

RESEARCH ARTICLE

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Palliative and Supportive Care for Patients with End-Stage Hepatocellular Carcinoma: Perspectives of Egyptian Domestic Caregivers

Ateya Megahed Ibrahim^{1,2*}, Reda M. Abdelmeged^{3,4}, Mohamed A. El-Sakhawy^{5,6}, Donia Elsaid Fathi Zaghamir^{1,7}, Mohamed Gamal Elsehrawy^{1,8}, Omima Mohamed Elalem^{2,9}, Mohammed Ateeg Abdelrahman Ahmed¹⁰, Hussein M. Magdi^{1,11}, Sameer Hamdy Hafez^{10,12}, Magda Ali Mohamed²

Abstract

Objectives: Palliative care is a holistic, patient-centered approach to improving the quality of life for those with terminal diseases and their families. The main objective of the current study was to evaluate the Egyptian domestic caregivers' knowledge, attitudes, and competencies related to palliative and supportive care. **Methods:** Three hundred and thirty-five family caregivers in total were recruited. A descriptive research design was used. Four tools were used to collect data; structured interview questionnaire to collect demographic questions, palliative care knowledge questionnaire, Palliative Attitude Scale, and Competence Scale. The study was conducted in oncology outpatient and pain clinics located at the Damietta Cancer Institute in Damietta Governorate, Egypt. **Results:** Nearly two-thirds of the informal family caregivers are aged between 30-40 years old; 54% are female, and 83% are married. Also, sixty-seven point eight of the informal family caregivers were working (part-time). Furthermore, 65 % of them had insufficient knowledge, 68 % had a positive attitude, and 58% of the informal family caregivers had non-competency skills regarding palliative and supportive care. **Conclusion:** Approximately two-thirds of informal care providers had insufficient total knowledge scores, more than half possessed a positive attitude, and more than half reported non-competency skills regarding palliative care of hepatocellular patients. **Recommendation:** It is highly advisable to launch extensive health education programs and campaigns aimed at all of the unpaid informal family careers of patients with serious terminal illnesses, including hepatocellular carcinoma, at various governments with greater sample sizes.

Keywords: Informal family caregivers- hepatocellular carcinoma- palliative care

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Introduction

Palliative care has been stressed as being crucial for improving the welfare and quality of life of patients with life-threatening illnesses and their families (WHO, 2019). It is also acknowledged that to reach patients with chronic, terminal illnesses like hepatocellular carcinoma (HCC), a palliative approach involving the adaptation

of palliative care knowledge and expertise needs to be integrated into various scenarios (Sawatzk et al., 2016; Harris et al., 2019).

Patients with serious or life-threatening illnesses can benefit from palliative care, which provides proactive, comprehensive care. By reducing and controlling symptoms like pain as well as preventing and treating suffering, it aims to make patients' and families' quality

¹Department of Nursing, College of Applied Medical Sciences, Prince Sattam Bin Abdulaziz University, Al-Kharj 11942, Saudi Arabia. ²Family and Community Health Nursing Department, Faculty of Nursing, Port Said University, Port Said, Egypt. ³Assistant Professor, EMS Department, AL-Ghad College for Applied Medical Sciences, Riyadh, KSA. ⁴Lecturer of Anaesthesia and Surgical ICU, Department of Anesthesia and Critical Care, Faculty of Medicine, Cairo University, Cairo, Egypt. ⁵Department of Medical Laboratory Sciences, College of Applied Medical Sciences, Prince Sattam bin Abdulaziz University, Al-Kharj 11942, Saudi Arabia. ⁶Department of Medicinal and Aromatic Plants, Desert Research Center, Cairo, Egypt. ⁷Lecturer of Pediatric Nursing, Faculty of Nursing, Port Said University, Port Said, Egypt. ⁸Lecturer of Nursing Administration, Faculty of Nursing, Port Said University, Port Said, Egypt. ⁹Community Health Nursing, College of Nursing, University of Hail, Saudi Arabia. ¹⁰Department of Community and Mental Health, College of Nursing, Najran University, Najran, Saudi Arabia. ¹¹Lecturer of Psychiatric and Mental Health Nursing, Faculty of Nursing, Beni-Suef University, Egypt. ¹²Assistant Professor, Community Health Nursing, Faculty of Nursing, Beni-Suef University, Egypt. *For Correspondence: ateyamegahed@yahoo.com

of life better (Radbruch et al., 2020; WHO, 2020). Patients with advanced cancer typically experience a great deal of physical discomfort, demanding medical care, and spiritual and emotional suffering, all of which can negatively impact their quality of life during their illness (Bauman and Temel, 2020).

Palliative care benefits cancer patients by easing their treatment-related stress. This involves the early identification and treatment of discomfort and other symptoms, the provision of psychosocial support to help cancer patients and their families cope with the disease and its treatment, as well as their assistance as they decide on their treatment goals (Temel et al., 2010).

The development of palliative care varies widely among Arab countries, but even in the most advanced countries, the availability of services is insufficient to meet the needs of the population given the high incidence of terminal cancer. Due to a lack of national regulations and funding, a shortage of human resources, restricted access to drugs, low public awareness, and a lack of coordination and collaboration among palliative care experts, the integration of palliative care into regional health systems has been hindered (Osman and Yamout, 2022).

The first project to offer palliative care services in Egypt was launched in 1981. It has been difficult to deliver community-based palliative care in Egypt up until recently, and there isn't a reliable framework in place to do so given the country's substantial population. At tertiary level hospitals in Saudi Arabia, there is a well-established system for the inpatient care of cancer patients. Oman is currently developing its palliative care infrastructure because the field is still in its infancy. In Jordan, the King Hussein Cancer Centre (KHCC), which offers both cancer management and palliative care, pioneered comprehensive cancer care in the Middle East in 2004 (WHO, 2020).

According to data published by the World Health Organization, there were 128,892 new cases of cancer in Egypt, which resulted in 85,432 cancer-related deaths overall. The incidence rate of various cancer kinds in Egypt was as follows: With a rate of 19.7%, liver cancer is the most common cancer, followed by breast cancer (17.9%), Non-Hodgkin lymphoma (7.6%), bladder cancer (7.4%), lung (4.7%), colorectal (4.2%), brain and central nervous system (3.5%), leukemia (3.3%), prostate (2.4%), and pancreatic (2.2%) (WHO, 2020).

Globally, HCC is a serious problem, and local variations in its epidemiology have been noted (Konyn et al., 2021). Egypt is the third-most populous country in the world and Africa, respectively, in terms of population. According to health officials, HCC is Egypt's most challenging health problem (Rashed et al., 2020). Hepatocellular carcinoma (HCC) is the sixth most common cancer in the world (Rashed et al., 2020). It is the fourth-most frequent cancer in Egypt. Several studies conducted in hospitals indicated a rise in the number of HCC cases (Abd-Elsalam et al., 2018; Ziada et al., 2016).

End-stage HCC patients experience a heavy symptom load, complex disease trajectories, and several comorbidities. End-stage HCC poses a serious risk to life and has a high mortality rate. They are also in a vulnerable situation because of the discomfort brought on by their

medical issues, a feeling of burden, and uncertainty about life and death. Throughout the disease, family members are faced with a series of increasingly demanding responsibilities that entail making difficult decisions, and they need help to be able to handle these situations. Palliative care hasn't always been the best choice for patients who need intensive care close to the end of their lives and have whatever requirements, which is difficult for these patients, although it hasn't always been the best alternative. Patients still require palliative care even when death is anticipated (Peng et al., 2020).

Informal domestic caregiving, typically provided by an unpaid family member, consists of assistance with necessary everyday tasks. Even though not all of the people providing this care are connected to us, we nevertheless refer to them as family carers. According to estimates, 27 million Americans will need palliative care by 2050. Both patients and family carers' quality of life (QOL) is threatened by the severe burden of liver disease and its physiological, psychological, and social complexity (Rabiee et al., 2021).

It is becoming increasingly clear that palliative care development is required to meet the needs of those who have HCC and their families. Further research is needed to incorporate palliative care into the framework for treating HCC. The degree to which informal caregivers value palliative care in this circumstance will determine how well this assignment adapts. The purpose of this study was to evaluate palliative and supportive care for patients with end-stage hepatocellular carcinoma as seen by Egyptian informal family caregivers.

Aim of the study

Evaluate the Egyptian domestic caregivers' knowledge, attitudes, and competencies related to palliative and supportive care.

Materials and Methods

The current investigation used a cross-sectional descriptive study approach to achieve its objective. Oncology outpatient and pain clinics at the Damietta Cancer Institute in Damietta Governorate, Egypt, were the sites of the study, which ran from early December 2022 to late February 2023. This Cancer Institute is one of the Major Oncology Centers in Egypt and serves about 5 governorates in the Delta zone, making diagnosis and treatment of cancer within reach of all North Egyptian Patients.

Participants

Total number 1,800 informal family caregivers who were available during data collection were the target population of this study. A systematic random sample was used to choose 360 informal family caregivers for HCC patients who met the inclusion requirements of (a) providing direct care to their patients, (b) possessing at least a year's worth of experience monitoring patients' homes and, (c) agreed to participate in the study. Following the selection of the necessary number of caregivers, the researchers collected all the necessary contact information

from the caregivers, including their phone number, email address (if available), and the times of the day they were accessible at the aforementioned settings. As 25 family caregivers declined to participate, the study's total sample was reduced to 335 informal family caregivers.

Measures

Four tools were used to collect the data; the demographic questions were adopted from (Lin and Huang, 2014) to ask about age, gender, education, marital status, work status, monthly income, age of the patients, degree of relationship to the patients, time since the patient was diagnosed, years number of providing the patient care, hours of daily care needed, family support for caregiving activities and the formal support services, and phases in which palliative care was received.

Second questionnaire was the palliative care knowledge questionnaire which was developed by (Pruthi et al., 2022). This questionnaire included 17 multiple close ended questions, which is based on the definition of palliative care and care given following a patient's condition, goal of providing palliative care, and suitable length of care, barriers while providing palliative care, and needs of informal care givers.

The scoring system of the questionnaire was as follow; a wrong answer was given a score of (0), while a correct answer was given a score of (1). The mean score was calculated by dividing the total item scores by the total number of things. Means and standard deviations were calculated. If the percentage score was lower than 75, it was considered insufficient; 75 was considered sufficient.

The third tool was; Palliative Attitude Scale which was created by Perry et al., (2020) to measure informal family caregivers' attitudes towards palliative care and interactions with terminally ill patients. The scale consisted of 14 questions on a Likert scale with a maximum of five points (1 being strongly disagreed with and 5 being strongly agreed with). Higher overall scores indicate better attitudes toward palliative care. To determine the mean score, the total item scores were divided by the total number of items. Our calculations included means and standard deviations. If the percent score was under 75, it was considered negative; otherwise, it was considered positive.

Fourth tool was; Competence Scale which was developed by Lin and Huang, (2014) to assess informal family caregivers' proficiency in palliative care. The scale consisted of 15 items that are answered on a five-point Likert scale with values ranging from "strongly disagree," "disagree," "neutral," "agree," and "strongly agree." Scores vary from 15 to 75 points overall. The respondent's competency is indicated by the total scores, which increase as they go up. The sum of the item scores was divided by the number of items to produce the mean score. We computed means and standard deviations. It is regarded as non-competent if the % score was <75 and competent for scores 75.

Content validity and reliability of questionnaires

Content validity for palliative care knowledge, attitudes, and competencies questionnaires was evaluated

using the translation-back-translation method. To maintain uniformity and minimize bias, the poll was back-translated from English into Arabic by a bilingual expert. The accuracy of the data was also confirmed by seven professors with expertise in public health and related fields. The survey was piloted with 36 informal family caregivers (the data were not utilized in the final analysis) to make sure there were no unclear questions. The Cronbach alpha test was used by researchers to evaluate the tool's dependability (the scales' respective Cronbach alpha test scores for knowledge of palliative care were 0.88, attitudes were 0.91, and competence were 0.89).

Procedure

The Scientific Research Ethics Committee provided official approval for the proposed study's conduct with code number (NUR (2/ 4/ 2023)((24). After receiving approval from accountable and authorized authorities to move forward with the current study, the researcher started gathering data. The researcher also got in touch with each prospective family caregiver to go over the goals and procedures of the study. Written consent was also taken from the family caregivers after explaining the study's goal to the participants, and then, the tools for data collection were given to them and they started to complete the required information through paper and pencil format. Each participant's estimated time was about in the 30- to 45-minute range. The individuals who couldn't read or write were interviewed by the researchers, who then filled out the data on their own for those people.

Statistical Analysis

The SPSS version 23 was used to analyze the data. Frequencies and percentages were used to compile the complete category of data. The data's normality was evaluated using the Kolmogorov-Smirnov test. The chi-square test was used to compare qualitative variables. The study variables' means and standard deviations were calculated. To check for variations in the study results based on demographic factors, an independent sample t-test and 1-way analysis of variance (ANOVA) were conducted. The informal group's knowledge, attitudes, and competence towards palliative care were assessed using the Pearson's r correlation coefficient. P 0.05 was used as the threshold for statistical significance.

Results

Table 1 reveals that 61.8% of HCC patients aged < 50, and 61.2% of the caregiver's patients are male. 63.3% of the informal family caregivers are aged between 30 and 40 years old, 54% of them are female, 48.6% reported having a moderate level of education, and 83% were married. Furthermore, the findings, demonstrated that 67.8% of the informal caregivers were working (part-time), and 84.2% of them reported having an insufficient monthly income.

Table 2 reveals that 60.6% of the family caregivers are patients' first-degree relatives. In addition, 52.2% of the patients were diagnosed with HCC less than two years ago, and 83.6% of the informal family caregivers provided palliative care to the HCC patients for less than

Table 1. Informal Domestic Caregivers' Distribution Based on Sociodemographic Personal Characteristics (n=335).

Variable	N (%)
Demographic data of patients	
Age	
< 50	128 (38.2)
≥ 50	207 (61.8)
Mean ± SD	83.4± 62
Sex	
Male	205 (61.2)
Female	130 (38.8)
Demographic data of the caregivers	
Age	
<30	90 (26.9)
30-40	212 (63.3)
≥ 40	33 (9.8)
Mean ± SD	36.18± 9.16
Sex	
Male	154 (46)
Female	181 (54)
Educational level	
Low	89 (26.6)
Moderate	163 (48.6)
High	83 (24.8)
Marital status	
Unmarried	57 (17)
Married	278 (83)
Employment status	
Not working	108 (32.2)
Working (Part-time only)	227 (67.8)
Monthly income	
Enough	53 (15.8)
Not-Enough	282 (84.2)

five years. Also, 55.8% of the caregivers spent more than 6 hours per day providing palliative care to the patients. The findings, also, elaborated that 40.6% of the palliative care was received by patients during the diagnostic phase.

Discussion

Hepatocellular carcinoma is a prevalent malignancy with a poor prognosis, substantial medical expenses, and a heavy disease burden. Patients may experience severe discomfort due to advanced disease, side effects of treatment, or decompensation of underlying cirrhosis, even though it is frequently asymptomatic in the early stages. Palliative treatment has been found to extend survival in several non-hepatocellular carcinoma cancers and has the potential to significantly improve the quality of life, physical symptoms, and psychological symptoms in patients with end-stage liver disease. However, due to factors like stigma, a lack of resources, a lack of training

Table 2. Distribution of Informal Domestic Caregivers, Patients According to Relationship, Patients' Diagnosis, Years of Providing Care, Time Spent and Kinds of Assurances (n=335).

Variable	N(%)
Degrees of relationship with caregivers	
First	203 (60.6)
Second	78 (23.3)
Third	54 (16.1)
Time since the patient was diagnosed	
< 2 years	175 (52.2)
≥ 2 years	160 (47.8)
Number of years provide care for the patient	
< 5 years	280 (83.6)
≥ 5 years	55 (16.4)
Time spent each day by caregivers providing care for the patient	
< 6 hours	148 (44.2)
≥6 hours	187 (55.8)
Kinds of assistance the caregiver can offer the patient	
Diagnostic phase	136 (40.6)
The phase of loss of normality	50 (14.9)
Phase of decline	71 (21.2)
Dying phase	78(23.3)

for physicians who do not provide palliative care, and inadequate role models for the integration of palliative and supportive care within liver disease services, this service is underutilized in cases of hepatocellular carcinoma, and referrals are frequently delayed (Laube et al., 2021).

Meaningful use of palliative care programs is hindered by poor understanding of the idea and misunderstandings around it. Given their crucial role in the care of patients who are nearing the end of their lives, caregivers' attitudes and views of the palliative care strategy must be evaluated. Thus, the researcher intended to conduct the present study to evaluate palliative and supportive care for patients with end-stage hepatocellular carcinoma from the perspective

Table 3. Total Palliative Care Knowledge, Attitudes, and Competencies Scores of the Domestic Informal Caregivers Regarding Palliative Care (n=335).

Items	Scores	p- value
Total Sufficient knowledge scores	35± 6.07	0.001*
Total Positive attitudes scores	68± 8.24	0.001*
Total competencies scores	42± 12	0.001*

significant at p-value 0.001

Table 4. Correlation between Knowledge, Attitude, and Competency among Informal Family Care Providers toward Palliative Care (n = 335).

Items	r	p
Knowledge vs. attitude	-0.104	0.285
Knowledge vs. competency	0.03**	*0.005
Attitude vs. competency	-0.069	0.465

Table 5. Relation between Personal Characteristics of the Informal Family Caregivers and Their Total Knowledge Scores (n=335).

Variables	Scores	(F)	P- value
Age			
<30	39.12±12.72		0.658
30-40	40.54±8.39	0.196	
≥ 40	48.26±3.15		
Sex			
Male	30.92±11.70	0.213	0.235
Female	62.57±4.18		
Educational level			
Low	57.91±13.17	1.642	0.025*
Moderate	52.45±12.81		
High	42.55±8.08		
Marital status			
Unmarried	40.31±10.45	2.07	0.165
Married	72.90±6.02		
Employment status			
Not working	51.70±9.17	2.610(t)	0.003*
Working (Part-time only)	51.58±11.07		
Monthly income			
Enough	56.50±3.31	3.018	0.176
Enough and more	52.78±3.12		

(F), ANOVAs Test; (t), t- test; *, Significant (P<0.05).

Table 7. Relation between Personal Characteristics of the Informal Family Caregivers and Their Total Competencies Scores (n=335).

Variables	Scores	(F)	P- value
Age			
<30	83.51±11.71		0.749
30-40	65.82±6.32	1.862	
≥ 40	79.62±4.67		
Sex			
Male	77.42±4.49	0.575	0.876
Female	76.45±3.85		
Educational level			
Low	75.05±5.52	0.945	0.459
Moderate	75.35±7.04		
High	78.20±7.39		
Marital status			
Unmarried	77.22±4.84	4.16	0.369
Married	76.02±5.80		
Employment status			
Not working	76.17±5.55	0.453	0.747
Working (Part-time only)	74.31±6.61		
Monthly income			
Enough	74.97±5.34	2.324	0.789
Enough and more	75.77±5.18		

(F), ANOVAs Test; (t), t- test; *, Significant (P<0.05).

Table 6. Relation between Personal Characteristics of the Informal Family Caregivers and Their Total Attitude Scores (n=335).

Variables	Scores	(F)	P- value
Age			
<30	56 ±13.22		0.005*
30-40	50.33±11.30	2.89	
≥ 40	40.62±13		
Sex			
Male	44.92±17	0.76	0.001*
Female	56.07±11.19		
Educational level			
Low	47.92±10.27	1.786	0.689
Moderate	43.40±16.8		
High	32.58±5.23		
Marital status			
Unmarried	32.21±9.45	1.167	0.585
Married	49.45±8.01		
Employment status			
Not working	56.70±5.34	3.412(t)	0.765
Working (Part-time only)	58.58±14		
Monthly income			
Enough	36.70±8.3	1.014	0.345
Enough and more	57.08±9.10		

(F), ANOVAs Test; (t), t- test; *, Significant (P<0.05).

of Egyptian domestic caregivers.

The findings of the current study elaborated that two-thirds of the informal family caregivers had a total insufficient knowledge score, slightly more than had total positive scores, and more than half were non-competent regarding palliative care for patients who suffered from HCC diseases. From the researcher's point of view, more than half of the informal caregivers had total insufficient knowledge and more than half were non-competent regarding the palliative care provided to the HCC patients. The reason for this may be that the vast majority of family caregivers had a level of education ranging between low and moderate. In addition, most of the caregivers are married and work, which increases the pressures of life and does not allow time to learn and practise palliative care for their families. Moreover, most cases were diagnosed a short time ago.

Likewise, the highest percentage spend more than six hours a day serving them. They also provide service during the most difficult stage of palliative care, which is the period of diagnosis for patients, which is considered the most difficult and darkest period for patients and caregivers. Moreover, a dearth of palliative care education programs in healthcare is a potential contributing factor.

This finding was matched with Zimmermann et al., (2021), who stated that around two-fifths of the studied sample had high perceived knowledge and competency regarding palliative care. Furthermore, Shalev et al., (2018) concluded that the majority of community-

dwelling individuals did not include the key elements of palliative and hospice care in their definitions, indicating a poor degree of understanding of these services and the prevalence of misinformation among this group. Initiatives for educating the public about palliative and hospice care are required to both raise awareness and correct misconceptions about these services.

Additionally, Patel and Lyons (2020) showed that there are many misconceptions and low competency regarding palliative care, and there is a lack of public awareness and education. These findings have not changed over time, despite advancements in the realm of personal computing, which emphasize the critical need for targeted educational initiatives.

Also, Bazargan et al., (2021) concluded that race and ethnicity play a significant role in how knowledgeable and competent California adults are about hospice, palliative care, and advance directives. In addition, knowledge of advance directives and palliative and hospice care was independently correlated with demographic and socioeconomic factors, health conditions, access to primary care physicians, and experience providing informal care. These complex consequences, which can be seen on the individual, social, and organizational levels, can be traced to several historical, social, and cultural causes. To raise awareness of end-of-life and palliative care, as well as the completion of advance directives and planning, a wide range of issues should be taken into consideration.

On the other hand, Shah et al., (2020), indicated that nearly half of the carers had an enhanced understanding of the palliative care approach. They showed consistent understanding of two foundational aspects, indicating correct knowledge across age groups: gender, education level, and the relationship with the patient. Also, Taber et al., (2019) concluded that most respondents were more knowledgeable and skilled regarding the palliative care provided to their patients.

The results of the present study revealed that slightly more than two-thirds of the informal family caregivers had a positive attitude regarding the palliative care provided to HCC patients. According to the study, satisfaction with justice and destiny as well as religious teachings that exhort patience, perseverance, and right conduct all of which are more prevalent among Egyptians could be the causes of this optimistic attitude. However, in addition to that, the majority of patients are first-, second-, and third-degree relatives of palliative care professionals. If this trend continues, people may develop sympathy for and empathy for their relatives who are suffering from this fatal illness. Girls make up a larger portion of careers, and they stand out for their kind hearts, sweet personalities, and upbeat attitudes towards their ailing relatives.

This result was supported by Mohamed et al., (2022), who showed that sufficient knowledge, 78.6% had a positive attitude, while 76.8% of them had inappropriate practices towards palliative care. Also, Yoo et al., (2018) showed that significant numbers of patients with advanced cancer and family caregivers showed positive attitudes toward early palliative care. While McIlpatrick et al., (2021) showed that Current knowledge and attitude gaps

and misconceptions derived from limited ad hoc personal experiences and fear of engaging in taboo conversations may deter people from accessing integrated palliative care services early in a disease trajectory, The results indicate the need for public education programs that go beyond merely raising awareness but provide key messages within a public health approach, that may change attitudes toward palliative care, ultimately improving end-of-life outcomes.

The current study's findings revealed a highly statistically significant correlation between the informal family caregivers' overall knowledge and their total competency. From the researcher's point of view, this correlation proves the strong connection between knowledge and practice: as one increases, the other increases, and vice versa. These results were confirmed by Shah et al., (2020) and Taber et al., (2019), who found that information and knowledge are remarkably correlated with the beliefs and attitudes of family care providers toward palliative care.

Results of the present study showed that there was a highly statistical significant differences between educational level and employment status with total knowledge scores of the informal family caregivers regarding palliative care. Furthermore, there was there was a highly statistical significant differences between age and sex with total attitudes scores of the informal family caregivers regarding palliative care while There was no statistical significant association between sociodemographic data of the informal care givers with their total competencies scores. These results were strongly approved by Shah et al., (2020) and, Patel and Lyons (2020) where education and working status was high associated with total knowledge scores of the studied participants, gender and age were highly related to total attitude scores of the studied sample regarding palliative care (Tables 3-7).

In conclusion, most of the informal family caregivers provided palliative care to the HCC patients for less than five years. Also, more than half of the caregivers spent more than 6 hours per day providing palliative care to the patients. Also, Two-thirds of the informal care providers had sufficient knowledge, slightly more than two-thirds had a positive attitude, and more than half were non-competent towards palliative care. Besides, there was a highly statistically significant correlation between the informal family caregivers' overall knowledge and their overall competency.

Recommendations

The study's conclusions suggest that informal family care for hepatocellular carcinoma patients should be provided with standard palliative care guidelines, which provide a framework for the care necessary for patients with hepatocellular carcinoma and other life-threatening disorders. To improve their comprehension of supportive and palliative care and raise awareness of it, a health education program with adequate training in how to deliver it to patients with liver cancer should be made available to them.

Arab nations should work to make palliative care

a standard part of cancer care and available to those who need it given the overwhelming data on the value of palliative care to oncology patients. Coordination of regional initiatives can promote the creation of legislation, norms, and policies. Expanding training programs and successfully advocating for palliative care's registration as a specialty with the Arab Board of Medical Specializations can be accomplished through cooperative efforts. Regional initiatives can serve to coordinate opioid analgesic access at the regional level, raise awareness, involve communities, and mobilize resources for instruction, research, and service provision.

Author Contribution Statement

All authors made substantial contributions to all of the following: A.I made conception and design of the study; acquisition of data; or analysis and interpretation of data; D.Z, M.M made the drafting the article, revising it critically for important intellectual content, A.I, R.M Wrote the paper and edition. All the authors revised and agreed publication.

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Ethical participation

Information was exclusively gathered for research reasons, and participation was entirely optional. Names, ID numbers, and phone numbers that may be used to identify a person were not collected. Because of this, privacy and confidentiality were upheld throughout the whole study process. Before completing the questionnaire, each participant was asked to give both verbal and written agreement. Each participant then signed the questionnaire to indicate their written approval. The survey was open-ended, allowing participants to leave at any time. The study's goals were explained to the managers of the aforementioned locations, and they were urged to participate while stressing the privacy of the information collected. The Port Said faculty's ethics committee gave its clearance before the study with the code NUR (2/4/2023) could begin (24).

Data Availability

Data of the research study will be available upon request.

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