Original Article

A Prospective Study to Compare Caregivers' Knowledge and Perception of Cancer Pain with Patients' Pain Assessment and to Evaluate their Quality of Life

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ABSTRACT

Objectives: Family caregivers (FCGs) play a crucial role in the home care of terminally ill patients. Therefore, evaluating their comprehension of patients' symptoms and doctors' advice becomes crucial. Moreover, this might negatively impact their quality of life (QOL). Thus, the purpose of the study was to examine FCGs' perception and understanding of cancer pain in relation to patients' pain assessments, as well as the effect this has on their own QOL.

Materials and Methods: The family pain questionnaire (FPQ) and patient pain questionnaire (PPQ) were used for both patient as well as their FCGs. The scores for each subscale, knowledge, and experience were calculated. Furthermore, FCGs' own QOL was assessed using the caregiver quality of life index-cancer (CQOLC) questionnaire. Results were statistically analysed.

Results: The FCGs of 93 individuals were examined. The Cronbach alphas for the current dataset showed that the FPQ (0.754) and PPQ (0.759) overall reliability scales were satisfactory. The knowledge, experience, and total average scores for the PPQ (FPQ) subscales were reported as 35.91 (35.31), 27.19 (26.86), and 63.10 (62.17), respectively. The knowledge, experience, and overall scales of the PPQ (FPQ) were evaluated to provide median scores of 37 (36), 28 (25), and 65 (62) correspondingly. A t-test was used to determine the significance of the observed average differences (d) for knowledge (0.602), experience (0.333), and overall (0.935). The results showed that there were no significant differences ($P > 0.05$). An inverse relationship was elicited between the total QOL and the pain assessment scores of FCGs, as well as the age of the patient. The difference was, however, majorly statistically non-significant ($P > 0.5$). Further, statistical significance was found only between the burden component of the CQOLC and the age of the patients ($P = 0.034$), as well as total pain knowledge ($P = 0.007$) and total pain scores ($P = 0.001$) of the FCGs'.

Conclusion: As per our analysis, FCGs had less knowledge and experience of patients' pain, though statistically, it was not significant. The age of the patient, as well as total pain knowledge and total pain scores of the FCGs' were found to affect the QOL of FCGs'. Studies with large sample sizes might help in strengthening the findings.

Keywords: Caregiver, Knowledge, Pain, Patient, Quality of life

INTRODUCTION

With the innovative advancements in science and technology over time, the average life expectancy is increasing. The incidence of cancer has been found to increase with the increase in life expectancy.[1] Cancer is the second most common cause of mortality after cardiovascular diseases.[2] Although symptoms vary site-wise, pain, fatigue, and weight loss represent the most common associated signs/symptoms in cancer patients. Insufficient pain control in cancer patients remains a significant challenge.[3-5] A meta-analysis published in 2007 highlighted that there has been no improvement in the treatment of cancer pain worldwide for over 40 years. It reported a prevalence of cancer pain of 59% in patients on anti-cancer patients, 64% in those with a terminal illness, and 53% across all stages.[6] Cancer-related pain has an overall prevalence of 45.6%, but this rate increases with the advanced disease stage (73.9%) and with the use of anti-cancer treatment (59%).[7]

Further, with the increase in patient load at hospitals, the home environment as the primary setting of care is now

being preferred in patients requiring palliative care. Family caregivers (FCGs) are the prime caretakers of their patients and, thus, have an important role in managing cancer patients at home. According to the available literature, FCGs who care for patients in pain report higher rates of depression, anxiety, dread, weariness, appetite loss, and sleep disturbances than their peer group of FCGs who care for patients who are not in pain.[8,9] Thus, FCGs' quality of life (QOL) might get hampered while taking care of their patients at home. As appropriate pain assessment by FCGs is important for taking care of patients' pain at home, it thus becomes paramount to assess FCGs' knowledge regarding cancer patients' pain while simultaneously managing their QOL. With this backdrop, we structured a prospective study evaluating the various relationships between these various parameters.

Objectives

Primary objective

Our primary objective was to assess and evaluate FCGs' knowledge and perception of cancer pain and to compare it with patients' pain assessment.

Secondary objective

The secondary objective was to assess the impact on QOL of FCGs', if any, while managing their patients at home.

MATERIALS AND METHODS

Consecutive patients who met the study's inclusion and exclusion criteria were included after receiving Institutional Ethics approval. Every patient was asked to name their primary FCG, which was the one who handled the majority of their care while they were at home. The patients who had histologically proven cancer, suffering from cancer-related pain and those registered under palliative care were included in this study. Informed consent was obtained from patients and FCGs' before inclusion. The only point of exclusion was patients' whose FCGs' did not live with them. The study is registered under CTRI via registration number CTRI/2019/07/019973.

Procedure

All the patients and FCGs' completed a self-administered paper-based questionnaire during their hospital visit. FCGs' own QOL was assessed using the caregiver quality of life index-cancer (CQOLC) questionnaire. Then, a member of the study team checked the completed questionnaires. Only completed questionnaires were included in the analysis. If patients or FCGs' were illiterate, questionnaires were completed after a one-to-one interview with the investigators. The 16-item ordinal patient pain questionnaire (PPQ) and family pain questionnaire (FPQ) are used to measure participants' awareness and experiences with cancer-related pain.[10] Nine items on the knowledge scale and seven on the experience scale make up each questionnaire. It was done using the Likert 11 score (0–10 points). The average score

combined with the individual item scores was the overall subscale score (0–10). Every item has been structured with 0 denoting the most favourable result and 10 denoting the least favourable result. The total of the individual components was used to score each parameter.

The CQOLC scale, created by Weitzner *et al.*, is a 35-item survey that asks questions on the physical, emotional, social, financial, and spiritual well-being of carers over the past seven days. It was used to gauge the effect of caring on the carer.[11] This measure was selected because it evaluated both the good and negative elements of providing treatment, had been validated in both inpatient and outpatient oncology settings, and had excellent test-retest reliability (0.95) and internal consistency (Cronbach's α = 0.91).

The CQOLC questionnaire has four conceptual domains: 'Physical functioning, emotional functioning, family functioning, and social functioning.' The 35 items on the CQOLC have a five-point Likert format, with the options being 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit) and 4 (very much). Ten of the items deal with the burden, seven with disruptiveness, seven with positive adaptation, three with financial concerns, and eight with single items that deal with additional factors (sleep disruption, satisfaction with sexual functioning, day-to-day focus, mental strain, informed about illness, patient protection, patient's pain management and interest of family in providing care). The overall score for the instrument is obtained by summing the scores on each item on the CQOLC scale, and scores can vary from 0 to 140. A higher score indicates a better QOL for all items and domains used to assess QOL.

Statistical analysis

A sample size of 93 was ascertained, assuming 60% had no/negligible knowledge of pain management with 80% power and 5% level of significance with 10% precision taken for the study. For the patient and FCG demographic characteristics, descriptive statistics were calculated. For the total and domain scores of the FPQ and PPQ, the mean, standard deviation, and lowest and maximum values were computed. To decide whether to utilise a parametric or non-parametric test, the normality test using the Shapiro–Wilk method was utilised. The Chi-square test was used to determine whether there was a significant difference in the pain ratings of patients and FCGs for nominal variables. For all numerical variables, the *t*-test was utilised for parametric data and the Mann–Whiney U-test for non-parametric data. The relationships between patients' ages, FCGs' pain scores, and their own QOL scores were investigated using Spearman's correlation coefficients. To analyse the data, IBM Statistical Package for the Social Sciences for Windows v23 was utilised. A significance level of $P < 0.05$ was used for all analyses.

RESULTS

A total of 93 patients and their FCGs' were recruited in this study. The baseline sociodemographics for both patients and

their FCGs' were obtained and are as depicted [Table 1]. The mean age of patients was 51.38 ± 5.701 years, and that of FCGs' was 44.38 ± 6.396 years. The majority of FCGs (88.2%) were in the 51–65 years age group. The age distribution between the patients and FCGs was not significantly different (P = 0.416). There is, however, a significant difference in sex distribution between the patients and FCGs cohort (P < 0.001), predominantly female patients and male FCGs' in this study. The majority of the patients (51.61%) and FCGs (67.74%) had less than a high school of education. Furthermore, the majority of the patients (74.19%) have poor performance status.

Amongst the patients and their FCGs, in the pain questionnaire, the mean scores were 35.91 ± 8.98 and 35.31 ± 10.15, respectively, in the knowledge domain while, in the experience domain, the scores were 27.19 ± 8.73 and 26.86 ± 6.11, respectively. The mean overall pain scores were calculated to be 63.11 and 62.17, respectively [Table 2a and b]. There was no significant difference between the pain assessment scores of FCGs and patients overall [Table 3].

For this study, the mean score of CQOLC was 79.09 ± 9.67. The COQOL index subscale scores of FCGs were 23.26 ± 3.41 for burden, 14.37 ± 2.89 for disruptiveness, 16.49 ± 2.85 for positive adaptation, and 6.32 ± 2.220 for financial difficulties [Table 4].

No linear relation was elicited between the pain scores and the QOL scores, as depicted in the scatter diagram [Figures 1 and 2]. An inverse relationship was elicited between the total QOL and the pain assessment scores of FCGs, as well as the age of the patient. The difference was, however, majorly statistically non-significant (P > 0.5). Further, statistical significance was found only between the burden component of the CQOLC and the age of the patients (P = 0.034), as well as total pain knowledge (P = 0.007) and total pain scores (P = 0.001) of the FCGs [Table 5].

DISCUSSION

Controlling cancer pain is a complicated process that involves the patient, the family, and the healthcare service providers. In this prospective analysis of 93 patients and their

Table 1: Patients' and caregivers' baseline characterstics.

Characteristics	Total number (%)
Patients (*n*=93)	
Gender	
Male	33 (33.5)
Female	60 (64.5)
Age (mean±SD)	44.38±6.396
Education level	
<High school	48 (51.61)
High school	09 (9.67)
>High school	36 (38.70)
Employment status	
Employed	51 (54.88)
Self-employed	42 (45.16)
Retired	09 (9.67)
ECOG performance status	
0–2	24 (25.80)
3–4	69 (74.19)
Duration of illness	
<6 months	38 (40.86)
>6 months	55 (59.13)
Economic status	
High	07 (7.52)
Middle	48 (51.61)
Low	38 (40.86)
Caregivers (*n*=93)	
Gender	
Male	71 (76.3)
Female	22 (23.7)
Age (mean±SD)	51.38±5.701
Education level	
<High school	63 (67.74)
High school	05 (5.37)
>High school	25 (26.88)
Employment status	
Employed	81 (87.09)
Self-employed	10 (10.75)
Retired	2 (2.15)
Economic status	
High	07 (7.52)
Middle	48 (51.61)
Low	38 (40.86)

SD: Standard deviation, ECOG: Eastern cooperative oncology group

Table 2a: Patient pain questionnaire.

Variables	Total items	Range	Median	Mean±SD
Knowledge	9	14–58	37	35.91±8.98
Experience	7	4–55	28	27.19±8.73
Total	16	18–95	65	63.11±14.27

SD: Standard deviation

Table 2b: Family pain questionnaire.

Variables	Total items	Range	Median	Mean±SD
Knowledge	9	7–60	36	35.31±10.15
Experience	7	13–45	27	26.86±6.11
Total	16	32–105	62	62.17±13.03

SD: Standard deviation

Table 3: Comparison of mean pain scores between patients and caregivers using *t*-test.

Pain questionnaire	*P*-value
Knowledge	0.669
Experience	0.763
Total	0.641

Table 4: CQOLC scores.

Variables	Total items	Range	Median	Mean±SD
Burden	10	14–33	23	23.26±3.41
Disruptiveness	7	6–21	14	14.37±2.89
Positive adaptation	7	9–23	17	16.49±2.85
Financial difficulties	3	0–11	6	6.32±2.22
Total CQOLC	35	50–98	80	79.09±9.67

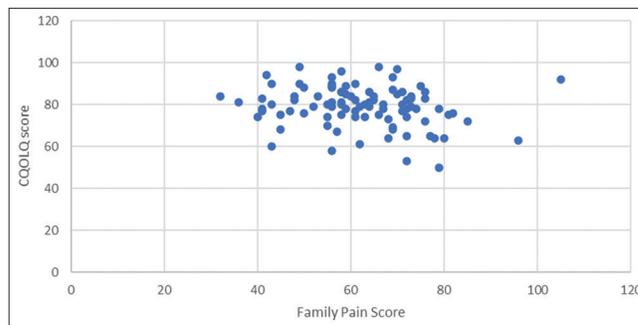SD: Standard deviation, CQOLC: Caregiver quality of life index-cancer

Table 5: Spearman's coefficient comparing QOL components (total and burden) with patients' and caregivers' age, knowledge, and experience parameters.

	Correlation coefficient	*P*-value
QOL final vs. total pain scores of caregivers'	−0.201	0.053
QOL final vs. total pain knowledge of caregivers'	−0.184	0.077
QOL final vs. total pain experience of caregivers'	−0.12	0.25
QOL final vs. age of caregivers'	0.031	0.766
QOL final vs. age of patients'	−0.033	0.752
QOL burden vs. age of patients'	−0.22	0.034
QOL burden vs. age of caregivers'	0.023	0.828
QOL burden vs. total pain scores of caregivers'	−0.327	0.001
QOL burden vs. total pain knowledge of caregivers'	−0.278	0.007
QOL burden vs. total pain experience of caregivers'	−0.186	0.075

QOL: Quality of life

Figure 1: Relationship between caregiver quality of life index-cancer score and family pain score.

Figure 2: Relationship between caregiver quality of life index-cancer burden and family pain score.
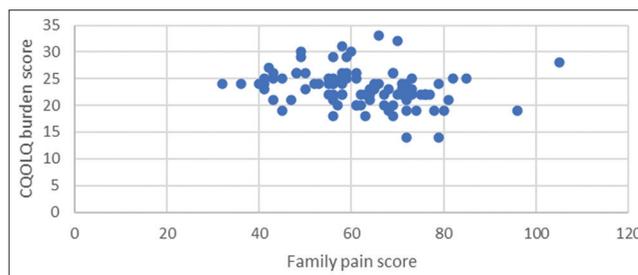
FCGs, statistical significance was found only between the burden component of the CQOLC and the age of the patients ($P = 0.034$), as well as total pain knowledge ($P = 0.007$) and total pain scores ($P = 0.001$) of the FCGs. However, there was no significant difference in the perception of pain between the FCGs' and the patients. Similar findings were observed in a study done by Yesilbalkan *et al*.[12] In addition, there was no correlation between the QOL of FCGs and pain scores.

Cancer-related pain can be the cause of unwelcome circumstances in the patients' functions. An increase in weariness and worry, a decrease in sleep and concentration, and other undesirable situations that impair a patient's QOL can all be attributed to pain connected to cancer. Cancer pain may impair every part of life, including working, interacting with others, and managing sickness, if the treatment is not received.[13,14] The majority of the literature that is currently available shows that inadequate physician

support for managing cancer pain, limited access to accurate information, and inadequate task preparation are the main causes of a suboptimal understanding of the main elements of pain management.[15] It has been noted that caregivers receive brief and disjointed explanations regarding cancer pain and its management from physicians and/or family and friends, with almost nil support for the evolving concerns and information regarding the nature of pain, its management strategies, proper management of side effects of medication used and their expected outcomes. Hence, their FCGs are left with no choice but to use their own experiences, and this may result in poor decision-making, feelings of helplessness, and a lack of confidence in times of need. Lee *et al*. found that concepts of dependence and tolerance were the primary lacunae in understanding the concept of pain management.[16] Furthermore, each of them had strong personal beliefs about the meaning of the intensity of cancer pain and the idea of disease progression in cancer. Optimal knowledge and appropriate skills enhance the skills of coping with the caregiving role, and inadequate knowledge regarding pain is a barrier to adequate pain control. However, in our department, with the help of palliative care physicians and healthcare workers, all the FCGs were counselled from the very 1st day, and this had a great impact on pain management. Hence, no significant difference was observed in the pain perception score of the patients as well as their FCGs. In a recent study, the researchers studied the impact of knowledge about pain

in caregivers as a key factor in determining the level of pain experienced. A positive effect, that is, improvement in pain experienced, was noted in the group of the study population who gained significant knowledge following the intervention. On the contrary, decreased knowledge with no improvement in pain experienced was observed in the control arm.[17]

In a study by Berry and Ward, it was observed that care providers in hospice settings had several misconceptions and visible concerns regarding reporting pain and using analgesics appropriately, particularly about their side effects, addiction, role in the progression of the disease, and injection phobia.[18] People who were older and less educated expressed great anxiety that reporting pain may cause a doctor to become sidetracked from their primary objective of treating or curing cancer. The results of this study are encouraging because they demonstrate that FCGs with sufficient training in pain management have fewer obstacles to preventing cancer patients from receiving grossly inadequate pain therapy.

In a cross-sectional observational study by Vallerand *et al.*,[19], the association between the level of pain and the beliefs of the patient regarding pain was studied. In around 300 patients suffering from cancer, they recognised two indices defining the beliefs of cancer patients about pain: Proper knowledge regarding pain and identifying barriers to pain control. The authors found that there was a positive correlation between the level of patients' pain and their distress level. Furthermore, it was studied that there is an evident relationship between the level of pain and their functional status and also a direct effect between the patient's beliefs about pain and their level of distress regarding pain. Therefore, controlling the factors affecting pain level might alleviate the QOL.

Care delivered by FCGs is an essential part of high-quality care overall. It is well recognised that cancer significantly lowers the QOL not only for patients but also for carers. Some studies indicate that the impact on carers' QOL in Asia is greater than in Western nations. QOL highlights symptom relief and, hence, may be used to assess the adequacy of pain management in cancer patients. Studies in China, Taiwan, Korea, Brazil, and Tokyo provide good evidence of the detrimental effect of pain on sleep, appetite, daily activity, mood, financial and emotional status, as well as the overall QOL.[20-22] This evidence has been supported by our study too. Cancer pain can be affected by pain intensity, clinical status, and treatment. It was seen that those with the end-stage disease had more pain and poorer QOL.[23]

Some of the limitations of the study included its small sample size and single-centre analysis.

CONCLUSION

As per our analysis, FCGs had less knowledge and experience of patients' pain, though statistically not significant. The critical role of FCGs in the management of cancer pain makes it very apparent that they need to be supported and educated if they are to potentially contribute to the process of achieving adequate control of pain. Further studies with larger sample sizes might help in strengthening the findings.

Ethical approval

Approved by the institute ethics committee, PGIMER, Chandigarh Ref no- NK/4983/Study/121, dated-25/3/19.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Nil.

Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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