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ORIGINAL ARTICLE

Family caregiver beliefs and barriers to effective pain management of cancer patients in home care settings

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Summary

Purpose: *Pain is one of the most common symptoms in cancer patients, and its management is a significant goal in supportive care. Many barriers interfere with its effective control. Nowadays, with a shift in care from the hospital to the home, there is an increasing tendency to involve family caregivers in pain management. Their beliefs may act as barriers to effective pain management in these homecare settings. This study aimed to validate and explore these beliefs using Barriers Questionnaire II (BQ II).*

Methods: *A cross-sectional survey of 202 individuals from a cohort of family caregivers in Greece.*

Results: *The reliability index Cronbach, a value for the translated version of the BQ II, calculated >0.9. Most participants reported worries about the side effects of analgesics. They often assumed these effects were irreversible, and equally, there were concerns about addiction to these drugs. They agreed on the effectiveness of analgesics in treating cancer pain but disagreed that reporting pain is a distracting factor in active cancer treatment.*

Conclusions: *This is the first time BQ II has been used in this population. The results are consistent with the international academic studies in this area, but more research is needed. BQ II was found to be a valid and reliable scale for defining caregiver attitudes and barriers to effective pain management in homecare settings. Health professional training, interventions targeted to caregivers and trained home care teams may improve the quality of cancer care in these settings.*

Key words: *analgesics, cancer, family caregivers, opioids, pain management*

Introduction

Pain is one of the most common symptoms of cancer patients and can occur at any intensity and at any point during the course of the disease. It affects many cancer patients, with an estimated prevalence that ranges from 33 to 59% and its management is a major aim of palliative care [1,2] . Pharmacological management is the cornerstone of cancer pain relief and includes opioids and non-opioid medications according to WHO guidelines that are known as analgesic ladder [3]. Many barriers interfere with the effective use of opioids in pain management and are related to health professionals, patients or health systems [4-6]. This study investigated the role of family caregivers and their beliefs about pain management.

Family caregivers and cancer patients

In several countries a shift appears in cancer care from the hospital to home [7,8]. While beneficial in terms of shortened hospital stays , the move may affect caregivers' well-being. Furthermore, families are increasingly involved in patient care including pain management.

Caring for a cancer patient can be stressful and emotionally demanding and often caregivers view themselves as critical components of a patient's

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pain management [9,10]. In recent years, there has been a growing interest in this cohort of individuals, frequently described as 'hidden patients' [11-13]. Home care includes complex and sometimes unfamiliar procedures. For healthcare professionals, monitoring pain, administering medication and recognising side effects are essential components of everyday practice, however this is not the case for carers who may become distressed at this increased burden [14,15].

Caregivers share the same beliefs as patients with respect to addiction, harmful analgesic side effects and masking disease progression. These attitudes can lead to undertreatment of pain and an over-zealousness in protecting patients from analgesic overuse [16,17]. Trying to identify and resolve caregiver barriers with respect to pain control can improve pain management quality and the quality of life (QoL) of the patient.

The role of Greek families in cancer patient care

The role of the family in Greece is of paramount importance and is a reliable support system for the cancer patient. However, in many cases it has been shown that relatives assume all responsibilities and decision-making powers on behalf of the patient [18,19]. Occasionally, they interfere in ethical issues such as truthfulness and honesty. They readily discuss available treatment options with the patient, but often they decide to withhold essential truths from the patient such as prognosis or disease progression [20]. In most cases, they behave this way as they believe they are 'protecting' the patient from stressful information, or they lack confidence in speaking about the disease.

Proot et al. in their study describe demands for greater active involvement in the caring of cancer patients, specifically in pain alleviation [21]. In one particular study in the Greek context, the majority of caregivers expressed a need for training and printed material containing information on the disease, chemotherapy side effects, emergencies and patient psychological support [22]. The research described feelings of insecurity when caring for these patients at home, a reason that could account for more cancer patients dying in hospital than at home [23]. In this closed family system, it appears that caregiver beliefs and attitudes are important factors in the management of cancer patients at home care settings including pain management.

The aim of this study was to describe family caregiver beliefs' that could be construed as barriers to effective pain management of cancer patients in homecare settings in Greece. This was done using the Barriers Questionnaire II (BQ-II) that was translated and validated on the current study.

Methods

This study is based on a descriptive cross-sectional survey design that generates quantitative research data. The methodology is fundamentally descriptive and incorporated a cohort of family caregivers, recruited consecutively over a 4-month period from a regional hospital in Komotini, Greece. The main characteristic of this design is that simultaneously and within a given period the extent or frequency of certain features in a defined population are measured .

As with other descriptive designs, cross-sectional studies cannot prove causality, and specifically to our study, we will not be able to identify why the participant's experiences in similar circumstances differ. However, such studies are valuable for the planning of health services as they provide information on a given population within a particular period.

The sample comprised 202 family caregivers of cancer patients. This figure is compatible with previous research in the field and representative of the investigated study population. The caregivers included in the study met the following criteria: 1) Aged 18 years or over, 2) Ability to read and write Greek, 3) A willingness to participate and signed informed consent, 4) Acting as primary caregiver, attending hospital with the cancer patient, 5) Actively involved in pain evaluation and analgesic use at home.

Instruments

Participants completed a self-reporting questionnaire separated into two parts. Part one included demographic information such as caregiver's age, gender, marital status, educational background and previous experience with analgesics. Part two included the current translated Greek version of the BQ-II. This is a 27-item self-reporting instrument developed by Ward and Gatwood to measure how patient attitudes to analgesics could act as barriers to effective pain management [24].

The questionnaire has been tested in several countries, with proven efficacy on describing patient beliefs and obstacles to effective pain management [25-28]. In the current study, this was applied to caregivers.

The questionnaire included four question subscales representing beliefs relating to: 1) physiological effects, 2) fatalism, 3) communications, and 4) side effects. Participants provided answers by scoring between zero and 5 (0=do not agree at all and 5=agree very much) on a 6-point Likert scale.

The creator of the Barriers Questionnaire (S. Ward) gave permission and approved use of the scale in this study. The research protocol was submitted to and approved by the hospital's ethics and scientific board. A language expert translated the questionnaire into Greek and another retranslated it back into English to identify compatibility of BQ-II. A third language specialist and two bilingual health professionals compared the two English versions and concluded there were no meaningful differences between them.

Informed consent was carried out by explaining the aims and procedures of the study to eligible participants. This was performed by the hospital's pain management

Table 1. Demographics of participants

Diagnosis	%	*Age, years*	%
Brain	1.2	19-40	47.6
Breast	7.3	41-50	25.6
Cervical	4.9	51-60	17.1
Colon	4.9	61-70	8.5
Gastric	4.9	71-80	1.2
Head/neck	6.1		
Kidney	1.2	*Educational level*	
Leukemia	3.7	Primary (<6 years)	11.0
Liver	4.9	Lower secondary (6-9 y)	8.5
Lung	25.6	Upper secondary (9-12 y)	34.1
Lymphoma	4.9	Bachelor or higher	46.3
Multiple	2.4		
Ovarian	11.0	*Relationship to patient*	
Pancreas	6.1	Spouce/partner	19.5
Prostate	7.3	Relative	72.0
Skin	2.4	Friend	8.5
Thyroid	1.2		

Table 2. Cronbach-a for subscales

Subscales	*Cronbach-a*
Physiological effects	0.889
Fatalism	0.718
Communication	0.682
Harmful effects	0.892

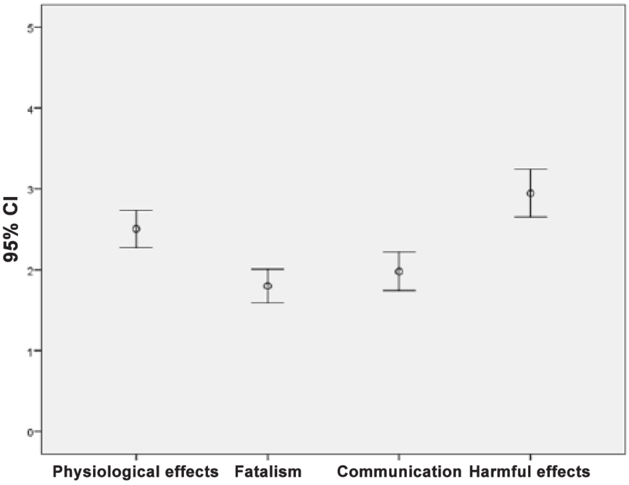

Figure 1. Mean values and 95% confidence interval for the four subunits.

specialist and a consultant in general medicine. The data was collected using the translated Greek version of BQ-II.

Statistics

Sample analysis was performed with the Statistical Package for Social Sciences (SPSS, v.19) to generate descriptive statistics and frequency distributions for responses to all items and reliability coefficients for the total scale and subscales (Cronbach's α). Bivariate analyses (t-tests, ANOVA, etc.) were conducted to assess the relationships between demographic data and caregiver beliefs. Multivariate analyses were not undertaken due to the small sample size. A value was considered statistically significant when $p < 0.05$, and a Cronbach a value >0.7 was accepted as reliable.

Results

Two hundred and two fully answered questionnaires were included in the study. Six questionnaires that were not fully answered were excluded. Of the participants 79.3% were women and 20.7% men. The largest age group was between 19 to 40 years (47.6%) and the next largest age group was between 41 to 50 years (25.6%). The majority of caregivers were holders of a bachelor or higher degree (46.3%). Graduates of upper secondary schools were 34.1%, 59.8% were married and 40.2% were single. The majority of caregivers were patient relatives (72.0%), spouses/partners (19.5%) or friends (8.5%). Approximately 63.4% had no previous experience in the use of opioid analgesics.

The demographics of participants are presented in Table 1.

In the questionnaire, there were four groups of questions (subscales) that used standard measurement scales for a particular characteristic. The internal reliability (*Cronbach-a* value) of these four subscales are presented in Table 2.

The reliability index was found to be high in 3 of the subscales. The third subscale - communication - had a reliability index that could not be considered as low, however it improved slightly when one question (No. 24) was removed.

The overall *Cronbach-a* value for the translated questionnaire was 0.925.

Complex variables

The first subscale, i.e. the effects of analgesics on patient physiology was shown to have a mean value of 2.5, placing it in the middle of the 6-point scale (Figure 1). This suggested that the impact of analgesics on patient physiology was moderate. Almost 60% of the participants stated that nausea, drowsiness and confusion were not reversible effects of analgesics. Approximately the same percentage of participants agreed that medication was masking changes in patient health and was blocking new pain.

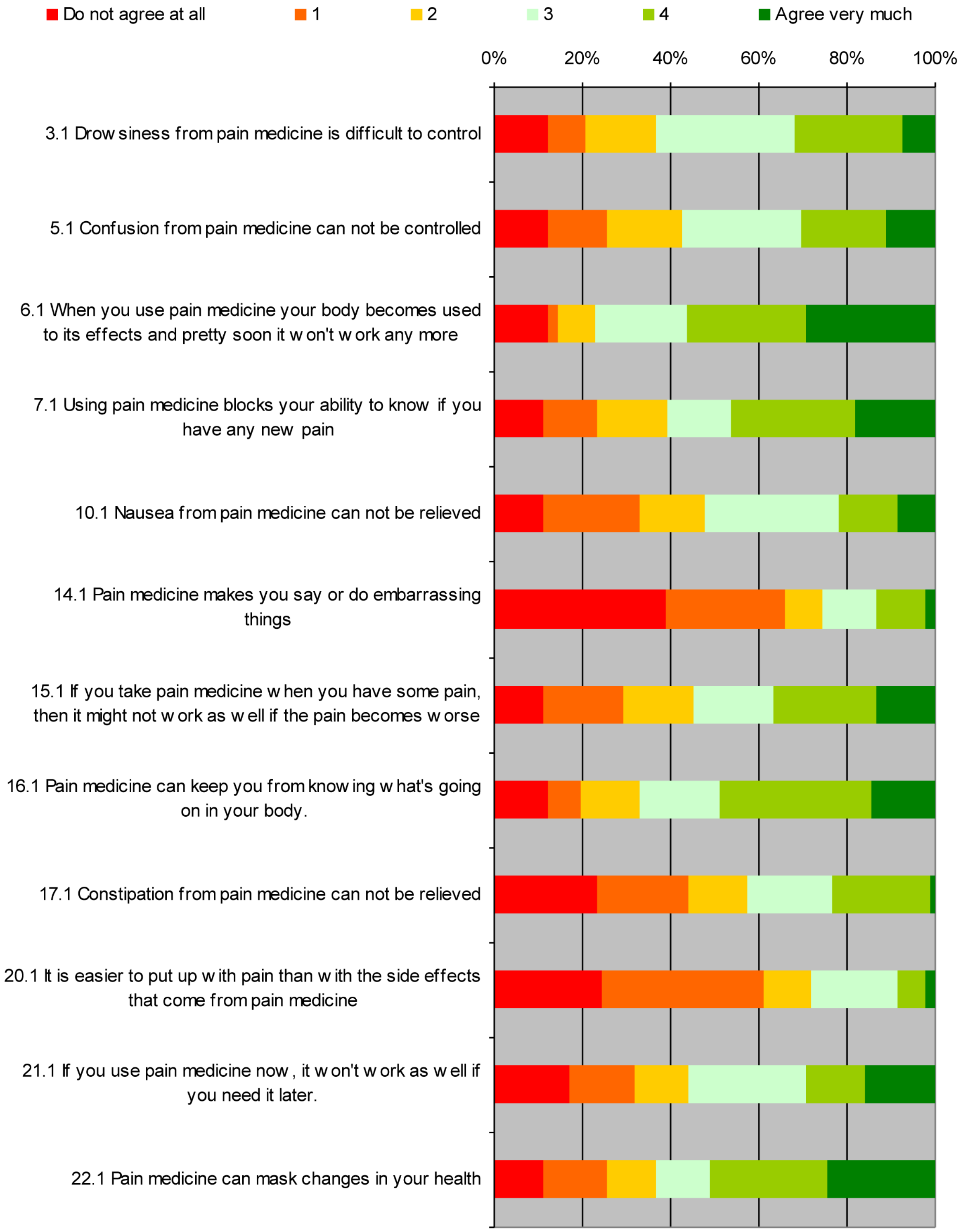

Figure 2. Physiological effects.

With a mean value of 3.35, over 70% of caregivers believed that during analgesic use, the body becomes acclimatised to their effects and they would fail to work after prolonged use. On the other hand, almost 80% of the participants disagreed with the fact that it was easier to put up with pain, rather than the side effects of pain medicine. They also specified that under the effect of analgesics, patients often did or said embarrassing things (Figure 2).

The second subscale, fatalism and its effectiveness during analgesic use had a mean value of 1.8 (Figure 1) and that reflected the participants' disagreements on statements relating to the ineffectiveness of analgesics in treating cancer pain (Figure 3).

The third subscale, the communication of pain as a distraction from the active treatment of disease had a mean value of 1.97 and the participants disagreed with these beliefs (Figure 1). Percentages

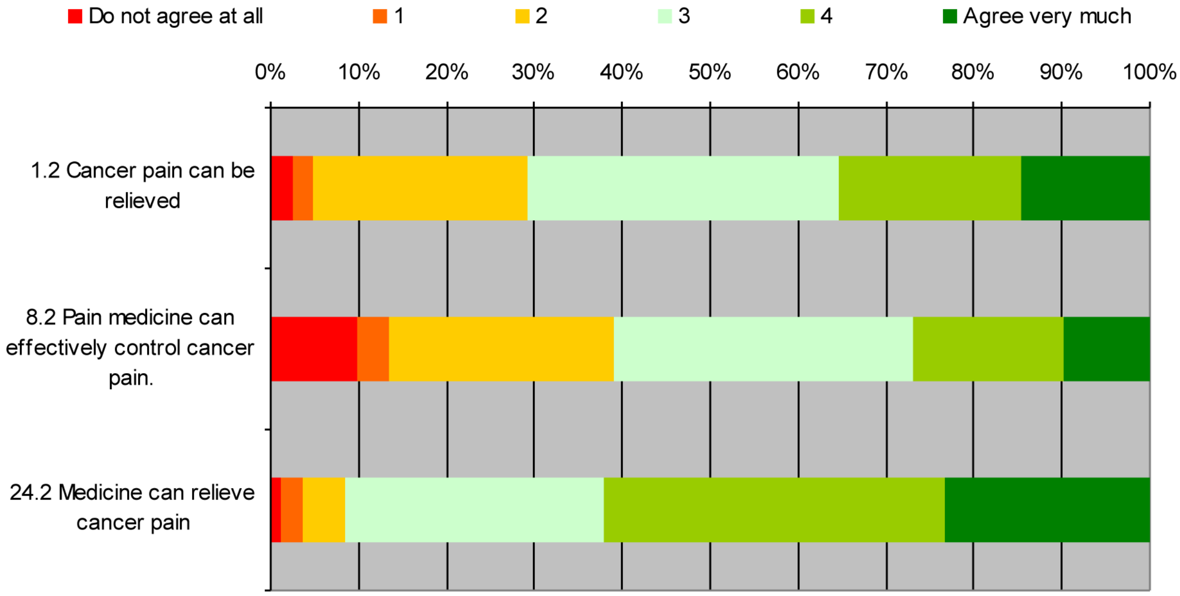

Figure 3. Fatalism.

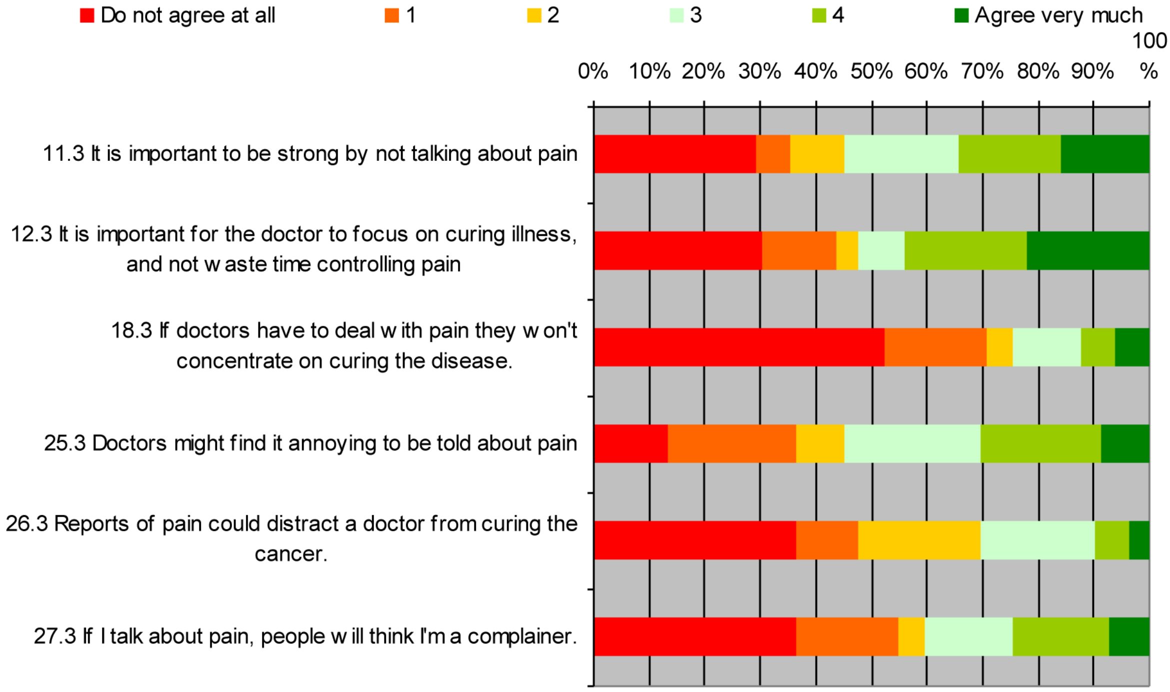

Figure 4. Communications.

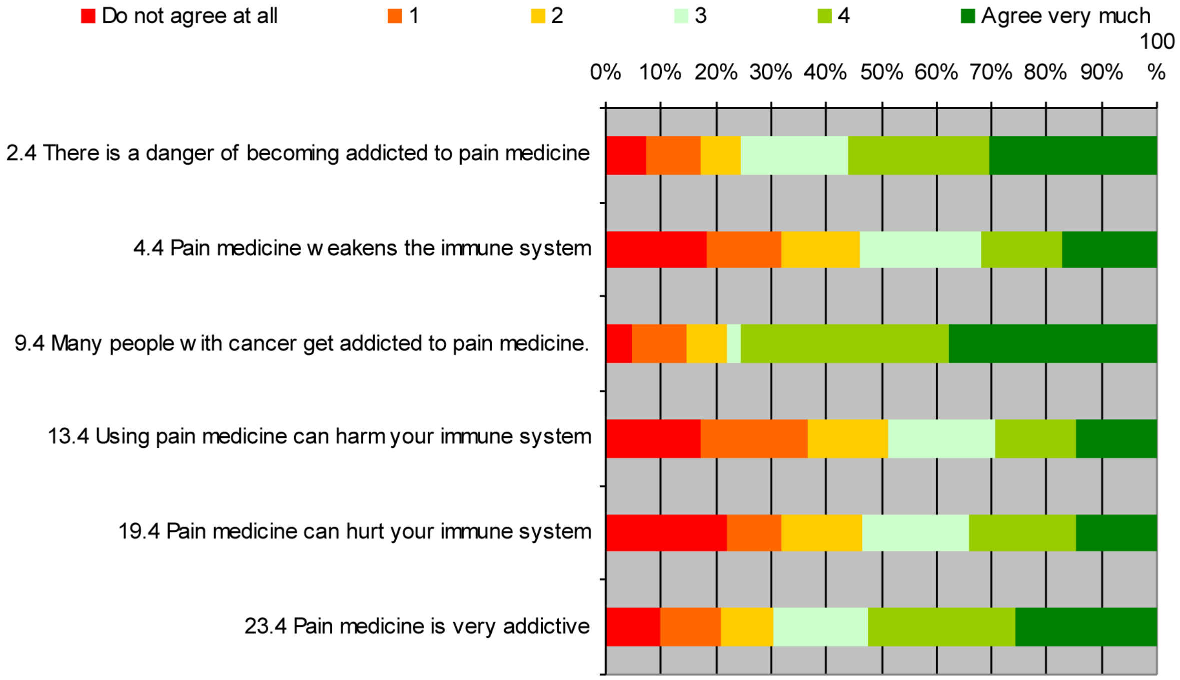

Figure 5. Harmful effects.

of strong disagreement varied from 13.4 to 52.4% (Figure 4).

Finally, the fourth subscale, i.e. the harmful effects of analgesics had a mean value of 2.94 (Figure 1). It was placed medium to high on the 6-point scale and therefore agreed with the sample on the harmful effects of analgesic use. Approximately 70-80% of the participants reported some agreement with the fact that analgesics were addictive, while 25.6-37.8% of the participants strongly agreed with this. Besides this, approximately 50% of the participants believed that analgesics could damage the immune system, whereas 14.6-17.1% strongly agreed with this statement (Figure 5).

Comparison of variables to demographic characteristics

The application of t-tests to categorical variables and ANOVA to multiple categories resulted in the following conclusions:

None of the four subscales was influenced by gender, however only 20% of the participants were male.

Statistically significant differences in caregiver attitudes appeared between various age groups for the second subscale - fatalism - (p=0.005). The mean values gradually increased, and hence the degree of disagreement decreased with decreasing age of the sample. Younger caregivers appear more confident about the effectiveness of analgesics in treating cancer pain.

Evaluation of the four subscales showed that participants' views were not affected by their marital status or previous use of analgesics.

Discussion

Barriers questionnaire

The results show that BQ-II, when translated into Greek, can be used as a valid and reliable analytical instrument to analyse family-based care of cancer patients. The Cronbach-a value which reflected the questionnaire's overall reliability and internal consistency was 0.925. The choice of Cronbach value only to assess the reliability and internal consistency is based on similar studies on other populations. However, other tests are also needed as this is the first time the translated questionnaire was used in Greece.

For the separate subscales, Cronbach-a values varied from 0.68 to 0.89. These values were relatively similar or higher when compared to other studies that used the same tool [25,28,29]. The subscales of fatalism, communication, physiological effects and harmful effects were compatible with the concept structure and appeared relevant to the Greek context and within this population.

The third subscale - communication - which had a relatively low reliability value, improved slightly when one question was removed, but in general it cannot be considered as weak. Higher participant numbers could lead to a potential improvement in its value.

Other studies have investigated the effects of additional barriers to pain management, e.g. fear of injections, tolerance to analgesics and disease progression [30,31]. It would be interesting to conduct further research on these or other barriers within a Greek context, to further establish their reliability and validity.

The sample comprised participants from a single hospital, however future studies should incorporate other hospitals to further validate the BQ-II test. Another limitation of the study is that the fourth and fifth inclusion criteria are based on carer-only report and were not verified with patients.

Beliefs and attitudes towards pain and its management

A foundational assumption for this research was that family caregivers actively participated in the pain management of cancer patients. The main purpose of this study was to explore their beliefs and attitudes ('barriers'). These are believed to influence caregiving processes and the quality of pain management. However, the extent of their involvement through interviews, self-reporting or free text comments was yet to be evaluated. Using barriers questionnaires, we assessed the extent to which caregivers endorsed inaccurate concerns and beliefs in relation to pain management. Future studies and qualitative research will need to analyse their attitudes and involvement in pain control in home care settings.

Physiological effects

It was evident that most caregivers used analgesics to deal with unrelieved pain, however, they did not believe they were a panacea. Most reported worries of side effects and tolerances that were assumed to be reversible in most cases. These beliefs could act as barriers to the rational use of analgesics.

Fatalism

A considerable number of caregivers agreed with the questions in this subscale (60-90%). Most believed that medicine could relieve cancer pain, therefore, fatalism did not appear as a potential barrier to pain management. It was interesting that agreement rates were higher in younger age groups, in those participants with higher education levels and in patient relatives. Older age groups and those with lower levels of education have been associated with barriers to pain management similarly to other studies [26,31,32].

Communication

The majority of participants believed that pain management was a doctors' key responsibility and duty. However, they believed it was annoying to speak about pain and it was a sign of the strength of the patient to deal with that pain alone. These beliefs can result in a hesitation in reporting pain to health providers to administer medication [33]. It is also a perception that may affect the communication of pain in home care settings and its effective management.

Harmful effects

There was some agreement within the sample on the adverse effects of opioid analgesics. Most participants agreed they are addictive and a significant section believed they could harm a patient's immune system.

Addiction and to a lesser extent the perceived damage to immune system are key concerns in this area and can act as the main barriers to effective pain management [30,31,34,35]. These side effects can promote hesitancy in caregivers on administering analgesics ans subsequently affect effective pain management in the home care setting.

Conclusions

These data and results have shown the translated Greek version of BQ-II can be used in Greece to investigate family caregivers of cancer patients. The four subscales of the questionnaire have shown to be valid and reliable.

The study presented results from a relatively small sample set of caregivers. Since all of the participants have practical experience of using analgesics in homecare settings, this sample will be representative of the population, and the sampling establishes the fundamental internal validity of the findings. This is the first time the questionnaire has been used in this population. Importantly, the results are consistent with the international academic research in this area, but replication of results in other samples in the Greek context will support further both the internal validity and the generalizability of these findings.

Studies have shown that educational interventions for pain management are often the first step in identifying and resolving common problems [36-38]. As a result, further education and training of health professionals are recommended. Through workshops, seminars and discussions, best practices for effective pain management for inpatients and those in homecare could be hugely beneficial. Similarly, such programmes could equip professionals with the skills and knowledge to cooperate with primary caregivers to identify their beliefs (barriers) and train them in analgesic administration.

When planning pain management in the home, health professionals must pay attention to caregivers' needs and beliefs. The concerns relating to analgesic side effects and addiction described in this study should be considered when planning pain management in homecare settings. Doctors must be available to answer questions and provide solutions. Development of pain centres, the recruitment of and easy access to pain management specialists in all major hospitals could offer more improved and specialised services. The evaluation of health services, the registration of common problems and the establishment of more home care teams could alter current practices and improve cancer care quality in the home.

Finally, the establishment of a national palliative care plan could incorporate research, recommendations and solutions to offer patients high-quality services and effective pain management.

Conflict of interests

The authors declare no conflict of interests.

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