Patient Health Engagement Model as the Predictor of Social Support, Self-efficacy, and Quality of Life in Breast Cancer Patients

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Abstract

Background: Patient health engagement (PHE) is a dynamic and evolutionary process that involves improving health; however, little information is available on the PHE model. This study aimed to investigate health engagement and its relationship with social support, self-efficacy, and the quality of life in women with breast cancer.

Methods: This cross-sectional study was conducted on 129 breast cancer patients who were referred to a specialized medical clinic and met the inclusion criteria. Data were collected using the EORTC QLQ-br23 questionnaire, Communication and Attitudinal Self-efficacy Scale for Cancer (19-item), Perceived Social Support Scale, NCCN Distress Thermometer, and PHE Scale. The statistical methods used in this study were linear regression, ANOVA, CATREG (Categorical regression with optimal scaling using alternating least squares), and descriptive statistics.

Results: The most commonly reported problem was tingling in hands and/or feet (43.3%). The median PHE score was 2. Additionally, 29.45% and 16.27% of the patients reported moderate and severe distress, respectively. The results of regression analysis showed that the PHE scale could predict social support, self-efficacy, quality of life and all of its dimensions (P<0.001). However, it is the strongest predictor of understanding and participating in care (P<0.001, r = 0.485).

Conclusion: Given that the model can predict factors effective in improving cancer and interventions based on this model have not been performed in Iran, it is recommended that health interventions based on this model should be designed and implemented.

Keywords: Breast cancer, Patient health engagement, Self-efficacy, Social support, Quality of life

Introduction

despite significant advances in the diagnosis and treatment of breast cancer, mortality remains a medical problem (1). Due to the threatening nature of cancer, the diagnosis of this disease causes each person with cancer to have some distress that may affect the patient’s health decisions and behavior (2). The lack of diagnosis and treatment of distress leads to more pain, decreased quality of life, longer hospital stay, and reduced adaptation to the treatment (2). Today, scientific research studies examine factors affecting patients’ ability to self-manage and adhere to the treatment. The concept of patient health engagement (PHE) is a dynamic and evolutionary process and involves improving the course of life rooted in health psychology. This model describes engagement as the result of a complex process of psychological adaptation to illness. The PHE model seeks to make patients understand that they should not be passive and must play an active role in the care and treatment process (3). PHE defines patient health engagement in multiple cognitive (think), emotional (feel), and behavioral (act) dimensions following their health status. The process of patient engagement as described by the PHE model involves four developmental phases, namely, blackout, arousal, adhesion, and eudaimonic project (3). In the blackout phase, patients feel unable to control their health and are upset. Consequently, they may experience an arousal phase in which they perceive anxiety and worry about their condition. In the adhesion phase, they learn to manage their health but have difficulty adjusting their health habits to the new life condition. Finally, in the eudemonic phase, they feel confident to control their health. They are optimistic about their future and perceive themselves as the main actors in their health and lives (4). The medical condition of cancer greatly affects the patient’s
mental performance and life experiences that may reduce patients' self-efficacy (5).

Bandura stated that a person's self-efficacy provides the necessary confidence for successful performance. Self-efficacy causes patients to overcome feeling of inability to perform the expected role (5).

Self-efficacy is a key factor in people's decision-making for health choices and can directly affect health-promoting behaviors through mediation. A study reported a significant relationship between social support and the ability to fight breast cancer (5). Social support, an important aspect of modern cancer care, is a multidimensional concept that includes four types: emotional, informational, instrumental, and evaluation. Social support is an effective factor in people's self-care behaviors and can help to improve the economic costs and quality of life in patients (6). Before performing health interventions, it is necessary to pay attention to the patient's emotional status (6). This research aimed to study the PHE and its relationship with the quality of life, social support, and self-efficacy in women with breast cancer.

Materials and Methods
In this cross-sectional study, 250 breast cancer patients referred to the oncology ward of Shiraz Namazi Hospital were randomly selected and according to the inclusion criteria (undergoing surgery, having the least education, and being under 65 years), 129 patients participated in the study. Data were collected by the following tools:

Communication and Attitudinal Self-efficacy Scale for Cancer (19-Item)
This questionnaire has three areas of understanding and participation in care, maintaining a positive attitude, and seeking and obtaining information. Each item is rated on a 6-point Likert scale (strongly disagree, moderately disagree, slightly disagree, slightly agree, moderately agree, and strongly agree). The reliability of this scale was calculated by Cronbach's alpha (α = 0.842), and the content validity ratio (CVR) and content validity index (CVI) were determined to be 0.863 and 0.857, respectively.

European Organization for Research and Treatment of Cancer (EORTC) QLQ-BR23
The specific quality of life questionnaire for breast cancer patients includes 53 questions in eight dimensions: body image, sexual functioning, sexual enjoyment, future perspective, systemic therapy side effects, breast symptoms, arm symptoms, and upset by hair loss. The questions were rated on a 4-point Likert scale (not at all, quite a bit, a little, and very much, respectively).

Perceived Social Support Scale
The reliability of this scale was 0.80. It contains 16 items rated on a Likert scoring scale (from strongly disagree to strongly agree). It measures the amount of social support an individual receives from various sources, i.e., family (4 questions), friends (4 questions), spouse (4 questions), and others (4 questions).

PHE 5-Item Scale
This scale examines patients' emotional states, with ordinal scores of 1-4 and 3 intermediate scores. The median of the row PHE-s scores should be calculated to obtain the PHE-s level. It is possible to transform the row PHE-s scores into the corresponding patient's engagement position with a simple conversion. An exploratory CATPCA, a confirmatory factor analysis (CFA) for ordinal data, and a Rasch Model were conducted to test and verify the unidimensionality of the scale. We assessed the internal consistency and reliability. The initial analysis yielded one factor with eigenvalue 2.4, over Kaiser criterion of 1, explaining 48.4% of the total variability. All factor loadings had a high value (>0.6), confirming the unidimensionality of the scale. Infit and outfit statistics ranged from 0.658 to 0.932, which all are within the acceptable range. The person separation index (PSI) was calculated to evaluate the reliability in the Rasch Model (PSI = 0.735). The ordinal alpha was 0.626 (acceptable reliability).

NCCN Distress Thermometer and Problem List for Patients
It consists of two parts: problem list (practical problems, emotional problems, physical problems, yes/no) and distress thermometer (0 = no distress and 10 = extreme distress). The cutoff point for this tool is 4, with scores of 0-4 for no distress, 4-7 for moderate levels of distress, and 7-10 for severe distress. The test-retest reliability analysis yielded an intraclass correlation coefficient of 0.87.

Statistical Analysis
Data were analyzed using linear regression, ANOVA, and CAPTCA (metrical factor resulting from the non-linear analysis of principal component). The median score, categorical regression (that quantifies categorical data by assigning numerical values to the categories, resulting in an optimal linear regression equation for the transformed variables; CATREG), correlation, reliability, and descriptive test were used for ordinal data.

Results
In the present study, Table 1 shows the subjects' demographic and clinical characteristics.

Smoking hookah was observed in 10.9% of the subjects. The median PHE score was 2. The total mean scores (± standard deviation) of quality of life, social support, distress, and cancer self-efficacy were 194.77 ± 14.33 (136-216), 50.70 ± 9.82 (79), 7.27 ± 3.04 (0-10), and 82.33 ± 10.59 (42-101), respectively. Patients reported low (7.8%), moderate (67.4%), and good (24.8%) self-efficacy. In terms of distress, 54.26% of the patients were not distressed, 29.45% had moderate distress, and 16.27% had severe emotional distress. The most commonly reported problem was tingling in hands/feet (43.3%), followed
by worry (31%), fear (25.6%), nervousness (22.5%),
fatigue, sleepiness, and mouth sores (18.6%), memory/
concentration (17.1%), sadness and pain (14.7%), and
sexual problems (13.2%). The overall mean distress
score was 7.27 ± 3.04, and the mean scores of self-efficacy
and social support were reported in Table 2.

Tumor grades I, II, and III were observed in 18.6%,
58.1%, and 23.3% of the patients. The overall quality of life
score associated with breast cancer was reported in Table 3.

The results of analysis of variance (ANOVA) showed
a statistically significant relationship between the global
health score and job (P < 0.03). Distress thermometer
scores were significantly correlated with the job of
employees and the level of education of subjects (primary
education). Weight was associated with self-efficacy and
was also significant in maintaining a positive attitude
(P < 0.003). Body mass index (BMI) was correlated to self-

efficacy and belonged to the overweight and obese group
(P < 0.03). In addition, the correlation of BMI with social
support in friends and special persons was significant
(P < 0.009, P < 0.007) (Table 4).

The present study indicated significant positive
correlations between all dimensions of self-efficacy and
distress scores; understanding and participating in care
(P < 0.005), maintaining a positive attitude (P < 0.001), and
seeking and obtaining information (P < 0.022). Distress
had a significant negative correlation with global health
(P < 0.001; r = −0.479). In addition, distress showed a
significant relationship with the score of breast symptoms
(P < 0.04; r = 0.18). Maintaining a positive attitude toward
self-efficacy had a significant negative correlation with the
body image (P < 0.02; r = −0.19). Additionally, seeking
information about breast cancer had a significant inverse
relationship with breast symptoms (P < 0.037; r = −0.183).
The overall score of social support had a significant
positive correlation with emotional function (P < 0.002;
r = 0.272) and social function of the quality of life
(P < 0.029; r = 0.192). Regarding the support dimension,
there was a significant correlation between the quality of
life and social support provided by the spouse (P < 0.01;
r = 0.223, Table 5).

The results of linear regression showed that education
level (P < 0.02) and BMI (P < 0.04) predicted distress.
Weight (P < 0.03) and marriage (P < 0.002) also predicted
social support. In addition, the weight could predict self-
efficacy (P < 0.03).

CATREG (Categorical regression with optimal scaling
using alternating least squares) between PHE items and
self-efficacy, social support, quality of life, and distress
thermometer scores showed that PHE items could predict
the quality of life and its all dimensions (P < 0.001, adjusted
r square = 0.299). Among the dimensions of quality of
life, the PHE scale predicted social function (P < 0.001;
r = 0.318) and sexual function (P < 0.001; r = 0.502) better
than the others, but it could not predict global health
(P < 0.222). PHE items predicted social support and its
dimensions, including family, spouse, friends, and others

### Table 1. Demographic characteristic among women with breast cancer

| Variable               | Mean | SD  |
|------------------------|------|-----|
| Age                    | 45.3 | 8.15|
| Weight                 | 70.74| 12.52|
| Blood pressure         | 113.59| 10.71|
| Diastolic              | 74.68| 7.94|

### Table 2. The Scores of Social Support and Cancer Self-efficacy

| Variable                              | Spouse     | Family     | Friend     | Special person |
|---------------------------------------|------------|------------|------------|----------------|
| Social support                        | 15.31 ± 5.1| 15.76 ± 4.1| 11.82 ± 5.17| 7.79 ± 3.99    |
| Self-efficacy                         | 30.67 ± 4.06| 21.78 ± 3.32| 29.87 ± 5.1|
| Understanding and participating in care|            |            |            |                |
| Maintaining a positive attitude       |            |            |            |                |
| Seeking and obtaining information     |            |            |            |                |
(P < 0.001; adjusted r square = 0.448; P < 0.001, adjusted R square = 0.255). This scale predicted total self-efficacy and all dimensions of cancer self-efficacy (P < 0.001), but it was the strongest predictor of understanding and participating in care (P < 0.001; r = 0.485).

**Discussion**

In this study, we investigated PHE and its relationship with social support, attitudinal self-efficacy, and the quality of life in women with breast cancer. The findings showed distress in patients even after cancer treatment, which is consistent with a previous study (7). Distress is an unpleasant experience that may be psychological, physical, emotional, or social and can affect the person’s thoughts, feelings, and actions. Hence, patients cannot cope with cancer (8). In the present study, distress was significantly associated with job and education level. This seems to be due to the lack of sufficient skills to manage unpleasant experiences, which is supported by other findings (9). This may cause low ability in performing job duties and responsibilities, job loss, sick leave, continuity of care, early retirement, and interference of social and personal roles with the physical condition (10).

Distress was also correlated to breast symptoms. In other words, the person feels more distressed when breast-related symptoms appear. These findings align with conservation of resources theory, which suggests that distress increases when physical health resources are threatened. However, distress was inversely correlated to perception and participation in treatment. Diagnosis of a serious illness and stress or anxiety due to it may disturb

### Table 3. Descriptive Statistics of EORTC Quality of Life-c30 and EORT-BR23

| EORTC-30 | Range | Minimum | Maximum | Mean | SD |
|----------|-------|---------|---------|------|----|
| Physical function | 9 | 11 | 20 | 18.13 | 2.10 |
| Role function | 4 | 4 | 8 | 7.71 | .762 |
| Emotional function | 10 | 6 | 16 | 14.36 | 2.12 |
| Cognitive function | 6 | 2 | 8 | 7.32 | 1.11 |
| Social function | 3 | 5 | 8 | 7.55 | .779 |
| Symptoms | 28 | 28 | 56 | 51.69 | 4.74 |
| Function scale | 21 | 39 | 60 | 55.10 | 4.77 |
| Global health | 12 | 2 | 14 | 6.11 | 2.71 |
| Total EORTC QLQ-C30 | 42 | 82 | 124 | 112.91 | 7.98 |

| EORTC QLQ-BR23 | Range | Minimum | Maximum | Mean | SD |
|----------------|-------|---------|---------|------|----|
| Functional scales | 3 | 4 | 16 | 11.82 | 2.66 |
| Body image | 12 | 4 | 16 | 6.27 | 1.47 |
| Sexual functioning | 6 | 2 | 8 | 3.05 | 0.803 |
| Sexual enjoyment | 3 | 1 | 4 | 3.02 | 0.870 |
| Future perspective | 3 | 1 | 4 | 3.00 | 0.870 |
| Systemic therapy side effects | 18 | 6 | 24 | 21.72 | 3.03 |
| Breast symptoms | 7 | 9 | 16 | 15.48 | 1.22 |
| Arm symptoms | 7 | 5 | 12 | 11.01 | 1.45 |
| Upset by hair loss | 21 | 7 | 28 | 25.44 | 3.43 |
| Total EORTC QLQ-BR23 | 45 | 47 | 92 | 81.86 | 8.08 |

### Table 4. The Results of One-Way ANOVA

| Variable | Self-efficacy | Social Support | Quality of Life | Distress Score |
|----------|---------------|----------------|-----------------|---------------|
| Age | P < 0.116 | P < 0.384 | P < 0.532 | P < 0.800 |
| Employment | P < 0.498 | P < 0.576 | P < 0.793 | P < 0.032 |
| Education level | P < 0.378 | P < 0.784 | P < 0.345 | P < 0.017 |
| Marital status | P < 0.447 | P < 0.002 | P < 0.295 | P < 0.838 |
| Weight | P < 0.033 | P < 0.847 | P < 0.103 | P < 0.054 |
| BMI | P < 0.276 | P < 0.965 | P < 0.057 | P < 0.527 |
| Tumor grade | P < 0.100 | P < 0.794 | P < 0.419 | P < 0.605 |
| Systolic blood pressure | P < 0.447 | P < 0.435 | P < 0.364 | P < 0.972 |
| Diastolic blood pressure | P < 0.787 | P < 0.468 | P < 0.02 | P < 0.964 |

### Table 5. Correlations between Distress and Social Support and Quality of Life

| Self-efficacy | Social Support | Quality of Life |
|---------------|---------------|----------------|
| Distress | P < 0.001 | P < 0.003 | P < 0.762 |
| r = 0.293 | r = 0.258 | r = 0.027 |
patients’ cognitive abilities and their perceptual and cognitive functions more than before. At the same time, it affects their emotional ability for conscious and skillful participation in the joint decision-making process (7). Muscle relaxation and guided visualization are effective in reducing the symptoms of distress and pain from cancer; therefore, it has been recommended that these skills be taught (11). In the present study, BMI was correlated to social support, which is important to achieve beneficial changes in healthy behavior.

Positive social support may affect communication and the search for information about the disease (12). The main providers of social support for participants were the spouse or partner and family, which is in line with a previous study. It seems that family support increases the ability to cope with cancer and facilitates self-management behaviors in breast cancer patients (5). Most patients wanted and received social support from their physicians, friends, and families (6). Recent findings indicate that a strong relationship between the social support of others and patients' cognitive abilities and their perceptual and cognitive functions more than before. At the same time, it affects their emotional ability for conscious and skillful participation in the joint decision-making process (7). Muscle relaxation and guided visualization are effective in reducing the symptoms of distress and pain from cancer; therefore, it has been recommended that these skills be taught (11). In the present study, BMI was correlated to social support, which is important to achieve beneficial changes in healthy behavior.

The PHE scale score reported that women with breast cancer were in the arousal phase. In the position of “arousal”, patients are hyper-attentive to every signal in their bodies (emotional alert). Symptoms are perceived as an alarm that worries the patient and may cause overwhelming emotional reactions, although their health knowledge is still superficial and fragmented (superficial knowledge) (14). Moreover, patients with chronic disease are behaviorally unable to self-manage their diseases and treatment prescription (behavioral disorganization) to health behaviors. Patients accept their health conditions in this phase and come to terms with the negative emotions associated with critical health events. With the help of health care professionals, patients increase their sense of self-confidence to deal with the disease, accept health conditions, and make changes in their lives (14).

The model scale predicts all dimensions of self-efficacy; however, it is a stronger predictor of understanding and participating in care. Accordingly, allowing patients to participate in care situations will improve care and causes them to have conscious participation in decision-making related to health care (15). In addition, PHE score predicts all aspects of cancer quality of life, except global health, but it is a stronger predictor of social and sexual function. The PHE score is a predictor of social support. This means that better physical and mental performance should be expected from patients when paying attention to the patient's emotional and mental status. PHE model is an important factor in improving the quality of care (4). In the present study, the self-efficacy score showed that more than half of women with breast cancer had moderate self-efficacy. Another study stated that the self-efficacy of women with breast cancer and those undergoing chemotherapy was moderate (16). Understanding and participating in care and seeking and obtaining information about breast cancer were associated with a higher score of self-efficacy.

Finding useful and relevant information can help patients seek treatment with renewed motivation and energy (17). Therefore, it is necessary to pay special attention to patients’ perceived self-efficacy and their participation in designing patient health promotion programs (18,19). Considering the quality of life, our results support other studies (16,20). Therefore, psychological interventions are needed to increase the quality of life of women with breast cancer to improve their physical, social, and emotional functions. Our findings show that marital status predicts social support. Family support, especially from the spouse, is the most important factor in breast cancer care and treatment, which is similar to the finding of other studies (21,22).

The correlation test indicated a significant negative relationship between distress and social support. Evidence shows that higher self-efficacy is associated with lower anxiety, general health, and higher quality of life (9). If patients manage their health and reduce their unpleasant psychological experiences, they will gain more control over their lifestyles (9). Physical and psychological symptom distress of breast cancer survivors can be alleviated by applying coping strategies related to social support and resilience (23). Another study indicated that social support was associated with improved mental function and symptom domains of quality of life and it was useful for reducing mental distress and improving the quality of life (23). This study supports the result of another previous study (24). Concerning the limitations of this study, most of our patients were married and there was heterogeneity in their marital status. In order to accurately report the side effects experienced by the patients, it is recommended that some questionnaires at the start of treatment should be completed, but the authors had to select patients who had passed the treatment.

**Conclusion**

The findings of the present study demonstrate that the PHE model predicts important and affective factors, such as social support, distress, and self-efficacy in breast cancer patients. The PHE model can be recommended as a scientific and reliable tool for health interventions. Therefore, due to the nature of the model, it is recommended to improve the quality of life of women with breast cancer. Considering that few studies have been conducted based on the PHE model, we recommend designing health interventions based on this model in psychological, emotional, and behavioral levels to achieve optimal self-management and quality of life.
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Authors’ Contribution
MC was the first author, the author of the introduction, main researcher, methodologist, principal researcher, statistical analyst, and writer of discussion (35%). LG was the corresponding author, main researcher, supervisor, and author of the introduction (30%). NA was the third author, main researcher, and supervisor (20%). MHK was the fourth author, supervisor, and methodologist (15%).

Conflict of Interests
Authors declare that they have no conflict of interests.

Ethical Permissions
This study was approved by the Ethics Committee of Shiraz University of Medical Sciences (IR.SUMS.REC.1399.131)

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