

PERCEPTION OF SOCIAL WORK INTERVENTION STRATEGIES OF PALLIATIVE CARE OF THE TERMINALLY ILL PATIENTS IN SELECTED HOSPITALS IN BENIN CITY, EDO STATE

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Abstract

This study examined the perception of palliative care services by social workers of the selected Hospitals in Benin Metropolis. It investigated the experience of social workers as it relates to palliative care service. The socio-ecology theory was adopted to explain the issue under investigation. A combination of quantitative and qualitative techniques was utilized to collect data from the respondents in the field and 400 copies of questionnaires were administered to respondents, while ten (10) social care workers were orally interviewed and also, 4 family members whose loved ones were terminally ill were also interviewed and 2 terminally ill were also engaged in an in-depth interview. In gathering information from the field and their responses were utilized in explaining the information gathered. The findings showed that majority of the participants (67.3%) agreed that palliative care service can help patients suffering terminal diseases though, about 30% agreed that terminally ill patients benefit from palliative care service in the hospital. Yet, 68% of the participants agreed that patients admitted more than three times in 12 months with same symptoms needs palliative care. This study among others recommended that patients with life-limiting illnesses and their family require a better quality of life that can be achieved through provision of good palliative care that is available and accessible through several initiatives like national health insurance scheme (NHIS) in most government hospitals.

Keywords: Care, Family, Health Intervention, Palliative

Background to the Study

Globally, compassionate palliative care requires commitment from all levels of health care management and the collaboration of the family of the patient that need care. This is alluded to the fact that many people who are diagnosed with chronic or advanced diseases or terminal diseases are inadequately cared for (Wagner, Austin, Davis, Hindmarsh, Schaefer, Bonomi, 2001). The reason for this attitude is that healthcare providers always attempt to give the patient conventional treatments and hence prolong the patient lifespan instead of focusing on the predominant goal of improving their quality of life. Palliative care focuses on patients who have serious life limiting illness by utilizing a holistic approach in order to decrease suffering and ameliorate their current situation (Sabrah, 2016).

Prognostication of life expectancy is of the utmost importance to patients, families and healthcare professionals particularly in the setting of advanced and/or terminal disease. Many important health care decisions, such as those regarding chemotherapy use, hospice referral, advance care planning, discharge, planning and personal finances are dependent on the expected survival duration (Hui, Nooruddin, Didwaniya, Dev, La Cruz, Kim, Kwon, Hatching, Lien, & Bruera, 2014).

Palliative care is an integrated approach that promotes the quality of life of patients and families who are confronted with the physical, psychosocial and spiritual problems associated with a life threatening illness. According to the World Health Organization (WHO) (2015) and the National Plan of Palliative Care (2014) in Almada, Casquinha, Cotovio, Heitor, Dos Santos and Caixeiro (2018) palliative care affirms life and accepts death as a natural process without trying to delay the process, constitutes a global and holistic approach to the patient suffering from a physical, psychological, social and spiritual point of view, seeks the well beings and quality of life of the patients, is centered on the needs of patients and their families, life and death, should not be restricted to terminally ill and agonized patients and should be addressed by a multidisciplinary team of medical, paramedical and other allied professions in the healthcare sector (Barbosa, Prina and Tavares, 2016).

The approach of death involves a number of activities as different practicalities pertaining to the end of life have to be organized. It is essential for these activities which are carried out by family member caregivers, medical personnel and social workers to meet standards that ensure appropriate living conditions until such time as clinical and biological death supervenes (UNO,

2017). Social workers have a very varied and challenging role in palliative care and one that potentially overlaps with that of psychologists and other allied professionals. Social work is integral to the professional practice of the multidisciplinary palliative care team both in hospice and hospital settings. Alongside nursing, medicine and a range of other clinical and complementary therapies, social work provides practical and psychosocial support to those coming to the end of their lives (Watts, 2013).

In Nigeria, palliative care are usually not formalized and institutionalized because the care of the dying and those suffering terminal illness are a combination of formal and informal approaches. This is because many people have not really have informed knowledge about the role of social workers in palliative care. The perceptions of the role of social workers in this context need a thorough scientific investigation in order to appreciate, incorporate and utilize the services of social workers in the quest for efficient healthcare delivering systems in Nigeria.

Statement of the Research Problem

Globally, many people who are infected and diagnosed with terminal, chronic or advanced diseases and infections are inadequately cared for by the caregivers (Wagner, et al 2001). The reason adduced for this inadequacy is that healthcare workers always attempt to cure the patient and prolong the patient's life span instead of focusing on the predominant goals of improving their quality of life. The philosophy of humanism provides a foundation for palliative care because it is the right of every human being to decide his/her treatment when diagnosed with a life-threatening illness. Humanism requires palliative care staff to be flexible and accept their patients, their life style, their culture, their values, and their decisions unconditionally (Connor, 2009; Tetrault, 2012).

Professional social workers collaborate and synergize with the nurses, doctors and other clinical and complementary therapeutic specialists like physiotherapists and physiologists to provide practical, psychosocial and even spiritual support to those suffering from terminal and end-of-life diseases. These end-of-life support becomes imperative because to a large extent, death and dying involves loss and transformation which usually overwhelmed the individuals experiencing such excruciating sore and painful experience hence they require help and support to manage their feelings, pains, sense of loss, despair and accept the realities of death and dying (Watts, 2013). Social work palliative care for people with terminal diseases is anchored on the philosophy and best practice

system of compassionate, terminal care that seeks to provide people with the opportunity to die as they choose, deciding where, under what circumstances, with whom present, in what state of consciousness, and with what life support he/she desires (Tang &McCorkel, 2001; Wright, 2015).

In Nigeria, social work profession is still in the formative stage hence the myriads of services provided by social workers are not utilized here. Palliative care social work is centered on helping people to deal with core existential questions associated with facing one's mortality, coping with serious illness and managing the dying process. But in Nigeria, existential questions are always anchored and interwoven in culture, tradition and belief systems which to a large extent seem to preclude professional services out of the family.

Objectives of the Study

The main objective of this study was to examine the perception of social work intervention strategies in palliative care of the terminally ill patients in selected Hospitals in Benin Metropolis. The specific objective was to explore the perception of palliative care services by social workers of the selected Hospitals in Benin Metropolis

Literature Review

Prognostication of life expectancy is of the utmost importance to patients, their families and the health care professionals including social workers, particularly in the setting of advanced disease management. This is because many crucial and requisite health care decisions such as those regarding chemotherapy use, hospice referral, advance care planning, discharge planning, and personal finances, are dependent on the expected survival duration (Hui, Nooruddin, Didiyaniya, Dev, Delacruz, Kim and Kwon, 2014).

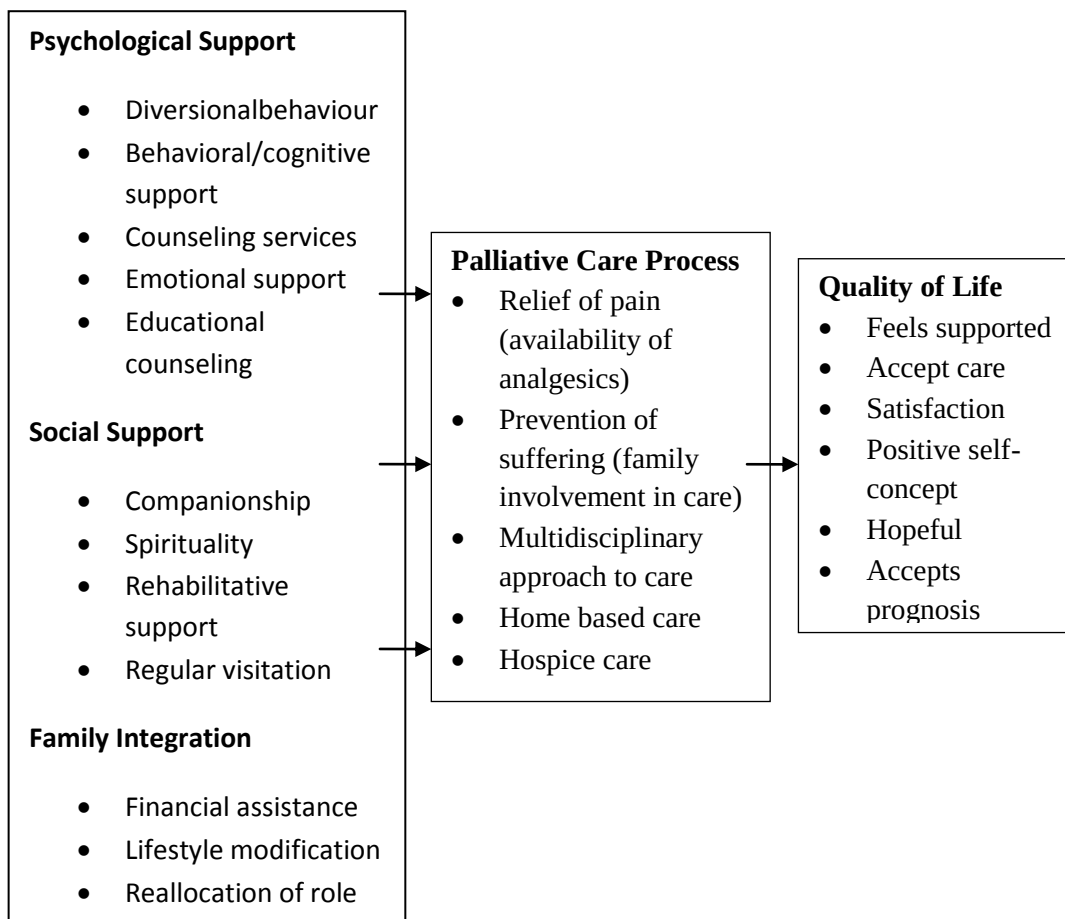
In this discourse, the term “end of life”, “terminally ill”, actively dying and hospice services were be used interchangeably because they all have prognostic implications and hence frequently used in clinical and psychological communication in the context of palliative care services delivery systems. Palliative care is an integrated approach that promotes the quality of life of patients and families who are confronted with physical, psychosocial and spiritual problems associated with life threatening or terminal illness (Almada, Casquinha, Cotovio, Santos and Caixeiro, 2018). Similarly, the World Health Organization (WHO) (2014) defined palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by early identification and impeccable assessment and treatment of pain and other

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problems, physical, psychosocial and spiritual. Palliative care is a program for patients with serious or life threatening illnesses where the main focus is to assist with managing pain and symptoms and providing emotional and spiritual support (Mayo Clinic, 2011 in Sonya, 2016).

In this context palliative care affirms life and accepts death as a natural process without trying to delay the process; constitutes a global and holistic approach to the patients suffering from a physical, psychological social and spiritual point of view, seeks the wellbeing and quality of life of the patients; is centred on the needs of patients and their families, life and death; should not be restricted to terminally ill and agonized patients; and should be addressed by a multidisciplinary team (Albuquerque& Cabral, 2014).

Framework for psychosocial supports and family integration in relation to palliative care process and quality of life of terminally ill patients.



Source: (Barbosa, Pina& Tavares, 2016).

Socio-Legal Basis of Palliative Care

Mankind has always been frightened and in awe of death; even though it is an irreversible end of life everyone would go through. The terminally ill persons experiences a lot of pain and anxiety which can lead to suffering and threat of quality of life which refers to an individual's total wellbeing and includes all emotionally, social and physical aspects of an individual's life (Sanda, 2015).

Social support is the perception and actuality that one is cared for has assistance available from other people and that one is part of a supportive social network often provided by the family care system. However, there is a gradual erosion of the hitherto extended family support and patients get isolated both at home and in the hospitals. The person with a life threatening illness feels in total pain and will there is the present context of individualism and postmodernism will need the services of a palliative care professionals. This is because patients with an advanced life-limiting illness experience great suffering, a complex negative state of malaise (bodily, affective, cognitive, spiritual) characterized by feeling threatened and destroyed in the integrity or continuity of their existence, a sensation of powerlessness to face this threat and exhaustion of their personal and psychosocial resources (Almada et al, 2018).

The needs of a person suffering from a serious and irreversible illness are multidimensional, and include physical, psychological, social and spiritual aspects. But in administering palliative care to the people in trauma, pain, helpless and end of life situation, their rights and dignity must at all time be protected and guaranteed in accordance with section 33 of the Nigerian Constitution (1999) as amended. According to the 1999 Constitution (as amended) the Nigerian State Social Order is founded on ideals of freedom, equality and justice. In furtherance of the Social Order, Section 17(1)(2); (a) and (b) states inter alia that every citizen shall have equality of rights, obligations and opportunities before the law (b) that the sanctity of the human person shall be recognised and human dignity shall be maintained and enhanced.

Moreover, access to palliative care services is legal obligation of the government to the people. This of course obtains in advanced and civilized world not in nations of the sub-Saharan African including Nigeria where life is short, British and barbaric because of the backwardness of the health systems occasioned by irresponsible government.

The Council of Europe has also went further by including palliative care in recommendation CM/Rec(2012)2 and its explanatory report (CDDH-AGE,

2013) which states that the legal basis for the inclusion is that human dignity must be respected at all stages of each individual's life (including terminal illness and death) and that palliative care helps to preserve the dignity by providing an appropriate environment for such patients help them in dealing with the pain and other distressing symptoms (UN-ECLAC, 2017). This document further recommends that palliative care should be provided in all areas in response to the progressive needs of older persons, and that member states should

- Offer palliative care for older persons who suffer from a life-threatening or life-limiting illness to ensure their well-being and allow them to live and die with dignity.
- Any older person or any person suffering terminal illness who is in need of palliative care should be entitled to access it without undue delay, in a setting which is consistent with his/her needs and preferences, including at home and in long-term care settings.
- Family members and friends should be encouraged to accompany older persons or persons who are terminally ill or in need of dignity. They should receive professional support for example by ambulatory palliative care services.
- Health-care providers involved in palliative care should fully respect patients' rights and comply with professional obligations and standards.

Theoretical Framework

The socio-ecology theory was originally propounded by Bronfenbrenner (1999) who posited that individuals are connected or linked to their environment by virtue of the fact that individual's behaviour is to be understood within the context of their environment in which the behaviour takes place. In other words individual behaviour is greatly influenced by their environment which provides the social stimuli and the other members of the environment which directly or indirectly affects the individual. Social ecology theory was developed to further the understanding of the dynamic interactions among various personal and environmental factors.

This theory postulates that in order to understand human development, the entire ecological system in which growth and survival occur needs to be taken into account (Bronfenbrenner, 1999). The ecological perspective uses ecological concepts from biology as a metaphor with which to describe the reciprocity between persons and their environments and the attention is on the goodness of fit between an individual or group and the places in which they live out their lives (Nuess, 1989). The ecological perspective is centred on the transaction of the

person-in-environment, including the person's ability to adapt to and cope with their environment (Zastrow&Kirst-Ashman, 2004), and the transactions occurs at micro, mezzo and macro systems levels (Ugiagbe, 2018).

An ecosystem is comparatively bounded structure consisting of interacting, interacted or interdependent elements that form a whole. Socio-ecology in this context is a framework or set of theoretical principles for understanding the nature, structure and dynamic interrelations among various personal and environmental factors. Social ecology pays explicit attention to the social, institutional and cultural contexts of people-environment relations. This perspective emphasizes the multiple dimension (physical environment, social and cultural environment, personal attributes), multiple level (individuals, groups, organizations) and complexity of human situations (cumulative impact of events over time) (Ernest-Detles, 2004; Rogoff, 2003).

Individual are key agents in ecological systems from an ecological perspective, the individual is both a postulate (a basic entity whose existence is taken for granted) and a unit of measurement. As a postulate, an individual, has several characteristics, for example he requires access to an environment, upon which he/she is dependent for knowledge, and second, he/she is interdependent with other humans, that is, always part of a population and cannot exist otherwise. Moreover, he/she is time bound or has a finite lifecycle and he/she has an inmate tendency to preserve and expand life. Furtherance, he/she has capacity for behavioural viability. Social ecology models are thus applicable to the processes and conditions that govern the life long course of human development in the actual environment in which human live (Hawley, 1986).

The social work discipline has expanded this perspective to explain that an individual is constantly creating, restructuring and adapting to the environment as the environment is affecting them (Ungar, 2002 in Ugiagbe, 2018). In this context, this theory helps to illuminate the concept of palliative care and the roles of the social worker in the provision of palliative care, how social workers perceives their roles in providing palliative care to patients within their ecosystem, which is the hospital and their interactions with patients, families and palliative care and what factors have influenced the ability to provide palliative care by professional social workers.

Research Methodology

The study adopted the survey research design whereby the prospective research participants would be part of the study. The one time survey contact

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with the prospective research participants was adopted in this study because it is cost effective and suits the nature of the phenomenon being investigated in this study.

The population of this study were all medical and paramedical staff of the selected Hospitals in Benin metropolis. It also included the families of patients suffering terminal illness available in the hospital during the fieldwork of this study. Preliminary studies carried out showed that the population of the medical and paramedical staff of the selected Hospitals is about 2,650 excluding the families of those suffering terminal diseases which were determined during the fieldwork. Hence the estimated population of this study was about 3,000 persons. It was from this population that the sample size were drawn.

The sample size of this study comprised 280 medical and paramedical staff of the selected Hospitals in Benin metropolis. It also included 100 members of the families of those suffering from terminal diseases and on admission and 20 out-care terminally ill patients– caregiver in the selected Hospitals in Benin Metropolis. This sample size was purposively arrived at as a fair representative number of the entire population. A total of 400 participants were administered the questionnaire while 10 were interviewed. Those interviewed were the senior doctors and some family members. The study adopted the convenience sampling method which allowed the researcher and her team to select sample size conveniently without employing any formula.

Socio-Demographic characteristics

These are the bio-data of the research participants. These include but not limited to the participants' age, marital status, sex, educational background, profession, ethnic and religious affiliation amongst others

Table 1: Socio-Demographic Characteristics of Participants

Variables	Responses	Frequency	Percentage %
Sex	Male	281	70.2
	Female	119	29.8
	Total	400	100
Age in Years	11-20	28	7.0
	21-30	57	14.3
	31-41	89	22.2
	41-50	120	30.0
	51 above	106	26.5
	Total	400	100
Marital Status	Single	105	26.3
	Married	240	60.0
	Widow/Widower	36	9.0

	Divorced	19	4.7
	Total	400	100
Religion	Christianity	306	76.5
	Islam	30	7.6
	Traditional	38	9.5
	Others	26	6.5
	Total	189	100
Ethnic Groups	Benin	141	35.3
	Esan	77	19.2
	Etsako	64	16.0
	Igbo	50	12.5
	Yoruba	48	12.0
	Others	20	5.0
	Total	189	100

Source Field Survey, 2021

The above table shows the socio-economic characteristics of the participants during the survey, this represents. With respect to the age of participants, the above chart shows that majority of the participants aged 41-50 years were 120 participants representing 30%, closely followed by those in age 51-60 years and above with 106 participants constituting 26.5% also, those that fell within the age bracket of 31-40 years were 89 participants which represent 22.2% participants, while 57 (14.3%) and 28 (7%) of the participants were within age 21-30 and 18-20 years respectively. This implies that majority of the participants were within the age bracket of 41-50 years.

Table 2: Categories of the participants

Variables	Responses	Frequency	Percentage %
Paramedical Staff	Therapist	65	16.25
	Ancillary Staff	95	23.75
Medical Staff	Nurses	82	20.5
	Doctors	38	9.5
	Subtotal	280	60.5
Patients' care giver	Out-care Patients care giver	20	5.0
Family members	Patients' families and relations	100	25.0
	Grand Total	400	100.0

Source: Field Survey, 2021

Table .2 above showed the categories of participants of the study. Most of the participants were the paramedical and medical staff who are on aggregate (subtotal) of 280 (60.5%). Meanwhile out-care patients' caregivers and patients

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families who are part of palliative care were 20 (5.0%) and 100 (25.0%) participants respectively. This implied that the study has several components of participants. Hence their respective contributions add value to the study

Table 3: Perception of Palliative Care Service provided by Social Workers

Variables	Responses	Frequency	Percentage %
As a social worker do you believe that palliative care service can help people suffering terminal diseases?	Strongly Agree	108	27
	Agree	161	40.3
	Undecided	21	5.3
	Strongly Disagree	47	11.7
	Disagree	63	15.7
	Total	400	100
Do terminally ill patients benefit from palliative care service in your hospital?	Strongly Agree	61	15.3
	Agree	123	30.7
	Undecided	37	9.3
	Strongly Disagree	49	12.2
	Disagree	130	32.5
	Total	400	100
As a social worker do you think patients admitted to the hospital three or more times for the last 12 months with the same symptoms need palliative care?	Strongly Agree	113	28.3
	Agree	159	39.7
	Undecided	19	4.7
	Strongly Disagree	49	12.3
	Disagree	60	15.0
	Total	400	100
Is your practice influenced by your religious beliefs?	Strongly Agree	27	6.7
	Agree	21	5.3
	Undecided	6	1.5
	Strongly Disagree	198	49.5
	Disagree	148	37.0
	Total	400	100
As social worker, should medical futility be discussed with terminally ill patients?	Yes	275	68.7
	No	104	26.0
	Undecided	21	5.3
	Total	400	100
Do you counsel every terminally ill patient that is admitted in your hospital?	Yes	336	84.0
	No	38	9.5
	Undecided	26	6.5
	Total	400	100

Source: Field Survey 2021

In Table 3 above, the result showed the perception of palliative care service provided by social workers in selected hospital in Benin, it showed that 67.3% participants who are social workers in the selected hospitals for this study agreed that palliative care service can help patients suffering terminal diseases, 27.4% of the participants disagreed about this assertion while 5.3% of the participants were indecisive in their response to the questions. The study also revealed that 30.7% and 15.3% of the participants who are social care workers agree and strongly agree that terminally ill patients benefit from palliative care service in the hospital where they work while 32.5% and 12.2% of the participants disagree and strongly agree and 9.3% were undecided on the question. Also the result shows that 68% of the participants agreed that patients admitted more than three times in 12 months with same symptoms needs palliative care and just 27.3% of the participants disagree and the remaining 4.7% did not respond to the question. Furthermore, table 4.2 showed that 49.5% and 37% of the participants strongly disagree and disagree that their social work practice is not influenced by their religious beliefs while 12% of the participants admitted their religion have influence on their practice and 1.5% where undecided on the question. Also the study analysis show that 68.7% of the participants admitted that medical futility can be discussed with terminally ill patients while 26% of the participants were negative about the question and 5.3% of the remaining participants did not respond to the question. Finally, this table result also shows that 84% of the participants said every terminally ill patient should be counseled while 9.5% of the participants said it is not necessary and 6.5% of the participants were undecided of the question. In addition, the qualitative response gathered from the field supported the quantitative analysis result.

On the issue of whether terminally ill patients benefit from palliative care service in the selected hospital this study was conducted.

One of the participants stated that:

“Yes, terminally ill patient’s benefits from palliative care service in our hospital but for few patients. This is because most of the patients and their families are not aware of the palliative care service” Mrs. D: (IDI 16/5/2021).

Another participant corroborated the above statement. According to him:

“Critically ill patients do benefit from palliative care service although there are some challenges that made a lot of patients not to benefit from it. About ten (10) of the admitted patients admitted that the hospital where they work as social workers render palliative care services and that patients with terminal diseases benefit from it but only few which is as a result of some challenges ranging from;

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ignorance regarding what palliative care is, reluctance of patients and families to refer, bureaucratic bottleneck etc”(Ms E.A: IDI 18/5/2021)

Also, one of the participant who is a mother to a patient that is terminally ill said:

“My child is 12years old and he has being admitted here for the past three weeks, the way the nurses talk to us is not encouraging, when I try to ask questions you don’t get a clear response from both the doctors/nurses and it can be so frustrating. To me, there is nothing like palliative health care in this hospital. The nurses need to be trained on how to care for patients and not just to treat patients alone.”
(Mrs B: IDI 18/5/2021)

Discussion of Findings

This study was carried out to thoroughly examine the perception of social work intervention strategies of palliative care of the terminally ill patients in selected hospitals in, Benin City Edo state. Based on the research questions and objectives, the findings revealed that;

- Majority of the participants believe that palliative care service can help improve the life’s of patients suffering from terminal diseases if the service is practically implemented by management of the hospital. The findings are in agreement with Almada, Casquinha, Cotovio, Santos and Caixeir, (2018).Palliative care is an integrated approach that promotes the quality of life of patients and families who are confronted with physical, psychosocial and spiritual problems associated with life threatening or terminal illness.
- The research finding also shows that only few terminally ill patients benefited from palliative care service. This is because in one of the hospital where this study was conducted they do not render palliative care services while the hospitals that offer palliative service do not have money to effectively implement palliative services to patients who are in need of care.
- Furthermore, the research findings revealed that most of the social work staff who participated in the study admitted that there are barrier impeding on the effective implementation/practices of providing palliative care to terminally admitted patients in their hospital and this barriers are: failure of government to support hospitals in providing palliative, lack of resources, lack of awareness of palliative care by patients and cultural belief of terminally ill patients and their family.

- It was also observe from the findings that majority of the family members who love ones are terminally ill that participated in the study said they have not being able to access palliative care service.

Conclusion

Palliative care social workers work in individual, family, and community level to provide comprehensive palliative care service and add to quality of life of the individuals suffering from terminal or life-threatening diseases and their families. Palliative care social work is in its infancy stage in Nigeria, in terms of practice, training, and research. However, the study showed that there is a significant and positive association in the responses of the participants especially the doctors, nurses and paramedical that “palliative care help people suffering terminal disease” and that “Culture and palliative health care can help in emotional wellbeing”

Recommendations

In order to improve the field of palliative social work, there is an urgent need to address several constraints which in could:

1. The issues around a national policy on palliative care at macro level need to take priority.
2. The issue of lack of human resources and trained palliative care social workers could be alleviate by improving education and training to increase the numbers of palliative care social work practitioners.
3. Training in palliative care and end-of-life care needs to be included in graduation level of social work education. More structured training programs are required during the academic period and as part of continuing education programs.

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