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The Effect of a Self-Management Program Based on the 5A Model on Caregiver Burden of Family Caregivers and Illness Perception of Patients with Colorectal and Lung Cancers Referred to Hospitals Affiliated with Shahrekord University of Medical Sciences

Marzieh Bahrami[1], Ali Hasanpour Dehkordi[2], Shahriar Salehi Tali*[4]

[1.] MSc Student in Critical Care Nursing, School of Nursing and Midwifery, Shahrekord University of Medical Sciences, Shahrekord, Iran

[2.] Full Professor, School of Nursing and Midwifery, Shahrekord University of Medical Sciences, Shahrekord, Iran

[*3.] Associate Professor, School of Nursing and Midwifery, Shahrekord University of Medical Sciences, Shahrekord, Iran

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ABSTRACT

Background and Aim:

Background & Objective: Within healthcare systems, the burden experienced by family caregivers and the ways in which patients perceive their illness remain major concerns, particularly in oncology. The present trial sought to determine whether implementing a self-management intervention based on the 5A framework could reduce caregiving burden among family members and modify illness beliefs in individuals diagnosed with colorectal or lung cancer.

Methods: A total of 56 patients (colorectal/lung cancer) along with their primary family caregivers took part in this quasi-experimental study. Participants in the intervention arm received the 5A-based program across five stages, delivered via a combination of face-to-face and virtual sessions. The effects were monitored over a two-month follow-up period. Data gathering relied on three tools: a demographic information sheet, the Zarit Caregiver Burden Inventory, and the Brief Illness Perception Questionnaire (B-IPQ). Statistical analysis was performed using SPSS-26, applying independent t-tests, Fisher's exact test, chi-square tests, and analysis of covariance (ANCOVA).

Results: At baseline, no significant difference in mean caregiver burden scores existed between the intervention and control groups ($p>0.85$). Nevertheless, immediately after the intervention and again two months later, a statistically significant difference emerged in favor of the intervention group ($p<0.001$). Regarding illness perception, however, mean scores did not differ significantly between the two groups at any time point neither immediately post-intervention nor after the two-month follow-up ($p>0.39$).

Conclusion: The 5A self-management model appears to be effective in alleviating caregiver burden among families caring for cancer patients. Its influence on patients' illness perception, however, may require a longer period to become evident.

Introduction

In the current century, no health challenge has hindered the rise in global life expectancy more than cancer, which stands as a leading cause of death worldwide [1]. According to data published by the International Agency for Research on Cancer (IARC) under the World Health Organization (WHO), over 19 million new malignancies were identified globally in 2020 [2].

Among these, lung and colorectal cancers respectively the second and third most frequent cancers that year are of particular concern [3].

Corresponding Author:* ***Shahriar Salehi Tali* *(sh_salehitali@yahoo.com)*

Lung cancer, the most common and deadliest malignancy in both sexes, now represents a major policy challenge for health systems [4, 5].

Evidence indicates that individuals with lung cancer suffer from the most severe symptom burden among all cancer types [6]. In developing nations, the likelihood of recovering from colorectal cancer is roughly one-third of that observed in patients from developed countries [7]. Given the high case numbers, the life-threatening nature of these diseases, and the complications they impose, supporting both lung/colorectal cancer patients and their caregivers can yield substantial benefits [5, 8].

More than half of the care demands of cancer patients throughout their illness trajectory are met by informal caregivers [9] In developing countries, where formal cancer care resources remain inadequate, the active performance of care tasks places a heavy burden on family members [10]. Some studies suggest that learning about a cancer diagnosis may affect family members even more deeply than the patients themselves [11]; however, because clinical attention typically centers on the patient, caregivers' needs often go unaddressed [12]. The prolonged responsibility placed on caregivers can generate excessive stress and adversely affect their physical and mental health [13].

Although caregivers' physical well-being is at risk due to lack of time for rest, exercise, and self-care, they frequently cannot seek medical attention because of time constraints [2]. Nearly half of all caregivers experience some form of psychological distress such as depression, anxiety, insomnia, reduced quality of life [14], or increased fear and death-related thoughts [15] yet they rarely use mental health services to address these emotional difficulties [16].

Moreover, a considerable number of cancer patients and their families suffer adverse financial consequences [17].

Strain are evident in many families caring for a cancer patient [18]. Although numerous studies have documented the negative, effects associated with caregiving [19], support for informal caregivers has often been suboptimal [20].

This imbalance between care demands and available support leads to caregiver stress (21). The distress that caregivers feel because of providing care is defined as caregiver burden [22, 23]

, reflecting the extent to which caregivers perceive that their emotional or physical health, as well as their social and financial circumstances, have been damaged by caregiving duties [24].

Because patients' well-being closely linked to their caregivers' problems [25], unresolved caregiver issues not only reduce caregivers' own quality of life but also negatively affect patient health outcomes [26]. Support has identified as the most fundamental need of cancer patients [27] and can contribute to psychological coherence, improved adaptation, enhanced coping ability, and better illness perception among this population [28].

. Given that unmet informational needs are high among these patients, most desire more information about their illness. Informational support one of the most accessible forms of assistance can help cancer patients by reducing uncertainty, increasing participation in decision-making, improving treatment satisfaction, and enhancing coping capacity [29,30]. When a person is told they have cancer, beliefs shaped by medical knowledge or prior experiences generally form in their mind, producing psychological effects that ultimately influence general health and social functioning [31, 32]. Promoting specific caregiving behaviors, such as illness perception, helps patients gain greater control over their daily lives and manage their social functioning [33].

Alongside traditional patient and caregiver education, self-management education serves as a complementary strategy for achieving the best possible quality of life with a chronic condition. While traditional education provides information and technical skills, self-management education teaches problem-solving skills [34].

Self-management described as the process of integrating an illness into daily life while maintaining an acceptable quality of life despite the condition [35].A self-management approach offers an excellent opportunity for the active participation of both caregivers and patients, enabling them to select relevant themes and strategies according to their needs [36]. One applicable nursing model in the field of self-management is the 5A Model, which comprises five stages: Assess Advise, Agree, Assist, and Arrange. It begins with identifying each individual's problems. Then, based on the assessment results, the client made aware of their problems and the potential risks those problems may pose. In the next stage, through agreement between the educator and the participant, specific behavioral goals are set, and practical plans for achieving those goals are determined. Subsequently, if some clients

require specific training or counseling, they provided with the necessary education. Finally, in the fifth stage (Arrange), follow-up conducted via telephone or in-person visits, aiming to achieve maximum independence, self-decision-making, health promotion based on the individual's abilities and lifestyle, and improved quality of life [37].

Because the unknown nature of cancer can lead to incorrect illness perception and anxiety in patients, the resulting burden of problems weighs heavily on family caregivers. Nevertheless, little attention has paid to addressing caregivers' needs. Given the lack of similar studies in Iran, the present research was conducted under the title: Evaluating a 5A Model-Based Self-Management Intervention: Outcomes for Caregiver Burden in Family Members and Illness Perceptions Among Colorectal and Lung Cancer Patients Attending Shahrekord University-Affiliated Hospitals.

Material and Method

Study Design: This quasi-experimental study carried out between December 2021 and June 2022 in the oncology department of Kashani Hospital, Shahrekord, Iran. The Ethics Committee of Shahrekord University of Medical Sciences approved the protocol under ethics code IR.SKUMS.REC.1400.183. The target population consisted of all family caregivers and patients with colorectal or lung cancer who met the predefined eligibility criteria.

Eligibility Criteria: For caregivers: being a family member fully responsible for patient care or spending the most hours per day providing care[38] ; literacy (ability to read and write); absence of mental disorders or intellectual disabilities; and no prior participation in a similar study.

For patients: confirmed diagnosis of lung or colorectal cancer; literacy; absence of mental disorders or intellectual disabilities; provision of written informed consent; no previous participation in a similar study; and age over 18 years[39].

Data Collection Instruments

Data were collected using three tools: (a) a demographic characteristics questionnaire, (b) the Zarit Caregiver Burden Inventory, and (c) the Brief Illness Perception Questionnaire (B-IPQ). The demographic form recorded age, gender, marital status, education level, occupation, and economic status for both patients and caregivers. For caregivers only, three additional items were included: relationship to the patient, daily care duration, and history of caregiving.

Zarit Caregiver Burden Inventory originally developed in 1980 contains 22 items measuring caregiver burden. Responses follow a five-point Likert scale: never (0), rarely (1), sometimes (2), often (3), and always (4). Total scores range from 0 to 88, with higher scores indicating greater burden. In Iran, the instrument's reliability has been established through content validity (textbooks, expert opinion from psychiatrists and psychologists) and test-retest reliability (r=0.94) [40].

Khalifehzadeh et al. (2017) further confirmed its validity [41].

Brief Illness Perception Questionnaire (B-IPQ) consists of nine items and was developed by Broadbent et al. based on a modified version of the same tool. Except for the causality question, all items are answered on a 0-10 scale. Each item measures one dimension of illness perception. Five items assess cognitive illness representations (consequences, timeline, personal control, treatment control, and identity/symptom perception). Two items assess emotional representations (concern about illness and emotional response). One item measures illness comprehensibility. The final open-ended question asks respondents to list the three most important causal factors of their illness. Responses to the open-ended question categorized, analyzed quantitatively. For scoring, items 3, 4, and 7 are reverse-scored and then summed with items 1, 2, 5, 6, and 8. The total score for the eight items ranges from 0 to 80, with higher scores reflecting a more threatening illness perception (42). The B-IPQ has demonstrated a Cronbach's alpha of 0.80 and test-retest reliability coefficients over a six-week interval ranging from 0.42 to 0.75 [42].

Study Procedure

The researcher first visited the oncology department of Kashani Hospital in Shahrekord. After fully explaining the research process and obtaining written informed consent, 56 family caregivers together with their colorectal/lung cancer patients all meeting the inclusion criteria were enrolled using convenience sampling. Participants assured of their right to freely enter the study and withdraw at any stage, and confidentiality of the collected data emphasized.

The intervention groups received self-management training based on the 5A model. Initially, participants read and signed informed consent

forms. Caregivers then completed the demographic and caregiver burden questionnaires in person, while patients completed the demographic and illness perception questionnaires. Participants subsequently randomly assigned to either the intervention control group (both caregivers and patients).

Stage 1 (Assess): Based on the results of the caregiver burden questionnaires, findings from previous studies, and initial interviews with caregivers and patients regarding their current situation, the educational needs and self-management problems of the research units were extracted. Educational content developed accordingly and approved by five faculty members.

Stage 2 (Advise): Only participants in the intervention groups were informed about the potential health risks associated with high caregiver burden and became familiar with the benefits of self-management during caregiving crises. At this stage, specific behavioral recommendations provided, emphasizing that their physical and psychological problems related to their own behaviors, that behavioral issues are as important as medication use, and that each individual is responsible for their own health and must strive to improve it.

Stage 3 (Agree): Based on the identified conditions, needs, and problems, behavioral goals were established through discussion and agreement between the intervention group participants and the researcher. Practical plans developed for each goal, and participants instructed to continue these activities for two months. Whenever possible, participants asked to set measurable and practical behavioral change goals. A scale from one to ten provided to each caregiver for each behavioral goal, and they requested to record their daily status regarding each goal in a logbook. This stage conducted in person and individually.

Stage 4 (Assist): Patients and caregivers were each separately divided into five groups. A group training session (5-6 people per group) then held in the oncology department of Kashani Hospital, lasting a maximum of 1.5 hours, for the intervention group participants [43]. During this session, participants received necessary training along with printed or electronic brochures, videos, and educational podcasts tailored to their needs. Caregivers received information to manage caregiver burden and the care process, while patients received information about the disease, treatment, complications, and disease progression. Those who could not attend the classes for any reason received the training virtually.

Stage 5 (Arrange): Follow-up was conducted through in-person meetings during chemotherapy sessions or home visits, as well as weekly telephone follow-ups for two months, to guide the intervention program, answer questions, and monitor participants' progress[44]. Participants asked to send weekly images of their completed goal logbook pages to the researcher. Two months after the completion of the interventions, follow-up period, the caregiver burden and illness perception questionnaires again completed by the respective participants using both written, electronic methods, and the variables reassessed. Data then analyzed using SPSS-26. The control group received only the routine hospital program (the education and recommendations provided by healthcare staff). At the end of the study, all interventions, particularly printed and electronic educational files, provided to the control group.

Statistical Analysis

All statistical analyses performed using SPSS version 26. Descriptive statistics (frequency, percentage) were used for qualitative variables, while mean ± standard deviation was employed for quantitative variables with a normal distribution. The normality of variable distribution assessed using the chi-square test and Fisher's exact test. For normally distributed quantitative variables, independent t-tests, paired t-tests, and one-way analysis of covariance (ANCOVA) applied. A significance level of $p \leq 0.05$ considered for all tests.

Results

In this study, 56 family caregivers of patients with colorectal and lung cancers were examined in two groups: intervention (n=28) and control (n=28). The two study groups showed no statistically significant differences regarding variables such as gender, marital status, caregiver's relationship to the patient, education level, occupation, age, duration of care per day, and caregiving history ($p<0.05$) (Table 1).

Table 1. Demographic characteristics of caregivers in the intervention and control groups

Variable	Subgroups	Intervention	Control	P-value
-	-	%	%)	0.42
Gender	Female	42.9 (12)	53.6 (15)	-
-	Male	57.1 (16)	46.4 (13)	-
Marital Status	Single	14.3 (4)	28.6 (8)	0.33
-	Married	85.7 (24)	71.4 (20)	-
Caregiver Relationship with Patient	Father/Mother	7.1 (2)	3.6 (1)	0.99
-	Spouse	28.6 (8)	32.1 (9)	-
-	Brother	7.1 (2)	7.1 (2)	-
-	Daughter	25.0 (7)	21.4 (6)	-
-	Son	32.1 (9)	32.1 (9)	-
-	Daughter-in-law	0.0 (0)	3.6 (1)	-
Occupation	Housewife	28.6 (8)	21.4 (6)	0.13
-	Student	3.6 (1)	28.6 (8)	-
-	Employed	46.4 (13)	35.7 (10)	-
-	Unemployed	7.1 (2)	7.1 (2)	-
-	Retired	14.3 (4)	7.1 (2)	-
Economic Status	Poor	35.7 (10)	42.9 (12)	0.89
-	Average	60.7 (17)	53.6 (15)	-
-	Good	3.6 (1)	3.6 (1)	-
Education	Primary	17.9 (5)	10.7 (3)	0.81
-	Guidance	10.7 (3)	17.9 (5)	-
-	Secondary	32.1 (9)	32.1 (9)	-
-	University	39.3 (11)	39.3 (11)	-
Variable	Intervention	Control	-	P-value
Age (years)	43.50 ± 11.69	39.11 ±15.18	-	0.23
Daily Care Time (hours)	14.15 ± 7.70	22.25 ±43.98	-	0.40
Caregiving Experience (months)	12.68 ± 11.35	20.36 ±39.81	-	0.33

The results showed that the mean and standard deviation of the caregiver burden score before the intervention did not differ significantly between the intervention and control groups based on the independent t-test (p=0.85). In addition, after completion of the intervention, the caregiver burden score was assessed using analysis of covariance (ANCOVA), and no significant difference was observed between the two groups (p = 0.09). However, two months after the completion of the intervention, the difference in the mean caregiver burden score between the two groups became statistically significant based on ANCOVA (p < 0.001) (Table 2).

Table 2. Mean caregiver burden scores before, immediately after, and two months after completion of the intervention among caregivers in the intervention and control groups

Variable	Group	Before	Immediately After	Two Months After	Within-Group P-value
Caregiver Burden	Intervention	28.50 ±15.97	27.64 ± 16.64	27.82 ± 15.60	0.80
-	Control	27.71 ± 15.30	29.53 ± 16.80	36.25 ± 15.35	<0.001

The mean score of illness perception between the intervention and control groups before the intervention, assessed using an independent t-test, showed no statistically significant difference (p=0.37). This score was also evaluated after the completion of the intervention and two months later using analysis of covariance (ANCOVA), which likewise indicated no statistically significant difference at either time point (p=0.10) and (p=0.39), respectively (table 3).

Table 3. Mean score of illness perception before, immediately after, and two months after the completion of the intervention among patients participating in the study in the intervention and control groups.

Variable	Group	Time	Time	Time	Within-group P-value	
Illness perception	Intervention	49.18±14.19	50.68±9.38	49.61±9.18	0.72	.72
-	Control	46.83±6.61	47.19±9.25	47.32±9.84	0.25	.25
Between-group P-value	-	0.39	0.10	0.37	-	

Discussion

The present study evaluated the effect of a self-management program based on the 5A Model on caregiver burden among family caregivers and illness perception among patients with lung and colorectal cancer.

Caregiver burden findings: Caregiver burden scores in the intervention group did not change substantially over a total commitment period of approximately five months (three months of active intervention plus two months of post-intervention follow-up); in other words, burden remained relatively constant among caregivers in the intervention arm. However, because caregiver burden in the control group increased significantly during the same period and the between-group difference two months after the intervention was statistically significant ($p<0.001$) we conclude that the intervention (implementation of the 5A-based self-management program) had a genuine effect on caregiver burden.

These results align with previous research. For instance, Heydari et al. (2019), in a study titled "The effectiveness of implementing a self-management program based on the 5A Model on the caregiving burden of caregivers of stroke patients," concluded that a 5A-based self-management program can empower stroke patients and their caregivers [45].

Similarly, Khoshkhoo et al. (2021) reported that self-management training based on the 5A Model positively affected self-care scores and quality of life among elderly patients with hypertension [46]. In a systematic review covering studies from 2000 to 2020, Bilgin et al. (2022) found that interventions targeting family caregivers could enhance their preparedness for care [47].

Bucher et al. (2001), who taught problem-solving skills and home cancer care to patients and caregivers, demonstrated that such skills training made a significant difference particularly for caregivers in how they approached home care [48].

Additionally, Aliakbariyan et al. (2019) measured the effect of group training on the caregiving burden of parents of children with cancer and ultimately concluded that training can reduce caregiver burden in the cancer context [49].

Illness perception findings: Data analysis revealed no statistically significant difference in mean illness perception scores between the intervention and control groups at any assessment point before the intervention, immediately after, or two months later. Thus, applying the 5A Model did not produce a measurable effect on illness perception within this timeframe. Few studies have specifically examined the effect of an intervention on illness perception in cancer patients. Nevertheless, some related research is worth mentioning. Hajloo et al. (2016), investigating the role of disease stage, illness perception, unmet needs, and fatigue in predicting quality of life among cancer patients, showed that illness perception does affect quality of life and underscored the importance of attending to psychological components alongside physical care [50]. Roshand et al. (2016), in a study titled "Investigating the relationship between illness perception and health-related behaviors in patients with multiple sclerosis," found that illness perception scores were associated with health-related behaviors [51]. Richardson et al., working with head and neck cancer patients, concluded that psychological interventions could positively influence illness perception and quality of life [52].

Finally, Kalhor et al. (2019) stated that applying the 5A self-management model could improve quality of life in cancer patients and recommended using this model as an optimal nursing intervention [53].

Conclusion

The results of the present study showed that the self-management program based on the 5A Model is effective on the caregiving burden of family caregivers of patients with colorectal and lung cancer. It seems that applying this model in the healthcare system could be effective as an easy, low-cost, and understandable tool to support family caregivers.

Clinical Application: Nurses are one of the appropriate groups to provide self-management support, and with this tool, they can bridge the gap between the needs of service recipients and healthcare services. Nursing managers can use the results of this study to design empowerment and training programs for caregivers, thereby helping to reduce their caregiving burden, as well as design interventions that can increase the perception of cancer illness in the community. It recommended that treatment centers and specialized oncology units in hospitals and specialized oncology clinics establish a consultation unit and, using experienced staff, teach self-management skills to cancer patients and their caregivers. Furthermore, by holding patient education working groups, they should enhance illness perception in cancer patients.

Conflict of Interest: According to the authors, this article has no conflict of interest.

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Authors' Contributions

All authors contributed to data analysis, drafting, and revising of the paper and agreed to be responsible for all the aspects of this work.

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