

Palliative Education of the Family in the Care of Terminal Patients: A Descriptive Correlational Study

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Abstract: Palliative care (PC) education is critical for proper practice and compassionate care. The training of health professionals in PC seems insufficient and of variable quality. Studies point towards the need for training of these professionals in PC. Several authors emphasize the need to develop communication skills consistent with PC quality standards. Secondary data comes from 370 adult oncology and non-oncologic patients in the terminal phase between July 2014 and June 2015. There is a statistically significant difference in 4 out of 21 criteria on education for patients and families: 1) Diagnosis, signs and symptoms, 2) Medical treatment, 3) Restrictions and, 4) Skin care. According to the results, nurses are more oriented to cancer patients than non-cancer patients.

Key-Words: Nursing Competencies, Palliative Care; Family Education; Continuing Education in Nursing, Quality of Life.

1. Introduction

Education in Palliative Care (PC) is considered critical for proper practice and compassionate care (Baker, 2005). Training of health professionals in PC has not been fully achieved and still shows variability in PC quality (Wenk, De Lima, Mutto, Berenguel, & Centeno, 2016). In studies about other

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perception of health professionals regarding PC knowledge, they concluded the need for training in this area (Basol, 2015, Meo, Hwang, & Morrison, 2011; Michelson, Ryan, Javanovic & Frader, 2009). Also, several authors emphasize the importance of training the first level professionals to acquire basic communication skills in accordance with the quality standards that patients with palliative needs deserve (Quinn, Hudson, Ashby & Thomas, 2008; Wenk et al. Wittenberg-Lyles, Goldsmith, Ferrel and Burchet, 2014). The health care team is an essential component to integrate the family in the provision of CP with the purpose of providing an optimal quality of life to the terminal patient (Astudillo, Mendinueta, & Granja, 2008). The family is a crucial element of PCs, so their education is extremely relevant (Araya, Guamán & Godoy, 2006).

Astudillo, Mendinueta, and Granja (2008) warn that it is important for the health care team to recognize both the family and the patient as part of the therapeutic triangle. The family is an essential part of the PC, so their education is extremely relevant (Rodríguez, Ruiz and Carvajal, 2007). The family can collaborate effectively and actively in the care of the patient and revert to the health care team the responsibility of educating adequately about the control of symptoms, postural changes and personal hygiene, among others (Araya, Guamán & Godoy, 2006).

According to Lolas (1994), in order to achieve collaboration between the family and other significant individuals, the health care team is useful in collecting certain data as to the way families face their lives and circumstances, be it their history, traditions, myths and theories about the illness that afflicts their loved one, as well as death, the data gathered by the health care team will facilitate the educational experience. In addition to providing the context that articulates the role of the PC team to prevent, as far as possible, situations of tension within the family and to assist in their resolution in the event that such situation emerges (Díaz, González, Silva & Zamora, 2012).

In this educational process, according to Ortega (2012), it is necessary to anticipate to the family relevant information related to the procedures in the framework of the disease process and the impact that the disease will have on marital, sexual and family relationships, as well as the factors that increase the stress in the family and their pain.

On the other hand, it is important to emphasize that when confronting the proximity of death the family could face certain fears that the health care team must take into consideration. These include fear of patient suffering, fear of talking to the patient, fear of being alone with the patient at the time of death or, contrariwise, being absent when the person dies, which impedes the need to rest and to carry out activities of a daily life (Monterola, 2010).

In another study conducted in Cuba, the researchers set out to identify the extent of education that the dependent elderly family receives in terms of attention and care. This was done through interviews before and after receiv-

ing treatment that consisted of lectures, demonstrations and family dynamics on the following topics: general characteristics of aging, general care of the prostrate elderly, dependent elderly quality of life, bio psychosocial rehabilitation, care of the caregiver, importance of family harmony in dependent patient care, how to improve attention and memory, attention to the elderly's social problems, and adequate nutrition for dependent patients.

The study results point out the importance of guiding or educating the family of older adults, since in the initial interview, 100 percent of the participants demonstrated inadequate knowledge in contrast to the exit interview in which 85 percent of the participants demonstrated adequate knowledge about patient and caregiver care (Caballero, Naranjo & Fong, 2002).

The communication in PC goes further than the words and the content, since it contemplates attentive listening, the gaze and the posture, so that a humane guided assistance can be obtained. Adequate use of this resource is a proven therapeutic measure for patients who need it (Araújo & Silva, 2007; Astudillo, Mendinueta, & Granja, 2008).

Terminally ill patients and their families report that, at the end of life, honest communication is of vital importance (Heyland et al., 2006). Lack of communication and lack of hospice care result in many terminally ill patients and their families being unable to experience a "good death." Nurses may appear to be ideally placed to facilitate and support communication regarding the prognosis and referral of hospice between patients, their families and other professional caregivers (Schulman-Green, Cherlin, McCorkle, Carlson, Pace, Neigh & Bradley, 2010).

Taking into consideration these approaches, this study aimed to determine the type of health education related to PC that provides the nursing staff to adult end-stage oncology patients and adult (chronic) non-oncologic patients in the terminal phase and to their family in a hospital of the government of Puerto Rico according to the parameters of the Guide of Clinical Practice on PC of the National Health System of Spain (2008).

Different authors have agreed on the need to carry out studies on PCs in the Caribbean, including Puerto Rico (Maharaj & Harding, 2016). These authors indicate that contextual studies will contribute to the establishment of health care policies, staff training, education and access to analgesia support services and PCs in this region.

This study can be replicated through other hospital and care facilities for elderly people in Puerto Rico and in other countries, with the objective of carrying out comparative studies aimed at establishing protocols of nursing interventions based on effective methodologies in palliative care (PC).

2. Method

2.1 Instruments and Participants

2.1.1 Instruments

For the data collection, eight (8) instruments were developed based on clinical documents commonly used in hospitals in Puerto Rico. This article presents those used to compile information related to the family education construct: Instrument IVa - Oncology Adult Patient Education Checklist in Terminal Phase and Family & Opiate Management Registry: Medical Record; and Instrument IVb - Adult (Chronic) Non-Oncological Outcome in the Terminal and Family Phase and Record of Administration of Opiates: Medical Record. Each instrument consists of two parts: Part I - General education of nursing staff to patients and families consisting of 21 criteria and Part II - Specific education of nursing staff to patients and families related to pain and administered opiates consisting of five Criteria. For each criterion, yes or no was identified if the education process was carried out; And Not Applicable to identify if the state of the patient did not apply the education criterion.

2.1.2 Participants

The population of the study consists of the total admissions of a hospital of the government of Puerto Rico during the period from July 2014 to June 2015 (n = 9,862). From this population, a convenience sample of 370 medical records that met the inclusion criteria were selected of oncological OT (185) and non-oncological (chronic) end-stage patients NOT (185) from the Department of Health Information Management. Inclusion criteria are end-stage adult oncology patient records and end-stage (chronic) non-oncologic adult patients with a life expectancy of six (6) months or less. The criterion was examined through the analysis of nursing notes in the medical record. Data were analyzed through descriptive and inferential statistics to identify, compare and correlate factors that influence PC.

The study follows a descriptive-correlational design of collection of secondary data from medical records of a government hospital in Puerto Rico. The Chi-square test was used to demonstrate the interdependence among variables related to health education with a 95% confidence index. To perform this test, we first calculated the frequencies of the "yes", "no" and "not applicable" alternatives for each variable in OT and NOT patients. Then the expected frequencies for each variable were determined to find Chi-Square (X²), degrees of freedom (GL), and probability (P). The value of P was determined if the null hypothesis for each health education and opioid administration variable was accepted or rejected.

Results. Table 1 summarizes the results of the X2 test on the general education area provided by nursing staff to patients and families. This table shows the statistically significant difference for 4 of the 21 criteria that tax the variable education to patients and families: 1) Diagnosis, signs and symptoms, 2) Medical treatment, 3) Restrictions and 4) Skin care.

Variable	X2	GL	P	Hypothesis
Advanced Intubation Guidelines (DNI)	4.0526	2	0.1318	Null
Non-Resuscitated Advance Guidelines (DNR)	2.5485	2	0.2796	Null
Diagnosis, signs and symptoms	16.8928	2	0.0002	Alternates
Medical treatment	9.1380	2	0.0104	Alternates
Nursing treatment	2.7935	3	0.3560	Null
Importance, precautions and effects of medications	2.9155	2	0.2328	Null
Diet and nutrition	2.4083	2	0.2999	Null
Restrictions	6.4555	3	0.0160	Alternates
Isolation	4.9868	3	0.1072	Null
Prevention of infection by multiresistant organisms	2.0088	3	0.4642	Null
Venous catheter care	2.7869	3	0.2732	Null
Urinary catheter care	3.4774	3	0.1621	Null
Cleaning and hygiene habits	0.4456	2	0.8003	Null
Skin care	6.1633	2	0.0459	Alternates
Enteral and parenteral feeding techniques and precautions	3.1803	3	0.3647	Null
Physical and occupational exercise techniques	2.1789	2	0.3364	Null
Breathing exercise techniques	3.3075	2	0.1913	Null
Use of treatment-related equipment	2.6574	2	0.2648	Null
Importance, precautions and adverse reactions to blood transfusions and their derivatives	2.8570	3	0.3326	Null
Spiritual counseling	1.7365	2	0.4197	Null
Guidance on psychosocial problems and needs	2.4724	2	0.2905	Null

Table 1: *Chi-Square statistical analysis for the fourth question of the study in the area of education to patients and families*

Table 2 summarizes the results of the X2 test on education in the area of opioid administration in which a statistically significant difference was found for all the criteria that tax the variable.

Variable	X2	GL	P	Hypothesis
Pain scale	14.2793	2	0.0008	Alternates
Description of pain- Includes generalized pain	9.8828	2	0.0071	Alternates
What relieves the pain?	12.5731	2	0.0019	Alternates
How does pain affect the patient?	10.2436	2	0.0060	Alternates
Opiates administered	36.5777	2	6.56E ⁻⁰⁹	Alternates

Table 2: *Chi-Square statistical analysis for the fourth question of the study in the area of education to patients and families on the administration of opiates*

Figure 1 summarizes the representation of the distribution of the Nurse Education Indicator Rate corresponding to the comparison between OT and NOT patients.

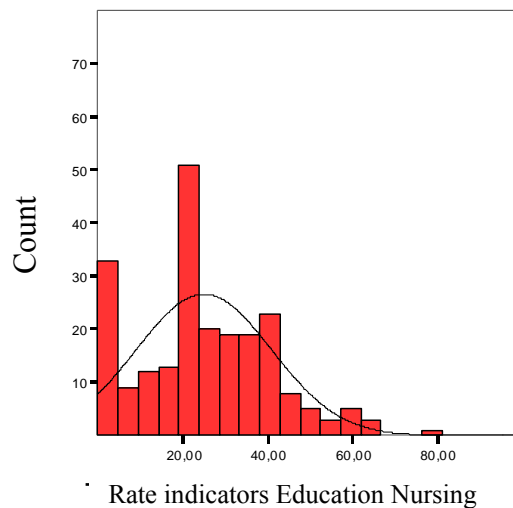


Figure 1: *Histogram Nurse Education Indicator Rate*

Table 3 contrasts the differences in health education provided by the nursing professional to the patient and the family. Significant differences were found for indicators number: 3, 4, 14, 22, 23, 24, 25, and 26. Likewise, a

health education achievement rate has been constructed, which is higher in OT patients.

Variables	OT (n=101)		NOT (n=124)		p
	n	%	n	%	
Part I. General education of nursing staff to patients and families					
1. Advance No-Intubation Guidelines (DNI) [Not applicable: OT= 1; NOT= 0]					
No	58	58.0	86	69.4	0.105
Yes	42	42.0	38	30.6	
2. Advance instructions for no resuscitation (DNR) [Not applicable: OT= 1; NOT= 0]					
No	59	59.0	83	66.9	0.277
Yes	41	41.0	41	33.1	
3. Diagnosis, signs and symptoms [Not applicable: OT= 1; NOT= 0]					
No	71	71.0	114	91.9	<0.001
Yes	29	29.0	10	8.1	
4. Medical treatment [Not applicable: OT= 1; NOT= 0]					
No	79	79.0	114	91.9	0.010
Yes	21	21.0	10	8.1	
5. Nursing treatment [Not applicable: OT= 1; NOT= 1]					
No	34	34.0	51	41.5	0.316
Yes	66	66.0	72	58.5	
6. Importance, precautions and effects of medications [Not applicable: OT= 1; NOT= 0]					
No	80	80.0	106	85.5	0.364
Yes	20	20.0	18	14.5	
7. Diet and Nutrition [Not applicable: OT= 1; NOT= 0]					
No	29	29.0	48	38.7	0.168
Yes	71	71.0	76	61.3	

8. Restrictions [Not applicable: OT= 8; NOT= 0]						
No	80	86.0	105	84.7	0.934	
Yes	13	14.0	19	15.3		
9. Isolation [Not applicable: OT= 3; NOT= 0]						
No	79	80.6	106	85.5	0.432	
Yes	19	19.4	18	14.5		
10. Prevention of infection by multiresistant organisms [Not applicable: OT= 2; NOT= 0]						
No	86	86.9	110	88.7	0.832	
Yes	13	13.1	14	11.3		
11. Venous catheter care [Not applicable: OT= 3; NOT= 0]						
No	65	66.3	79	63.7	0.792	
Yes	33	33.7	45	36.3		
12. Urinary catheter care [Not applicable: OT= 4; NOT= 0]						
No	85	87.6	109	87.9	1.000	
Yes	12	12.4	15	12.1		
13. Cleaning and hygiene habits [Not applicable: OT= 1; NOT= 0]						
No	75	75.0	97	78.2	0.682	
Yes	25	25.0	27	21.8		
14. Skin care [Not applicable: OT= 8; NOT= 4]						
No	80	80.0	112	90.3	0.045	
Yes	20	20.0	12	9.7		
15. Enteral and parenteral feeding techniques and precautions [Not applicable: OT=1; NOT= 0]						
No	78	83.9	105	87.5	0.578	
Yes	15	16.1	15	12.5		
16. Physical and occupational exercise techniques [Not applicable: OT=3; NOT= 9]						
No	97	7.0	115	92.7	0.268	

Yes	3	3.0	9	7.3	
17. Respiratory exercise techniques [Not applicable: OT=1; NOT= 0]					
No	90	91.8	105	91.3	1.000
Yes	8	8.2	10	8.7	
18. Use of treatment-related equipment [Not applicable: OT=1; NOT= 0]					
No	63	63.0	75	60.5	0.805
Yes	37	37.0	49	39.5	
19. Importance, precautions and adverse reactions to blood transfusions and their derivatives [Not applicable: OT=1; NOT= 0]					
No	80	80.8	109	87.9	0.202
Yes	19	19.2	15	12.1	
20. Spiritual counseling [Not applicable: OT=1; NOT= 0]					
No	93	93.0	118	95.2	0.689
Yes	7	7.0	6	4.8	
21. Guidance on psychosocial problems and needs					
No	89	89.0	100	80.6	0.127
Yes	11	11.0	24	19.4	
Part II. Specific education of nursing staff to patients and families related to pain and opiates administered					
22. Pain scale [Not applicable: OT=1; NOT= 0]					
No	14	14.0	44	35.5	<0,001
Yes	86	86.0	80	64.5	
23. Description of pain- Includes generalized pain [Not applicable: OT=1; NOT= 0]					
No	82	82.0	117	94.4	0.007
Yes	18	18.0	7	5.6	
24. What relieves the pain? [Not applicable: OT=1; NOT= 0]					

No	81	81.0	118	95.2	0.002
Yes	19	19.0	6	4.8	
25. How does pain affect the patient? [Not applicable: OT=1; NOT= 0]					
No	83	83.0	118	95.2	0.006
Yes	17	17.0	6	4.8	
26. Opiates administered [Not applicable: OT=2; NOT= 0]					
No	21	21.2	76	61.3	<0,001
Yes	78	78.8	48	38.7	
Indicator Rate of Education Nurse Fulfilled (%)					
Media - DE	29.1	14.7	21.6	16.2	<0,001
Indicator Rate of Education Nurse Fulfilled (%)					
<=50%	92	92.0	120	96.8	0.201
>50%	8	8.0	4	3.2	

Table 3: *Evaluation of the type of Health Education provided by the nursing professional to the patient and the family*

4. Discussion and Conclusions

4.1. Discussion

Facing a potentially deadly disease poses challenges not only for the patient and his / her family, but also for the nursing staff (WHO, 2002). This need has contributed to the historical development of the concept of palliative care (PC) throughout the world (Centeno, 1997; Del Río & Palma, 2007; García, 2011; González & Valdovino, 2012; SECPAL, 2014; Webster, Lacey & Quine, 2007, among others) and proposes a sensible intervention that integrates the relief of symptoms in the traditional scheme whose main purpose is to cure (Avellaneda, 2003). The PC trajectory warns of the need to establish health care policies and their integration into the training of personnel facing this challenge (Maharaj & Harding, 2016). Several authors emphasize the importance of paying attention to the control of clinical symptoms such as pain, as well as the psychological, social and spiritual aspects of both the patient and his / her family (Gigena, 2015; Jocham, Dassen, Widdershoven & Nervi & Taboada, 2005). Due to the contact between the nursing staff and the terminal patient, the importance of that link could be affirmed by the trust that promotes the environment that contributes to a "dignified death" or "good

death" through the education of the patient and caregivers (Heyland et al., 2006; Schulman-Green, et al., 2010).

In Puerto Rico initiatives are identified that ascertain the need to establish policies aimed at serving the COP. These have culminated in projects and laws that clarify the concepts: hospice and CP; in addition, the creation of organizations that provide services, although much remains to be accomplished.

As part of the original study from which this analysis is derived, a profile was outlined that contains the peculiar features that characterize each group. The epidemiological profile of adult end-stage oncology (OT) patients whose records were evaluated for the purpose of the study resulted in a 63-year-old male, unemployed male with a college degree, single, born in Puerto Rico, who lives with him, whose main language is Spanish, belonging to the Catholic religion and covered by medical insurance. In addition, it was identified that the type of pathology more frequent of patient of the OT adult was Leukemia.

While the epidemiological profile of end-stage (chronic) non-oncologic adult (NOT) patients whose records were evaluated for the purpose of the study turned out to be a person over 63 years of age, unemployed male with a college education, single, born in Puerto Rico, who lives accompanied, whose main language is Spanish, belonging to the Catholic religion, and covered by medical insurance. Also, it was identified that the type of pathology more frequent of the adult chronic patient (NOT) were the diseases of the brain.

Both groups resemble each other in their profile differentiating themselves in the most frequent type of pathology: OT Leukemia and NOT brain diseases. However, the presence of these identified diseases is in line with McNamara (2006), who presents a list of diseases that qualify recipients of palliative care, including cancer, Motor neuron disease. Apart from the prevalence of the conditions that patients suffering from palliative care, at the time of this study, no literature was identified on the epidemiological profile of these patients in Puerto Rico (Department of Health, 2015). On the other hand, according to vital statistics, in Puerto Rico heart disease, malignant tumors or cancer and diabetes mellitus tend to be the first causes of death. Of these deaths, "cancer is the second cause of death in Puerto Rico with an average of 5,000 lives lost annually and its negative effects have been felt in the Puerto Rican family" (Department of Health, 2015, p.6), which is partially consistent with the results of this study.

This study seems to confirm the assertion by Yong et al. (2008) that in general terms patients are reluctant to raise spiritual issues, since in 18% of the total of study files no data was recorded on religious belief.

The Ministry of Health and Social Policy of Madrid (2009) states that primary care is the basic level in providing care to patients with terminal illness, facilitating access to necessary therapeutic and care resources in the

patient's domain through education that contributes to improve the self-care of both the patient and the caregiver. This approach seems to contradict the results of this study, since there is evidence in the patient and family education records in most of the criteria, except for nutrition and diet education that was highlighted only in NOT patients with 61.3 percent. Likewise, the closest score for both groups was 66 percent for OT and 58.5 percent for NOT patients in nursing treatment education. The lowest scores were those of OT patient for enteral and parenteral feeding and parenteral techniques and precautions with 3 percent and for NOT patient the score of 4.8 percent for importance, precautions and adverse reactions to blood transfusions and their derivatives.

Although the literature points out the importance of educating the family so that they can collaborate effectively and actively in the care of the patient in the present study, this effort is not documented. Nevertheless, scholars of the subject claim that the responsibility of educating adequately on the control of symptoms, postural changes and personal hygiene, among others (Araya, Guamán & Godoy, 2006) is reinstated in the health team, which is not confirmed in the results of this study. In this educational process, according to Ortega (2012), it is necessary to anticipate to the family relevant information related to the procedures in the framework of the disease process and the impact of the disease, as well as the factors that increase the stress in the family and their pain.

In contrast, it should be noted that for this study psychosocial education was considered, with a low presence in OT patient files with 11 percent and NOT with 19.4 percent. Researchers warn that faced with the imminence of death, the family could face certain fears that the health care team must take into consideration (Monterola, 2010). That is why there must be an appropriate approach by the health care team that allows the identification of these or other fears such as: not having the resources to help you, not being present in those moments, not knowing how to distinguish the last phase, not how to confront them (Gómez, Roca, Pladevall, Gorch & Guinovart, 1993). In the data found, there is insufficient evidence to corroborate the importance of psychosocial education in the experience of these patients in the hospital.

In the course of the evolution and the illness crises can appear of decompensating of the patient and his relatives, in which the problems or their impact are emphasized (SECPAL, 2014). The most frequent causes of decompensating are: poorly controlled symptoms or the appearance of new ones, especially pain, dyspnea, hemorrhage and vomiting. Others like feelings of loss, fears or uncertainty, depression, anxiety, loneliness and doubts about previous treatment or evolution. In the educational development of the family throughout the process, the PC team emphasizes its usefulness in identifying the multiple needs they may have and the supply of knowledge corresponding to the need (Alonso, Vilches and Díez, 2008; Caballero, Naranjo & Fong,

2002, Marín, 2015). We are concerned that unfortunately this educational process is not highlighted in the results.

Also the results contrast significantly the absence of indicators of compliance with the CPG with training actions that have been carried out by several Autonomous Communities of Spain (CAAC) on this subject, among them, a Guide for information to citizenship (Ministries of Health, Social Policy and Equality, 2011). In addition, we emphasize a remoteness in compliance with the indicators when comparing the results of this study, 10 percent for indicators of treatment of nursing and nutrition and diet, with those of an Autonomous Community (CA) that assessed the quality of health services partners who showed a 60 – 70 percent of compliance of the indicators related to the information (Sánchez, Garzón, Sánchez, Díaz, Gil & Pérez, 2008).

Another significant finding rests on what is found in the indicator on education in spiritual counseling in which OT patients got 7 percent and NOT patients with 4.8 percent. Several authors emphasize the patient's spiritual needs such as hope, sense, love, religious or divine inclinations, and coping with death (Benito et al, 2014, Galek, Flannelly, Vane & Galek, 2005, Nixon & Narayanasamy, 2010; Yong et al., 2008); with the very low percentages documented in this study, the long journey that remains for GPC compliance is inferred. According to the results, there is no evidence to show that our results are consistent with the recommendation of Buzzi et al. (2009), which includes the psychological and spiritual aspects of the patient's treatment.

However, the results obtained are consistent with the assertion of several authors that the spiritual dimension has been the least developed area of the PCs (Galiana, Oliver, Gomis, Barbero & Benito, 2013). Two reasons were identified in the literature that seem to explain this. One of them proposed by Selman et al., (2013) in which it is argued that spiritual aspects are poorly handled in clinical practice due to the lack of competence of health personnel in identifying and evaluating spiritual distress. The other reason according to Yong et al. (2008) responds that in general terms patients are reluctant to raise spiritual issues, which makes it difficult to identify this dimension. This was also observed in the lack of data on the spiritual or religious aspects that the patients themselves should report and that for this study were contained in the epidemiological profile in which 18 percent did not record data on religious belief. Both reasons are plausible to mean what was found in this study.

Contrary to the results presented on general education, there is evidence of greater compliance with specific education related to pain and opiates administered, although not in all the indicators that are related to the variable education. A robust compliance was highlighted in indicator one: pain scale, in which OT patients accumulated 86 percent while NOT patients reflected 65 percent. This goes hand in hand with adherence to some fundamental principles of symptom control documented in this study such as: (1) Evaluate prior to treatment to avoid attributing symptoms only to the fact of terminal illness;

(2) Explain the causes of these symptoms; and (3) monitoring of symptoms using standardized measurement instruments (scales or analog scales) and adequate recording schemes (body chart of pain, symptom tables). (SECPAL, 2014).

In indicator five on the education that patients and relatives received regarding opiates, 78 percent were found in OT patients and 61 percent in NOT patients. In general terms, it is more oriented to OT patients than to NOT patients. When considering the analgesic ladder of the World Health Organization (WHO), which proposes a simple scheme for pain relief in cancer; the use of potent opioids such as Morphine and Fentanyl, equivalent to level three used for moderate and severe pain, is highlighted in the results. We also identified Tramadol, Percocet, Tylenol with Codeine and Ultracet equivalent to the second level of the WHO analgesic ladder representing weak opioids for a moderate pain level. Finally, at level one that includes non-opioid analgesics, Demerol was identified for mild pain level. The use of opioids is recommended for the relief of symptoms in particular for cancer patients (Ben-Aharon, Gafter-Givili, Paul, Leibovici & Stemmer, 2008). The pain seems to consistently accompany the patient OT and NOT in the terminal phase.

On the contrary, the following three indicators received the lowest scores for compliance with education. For example indicator two: in pain description OT patients obtained 18 percent and 5.6 percent for NOT patients. Also indicator three: What relieves pain? in OT patients was evidenced by 19 percent and in patients NOT 4.8. Equally low is the score received for indicator four: how does pain affect the patient? with 17 percent for OT patients and 4.8 for NOT patients.

According to the results and the discussion of these, it is imperative to note as one of the limitations of the study is the fact that the results obtained cannot be generalized to the population due to the type of sample selected for convenience. Also note that the admission of cancer patients during the study period was 247 which made it difficult to reach the suggested sample of 185, this study could only obtain a sample of 101 patients that met the inclusion requirements. In addition, during the review of the files it was found that documents relevant to this study were incomplete or blank. On the other hand, some drugs recommended by GPC for PCs are not included in the offer of the participating hospital of this study. Finally, access to the files was limited to the attendance and schedule of the person authorized to provide them.

The discussion presented in this chapter demands us to consider some routes for the continuity of future research on this subject in view of the importance, relevance and scarcity of studies in Puerto Rico. Among these: 1) present recommendations on public policy related to the implementation of CP protocols in hospitals of the Government of Puerto Rico; 2) to carry out qualitative and quantitative design studies in order to ascertain the status of PC in the public and private hospital facilities of Puerto Rico; 3) to carry out

mixed design studies (QUAL / QUAN) aimed at knowing the experience of patients in terminal phase and family on the services they receive in hospitals in Puerto Rico; 4) to study the spiritual and psychosocial aspects of the terminal patient; 5) to know the opinion and perception of the nursing professional about PCs and their training and development needs; And, finally, 6) to study university curricula to determine the content and scope of PCs in programs for the preparation of nursing staff.

Finally, the discussion presented also places us in a better perspective to make recommendations on the management of PCs in Puerto Rico. Among the highlights are: 1) The first step is part of the revision of the protocols for the administration of drugs for the terminal patient, particularly the routes used to include the recommendations of the CPG; 2) Exploration and feasibility of strategies such as the subcutaneous route of hydration to terminal patient; 3) To recommend that a procedure be established to document the dossier in a manner that ensures the follow-up of guidelines for end-stage patient care; 4) Raise awareness about the use of different instruments to assess the patient's autonomy as well as the identification of the pain scale and include them in the medical record; 5) Emphasize the importance of documenting the general education of nursing staff to patients and family as well as the specific education of nursing staff to patients and families related to pain and opiates administered.

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