caregiving difficulties. These processes may have enabled mothers to develop more flexible narratives about themselves, not solely as helpless observers of their child's illness but as capable caregivers who could act effectively despite uncertainty.

The problem-solving components of the intervention may have contributed substantially to the observed improvement. Problem-solving skills training has demonstrated specific benefits for mothers of children newly diagnosed with cancer (Sahler et al., 2013). Mothers in the present study learned to define problems clearly, distinguish solvable from unsolvable concerns, generate alternative responses, evaluate likely consequences, and select feasible actions. These skills were applied to future-oriented worry, interpersonal conflict, the child's behavioral difficulties, and mothers' perceived inability to manage themselves and their children. Distress often becomes more difficult to tolerate when it is accompanied by confusion, perceived helplessness, or the belief that no effective response is available. Structured problem-solving can transform an overwhelming situation into a sequence of manageable decisions, thereby increasing perceived control and reducing emotional paralysis.

The findings may further be interpreted through the role of emotion regulation. Mothers of children with cancer commonly experience simultaneous fear, sadness, anger, guilt, hope, and uncertainty, requiring continual regulation of emotionally conflicting states. Qualitative conceptualization of emotion regulation among these mothers has highlighted both adaptive and maladaptive strategies, including acceptance, reappraisal, support seeking, rumination, suppression, catastrophizing, and self-blame (Mohajeri Tehrani et al., 2024). The present program addressed several maladaptive patterns through mindfulness, body scanning, attention control, thought postponement, behavioral activation, cognitive distancing, and imaginal exposure. These strategies may have reduced rumination and emotional absorption, allowing mothers to experience distress without becoming entirely dominated by it. Since absorption is a central component of distress intolerance, improved attentional control may have directly contributed to higher distress tolerance scores.

The improvement found in this study also corresponds with Firoozi's finding that distress tolerance in mothers of children with cancer is associated with parenting styles and children's attachment behaviors (Firoozi, 2020). The current intervention went beyond intrapersonal emotion management and included skills related to communication, compassionate behavior toward the child, management of the child's behavioral difficulties, reinforcement, extinction, shaping, and realistic expectations. Enhancing maternal competence in these domains may have indirectly increased distress tolerance by reducing uncertainty about how to respond to the child. When mothers possess practical caregiving and behavioral management strategies, they may feel less overwhelmed during emotionally demanding interactions and more confident in their ability to remain calm and effective.

This interpretation is supported by research emphasizing maternal self-efficacy and empowerment. Self-efficacy has been associated with caring behaviors among mothers of children with cancer, suggesting that perceived competence contributes to more adaptive caregiving (Barani et al., 2019). Empowerment-based interventions have also improved self-efficacy and quality of life among mothers caring for children with chronic illness (Shahsavari et al., 2022). The present intervention repeatedly emphasized personal competence, responsibility, choice, recognition of achievements, appropriate use of support systems, and selection of workable solutions. As mothers became more confident in managing emotional and caregiving demands, their distress may have seemed less threatening and more manageable. Thus, increased distress tolerance may partly reflect a broader improvement in perceived self-efficacy.

The self-care elements of the program are also relevant. Implementation of Orem's self-care model has been shown to improve health-promoting behaviors in mothers of children with leukemia (Famili Khalili & Salehi, 2021). Mothers frequently neglect their own emotional and physical needs because of continuous attention to the ill child. Such neglect may increase exhaustion, emotional reactivity, and vulnerability to distress. The program encouraged self-reinforcement, recognition of personal needs, compassionate self-treatment, and balanced responsibility. These elements may have helped mothers view self-care not as selfishness but as a necessary condition for sustained caregiving. Improved self-care may in turn strengthen emotional

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capacity and reduce the likelihood that ordinary stressors exceed the mother's coping resources.

The findings also correspond with studies showing that resilience-oriented interventions can improve psychological adaptation among mothers of children with cancer. Reality therapy has been found to increase resilience in this population (Shamli & Hasani, 2017). Although distress tolerance and resilience are distinct constructs, they are conceptually related because both involve maintaining adaptive functioning under adversity. The present program emphasized acceptance of current realities, responsibility for controllable actions, effective communication, problem-solving, and alignment between expectations and the child's actual condition. These components may have enhanced mothers' capacity to recover from emotional setbacks and continue functioning despite ongoing uncertainty.

The lived-experience foundation of the intervention may have been one of the principal reasons for its effectiveness. Qualitative studies have demonstrated that mothers of children with leukemia experience fear, uncertainty, disrupted family roles, social isolation, emotional exhaustion, concern about recurrence, and difficulty adjusting to the demands of treatment (Al Omari et al., 2023; Shaygani et al., 2024). Recent qualitative evidence has similarly described the caregiving transition as being immersed in fear and doubt, particularly when mothers move between hospital-based treatment and home-based care while feeling uncertain about their competence (Ghanbari et al., 2025). Because Behfar's protocol was developed from the lived experiences of mothers facing these challenges, its content directly reflected the participants' actual concerns rather than imposing a generic set of psychological skills (Behfar, 2026). This congruence may have increased the perceived relevance and credibility of the sessions, facilitated emotional engagement, and reduced resistance to the intervention.

A lived-experience-based intervention may also normalize mothers' emotional responses. Parents of children with advanced cancer can experience substantial psychological distress, including anxiety, depressive symptoms, and uncertainty regarding the future (Rosenberg et al., 2014). Mothers may interpret such reactions as evidence that they are weak or incapable, particularly when social expectations encourage them to remain consistently strong. Hearing that similar reactions are shared by other mothers may reduce shame and isolation. The group context may also create opportunities for mutual recognition and observational learning, enabling participants to learn coping strategies from others who face comparable circumstances. This process can strengthen both emotional validation and practical competence.

The significant maintenance of treatment gains at the three-month follow-up is particularly important. The absence of a significant difference between posttest and follow-up suggests that participants continued to use the acquired skills after the formal sessions had ended. Several components of the program were designed for repeated application in daily life, including mindfulness, thought monitoring, compassionate self-talk, scheduled worry, cognitive defusion, behavioral activation, communication skills, and structured problem-solving. These techniques may have become part of the mothers' ongoing coping repertoire. The durability of the findings is also consistent with the view that interventions are more likely to produce lasting change when they target transdiagnostic processes, such as experiential avoidance, self-criticism, cognitive fusion, and ineffective emotion regulation, rather than focusing solely on temporary symptom reduction.

The maintenance of effects may additionally be related to the intervention's emphasis on meaning, hope, and personal values. Positive psychotherapy highlights the importance of strengths, engagement, relationships, meaning, and accomplishment in promoting psychological adjustment (Rashid & Seligman, 2018). In pediatric advanced cancer, parental hope has also been associated with communication patterns and the way families navigate difficult information (Rosenberg et al., 2020). The present program did not seek to eliminate fear or create unrealistic optimism. Instead, it helped mothers clarify values, recognize achievements, develop realistic expectations, and continue meaningful caregiving despite uncertainty. This form of flexible hope may be more sustainable than reassurance because it is grounded in purposeful action rather than certainty about medical outcomes.

The findings also support recommendations that psychosocial care should be integrated into pediatric oncology services. Clinical guidelines emphasize routine psychosocial assessment, family-centered care, risk screening, and evidence-based intervention for children with cancer and their families (Kazak et al., 2021). Family psychosocial risk screening can identify caregivers who require more intensive support and guide interventions matched to their level of need (Kazak et al., 2015). The present results suggest that mothers with low distress tolerance may benefit from structured, culturally responsive programs that combine cognitive, emotional, interpersonal,

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and behavioral skills. Such programs may be especially valuable during periods of diagnosis, intensive treatment, recurrence, or transition to home care.

The effectiveness of the intervention is also compatible with research on educational and digital support for parents of children with cancer. A web-based educational intervention has been shown to reduce parental distress (Wiener et al., 2020), indicating that psychoeducation and structured coping guidance can produce meaningful psychological benefits. However, the present study suggests that education may be particularly effective when it is interactive, experientially grounded, and linked to the specific concerns expressed by mothers. The opportunity to practice techniques, discuss experiences, receive feedback, and observe other participants may have added therapeutic value beyond information provision alone.

The program's multidimensional nature is consistent with family-centered and palliative care perspectives. Pediatric palliative care emphasizes communication, psychosocial support, symptom management, family functioning, and quality of life throughout the illness trajectory rather than only at the end of life (Jones et al., 2014). Mothers' distress tolerance can affect their ability to participate in treatment decisions, communicate with healthcare teams, support the child emotionally, and maintain family stability. Therefore, enhancing distress tolerance may have implications beyond the mothers' personal well-being. It may also improve the psychosocial environment in which the child receives care.

5. Conclusion

Finally, the relevance of the present findings should be considered within the broader burden of cancer. Cancer remains a major global health concern, and the continuing incidence of childhood malignancies means that large numbers of families require prolonged psychosocial support (Siegel et al., 2024; Sung et al., 2021). Medical advances have increased survival for many children, but improved survival can also extend the duration of caregiving, uncertainty, and adjustment demands. Consequently, psychosocial interventions should not be viewed as optional additions to medical treatment. Rather, they are essential components of comprehensive care for children with leukemia and their families. The present study contributes to this field by showing that an intervention derived from mothers' lived experiences can significantly and durably improve distress tolerance.

6. Limitations and Suggestions

Several limitations should be considered when interpreting the findings. The participants were recruited through convenience sampling from a single pediatric medical center in Tehran, which may limit the generalizability of the results to mothers receiving services in other regions, hospitals, cultural contexts, or healthcare systems. The relatively small sample size may also have reduced the precision of effect estimates and limited the examination of subgroup differences based on factors such as the child's age, disease stage, treatment phase, family income, marital status, or previous caregiving experience. Distress tolerance was assessed using a self-report instrument, and participants' responses may have been influenced by social desirability, recall bias, or expectations regarding the intervention. The control group was placed on a waiting list and did not receive an active comparison intervention; therefore, nonspecific factors such as group support, facilitator attention, and expectations of benefit cannot be completely separated from the specific effects of the protocol. In addition, the follow-up period was limited to three months, and the long-term maintenance of intervention gains remains uncertain.

Future studies should replicate the present research with larger and more diverse samples recruited from multiple pediatric oncology centers and different geographical and cultural settings. Randomized controlled trials using active comparison groups would help clarify whether the observed benefits are attributable to the specific content of the lived-experience-based protocol rather than to general therapeutic attention or group participation. Researchers should also include longer follow-up periods, such as six months or one year, to evaluate the durability of treatment gains across different phases of the child's illness. The use of multimethod assessment, including clinical interviews, behavioral indicators, physiological measures, caregiver diaries, and reports from healthcare professionals or family members, could provide a more comprehensive evaluation of distress tolerance. Future studies may also examine potential mediators and moderators, including self-compassion, emotion regulation, experiential avoidance, resilience, self-efficacy, social support, severity of the child's illness, and mothers' baseline psychological distress. Comparative studies could determine whether the protocol is more effective than acceptance-based, cognitive-behavioral, compassion-focused, or supportive interventions delivered separately.

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Pediatric oncology centers should consider incorporating lived-experience-based educational programs into routine psychosocial services for mothers of children with leukemia. Healthcare professionals should screen mothers for low distress tolerance, severe worry, rumination, social isolation, self-blame, and caregiving exhaustion at different stages of the child's treatment. Psychologists, nurses, social workers, and counselors can use structured group sessions to teach mindfulness, cognitive restructuring, self-compassion, acceptance, communication, behavioral management, and problem-solving skills. Intervention content should be adapted to the mothers' cultural background, educational level, treatment phase, and most pressing caregiving concerns. Brief booster sessions, telephone follow-up, digital practice materials, and peer-support components may help maintain treatment gains after the formal intervention ends. Family members should also be encouraged to share caregiving responsibilities and support mothers' self-care so that the burden of the child's illness does not remain concentrated on one caregiver.

Authors' Contributions

Authors equally contributed to this article.

Declaration

In order to correct and improve the academic writing of our paper, we have used the language model ChatGPT.

Transparency Statement

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Declaration of Interest

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The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants.

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