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Public Awareness toward Palliative Care: Integrative Literature Review

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Abstract

Background: Public awareness toward palliative care is playing a very important role in demanding various palliative care resources in different countries. A comprehensive assessment of public awareness toward palliative care is needed in order to intervene appropriately according to the public needs in this matter.**Purpose:** To assess current level of public awareness towards palliative care.**Method:** An integrative literature review design was utilized. CINAHL, PubMed, MEDLINE were searched. The following keywords (palliative care, general public, awareness, knowledge) were used in combination and/or mesh. After removing the duplicate articles and applying the inclusion criteria, a total of eight articles were retrieved to be considered the core of this review. **Findings:** There is a strong relationship between public awareness and the length of establishment of palliative care in different countries (Northern Ireland, New Zealand, Canada, & Australia). Also, it can be inferred that there is a highly public awareness of palliative care whenever there is a national guidelines and programs well established to enhance palliative care (New Zealand & Australia). Contrariwise, limited public awareness is reflected in countries where the concept of palliative care is relatively new (India). **Conclusion:** Demanding palliative care resources is highly connected to public awareness. **Implication:** Raising public awareness must be taken into consideration within international strategies for palliative care, that requires the concept of palliative care to be brought forward and integrated within the delivery of health care systems, palliative care services, and policy.**Recommendations:** Future researchers should assess the current level of knowledge and factors contribute to public awareness; due to scarcity of research literature related to public awareness toward palliative care.Policy makers should be urged to develop a national guidelines or methods to increase the public awareness towards palliative care.

Keywords: Palliative care, General public, Awareness, knowledge.

1. Introduction

Public awareness toward palliative care was reported to be acceptable in only twenty countries (Lynch, Connor, & Clark, 2013). In spite of extensive effort to increase awareness of palliative care, the required goals have not achieved in many countries until now (Gwyther, Brennan, & Harding, 2009; IFHHRO, 2011).

In addition, public awareness to date varies widely according to international research, and indicate a low level of knowledge toward palliative care (CAPC, 2011; Hirai et al., 2011; McCarthy, Weafer, Loughrey, 2011), low level of awareness may have limitation of care, lead to negative impressions and impact on access to palliative services, resulting in low quality of care provided to palliative care population (Krishbaun, Carey, Purcell, & Nash, 2011).

According to the World Health Organisation (WHO) Palliative care is defined as a way to enhance the quality of life of patients having a life threatening diseases and their families, through management of symptoms such as pain, and treatment of all other dimensions of health, physical, psychosocial and spiritual. The goal of this care is to preserve dignity of the patient even in death and to sustain and rehabilitate the individual's family (Walsh, Gombeski, Goldstein, Hayes & Armour, 1994).

Based on this definition; Palliative care services establishment are gradually increased by time all over the world countries (e.g., in 2011, one hundred thirty-six of the world’s two hundred thirty-four countries (58%) had one or more hospice-palliative care services instituted with an increment of twenty one various countries (9%) from 2006 (Lynch, Connor, Clark, 2013). Where advancement in the services extent is improved by time as well, (e.g., in U.S., around 87.9% of hospitals with more than three hundred beds have palliative care teams today (CAPC, 2012).

Consequently, adjustment of public awareness toward palliative care is essential to improve knowledge of persons, access to services, empowering individuals, and involving communities in palliative care (McIlfatrick, 2013). Therefore, the purpose of this integrative literature review is to assess the current level of public awareness towards palliative care. Pender health promotion model was utilised to guide this literature review.

2. Methods

In order to examine the body of knowledge related to public awareness toward palliative care, a comprehensive literature search was conducted using the electronic databases of Pubmed, MEDLINE and CINAHL for articles published between 2003 and 2015.

The following key words were used to search the electronic databases: Palliative care, General public, Awareness, and knowledge. The key words were used in multiple combinations to conduct an extensive search of these databases. Computerize list from Pubmed, MEDLINE and CINAHL contained 3, 15 and 11 research articles, respectively.

All obtained and reviewed for possible inclusion in this integrative review based on the specific inclusion criteria pre-established. Inclusion criteria for the selected articles were as the following: 1): a quantitative study with any research design, 2): investigated the level of public awareness towards palliative care, 3): published between 2003 and 2015, 4): written in English language.

Initial selection took place by assessing the titles and abstracts. When the articles appeared to meet the inclusion criteria, full-text articles were obtained, read comprehensively, and assessed in depth according to the criteria mentioned before.

From 29 articles that were found in relation to search terms, only eight articles met the inclusion criteria for literature review. Duplicate articles were excluded, as well as abstracts that did not meet the inclusion criteria. Studies included in this review focused on the level of public awareness towards palliative care. Countries within which the studies for this review were conducted include Northern Ireland, Canada, Australia, Italy, Scotland, New Zealand, Japan and India.

2.1 Methodological Characteristics

The eight studies that form this integrative review were quantitative studies, all of the studies used survey or cross-sectional research design.

The questionnaires were used to collect information to measure the level of public awareness toward palliative care. No one of the studies was specifically based on a theoretical model.

2.2 Sample Characteristics

The sample sizes in the eight studies in this review ranged from 170 to 3984 of general population aged between 18 and 90 years. In terms of gender characteristics there were around 38% male and 62% females in all selected articles. The articles were retrieved from different areas such as Northern Ireland, Canada, Australia, Italy, Scotland, New Zealand, Japan and India.

3. Findings

Among the reviewed articles, there were a general conclusion that there is a highly public awareness and good understanding of the concept of palliative care; whenever there is a national guidelines and well established programs (Mcllfatrick et al., 2013; Macleod, Thompson, Fisher, Mayo, Newman, & Wilson, 2012; Stephen, Jane, & Rishchynski, 2004; Wallace, 2003; Australian Government Department of Health & Ageing, 2003).

In the contrary, in countries where is the concept of palliative care is relatively new, it is reflected limited public awareness toward palliative care. For example, according to Joseph and his colleagues in a study conducted in India 2009 with a sample of 350 people, they found that only 47 (13.4%) of them have heard about palliative care (Joseph et al., 2009).

Also, there is a very strong relationship between public awareness and the length of establishment of palliative care in different countries. A study conducted in Canada by Claxton-Oldfield and his colleagues in 2004 with a random sample of 89 adult subjects to evaluate people understanding of palliative care, the results were 75.3% had heard of palliative care, however, only about half of these (48.4%) defined it as care for terminally ill or dying persons (Claxton-Oldfield et al., 2004).

In New Zealand, MacLeod and his colleagues conducted online survey aimed to investigate New Zealanders views about palliative care and hospice. A representative sample of 1011 from population was anticipated; they found a good understanding of the concept of palliative care, with 85% believing that palliative care staff provides comfort to people with terminal illness. These findings are consistent with the expectations of a community where palliative care has been a part of some regions health services for over 30 years (MacLeod et al., 2012).

Italy and Japan, These countries are characterised by rapid development of palliative care in a wide range of locations, providing of all types of palliative care by multiple service, broad awareness of palliative care on the part of health professionals, local communities, and society in general (Lynch, Connor, Clark, 2013). In the contrary, a study conducted in Italy by Benini and his colleagues to assess the level of awareness of palliative care among Italians. A random representative sample of 1897 adult subjects, aged 18 to 74 years, of the Italian population was interviewed. They found more than 40% had never heard of palliative care with only 23% stated having an adequate idea of what palliative care is (Benini, Fabris, pace, Vernò, Negro, Conno, & Orzalesi, 2011). As well as in Japan, Hirai and his colleagues conduct a study to explores the distribution of public awareness, knowledge of availability, and readiness for palliative care services, a total sample of 3984 have complete the questionnaire survey, they found that a total of 63.1% of respondents do not have knowledge about palliative care (Hirai et al., 2011). This result indicates that public awareness of palliative care is strongly related to the length of establishment of palliative care and not merely the distributions of the services.

4. Conclusion

It can be conclude that there is a strong relationship between public awareness and demanding palliative care resources. The society needs to have a basic knowledge about palliative care in order to be able to consider it as an option, they needs to understand what palliative care is, types of services exist, its availability and what the costs is (Australian Government Department of Health & Ageing, 2003).

Public awareness remain inadequate in different countries (Hirai et al., 2011; Benini et al., 2011; Joseph et al., 2009), this highlight the need of palliative care services and health care professionals to increase the public awareness in order to improve knowledge and access to palliative care.

Raising public awareness must be taken into consideration within the international strategies for palliative care, that requires the concept of palliative care to be brought forward and integrated within the delivery of health care systems, palliative care services, and policy.

The role of nurses as a health promoter should increase their effort to enhance the public awareness toward palliative care through educational strategies in the society.

Also it is recommended that the public should be educated about all aspects of palliative care, not just focusing on end of life care and terminally ill care.

However, it is very important that information regarding to palliative care to be easily available and disseminated to the public.

It worth to note, that research studies considering public awareness toward palliative care somehow is still limited. Therefore, researchers are highly encouraged to investigate in depth various issues related to this area in their future studies.

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