

Predictors of the Relationship Between the Duration of Cancer and Care Time With the Supportive Care Needs of Patients and the Quality of Life of Their Caregivers: A Path Analysis

Seyedeh Maryam Attari

Guilan University of Medical Sciences

Zohreh mahmoodi

Alborz University of Medical Sciences

Mozhgan Mohammadzadeh Nimekari

Shahid Beheshti University of Medical Sciences: Shaheed Beheshti University of Medical Sciences

Malihe Nasiri

Shaheed Beheshti University of Medical Sciences

Yaghoub Ashouri taziani

Hormozgan University of Medical Sciences

Giti Ozgoli (✉ g.ozgoli@gmail.com)

Shahid Beheshti University of Medical Sciences School of Nursing and Midwifery

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Abstract

Background: Breast cancer patients face various material, physical and psychological problems. The growing trend of breast cancer in Iran, the referral of patients in the advanced stages of the disease, and the mutual impact of patients and caregivers on each other show the need for further supportive care from the community and family. This study aimed to identify the predictors of the direct and indirect relationships of the duration of cancer and care time with the supportive needs of the patients and the quality of life of their family caregivers.

Methods: This descriptive-analytical study was carried out on 150 patients and their caregivers in Iran. Data were collected using the Supportive Care Needs Survey-short form (SCNS-SF34), the Caregiver Quality of Life Index-Cancer (CQOLC) scale, and a socio-demographic checklist and were then analyzed in SPSS-24 and Lisrel-8.8 software using descriptive-analytical statistics and path analysis.

Results: The mean age of the patients and caregivers was 45.76 ± 10.44 and 43.46 ± 9.5 , respectively. Based on the test results, the duration of cancer was positively correlated with the total score of supportive needs in both paths ($B=0.799$). The patients' sexuality needs had the highest negative correlation with their duration of cancer in the direct path ($B=-0.87$) and psychological needs the highest negative correlation in the indirect path ($B=-0.32$). The care time (in hours) had the highest positive correlation with the total score of supportive needs ($B=15.6$) in both the direct and indirect paths, and the highest positive correlation with physical needs in the direct path ($B=10.65$). The caregivers' quality of life had a negative and direct relationship with the duration of cancer ($B=-0.27$) and there was a positive and direct relationship between care time and the caregivers' quality of life ($B=3.09$).

Conclusions: Duration of cancer and care time had the highest positive correlation with the patients' supportive needs, and the caregivers' quality of life had a negative correlation with the duration of cancer and a positive correlation with care time. It is therefore vital to emphasize the design and implementation of supportive care programs for breast cancer patients and their family caregivers.

Background

Breast cancer is the most common cancer [1, 2] and the second leading cause of death in women around the world [3]. Global statistics indicate an increase in the incidence of breast cancer and its faster rise in developing countries [4], including Iran [1, 2], and have predicted a 3-fold increase in the incidence of breast cancer by 2030 [5]. The age of onset of this disease in Iran is almost a decade earlier than in developed countries [1]. Breast cancer patients face various material, physical and psychological problems; however, due to the delays in their timely referral, they are usually in the advanced stages of the disease when they begin seeking treatment [6], which necessitates the need for more supportive care from the community and families. Patients who receive greater social support have less risk of morbidity (disability) and mortality [6] and enjoy an overall better quality of life [7].

Supportive care needs can arise at any stage of illness (from diagnosis to treatment and even palliative care) and are divided into dimensions including physical, health information & systems, emotional, social, and sexual needs [8]. Supportive care needs denote the patients' perception of their need for help and whether or not these needs are being met [9]. Unmet supportive care needs indicate the difference between the needed services and support with the actual services and support received [10, 11]. One study (2017) found that nearly half of women with breast cancer had unmet needs after their diagnosis of cancer [12]. Identifying and meeting these needs helps control the symptoms and complications of the disease, increase the ability to adapt, better understand the situation, make informed decisions, and minimize dysfunction in patients [13].

According to studies, most unmet care needs in this group of patients revolve around system & information, physical & daily living, psychological factors, and especially care & support and sexuality [14, 15].

Several factors have been suggested as predictors of increased need, including the patient's age, stage of disease progression, time since diagnosis, and level of anxiety, depression, and distress [16]. Identifying these characteristics is very important in identifying vulnerable subgroups who need more care [12].

As the family caregivers of breast cancer patients, family members play an important role in their disease management and home care delivery. The primary caregivers of women with breast cancer can play a crucial role in their adaptation to and coping with the disease at any stage of treatment as well as in supporting them in making the right decisions [17, 18]. If caregivers are under stress and experience difficulties, family care and support will be severely hampered [19].

Cancer affects not only the quality of life of patients but also the quality of life of their caregivers [20]. The quality of life of caregivers as a result of their caregiving duties varies from the time of initial diagnosis to one and two years after diagnosis, and during this period, caregivers tend to experience greater mental burden. In care instances where more than two years have elapsed since the diagnosis, the patients and their caregivers have better adapted to the disease and enjoy a higher quality of life [21]. Caregivers focus more on the well-being of the patients, often meaning that their own health and needs are ignored [22–24]. The negative impact of care responsibilities are manifested in various forms, especially as mental and economic burdens [22, 24]. The prevalence, severity and persistence of the burden of caregiving have a profound effect on the quality of life of the patients and the caregivers themselves [18].

In general, there is an inverse correlation between quality of life and needs [19]. Therefore, maintaining the quality of life of caregivers is associated with their ability to provide better care to patients and meet their needs [25].

Due to the growing trend of breast cancer in Iran and the referral of patients to treatment centers in advanced stages [6], the cultural diversity in the world and even in a single country, and given that patients and caregivers are mutually affected by each other, reviewing and addressing these issues are

important for improving the quality of life of patients and their caregivers. Understanding the needs of caregivers is a step toward empowering patients and their caregivers. The review of literature did not yield any comprehensive studies on the direct and indirect relationship of the duration of cancer and care time with the supportive needs and quality of life of patients and caregivers both in one model. Therefore, this study was conducted to identify the predictors of the relationship between the duration of cancer and care time with the supportive needs of the patients and the quality of life of their family caregivers in southern Iran, so that the results can be used in plans for improving services, meeting these needs and increasing the quality of life of patients and their caregivers.

Methods

Type of study

This descriptive-analytical study examined 150 patients and 150 of their caregivers in 2019. Omid Chemotherapy and Radiotherapy Center in Bandar Abbas, Iran, was selected as the research setting. This center is the only referral center in Hormozgan Province. It covers all the patients in the cities of the province and provides them with all the relevant services, including initial diagnosis, treatment, and follow-up.

Participants

The sample size for the patients with breast cancer was determined as 140 people based on a study by Abdollahzadeh et al. [26] and considering the standard deviation of the mean score (σ) and the error (d) ($z=1.96$, $\alpha=0.05$, $d=1$, $\sigma=6$). According to the following formula and a study by Sajadian et al. [27], the sample size for the family caregivers of patients with breast cancer was also determined as 140 ($z=1.96$, $\alpha=0.05$, $d=1$, $\sigma=7$). Finally, to take account of potential sample loss, 150 samples were allocated each to the groups of patients and caregivers (equation (1)).

Equation 1- sample size

$$n = \frac{z_{\alpha/2}^2 \sigma^2}{d^2}$$

The eligible women with breast cancer were selected to participate in the study.

The inclusion criteria were being 18 or older and having a definitive diagnosis of breast cancer (in any of the stages, from 1 to 4) with at least three months since the diagnosis, not having a known mental disorder based on the patient's records, and the ability to cooperate and answer the questions.

The inclusion criteria for the family caregivers of breast cancer patients included no self-reported history of physical and mental problems requiring treatment and being able to cooperate and answer the

questions.

Data collection tools

Data were collected using the Supportive Care Needs Survey-short form (SCNS-SF34), the Caregiver Quality of Life Index-Cancer (CQOLC) scale, and a socio-demographic information checklist.

1. The Caregiver Quality of Life Index-Cancer (CQOLC) scale

The Caregiver Quality of Life Index-Cancer (CQOLC) scale has 35 items, which are scored based on a 5-point Likert scale, and has four dimensions: Mental/emotional burden, lifestyle disruption, positive adaptation, and financial concerns. The scale scores range from 0 to 140, with higher scores denoting better quality of life. The questionnaire was translated into Persian by Khanjari et al. (28) using the forward-backward translation method and validated using face, content, and construct validity methods. The scale reliability using Cronbach's alpha method was reported to be 89%. In this study, the alpha coefficient was calculated to assess internal consistency and the test-retest coefficient to assess reliability. The Cronbach alpha for the different dimensions of the scale was 0.76-0.84 and ICC was 0.93-0.98.

2. The Supportive Care Needs Survey-short form (SCNS-SF34)

This questionnaire consists of 34 items scored based on a Likert scale and has five domains, including psychological needs, health system & information, physical & daily living, patient care & support, and sexuality domains. The scale scores range from 0 to 100 and a higher score denotes more unmet needs.

Abdollahzadeh et al. (2014) translated the English version of the questionnaire into Persian using the forward-backward translation method. The content validity of the questionnaire was approved by a panel of 12 experts and its reliability was confirmed with Cronbach's alpha coefficient of 0.9 [26]. In this study, the alpha coefficient was calculated for internal consistency and the test-retest coefficient for reliability. The Cronbach alpha for the different dimensions of the questionnaire was 0.74-0.87 and ICC was 0.99.

Study procedures After obtaining the necessary permits and the code of ethics for the study, the researcher visited the mentioned center and extracted the names of all the people with breast cancer who visited every day from the reception desk. Each patient and their family caregiver were separately consulted about the research subject, and in the case of eligibility and willingness to participate in the study, informed written consent was obtained from them. The questionnaires were then distributed among the women with breast cancer and their family caregivers to complete. Sampling continued among patients in any stage of cancer treatment, from chemotherapy and hormone therapy to follow-up, until the desired sample size was reached. Data were extracted using SPSS-24 and Lisrel-8.8 software, and descriptive-analytical statistical tests and path analysis were used for the data analysis.

Strengths: In the present study, the supportive care needs of patients with breast cancer and the quality of life of their family caregivers were assessed simultaneously in different courses of treatment

(chemotherapy and hormone therapy) and the post-treatment follow-up.

Limitations: Since this research was carried out in Bandar Abbas, its results should be generalized to other parts of Iran only with caution. Also, due to the high impact of disease periods (chemotherapy, radiotherapy, and follow-up) on the supportive needs of patients, further studies with larger sample sizes are required on patients in different stages of the disease and especially in the follow-up period.

Results

The mean age of the patients and the caregivers was 45.76 ± 10.44 and 43.46 ± 9.5 years, respectively; the mean duration of cancer was 16.3 ± 9.3 months and the mean care time was 2.34 ± 0.75 hours (Table 1).

Table 1
The sociodemographic characteristics of the patients and their caregivers

variables		Mean \pm SD	Mean \pm SD
Age		45.76 ± 10.44	43.46 ± 9.5
Duration of cancer (months)		16.3 ± 9.3	-
Care time (hours)		-	2.34 ± 0.75
		N(%)	N(%)
Gender of caregivers	Female	-	38(25.3)
	Male	-	112(74.7)
Stage of cancer	Level 1	2(1.3)	-
	Level 2	67(45)	-
	Level 3	77(51)	-
	Level 4	4(2.7)	-
	Husband	-	99(66)
Relationship with the patient	Sister	-	13(8.7)
	Daughter	-	24(16)
	Son/Brother	-	8(5.3)
	Mother/Father	-	6(4)

The lowest general need for care was in the patients in the follow-up group (27.58 ± 12.41). In the chemotherapy and hormone therapy groups, the highest care needs were related to physical needs, and

the lowest to sexuality. In the follow-up group, the highest need was related to supportive needs, followed by physical needs.

There was a statistically significant difference between the three groups of patients in terms of the duration of cancer. The shortest duration of cancer pertained to the chemotherapy group (8.06 ± 6 months) and the longest to the follow-up group (24.02 ± 6.87 months). There was a significant relationship between the physical needs score in the chemotherapy group and the quality of life of their caregivers ($P = 0.02$); that is, with each unit of increase in the physical needs of the patients in the chemotherapy group, the quality of life score of their caregivers decreased by 60%.

The one-way ANOVA showed a statistically significant difference in the mean total score of quality of life between the caregivers of the three groups of patients ($P = 0.012$). Also, based on Tukey's post-hoc test, a significant difference was observed between the follow-up group and the chemotherapy group ($P = 0.015$).

Based on the results of the path analysis, the duration of cancer had a positive relationship in both the direct and indirect paths with the total score of supportive needs (total effect $B = 0.799$). In other words, as the duration of cancer increased, the patients' supportive needs also increased. Among the variables that were related to the duration of cancer only in one path, sexuality had the highest negative relationship with the duration of cancer in the direct path ($B = -0.87$) and psychological needs in the indirect path ($B = -0.32$). In other words, when the duration of cancer was shorter, the patients had more unmet sexual and psychological needs – in other words, this dimension of the patient's supportive needs would be more unfavorable.

According to the findings, the care time in hours had the highest positive relationship with the total score of supportive needs in both the direct and indirect paths ($B = 15.6$). In the indirect path, the care time was linked to the total score of supportive needs through physical needs. In other words, when the hours of care increase, more of the supportive needs of the patient, and mostly their physical needs, are met. In the direct path, the care time had the highest relationship with physical needs ($B = 10.65$). In other words, the higher were the physical needs, the higher would be the hours of care allocated to the patient.

The quality of life of the caregivers had a direct negative correlation with the duration of cancer ($B = -0.27$). In other words, the longer was the duration of cancer, the worse would be the quality of life of the caregivers. Also, there was a positive and direct correlation between care time and the quality of life of the caregivers ($B = 3.09$) (Table 2).

Table 2

The direct and indirect effects of cancer duration and care time on the patients' supportive needs and their caregivers' quality of life

Variable			Direct Effect	Indirect Effect	Total Effect	T-Value (for Direct)
Duration of cancer	Patients' supportive needs	Physical needs	-0.61	-	-0.61	3.22
		Psychological needs	-0.07*	-0.32	-0.32	
		Sexual needs	-0.87	-	-0.87	3.31
		System & information needs	0.05*	-0.219	-0.219	0.38
		Total score of supportive needs	1	-0.201	0.799	3.67
	Quality of life of the caregivers	-0.27	-	-0.27	2.40	
Care time	Patients' supportive needs	Physical needs	10.65	-	10.65	4.51
		Psychological needs	3.12	3.94	7.06	1.98
		Sexual needs	2.66*	-	-	0.77
		System & information needs	6.36	3.83	10.19	3.58
		Total score of supportive needs	12.09	3.51	15.6	3.43
	Quality of life of the caregivers	3.09	-	3.09	2.19	
* = NOT SIGNIFICANT						

Assessing the fit indices of the model indicate the desirability and high fit of the model, and the rationality of the relationships between the variables based on the conceptual model. Accordingly, the fitted model does not have a significant difference with the conceptual model (Table 3).

Table 3
Model fit indices

Fit Index	χ^2	df	χ^2/df	CFI	GFI	NFI	RMSEA
Model Index	22.04	14	1.57	0.97	0.97	0.94	0.063

Discussion

According to the present findings regarding the patients' supportive needs, the duration of cancer and care time or hours had the highest relationship with the total score of supportive needs in both the direct

and indirect paths. Also, the caregivers' quality of life had a negative and direct relationship with the patient's duration of cancer, and a positive and direct relationship with the care time.

Meeting the physical needs of patients is of particular importance [29–31]. The positive correlation observed in the present study between physical needs and the other dimensions of supportive care needs indicates the reduction in the patients' physical needs over time. In other words, the shorter was the duration of illness, the more did the patients need psychological, sexual, and supportive care. In a study by Mohammadzadeh Nimekari (2019), physical needs and sexual needs had the highest and lowest mean scores among the patients' supportive care needs, in respective order. The psychological dimension, system & information, and supportive dimensions had a moderate mean score. Higher scores indicated the patients' greater supportive care needs [32].

Similar to the present findings, Wang et al. [33] also found that the length of time from the diagnosis was negatively correlated with supportive care needs. A higher score of supportive care needs was observed among the women who had a shorter duration of cancer or were in the higher stages of cancer. In a study by Shahsavari et al., the most dire need of the participants in the chemotherapy stage was related to the physical dimension and the lowest to the supportive dimension.

Unmet needs can vary even in patients with the same conditions [34]. In the present study, the most common unmet needs of the patients in all the groups were related to the physical dimension. In the follow-up period, women with breast cancer had more unmet needs in the supportive dimension followed by the physical dimension, and their lowest level of supportive care needs pertained to the sexual dimension. In contrast to the present findings, some studies [12, 15, 33, 35] have reported the need for system & information to be the most prevalent unmet need. In the present study, the decreased physical needs of the patients in the follow-up period compared to the chemotherapy period may have been because the patients had passed the active phase of treatment and its side-effects and had somewhat regained their physical strength. Abdollahzadeh examined patients four to six months after their initial treatment; also, half of the participants were recruited from patients visiting a non-governmental breast cancer support center that provided training as well [35].

In the present study, sexuality needs decreased with age. Also, a significant direct relationship was reported between the patients' age and the duration of cancer and care time. The mean duration of cancer was two years. It could be the case that the lack of a support association or institution in Bandar Abbas has made the need for support one of the greatest unmet needs in this group of patients. The reason for the difference in the results of these studies with the present study may be that, in the above studies, patients had completed the initial courses of treatment. Chemotherapy is associated with serious and non-serious drug side-effects [36, 37]. The side-effects of treatment can affect the needs of patients in the physical dimension.

The elapse of one year from the major breast cancer treatments received is associated with a gradual increase in sexual activity in these women [38]. In the present study, the duration of cancer correlated directly with the highest score of care needs; in other words, as the duration of cancer increased, the total

score of the patient's supportive needs also increased. Moreover, an increased duration of cancer was directly associated with less fulfillment of sexual needs and indirectly with less fulfillment of psychological needs. The differences in the duration of cancer in the chemotherapy, hormone therapy, and follow-up groups could be the reason for the difference in the unmet sexual needs of the patients between the three groups. The duration of cancer was 8.06 ± 6 months in the chemotherapy group and 24.02 ± 6.37 months in the follow-up group.

Socio-demographic characteristics play a clear role in predicting care needs. According to previous studies on the care needs of breast cancer patients, younger patients and patients with a sexual partner had more sexual needs [16, 39] and unmet physical and daily living needs [40] than the older patients. Similarly, a study by Shahsavari et al. [31] showed that the need for care decreases with age and increases with disease stage.

Asian women are generally reluctant to talk about their sexual issues and consider talking about such matters embarrassing and unreasonable [41]. It appears that the taboos about sexual issues in the Iranian society can justify the subtle role of sexual needs among patients with breast cancer. In addition, the social culture may influence the answers to the question of sexual needs.

In the efforts to cope with their caregiving burden, the caregivers of cancer patients have reported unmet needs of their own during their patient's active treatment or completion of treatment [11, 42].

In the present study, the mean total quality of life scores of the family caregivers of breast cancer patients in the three groups, i.e. the chemotherapy, hormone therapy, and follow-up groups, was 55.26 ± 15.6 , 54.12 ± 13.4 , and 48.10 ± 7.9 , respectively. Meanwhile, in some studies [43, 44], the total quality of life score of caregivers has been reported as above 80%. In the present study, the highest and lowest mean scores of the caregivers in the domains of quality of life pertained to psychological stress and financial concerns, respectively. The caregivers of cancer patients had a poor quality of life due to fatigue, anxiety, and care pressures. A study in China found that the burden of care in caregivers has an adverse effect on their quality of life, especially their mental health [45].

In contrast to the findings of some studies, the present study observed a negative and direct relationship between the caregivers' quality of life and the patients' duration of cancer (especially in patients in the follow-up period). As the hours of caring for the cancer patient increased, the score of the mental and psychological burden of caring decreased in her caregiver. Khanjari et al. investigated the caregivers of recently-diagnosed cancer patients (two to three weeks after diagnosis and six months later) [43], while in the present study, the mean care time was eight months at the very least (in the chemotherapy group). The quality of life of caregivers as a result of the care given varies from the time of diagnosis until one to two years later, and during this time, they experience greater psychological burden; meanwhile, for the care given to patients with more than two years since their diagnosis, both the patient and her caregiver tend to have gotten more adapted to the disease by this time [21].

Demographic characteristics such as age and gender are the most important predictors of quality of life in patients' caregivers [46]. In the study by Hashemian et al., the mean quality of life scores of caregivers were similar to the scores in the present study. In the present study, the mean age of the caregivers was 43.46 ± 9.5 years and most caregivers were the patients' husbands, which justifies the disparity between the present study and some other studies [43, 47, 48]. Turkoglu et al. studied the family caregivers of patients with different types of cancer (47). In these three studies, most caregivers (60–80%) were female, while in the present study, most caregivers were the husbands of the patients and were male.

Conclusion

The results of this study showed that the patients' duration of cancer and care time had the highest positive correlation with the patients' supportive needs and that the caregivers' quality of life had a negative correlation with the duration of cancer and a positive correlation with care time. Therefore, the design and implementation of supportive care programs for breast cancer patients and their family caregivers, especially in patients undergoing chemotherapy and hormone therapy, are crucial for reducing the patients' physical needs and empowering their families. The present findings suggest the need to adopt decisions for more extensive activities in the form of associations and free counseling centers for breast cancer patients and their families, especially in the post-treatment follow-up period.

Abbreviations

CANCERT= Cancer time, CARET= Care time, QLF= Quality of life, SEXN= Sexual needs, PHSYN= Psychological needs, SN= Supportive needs, HEALTN= Health system & information needs, PHN= Physical needs, SCNS-SF34= Supportive Care Needs Survey-short form, CQOLC= the Caregiver Quality of Life Index-Cancer

Declarations

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Author Contributions

S.M.A Participated in study design, drafting and the conclusion, drafting the manuscript, which was revised by G.O. **Z.M**, Participated in study design and interpretation of data and drafting the manuscript. **M.M.N** Participated in study design, data collection. **M.N** Contributed to drafting data, evaluation and statistical analysis, and interpretation of data. **Y.A.T** Participated in study design, data evaluation and the conclusion. **G.O** was responsible for overall supervision, Participated in study acquisition, interpretation of data and the conclusion, revision and final approval of the manuscript. All authors read and approved

the final manuscript and are accountable for all aspects of the work. All authors read and approved the final manuscript.

Ethics Approval and Consent to Participate

The study began after obtaining the necessary permits and receiving a code of ethics from the Ethics Committee of Shahid Beheshti University of Medical Sciences (IR.SBMU.PHNM.1395.574 on Jan. 3, 2017) and obtaining informed written consent from the participants.

Consent for publication

This manuscript does not contain any individual person's data in any form.

Competing Interests

There is no conflict of interest in this study.

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Figures

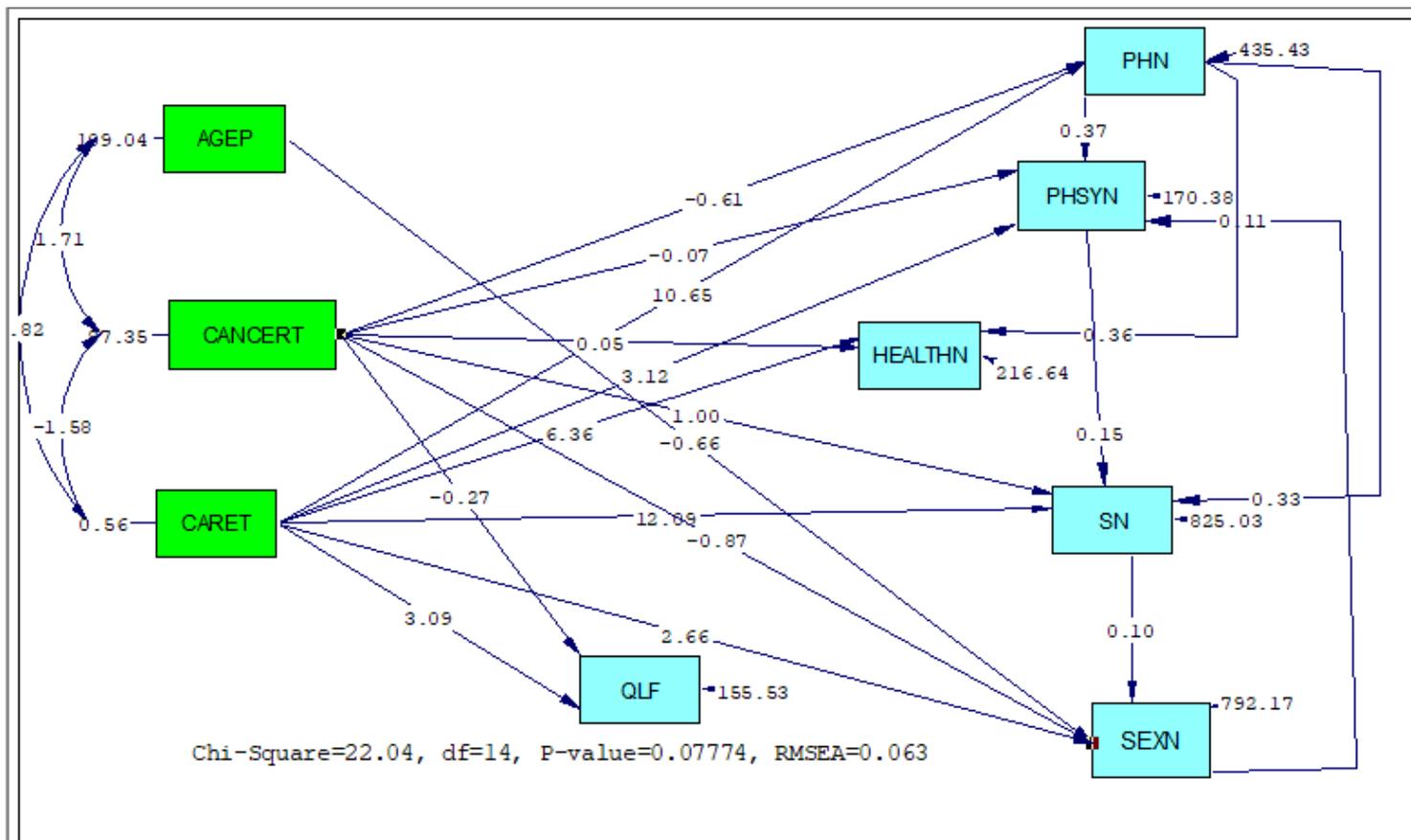


Figure 1

The path analysis model of the relationship of cancer duration and care time with the patients' supportive needs and the caregivers' quality of life. CANCEP=Cancer time CARET=Care time QLF=Quality of life SEXN= Sexual needs PHSYN=Psychological needs; SN=Supportive needs; HEALTHN=Health system & information needs; PHN=Physical needs