Effects of supportive-expressive discussion groups on loneliness, hope and quality of life in breast cancer survivors: a randomized control trial

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Abstract

Purpose: Evaluation of the effect of supportive expressive discussion groups on loneliness, hope and quality of life in breast cancer survivors.

Methods: A randomized control trial including breast cancer patients who had completed chemotherapy and randomly allocated into two groups: intervention ($n = 41$) and control ($n = 40$). The intervention consisted of twelve weekly 90-min sessions for groups of six to eight breast cancer survivors. Data were obtained pre-to -post the intervention and at 8-week follow-up. The data were analyzed using a repeated-measures analysis of variance (ANOVA).

Results: The findings revealed a significant reduction in loneliness scores ($F = 69.85, p < 0.001$), promotion in total hope ($F = 20.8, p < 0.05$) and enhancement in quality of life from pre- to post-intervention, and then over the 8-week follow-up period in the intervention group, while scores of control participants did not show this pattern during the study. The strongest effects were found for global quality of life (effect size) = 0.59), for future perspectives (effect size = 0.51), emotional functioning (effect size = 0.35) and social functioning (effect size = 0.31).

Conclusion: The intervention was effective on loneliness, hope and quality of life in the intervention group. The intervention needs further evaluation in a larger study and with other cancer types. Copyright © 2016 John Wiley & Sons, Ltd.

Introduction

Breast cancer is the primary cause of cancer death among women globally. It is estimated that over 40450 women die in 2016 because of breast cancer in the United States [1]. Although breast cancer is thought to be a disease of the developed world, almost 50% of breast cancer cases and 58% of deaths occur in less developed countries [2]. According to the most recent Iranian cancer registry report, breast cancer is the most prevalent cancer among Iranian women [3]. Iranian women are affected by breast cancer at least 10 years earlier than their counterparts in developed countries [4].

The diagnosis of breast cancer is a stressful condition that influences physical and psychological functioning and impacts lifestyle and relationships with family and friends [5,6]. Breast cancer treatments, including systemic adjuvant therapy, lead to long-term deterioration of QoL in breast cancer survivors [7]. In addition, treatment-related changes to women's physical appearance may influence self-image, and other effects of treatment, include fatigue, nausea, and pain, which may reduce opportunities for social interactions and restrict the capability of women with breast cancer to continue their normal lifestyle and social activities [8].

In a recent literature review, Chi [9] realized hope as one of the single most essential elements in the lives of patients struggling with a cancer diagnose. Hope helped them deal with the distress and uncertainty of their diagnosis [10].

Social support has been shown to be protective for health and in particular for reducing cancer-related distress [11]. Previous studies have illustrated that obtained social support may be related to lower loneliness, higher life satisfaction [12,13] and higher quality of life [14] in patients with prostate, and gynecological cancer [15–17].

Making friends, mentoring, community navigators, social group schemes and perceived social support in supportive and expressive groups are interventions to decrease loneliness and social isolation in the groups [18]. The purpose of the current study was to determine the effects of supportive expressive discussion groups on the loneliness, hope and consequently QoL of the Iranian women with breast cancer.

Methods

The current double-blind randomized clinical trial (IRCT 2014031516564) was conducted during 2013 – 2014. Our main hypotheses included: participation in the intervention

group (IG) significantly changes (a) the level of loneliness, (b) hope and (c) QoL in breast cancer survivors with a follow-up period of 8 weeks.

Subjects

As illustrated in the CONSORT flowchart (Figure 1), 140 women with breast cancer were invited into the study by oncology ward supervisor, of which 59 women were excluded; did not meet inclusion criteria ($n = 40$), declining participation ($n = 13$) and other reasons ($n = 6$) with a final sample size of 81 women . Sample size was calculated based on the results of a study by Fukui *et al.* [19]. Considering the mean differences in intervention and control groups (IG: 32.8 and CG: 36.6), type I error probability of 5%, power of 0.9, it was estimated that 40 subjects were needed in each group.

Participants were women who met the following inclusion criteria: (a) diagnosis of primary, biopsy-proven breast cancer, stages I through IIIA, (b) surgery within the previous 4–18 months, (c) completed chemotherapy, and (d) no detectable disease present. Exclusion criteria consisted of: (a) evidence of metastases beyond lymph nodes, including chest wall involvement, bone or viscera, (b) recurrence of the cancer prior to randomization, (c) diagnosis of other cancers, (d) any other major medical complications likely to limit life expectancy to less than 10 years, (e) a history of major psychiatric illness for which the patient was hospitalized or medicated, and (f) attendance at a cancer support group for more than two months.

Participants were selected from a group of outpatients with breast cancer treated at the Omid Cancer Center affiliated to Urmia University of Medical Sciences located in North West of Iran.

Figure 1. Flow diagram of the study

Description of the randomization conditions

Random assignment followed a method combining elements of biased coin randomization with adaptive randomization [20]. These stratification variables were: (a) type of surgical procedure: breast conservation vs modified radical mastectomy, (b) axillary node involvement: 0 vs 1–3 vs 4 or more positive, (c) age: < 50 vs 50 or older, and (d) estrogen receptor status: positive vs negative. Data collection was scheduled at baseline (t0), post-intervention (t1) and at a follow-up of 8 weeks (t2). Baseline measures (t0) were obtained prior to randomization. Although the data entry and analysis were conducted by blinded researchers and authors with master's degree, student as a tutor could not be blinded to treatment allocation for practical reasons.

Instruments

The GHQ-28 was used to screen the subjects' mental health. The GHQ-28 consists of four subscales including somatic symptoms (items 1–7), anxiety/insomnia (items 8–14), social dysfunction (items 15–21) and severe depression (items 22–28). All items are responded on a 4-point Likert scale of none, mild, moderate, and severe which are scored from zero to three. The score 23 or above was the cut-off point for probability of having a mental health disorder [21]. Accordingly, women who obtained scores >23 were excluded from the study.

Loneliness was measured with the 20-item, Revised UCLA Loneliness Scale [22], in which subjects were asked to rate each of the 20 statements according to how often they agreed with the description. The item responses range from 4 (often) to 1 (never), with a total possible score of 20–80. Higher scores indicate a greater level of loneliness. This instrument has an internal consistency of alpha equal to 0.94. The validity and reliability of the Iranian version of the Revised UCLA Loneliness Scale have been confirmed [23].

Hope was assessed with the State Hope Scale (SHS), an instrument that measures hope as a cross-situational, long-term trait in general populations [24]. Twelve items are rated on a 4-point response scale ranging from 'definitely false" to 'definitely true' and summed to produce a total score. Two subscales measure belief in one's capacity to initiate and sustain actions (agency), and ability to generate routes for reaching goals (pathways). These two constructs are pretended to be reciprocal, additive, and positively related to one another, but not synonymous, because people may feel able to act without knowing how to achieve a goal and vice versa [25]. Research has found SHS scores to be positively associated with goal-related activities and coping strategies [26]. Internal consistency for the total scale was α=0.82, with α=0.80 for the agency subscale and α=0.63 for the pathways subscale.

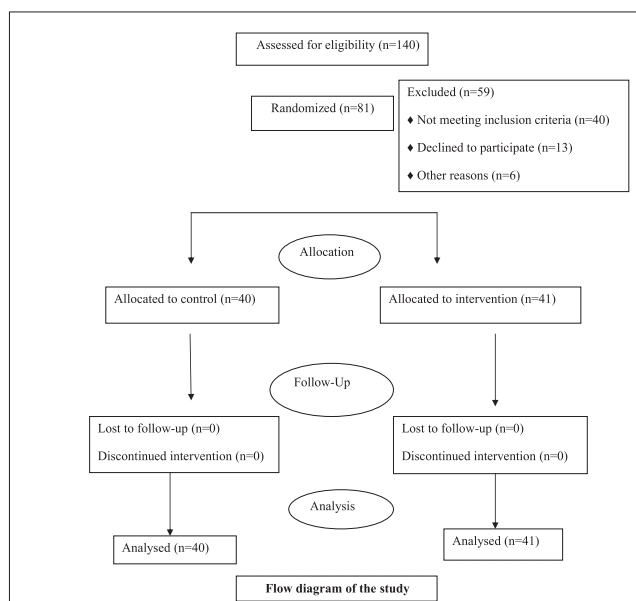The European Organization for Research and Treatment of Cancer QoL Core Questionnaire (EORTCQLQ-C30) is

a 30-item core-cancer-specific questionnaire integrating system, focusing on the patients' experiences over the last 4 weeks. The scale includes five functional scales (physical, role, emotional, cognitive and social), three symptom scales (fatigue, nausea and vomiting, and pain), a global health and QoL scale and single items to evaluate additional symptoms frequently announced by cancer patients (e.g. dyspnea, sleep disturbance, appetite loss, constipation and diarrhea) and the perceived financial impact of the disease and treatment. All items are scored on four-point Likert scales, ranging from 1 ('not at all') to 4 ('very much'), except for two items on the global health/QoL scale, which use modified seven-point linear analog scales [27]. Domain scores were computed according to the scoring guideline. Higher scores for this scale (range, 0–100) indicate better HRQoL [28]. The alpha coefficients for the subscales for Iranian version range from 0.63 to 0.95 [29].

Intervention

The intervention was an unstructured supportive expressive discussion groups, consisting of 12 weekly 90-min sessions designed for groups of seven to nine cancer survivors.

Leader during the sessions tried to facilitate the situation so that all participants could have a good opportunity to express fears and feelings, allowed participants to confront existential issues. The topics of sessions consisted of different domains such as psychological information like stress of having cancer, fear of recurrence, explaining stress management, coping strategies for cancer, managing physical and mental activity, setting goals, being positive and having plans for the future and medical information about cancer. With attendance at group and expression of the feelings, the participants tried to improve their affective interactions and have more mutual understanding. During the sessions, the participants tended to build new bonds of social support, seek on sources of support, design and enhance communication with physicians and nurses, ask for information, enhance symptom control, and deal directly with existential concerns such as fears of dying and death, changes in self concept, negative thinking, problem-solving and body image, and finally to make meaning out of illness, cope with feelings of isolation and reorder life priorities. Control group received only routine care (a brochure regarding self-care during chemotherapy). They participated in the program after the IG was completed.

Ethical considerations

The study protocol was reviewed and approved by the institutional review board and the ethics committee of the Urmia University of Medical Sciences (Ir.umsu. rec.1393.108 1393/04/24). Participants were provided with detailed information about the study and were assured that confidentiality would be maintained at all times. Written consent was obtained prior to data collection.

All sessions were audiotape-recorded to monitor the supportive expressive intervention process. Outside interaction between members was encouraged. Upon completion of every session, the participants were given a small gift as a token of appreciation for their involvement in the study.

Statistical analysis

We used a group-by-time two-way analysis of variance (ANOVA) statistics with time as the repeated factor. Group-by-time effects on changes in patients' outcomes and partial eta-squared ($\eta2$) values were calculated. The outcome measures were loneliness, hope and quality of life. We considered the results to be statistically significant if the two-sided p-values were less than 0.05. All statistical analyses were carried out using SPSS for Windows Release 18.

Results

The demographic factors of the sample are pictured in Table 1. The mean age of the samples was 47.9 (SD = 11.4). Most of them (71.34%) were married and 57 (70.11%) had attended high school and above, and about 67% of the sample were not employed. Regarding financial situation only 20% of the sample demonstrated that they had no money problem. A summary of the demographic characteristics of the participants is presented in Table 1.

The findings revealed a significant reduction in loneliness scores in the intervention group over the study period ($F = 69.85$, $p < 0.001$) (see Table 2).

In the intervention group, total hope scores improved from pre- to post-intervention, and then continued to rise over the 8-weeks follow-up period ($F = 20.8$, $p = 0.01$), while scores of the control participants did not show this pattern of improvement over time ($F = 2.06$, $p = 0.52$) (see Table 2).

Positive changes from pre to post intervention occurred in QoL in intervention group ($F = 19.8$, $p = 0.002$) (Table3). The worthy effects were found for global quality of life (effect size = 0.59), for future perspectives (effect size = 0.51), emotional functioning (effect size = 0.35) and social functioning (effect size = 0.31). Little effect sizes based on statistically significant pre-post differences were detected the symptom of fatigue (effect size = 0.27) (Table 3). In addition, small effect sizes were seen in terms of sexual functioning, arm symptoms, physical functioning, reduction in sleep disturbances and the intensity of pain, although pre-post differences were not significant.

Discussion

This study aimed to investigate the effect of supportive-expressive discussion groups on loneliness, hope and

Table 1. Demographic and clinical characteristics of women with breast cancer

Characteristics	Categories	n (%)
Age	Mean (SD)	47.9 ± 11.4
Marital status	Unmarried	6(7.38%)
	Married	58(71.34%)
	Widowed/divorced/separated	17(20.91%)
Education status	Primary	7(8.61%)
	High school	57(70.11%)
	College certificate	17(20.91%)
Current occupation	Housewife	55(67.65%)
	Employed	17(20.91%)
	Retired	9(11.07%)
Financial situation	No money problem	16(20%)
	Fair	41(51%)
	Not enough	24(29%)
Comorbidities	yes	56(68.88%)
	no	25(30.75%)
Most prevalent comorbidities	Hypertension	14(17.22%)
	Diabetes	8(9.84%)
	Other	34(41.82%)
Duration of breast cancer diagnosed	<6 months	11(13.53%)
	>6 months	70(86.1%)

All data in 'n (%)' unless otherwise stated.
There were no significant differences between groups on any of the demographic/clinical variables at baseline.
Intervention group (n = 41) participated in the supportive expressive discussion groups focused on obtaining social support intervention; Control group (n = 40) participated in routine oncology ward care.

quality of life in patients with breast cancer who experienced mastectomy. The findings of the present study confirmed the research hypothesis which emphasized the effects of intervention on loneliness, hope and QoL of the women with breast cancer. The findings suggest that supportive expressive discussion groups played a protective role and had a significant effect on reducing loneliness, promoting their hope and enhancing the QoL of women with breast cancer. In other words, the results of the present study suggest that patients who were attending the intervention group sessions were enabled to decrease loneliness, overcome social isolation, strengthen hope and were also empowered to have higher quality of life compared to women in control group who received only simple brochures regarding self-care.

It is clear that the combined roles of several major components of these kinds of interventions are responsible for changes in patients' QoL. Social support is one of the most common and most prominent states to deal with loneliness and hopelessness [30,31]. The results of the qualitative study conducted in Iran [32] revealed that women with breast cancer are experiencing separation from the community, hopelessness and depression.

Lack of knowledge about the causes of cancer and wrong beliefs such as cancer as a punishment from God cause psychological problems for cancer patients [33]. Breast cancer was as a stigma for them [34], so they were trying to hide their situation and at the same time they were searching trustworthy person to open up about their inner feelings, express their emotions and concerns and even to talk about the topics that are taboo in their culture. Because the core feature of the supportive expressive group model is open expression, we decided to create an opportunity whereby women can share their information to have a better quality of life. Thus in the current study, they found very good opportunity to discuss their challenge with their needs (spouse and family support, worship, receiving and sharing information), losses (loss of breast and hair) and changes (everyday life, self-perception).

In these issues, women expressed their feelings and tried to solve these misconceptions with reasonable solutions. Some women noted that they avoid participating in communities and public places such as swimming pools and wedding ceremonies. The sense of coherence and belonging to group made them describe their experiences and sometimes they intended to open their scarves, even they were showing their mastectomy scar. Sometimes they were discussing concerns related to more private issues for example their sexual issues that is taboo in their culture. In group, they tried to create a suitable atmosphere to express their feelings, unspoken words, fears and doubts. Group created a friendly condition and they learned how to strengthen confidence, find real friends and have their support and even try to have a new and effective coping skill. They saw other women with more difficult situation still trying to manage their stress and anxiety and learnt to enjoy

Table 2. Changes in loneliness and hope of patients in intervention group and wait-list control group

| | Pre-intervention Mean (SD) | Post-intervention Mean (SD) | Follow-up at 8 weeks | | |
			Mean (SD)	F	p
Loneliness					
Intervention group	34.15(8.45)	31.42(7.15)	30.89(6.94)	69.85	<0.001
Control group	34.82(7.38)	34.82(7.38)	34.87(7.43)	2.53	0.76
Hope total					
Intervention group	16.64 (4.31)	23.92(3.73)	24.24(3.92)	20.8	0.01
Control group	16.68(4.77)	17.79(4.79)	17.66(4.71)	2.06	0.52

Intervention group (n = 41) participated in the supportive expressive discussion groups focused on obtaining social support intervention; Control group (n = 40) participated in routine oncology ward care.

Table 3. Changes in Quality of Life of patients in intervention group and wait-list control group

	Pre-intervention Mean (SD)	Post-intervention Mean (SD)	Follow-up at 8 weeks Mean (SD)	Group × time F	Group × time p	Partial eta- squared (η^2) Group × time
Quality of life (0–100)						
Global quality of life						
Intervention group	53.8 (18.1)	64.5 (16.9)	65.5 (16.7)	19.8	0.002*	0.58
Control group	53.9 (17.1)	54.0 (18.0)	53.8 (19.1)	2.43	0.081	
Physical functioning						
Intervention group	77.8 (16.7)	80.5 (16.4)	81.5 (15.4)	5.32	0.331	0.13
Control group	78.0 (17.7)	77.4 (16.7)	78.4 (16.7)	8.64	0.071	
Role functioning						
Intervention group	55.9 (29.1)	61.0 (27.2)	62.0 (28.2)	4.23	0.284	0.17
Control group	56.2 (26.6)	56.0 (30.1)	56.1 (29.6)	6.23	0.082	
Emotional functioning						
Intervention group	47.9 (22.2)	56.0 (22.1)	56.8 (22.1)	17.4	0.047*	0.35
Control group	47.6 (23.2)	48.0 (23.2)	46.8 (20.4)	7.13	0.101	
Cognitive functioning						
Intervention group	63.7(27.2)	68.0 (28.3)	67.8 (29.3)	8.01	0.103	0.19
Control group	63.0(25.1)	62.5(23.2)	62.1(20.2)	9.32	0.097	
Social functioning						
Intervention group	55.8 (29.0)	60.5 (24.9)	61.0 (25.0)	18.76	0.024*	0.31
Control group	55.0 (25.6)	54.2(26.0)	53.8 (27.0)	8.01	0.104	
Fatigue						
Intervention group	52.9 (24.1)	47.0 (22.4)	48.0 (20.9)	17.6	0.046*	0.27
Control group	53.3 (24.1)	54.0 (20.1)	53.4 (21.2)	6.35	0.182	
Sleep disturbance						
Intervention group	37.2 (40.4)	50.0 (33.0)	51.0 (32.0)	8.04	0.077	0.15
Control group	37.8 (37.4)	38.0 (37.4)	38.6 (30.4)	7.96	0.098	
Body image						
Intervention group	52.5 (31.7)	59.0 (28.2)		6.88	0.201	0.16
Control group	52.9 (28.7)	53.0 (30.4)	52.5 (30.3)	5.29	0.110	
Sexual functioning						
Intervention group	29.4 (22.5)	30.1 (26.3)	31.1 (25.3)	2.43	0.701	0.09
Control group	29.0 (24.6)	28.6 (20.5)	27.4 (32.5)	2.01	0.963	
Sexual enjoyment						
Intervention group	62.9 (34.2)	65.6(17.0)	66.0 (18.0)	2.76	0.632	0.12
Control group	62.1 (33.7)	61.5 (35.2)	61.7 (31.2)	1.99	0.870	
Future perspective						
Intervention group	27.9 (27.0)	41.4 (30.8)	41.8(30.0)	18.93	0.031*	0.51
Control group	28.5 (22.5)	28.4 (26.0)	27.9 (22.0)	1.08	0.993	
Systematic therapy side effects						
Intervention group	34.0 (20.2)	31.2 (20.5)	32.0 (20.5)	2.11	0.182	0.11
Control group	34.8 (19.2)	34.8 (22.2)	34.9 (20.7)	1.09	0.211	
Breast symptoms						
Intervention group	34.9 (21.4)	31.5 (23.1)	30.5 (22.1)	3.06	0.478	0.18
Control group	34.7 (20.1)	35.1 (31.4)	35.7 (31.4)	3.14	0.492	
Arm symptoms						
Intervention group	35.8 (24.7)	35.7 (27.9)	34.9 (29.0)	2.93	0.599	0.05
Control group	36.1 (20.8)	36.0 (24.6)	36.6 (25.7)	2.86	0.487	
Upset by hair loss						
Intervention group	51.0 (36.7)	49.0 (41.0)	49.0 (41.0)	4.11	0.324	0.18
Control group	50.8 (35.7)	51.0 (33.7)	50.5 (37.7)	3.88	0.711	
Intensity of pain (range 0–10)						
Intervention group	4.5 (2.1)	3.7 (2.4)	3.6 (2.4)	2.34	0.151	0.13
Control group	4.6 (3.1)	4.3 (2.2)	4.4 (3.1)	2.07	0.232	

Intervention group (*n* = 41) participated in the supportive expressive discussion groups focused on obtaining social support intervention; Control group (*n* = 40) participated in routine oncology ward care.

life. They shared their helpful experiences to deal with these challenges and new facilities such as proteases and wigs.

Regarding being hopeful to accelerate the healing process, women advised having spirituality and trust in God.

Some women in group felt that their illness is something coming from God, the idea that it was their fate to get breast cancer was common. This situation was expressed as 'the disease coming from God'. Thus the effect of

treatment worked only if God allowed it to work, so there was nothing else to do. In contrast, some other women expressed that if they trust in God and struggle and focus on their inner factors, God will help them get rid of the illness. Regarding this idea women were reciting some verses from holy book saying 'And that the human being attains only what he strives for' which emphasizes that human being is able to change his own destiny. Thus these kinds of different approaches were modifying women attitudes and reforming their challenges to be more hopeful leading to a better quality of life. Members in group encouraged each other to attend religious festivals, pray and read holy book. These kinds of programs made them leave home into community and have relationship with friends, in this way they could be away from negative thoughts.

Attending in group and expressing the feelings provided the opportunity to receive information regarding women's attitudes and feelings about their illness, helped them to improve planning and designing new programs to deal with their challenges, provided a means of evaluating current life style, produced insights for developing strategies for better quality of life. Women naturally interacted and were influenced by others, improved communication skills which led to new friendships; moreover, they realized that their problem is not unique, so an improved sense of well-being was the outcome. Even low income women were introduced and referred to financial supportive institutes and centers.

In agreement with our study, Kissane et al. (2007) revealed that attending supportive-expressive group prevented the development of helplessness and hopelessness [35]. The new created social support by emotional expression caused social interaction in women. Perese (2005) demonstrated that social interaction creates an opportunity to make friends[36]. Consistent with our findings, other studies showed that social support promotes wellbeing and quality of life if it makes a sense of intimacy, affection and provides emotional support[5]. Also our results are consistent with the study conducted in China [37] showing that the influence of social support on QoL may depend on the extent to which survivors use situation-specific support. For instance, cancer survivors who relied on peer survivors and family members for emotional support might be likely to meet their basic needs for affection and support, and therefore, have a high likelihood of increased QoL. Reuter et al. in a study conducted in Germany revealed that women in group were receiving support and encouragement and gaining information and understanding. In their study, participation in the group led to positive changes in relationships with others, changes in life priorities as well as intrapersonal changes. Patients also emphasized the importance of the opportunity to express their feelings and discuss their fears about death with others during the group therapy. Studies conducted in Iran showed the positive association between depression, mental health, quality of life and social support [38–40].

As a result of the discussions, the patients realized that they were not alone with their fears. Furthermore, patients expressed through follow-up calls that even after 1 year the group still plays a role in their everyday life.

Strengths and limitations

The major strengths of this study were the well-balanced distribution of demographic and clinical characteristics at baseline in both groups with no dropout/withdrawal. So not surprisingly women were interested in continuing attendance at the group and because our sessions were weekly, sometimes they were insisting on having sessions twice a week. All patients who attended the sessions completed the questionnaires.

Moreover, patients with a wide range of educational backgrounds participated in the study.

A careful analysis of the videotaped groups was done to ensure that no problem was observed in the quality of the group facilitation. It was necessary to ensure that the program is conducted in an appropriate way.

The other positive point of this study is the results of global QoL especially for future perspectives and emotional functioning as an objective experience of hope enhancement and social functioning as an objective experience of loneliness reduction in patients. Therefore, our results would be less biased in terms of changes in QoL domains.

The outside interaction between members and the role of behavior changes of the family members were not monitored.

Conclusion

The study demonstrates the potential benefit of supportive expressive discussion groups intervention for women with breast cancer, because the study provided better QoL in breast cancer patients, at least during the intervention.

Suggestions

Our data suggest that expression of emotional and affectionate positive social interaction were important in QoL. Thus, encouragement of activities and behaviors to promote companionship with those who can provide these types of support should be emphasized.

Healthcare workers should try to connect patients with family, relatives, colleagues and friends and highlight the importance of their empathy and social interaction to modify psychosocial effects of the stressors.

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Conflict of Interest

The authors have declared that there is no conflict of interest.

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