

Palliative Care Nursing in Cyprus

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Abstract

Palliative homecare in the Republic of Cyprus is limited to cancer patients and only provided by two non-governmental organizations (NGO's) which offer free services to adults. Nurses employed by these charities support patients and assist families in the provision of necessary care. They play a vital role in helping to improve quality of life, using a holistic approach when addressing issues of concern and when helping to overcome the difficulties which may arise from pain and other symptoms. They advocate best practice and strive to educate, not only patients and their care givers, but also other healthcare professionals and the general public, in an effort to empower, ensure safety and promote good palliative care. Although these services have evolved since their onset in the 1980's there is a continuing need for improvement and expansion in order to ensure that 24 hour care is available for all, both adults and children, regardless of disease.

Keywords: Palliative care; Home care; Middle East countries; Paediatric palliative care

Background

The island of Cyprus, which lies in the Eastern Mediterranean Sea, has been divided into two communities since 1974. The total population of the island is 1.153 million [1] with 862,000 people living in the Republic of Cyprus [2] and the remainder living in the Turkish occupied area of Northern Cyprus. Because of its strategic position, the island attracts many visitors and immigrants, especially from other member countries of the European Community but also from neighboring Middle Eastern countries, the Eastern Bloc and, more recently, China. Consequently a multicultural, multiethnic society has developed where the predominant religions are Christianity and the Muslim faith.

Healthcare in the south is provided by the public and private sector and, although there have been efforts since 2002 to implement a universal health plan, this has not yet come to fruition. Primary care remains "underdeveloped" [3] and the health care services in general have been described as fragmented, partly due to poor communication between the public and private systems [4].

The most recent data published by the Ministry of Health indicate that cardiovascular disease is still the leading cause of death in Cyprus, with the second being malignant neoplasms, which accounted for a total of 1194 deaths in 2011 [5]. National Cancer Registry figures show that, of the 1465 new cases of male cancer diagnosed in 2008, 381 [26.0%] were prostate and 184 [12.6%] were lung. Among females, there were 1379 new cases, 444 [32.2%] of which were breast cancer and 132 [12.2%] were colorectal cancers. The third leading cause among men was colorectal and among women it was thyroid [6].

Palliative care services began in the early 1980's with the opening of the Arodafnosa Hospice, a project which sought to provide a caring place for patients with advanced cancer. The need for in-patient end of life care was great because hospital beds were limited and the island's

one oncology unit provided services only to those receiving chemotherapy and radiotherapy. Staff at the hospice were fortunate enough to meet with Dame Cicely Saunders who played a role in introducing them to palliative care, a concept they had been unfamiliar with up until that time [7].

Today, Cyprus offers "generalized palliative care provision" in various localities funded by multiple sources with provision of some training and education, as classified following a study which was carried out by the Worldwide Palliative Care Alliance [8]. The Cyprus Association of Cancer Patients and Friends (PASYKAF) and the Cyprus Anticancer Society [CACS] are the only two organisations which provide palliative homecare. They are not-for-profit NGO's, both of which offer free support to adult cancer patients, leaving those suffering from other chronic conditions to rely on limited support from general community nurses. There are currently no health professionals with training in pediatric palliative care but there are however hopes of change following the 2011 strategic plan issued by the Ministry which incorporates the inclusion of both adult and pediatric palliative care into the health care system [9].

Education

In-service education in both NGO's is encouraged and supported by the Middle East Cancer Consortium [MECC] which has funded education both locally and abroad and began holding workshops on the island in 2004. Thanks to MECC, some members of the nursing teams have been fortunate enough to have had the opportunity to spend time at Calvary Hospital in the United States [10], an experience which has left a lasting impression and has led to changes in practice throughout PASYKAF. Others have been able to undertake post graduate education, particularly in palliative care. All members of staff are encouraged to engage in educational activities and to participate in conferences/workshops organized by the oncology units, PASYKAF and CACS which work side by side with the MOH to coordinate and host events aimed at educating public and private health professionals from all specialties.

The Cyprus University of Technology (TEPAK) has incorporated an optional palliative care module into its nursing program. This is offered in the third year and has proved to be very popular, partly due to its interactive nature. It includes topics such as communication, breaking bad news, bereavement, loss, death theories and interdisciplinary team work. As of September 2013 a further palliative care module, totalling 24 hours, has been offered to TEPAK post graduate students.

Nursing Roles

Development of services in PASYKAF and CACS has been driven by patients' needs over the years. PASYKAF, for example, was founded in 1986 by a group of 21 patients who had received medical care abroad and were therefore aware of how much work needed to be done in Cyprus if healthcare services in the cancer domain were to be improved. Today patients play a crucial role on the association's board of directors and members of the interdisciplinary teams are motivated by the need to address issues surrounding quality of life and total pain, whether supportive or palliative in approach [11,12].

Early referral is preferred so that patients can have full interdisciplinary support from diagnosis to remission or end of life, thus helping to develop a trusting relationship between the patient, his family and members of staff. Nurses usually provide the first point of contact with the patient, assessing his needs and formulating a plan of action with him. A supportive/palliative approach begins immediately, taking into consideration physical, psychological, social and spiritual needs and involving other members of the interdisciplinary team as soon as possible.

There is close cooperation between nurses and psychologists who support patients and their families, either at home, in hospital/hospice or in the organization's offices, where they also facilitate various group sessions. Social workers often receive referrals from the nursing team and have the difficult role of assisting applications for social service benefits which have become increasingly difficult and slow to access. This can be extremely frustrating, especially when time is of essence and when extra funds are necessary for quality to be improved at end of life.

A venepuncture clinic relieves the patients' burden of travelling to their oncology unit for a simple blood test and gives nurses an "excuse" to meet patients as early as possible in their disease trajectory. In such a small community it is likely that people will already be familiar with the NGO homecare services and may associate these with the end of life care that someone they once knew had received. Patients may therefore be reluctant to accept nursing support, fearing that this might forebode a poor prognosis. They are however more likely to agree to a referral if it is simply for straightforward blood tests. These appointments in turn then present excellent opportunities to develop a trusting relationship between the nurses and the patients.

Palliative care is concerned with quality of life, [13] whether at diagnosis or in the later stages and, as such, a flexible approach assists PASYKAF nurses to meet the ever changing needs of each patient and his family. Efforts to educate patients and their family members help to empower them and provide a sense of security in the home setting [14,15], where necessary, caregivers are taught how to attend to patients' needs and equipment is loaned out to ensure safety and comfort.

Patients' wishes are respected and honoured and every effort is made to ensure that they are able to stay at home to die if this is their

wish. Symptom relief is provided orally/transdermal/rectally and then via continuous subcutaneous infusion when swallowing is no longer possible. Where necessary subcutaneous end of life hydration is offered and nurses may be required to assist the homecare physician in carrying out procedures such as abdominal paracenteses. In situations where the family members find it difficult to cope, solutions are sought to help to alleviate their burden, either with extra support or respite care in one of the hospices.

In the last year, PASYKAF has begun to offer a 24 hour nursing service in two of its districts. The positive impact of this is already evident. As yet unpublished figures show that home deaths in the Nicosia district between January and April increased from 26% in 2014 to 52% in 2015. It is hoped that this service will expand to include the entire Republic of Cyprus in the future, although this is dependent entirely on sourcing the required funds.

Barriers to Palliative Care in Cyprus

The shortage of hospice/respite beds presents a major difficulty which was complicated by the March 2013 financial crash and subsequent severe cutbacks. This resulted in a reduction in the total number of beds in Arodafnousa from 15 to 12 [16]. Fortunately, the three closed beds are now back up and running and the recent opening of the Archangel Michael Hospice in Paphos has also helped to alleviate the burden. This is a nine bedded unit and the only one on the island which can offer palliative care services to children [17]. The Friends' Hospice, an adult six bedded facility, is also located in the same district [18]. Although there has been a recent increase in palliative care beds, these are limited to only two of the Republic's five districts, leaving the remaining areas unsupported. The local hospitals are therefore often forced to relinquish some of their limited beds to the end of life care of patients, a situation which is far from ideal for all concerned.

Nurses are frequently faced with ethical dilemmas which lead to scenarios involving issues such as collusion and denial. These are further complicated by the lack of advanced care planning [19] or advanced directives [20] legislation in Cyprus. It is not uncommon for the patient to be the last to learn of his diagnosis in a country where, anecdotally, the culture is such that any decisions regarding disclosure may be left to the next of kin. As patients' advocates and constantly aware that the family members are gatekeepers, nurses often have the challenging task of trying to facilitate honesty within the family and more importantly of trying to encourage and respect the patient's right to autonomy.

Limited out-of-hours [OOH] services can affect patients' quality of life, especially in the final stages and can have a negative impact on nurses' job satisfaction, leading to a source of stress [21]. However hard nurses try to honour patients' wishes, inappropriate hospital admissions due to crises, particularly at end of life, can lead to unplanned hospital deaths. Even more tragic has been the death of patients in an ambulance or on a trolley in the accident and emergency department due to last minute panic within the family. A 1993 study indicated that reduced numbers of home deaths are influenced by non-availability of 24-hour support, that 75% of crises occur outside normal working hours and that, although much of the final year may be spent at home, most people die in hospital [22], while Jones et al attribute such hospital admissions mainly to the breakdown of care givers and to the need for symptom control [23].

When caring for dying patients at home in areas where official 24 hour cover is not offered, nurses often feel the need to leave the on-call phone switched on throughout the night in order to provide, at least, telephone support. This is an informal arrangement and is left to the discretion and goodwill of individual nurses. Whilst there is no financial compensation for this, nurses realize the importance of being available to offer advice and reassurance to patients and their families [24] and the ethical rewards can be immeasurable. However, with only limited OOH medical back-up, no emergency drug box facilities and no pathways and guidelines, it is vital that the nurses recognize their limitations and practice safe, anticipatory care, ensuring that any necessary doctor's orders/instructions, drugs and equipment are in place, should the need arise.

Although opioids are officially available to whoever requires them for pain management [25], usage in Cyprus remains low [26]. The 2011 Cyprus Morphine equivalence [ME] consumption was 35 mg/capita, in comparison with the United States figure for the same year which was 750 mg/capita [27]. The results of recent studies carried out by members of staff at the Bank of Cyprus Oncology Centre suggest that pain in Cyprus is under-treated, leading to the conclusion that further research is needed to examine physicians' knowledge, practice and prescribing habits and to look at patients' knowledge and attitudes towards opioids.[26] A subsequent unpublished study aimed at examining barriers which hinder patients' access to opioids was undertaken by the author, with PASYKAF sponsorship and in coordination with the Access to Opioid Medication in Europe [ATOME] project [28]. Findings showed that 77% of physicians who participated in the study believe that healthcare professionals do not have adequate educational opportunities to learn about use of opioids and 70% agree that fears of opioid dependency interfere with pain management.

The Future

A 2009 report issued by the Republic of Cyprus Ministry of Health stated that palliative care is offered "randomly by various private bodies" and recognized that this support needed to be organized and coordinated. The statement, which was made in reference only to cancer patients, called for a "holistic approach from trained personnel," with specialized services and accommodation for patients in the final stage of their lives [29]. Although palliative care in Cyprus has developed since the 1980's, there are still obstacles which need to be overcome if our services are to include a comprehensive system, easily accessible to all [30].

Further research needs to be undertaken in order to assimilate evidence with which we can lobby the government and increase public awareness. Education campaigns targeting health professionals and universal, evidence based guidelines are vital if we are to improve palliative care services and ensure that they are available to those who require them, regardless of diagnosis. Although the enthusiasm shown by the TEPAK student nurses is encouraging, there is a need to target existing health professionals who have never received any palliative care education. An on-going compulsory education program would help to ensure patient care improvement in all specialties within the healthcare system, including the government community nursing scheme. Nurses working in the field of palliative care in Cyprus are few and limited to the cancer NGO's and hospices. Hence they play a crucial role in patient advocacy and in the education of patients, their care givers, the general public and, perhaps more importantly, other healthcare professionals.

Following the 2013 catastrophic financial crisis, the future of palliative care in Cyprus is uncertain and the strategic plan to integrate it within the National Health Service is likely to be delayed even further. Unavoidable cutbacks in spending mean that, for the time being, the vision of providing an island wide 24 hour homecare service seems distant, both for PASYKAF and CACS. However, although the future is clouded by financial restraints, nurses involved in palliative care seem to be even more determined in their efforts to raise the necessary funds required, not only to survive but also to continue to evolve and improve services.

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