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## SOCIAL WORK INTEGRATION AND PERFORMANCE OF PALLIATIVE CARE AT THE AGA KHAN UNIVERSITY HOSPITAL, NAIROBI COUNTY, KENYA

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**Abstract:** *This study investigated the integration of social work and performance of palliative care at the Aga Khan University Hospital in Nairobi city county Kenya. Palliative care is an approach aimed at improving the quality of life of patients and families facing life threatening or life limiting illnesses through early identification and control of symptoms. Social workers play an important role in the delivery of Palliative Care; they encounter adults, children and families who are facing progressive life limiting illness, dying, death, or bereavement. A multidisciplinary team-based approach is better equipped than any one clinician alone, in creating an environment to address all components of care for seriously ill patients. The study examined the relationship between the integration of social work and the performance of palliative care. It also looked at the influence of needs assessment to inform decision making and plan of care. The role of communication and inter-collaborative approach in palliative care. Social cultural influence on palliative care was also interrogated. The study was an explorative research since few studies have been done in this area, the study design was mixed method, quantitative data was analyzed by the use of SPSS and qualitative data was organized into themes and analyzed thematically. The study findings were presented frequency tables, figures, charts and graphs. The study established that social work integration in palliative care is very important with 92.9%. 91.9% agreed that social work integration and needs assessment is very important while 92.9% agreed to the need of effective communication amongst the team and between the team, patient and family at the end of life. Similarly 83.9% agreed that understanding individual sociocultural, spiritual and beliefs is very important in palliative care. The study concluded and recommended that, working together provides the best quality of care and encourages sharing of information and coordination in the team which is critical. Need assessment to include pain, depression, anxiety, nausea, fatigue and wellbeing is of utmost importance. Communication between the team, patient and family is essential in the end of life care. Socio-cultural practices in palliative care must be considered.*

**Key terms:** *Social work integration, Needs assessment, communication and socio-cultural practices*

## 1.1 Study background

Palliative care is an approach aimed at improving the quality of life of patients and families facing life threatening or life limiting illnesses through early identification and control of symptoms (WHO, 2012). Social workers play an important role in the delivery of Palliative Care (PC); they encounter adults, children and families who are facing progressive life limiting illness, dying, death, or bereavement. The social workers advocate for the needs and rights of clients and families in palliative and end of life care. The Massachusetts General Hospital was the first American hospital to have professional social workers on site, in the early (Gehlert & Browne, 2011)

The major duties were case management, data collection, follow ups, care coordination, health education, financial assessment and discounting patient medical fees. (Gehlert & Browne, 2011). Operating within the theoretical framework of person-in-environment, social work practice in the hospital setting included comprehensive interventions that targeted improving outcomes for patients and initiating change in the larger community. (Beder, 2013). Medical social workers in Britain and Ireland were originally known as hospital almoners or "lady almoners" until the profession was officially renamed medical social work in the 1960s. (Nottingham & Dougall, 2007). Ida Pruitt started Medical social work in Beijing China in 1921. Dr. Clifford Manshardt in 1936 started formal training in social work in India (Madan, 1967). Ella Webb established Social Work in Ireland. (Kearney & Skehill, 2005). Social work is relatively a young profession in Africa introduced in the 1960s. (Darkwa, 1999). Social work now exists in countries like Zimbabwe, South Africa, Zambia, Ethiopia, Swaziland, Nigeria, Uganda, Ghana, Kenya, Tanzania, Rwanda and Egypt training their own social workers. (Mupedziswa, 2005). The practice of social work requires knowledge of human development and behavior; of social and economic, and cultural institutions; and of the interaction of all these factors. (Greene, 2017).

Integrated health is the "systematic coordination of physical and behavioral health care. The idea is that physical and behavioral health problems often occur at the same time. Integrating services to treat both will yield the best results and be the most acceptable and effective approach for those being served"(Hoge et al., 2013).The engagement starts with a person-centered approach, which is individualized, holistic and includes the individual's family and community in both assessment and subsequent intervention plan. There are two levels of integration: the structural, which refers to health care systems and clinical, which refers to how providers work with each other. (Zapka et al., 2006). Social workers are found in every facet of community life, including schools, hospitals, mental health clinics, senior centers, elected office, private practices, prisons, military, corporations, and in numerous public and private agencies. (Kelley, 2007). Social work in practice naturally invites collaboration with the family, the inter-professional care team, and the community; this includes an appreciation of cultural and spiritual dimensions of the family's life. (Brown, Tucker & Domokos, 2003). Social work values, knowledge, and skills are inherently consistent with the principles of palliative care: The social work role as patient advocate is also crucial to palliative care. Linking patients to resources and helping patients negotiate the goals of care. (Brown et al 2003).

### 1.2. Statement of the problem

It is against this background that the researcher shall investigate on the extent to which social work has been integrated in palliative care in the study area. Majority of health care providers have no adequate information on the role of social workers. This lack of education can affect the desirability of including social workers in treatment teams. Other professions occupy jobs that were designed as social work in the first place. Additionally, the term ‘social worker’ is not protected so even lay persons call themselves social workers.

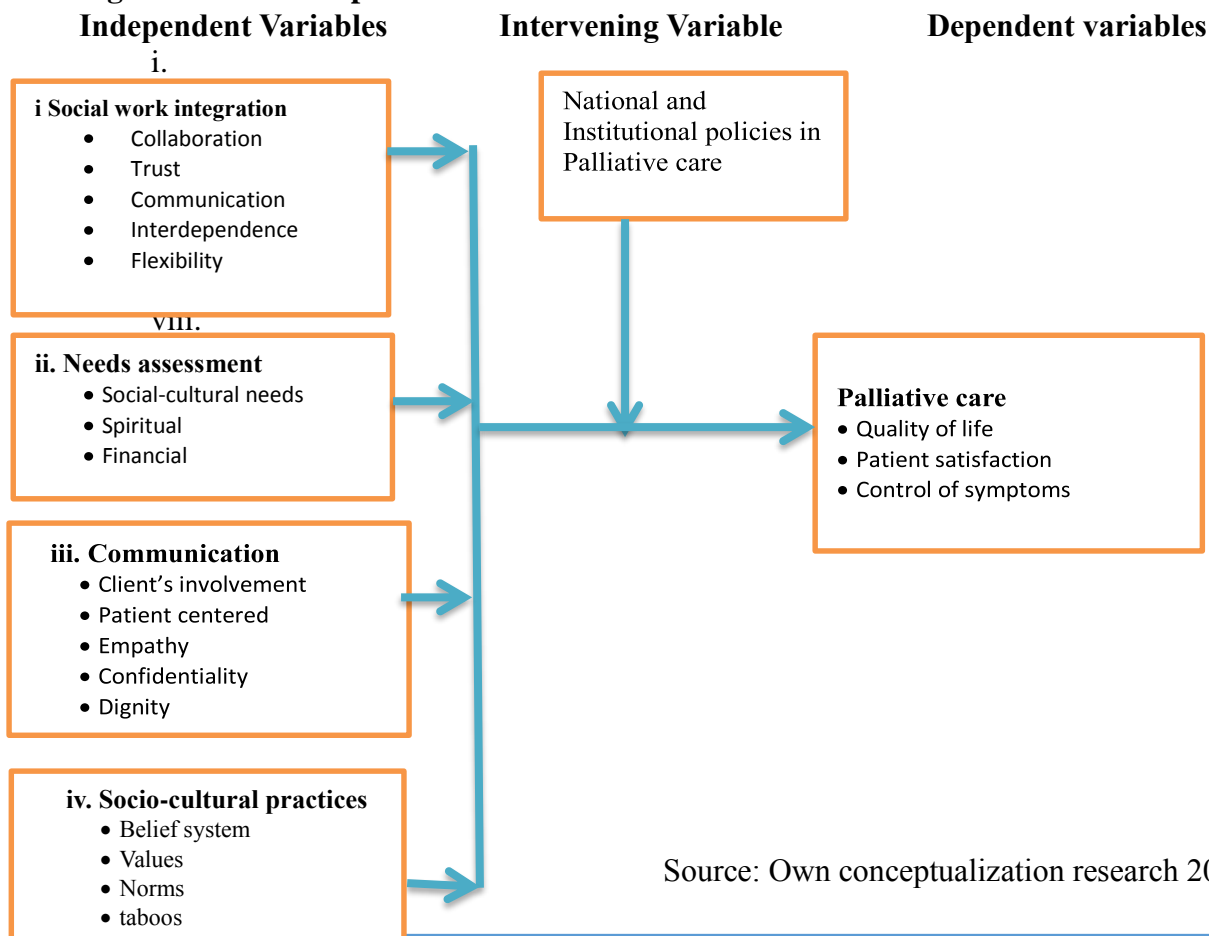
The main objective of the study is to investigate the extent to which social work has been integrated in palliative care at the Aga Khan University Hospital Nairobi City County.

### 1.3. Specific research objectives

- i. To determine how social work integration affects the performance of palliative care at the Agha khan University hospital, Nairobi City County
- ii. To investigate the influence of social work need assessment on palliative care practice in Agha khan University hospital, Nairobi City County
- iii. To examine the role of communication in palliative care practice in Agha khan University hospital, Nairobi City County
- iv. To establish the influence of socio-cultural practices on palliative care in Aga Khan University Hospital Nairobi.

### 1.4. Conceptual Framework

Figure 1: The Conceptual framework



Source: Own conceptualization research 2018

## 1. 5.Theoretical framework

This study is guided by the following theories; systems and social constructionist theory.

**Systems Theory:** Systems theory was proposed in the 1940's by the biologist Ludwig von Bertalanffy and furthered by Ross Ashby. (Hutchison,2008). He was both reacting against reductionism and attempting to revive the unity of science. He emphasized that real systems are open to, and interact with, their environments, and that they can acquire qualitatively new properties through emergence, resulting in continual evolution. The systems theory perspective sees human behavior as the outcome of reciprocal interactions of persons operating within linked social systems. (Hutchison, 2008). Systems are interrelated parts constituting an ordered whole, each subsystem impacts all other parts and whole system. Persons are in continual transaction with their environment Systems tend toward equilibrium and is Useful for developing holistic view of persons-in-environment Enriches contextual understanding of behavior. (Hutchison, 2008). The physicians, nurses, social workers and other professionals are subsystems which are interrelated and work together to provide a holistic care for their clients. Systems theory, as much as it addresses the interdisciplinary collaboration and communication variables, systems theory does not factor in the needs assessment and sociocultural variables in this study. It is in this view then that the social constructionist theory is brought in to address these variables.

**Social Constructionist Theory:** Social constructionist theory is rooted in symbolic interactionism and phenomenology; with Berger and Luckman's "the social constructionism of Reality in 1966. More than four decades later, a number of theory and research pledged to the basic tenet that people "make their social and cultural worlds at the same time these worlds make them. (Hutchison, 2008).The social constructionist perspective focuses on how people learn, through their interactions with each other, to classify the world and their place in it. People are seen as social beings that interact with each other and the physical world based on shared meanings or shared understandings about the world. (Hutchison, 2008). Through this theory the palliative care team interacts with each other, the patient and the family, to understand the sociocultural dynamics and how these dynamics influence the palliative care. As the team understand the influence of sociocultural factors on palliative care, these theory guides in the needs assessment of the patients in relation to their perceptions, beliefs, values, norms and taboos in end of life care.

## 1.6. Empirical Literature Review

### *Social work integration and Interdisciplinary collaboration in Palliative Care*

A palliative care team is a comprehensive group of specialists from a variety of disciplines who share a common goal to improve the quality of life for patients and families facing serious illness. (Tuggey, and Lewin, 2014). Social workers integrate expert knowledge of psychosocial supports and assistance with practical matters including finances, housing, and access to services in the community. A multidisciplinary team-based approach is better equipped than any one clinician alone, in creating an environment to address all components of care for seriously ill patients. (Tuggey & Lewin, 2014).

Palliative care team members need to have a common ideal and understanding of the team role and the contribution each team member makes to achieve successful team

outcomes. Time spent exploring the values underpinning both the individual motivations and the collective identity of the team is important.(Arber & Gallagher, 2009). They too observe that, each team member contributes specific skills, experiences, attitudes, and values to the whole.

#### ***Influence of needs assessment in palliative care***

All people with life-limiting conditions irrespective of age or setting should be assessed; Assessment should be an ongoing process throughout the course of a patient's illness. The guidance suggest that assessments be carried out at key transition points in the patient pathway, that is at diagnosis of a life-limiting condition, at episodes of significant progression/exacerbation of disease, a significant change in the patient's family/social support, a significant change in functional status, at patient or family request, and at end of life. (Albizu-Rivera et al., 2016). Assessment should include pain, fatigue, respiratory distress, appetite, constipation, sleep patterns, and confusion.

#### ***Role of communication in palliative care***

The importance of communication in healthcare has long been recognized within medical education as a foundation of good care, and reports continue to highlight the need for open and honest discussions with patients, and those close to them at critical times. (Francis, 2013). Despite this, 60%–90% of patients with life-threatening illness report never having discussed end-of-life care issues with their clinician.(Leung, Udris, Uman, & Au, 2012). Effective communication with patients and their families is one of the biggest challenges. Communication is a fundamental component in the provision of end of life care. (Schulz et al., 2003). Some people feel uncomfortable talking about death, but when you're taking care of a patient who is dying it becomes necessary and beneficial to communicate clearly, and therefore it is essential to open up these conversations. Truth telling in contemporary Western medicine has come to refer to the way in which information about the futility of treatment, a person's impending death, possible clinical pathways to death, and the possible impact of end-of-life decisions along those pathways should be communicated.(Deschepper et al., 2008)

#### ***Cultural practices that influence Palliative Care***

Culture is a vital factor for the clinician aiming to deliver person-centered health care. As clinical populations become increasingly diverse there is a growing premium on understanding and respecting cross-cultural difference and thus avoiding cultural stereotyping .(Lasch, 2000). The cultural factors which influence truth telling and consent around health care are complex. Age, gender, and ethnicity can all combine with spiritual beliefs, traditional family roles, and assumptions about the causes of an illness or stigma associated with treatments (e.g. opioids). Consequently, culture can have a powerful influence on what clinicians and persons with illness are prepared to talk about, how they interpret one another's communications, and how they and their families make decisions. (Lasch, 2000). There is a big gap in how cultural practices influence the perception of the disease and how the clinicians address it as they plan for interventions that this study seeks to understand. Cultural meanings mediate the experiences of suffering, which then affect how individuals and family members approach decision making about care. Palliative care must understand culture as a source of meaning, whether an individual expects to make decisions autonomously or with input from family members or clinicians is derived, in part, from grossly glossed cultural orientations toward individualism or communalism as primary values of how individuals express or suppress their autonomy.

(Hobbs et al., 2015).

### 1.7. Design and methodology

This study used the exploratory research design method because there are limited studies that have been done on this area. Exploratory research is often conducted in new areas of inquiry, where the goals of the research are: To scope out the magnitude or extent of a particular phenomenon, problem, or behavior, to generate some initial ideas or “hunches” about that phenomenon, or to test the feasibility of under taking a more extensive study regarding that phenomenon.(Bhattacharjee, 2012). The study was carried out at the Aga Khan University Hospital Nairobi; a tertiary hospital situated in the parklands area along the 3<sup>rd</sup> Parklands and Limuru roads, opposite the Nairobi City Park Market. The Aga Khan University Hospital (AKUH) in Nairobi is part of the Aga Khan Health Services (AKHS). Established in 1958, it is a 254-bed long-term care facility offering quality general medical services, specialist clinics and high-tech diagnostic services.

Sample size was obtained using Slovin’s formula  
 $n = \frac{N}{1 + Ne^2}$   
 n= sample size, N= population size, e = confidence level  
 Taking a confidence level of 95% = 0.05 and total population of 80.  
 $n = 80 / 1 + 80(.05)^2 = 67$ . The target populations were Doctors, Nurses, Counsellors, Social Workers, Chaplains, Nutritionists, Patients and home based care givers.

$$n = \frac{N}{1 + Ne^2}$$

#### Sampling Frame

Doctors	5.
Social Workers	2.
Counsellors	2.
Nurses -	15
Chaplains	1.
Patients –	20.
Care givers -	20.
Nutritionist	2
<b>Total</b>	<b>67</b>

**Source: Own formulation, 2018**

This study used three sampling techniques i.e. Accidental or convenient sampling. Purposive sampling and snowball sampling.

This study used both qualitative and quantitative methods of data collection. The study used both questionnaires and interview to collect data from the research participants.

## 1.8 Findings and discussions

### *Response rate*

A sum of 67 individual was targeted in this study. From these participants, 27 of them were health care providers and 40 were clients and caregivers.

Three of the health care providers did not respond and 8 clients and care givers also did not respond to the questionnaires. The participation was well done as the response rate was 83.58%. This information is summarized in the table.

### **Response rate**

Category of participants	Frequency	
	Returned	Failed
health care providers	19(28.36%)	8(11.94%)
clients and care givers	37(55.22%)	3(4.48)
Total	56(83.58%)	11(16.42%)

**Source; researcher 2018**

The study wanted to determine the social work integration and inter-professional collaboration. Likert scale questions were provided to help achieve the objective. The scale was as follow; 1- strongly agree, 2- agree, 3- Neutral, 4- disagree, 5- strongly disagree.

This section was same for all the participants' health care givers, clients and the care givers. The participants response of the findings are provided in the table

### *Social work integration and inter-professional collaboration*

<b>social work integration and Inter-professional collaboration</b>	1	2	3	4	5
Respect and trust is important for palliative care team	56(100%)				
Openness and flexibility is important in P C	52(92.9%)	4(7.1%)			
Working together provides the best quality care	42(75.0%)	14(25.0%)			
Sharing of information and coordination in the team is critical	51(91.1%)	5(8.9%)			
Multidisciplinary team meetings to share pertinent patient details and goals of care are important in PC	46(82.1%)	5(8.9%)	5(8.9%)		
Debriefing, service planning, academic development and socializing together builds a strong team in PC	50(89.3%)	6(10.7%)			
Time spent exploring the values underpinning both the individual motivations and the collective identity of the team is important.	40(71.4%)	10(17.9%)	5(8.9%)		

*Source: researcher 2018*

The findings in the table addressed the first objective which was To determine how social work integration affects the performance of palliative care at the Aga Khan University hospital, Nairobi City County the findings showed that social work integration into palliative care is very important with all the participants strongly agreeing that respect and trust is important for palliative care team, 52(92.9%) strongly agree that openness and flexibility is important in P C, 42(75.0%) strongly agree and 14(25.0%) agree that

working together provides the best quality care, 51(91.1%) strongly agree that sharing of information and coordination in the team is critical, 46(82.1%) strongly agree that multidisciplinary team meetings to share pertinent patient details and goals of care are important in PC, 50(89.3%) strongly agree that debriefing, service planning, academic development and socializing together builds a strong team in PC and 40(71.4%) strongly agree that time spent exploring the values underpinning both the individual motivations and the collective identity of the team is important. Palliative care team members need to have a common ideal and understanding of the team role and the contribution each team member makes to achieve successful team outcomes. Time spent exploring the values underpinning both the individual motivations and the collective identity of the team is important. The study also answered the first research question which was to assess how the integrated service delivery impact on the life of palliative care patients.

### ***Need assessment in palliative care***

The second objective which was to investigate the influence of social work need assessment on palliative care practice in Agha Khan University hospital, Nairobi City County. Social work integration and need assessment in palliative care was supported by all the participants. The needs to be assessed includes pain, depression, nausea, fatigue anxiety and psychosocial status. Health care givers, care givers and client were involved in need assessment. Using a scale of 1 to 5, to indicate; 1-strongly agree, 2- agree, 3- Neutral, 4- disagree, and 5- strongly disagree

#### **Need assessment**

<b>Needs assessment</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>Pain assessment in palliative care is very necessary</b>	51(91.1%)	5(8.9%)			
<b>It is important to assess the level of depression in PC</b>	42(75.0%)	14(25%)			
<b>Assessing psychosocial status is very necessary in PC</b>	47(83.9%)	9(16.1%)			
<b>Assessing appetite and nausea is very necessary in PC</b>	47(83.9%)	9(16.1%)			
<b>Assessing fatigue in PC is very necessary</b>	42(75.0%)	14(25.0%)			
<b>Anxiety assessment is very important in PC</b>	37(66.1%)	19(33.9%)			
<b>Assessing feeling of wellbeing and self-care is important in palliative care</b>	36(64.3%)	20(35.7%)			

*Source; researcher 2018*

The findings on the need assessment in the table 4.6, 51(91.1%) participants strongly agree that pain assessment in palliative care is very necessary, 42(75.0%) strongly agree that it is important to assess the level of depression in PC, 47(83.9%) strongly agree that assessing psychosocial status is very necessary in PC and assessing appetite and nausea is very necessary in PC. the study also shows that 42(75.0%) the participants strongly agree that assessing fatigue in PC is very necessary, 37(66.1%) of the participants strongly agree and 19(33.9%) agree to the same sentiment that anxiety assessment is very important in PC, and lastly 36(64.3%) strongly agree



and 20(35.7%) agree that assessing feeling of wellbeing and self-care is important in palliative care.

### ***Communications in Palliative Care***

The study wanted to determine the importance of social work integration and communication in palliative care as a multidisciplinary team, this was to answer the third objective which was to examine the role of communication in palliative care practice in Agha Khan University hospital, Nairobi City County. A scale of 1 to 5 was used to rate statements on the importance of communication and the scale show 1-strongly agree, 2-agree, 3- Neutral, 4- disagree, 5- strongly disagree. The participants' response is shown in the table

### ***Communication in Palliative Care***

<b>Communication In PC</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>Communication is an important component in PC</b>	36(64.3%)	20(35.7%)			
<b>Effective communication with patients and their families is important in PC</b>	37(66.1%)	19(33.9%)			
<b>Ongoing communication with patient and families at end of life is essential</b>	52(92.9%)	4(7.1%)			
<b>Truth telling on diagnosis and prognosis is critical</b>	42(75.0%)	14(25.0%)			
<b>Pre-bereavement counseling provides better outcome</b>	33(58.9%)	13(23.2%)	10(17.9%)		

*Source; researcher 2018*

The findings also answered the research question on the role of communication in palliative care with the results showing that 36(64.3%) of the participants strongly agree and 20(35.7%) agree that communication is an important component in Palliative Care as a multidisciplinary team, 37(66.1%) strongly agree and 19(33.9%) agree that effective communication with patients and their families is important in Palliative Care, 52(92.9%) strongly agree that ongoing communication with patient and families at end of life is essential, 42(75.0%) strongly agree that truth telling on diagnosis and prognosis is critical, and also, 33(58.9%) strongly agree that pre-bereavement counseling provides better outcome. The study addressed the objective and the research question on the influence of sociocultural issues in palliative care by wanting to establish how social work integration and socio-cultural practices influence palliative care services at the Aga Khan University Hospital Nairobi. Using a scale of 1 to 5, as 1-strongly agree, 2- agree, 3- Neutral, 4- disagree, and 5- Strongly disagree. The participants were asked to respond to the provided statement. The findings are shown in the table

***Social cultural practices***

<b>Socio-cultural Practices</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>Understanding socio-cultural/ spiritual issues is very important in Palliative care</b>	47(83.9%)	9(16.1%)			
<b>Cultural practices can influence the perception of PC</b>	31(55.4%)	25(44.6%)			
<b>Respect for individual cultural values, beliefs and practices is critical to palliative care</b>	46(82.1%)	10(17.9%)			
<b>Age, gender, ethnicity, traditional beliefs and spirituality can influence the assumption of cause of illness and treatment plan</b>	37(66.1%)	19(33.9%)			
<b>Patients and families should be told the truth irrespective of their cultural orientation</b>	23(41.1%)	33(58.9%)			

*Source; researcher,2018*

From the findings in the table 4.8, it is well demonstrated that sociocultural issues influence the palliative care services. 47(83.9%) of the participants strongly agree that understanding socio-cultural/ spiritual issues is very important in Palliative care, 31(55.4%) strongly agree 25(44.6%) agree that cultural practices can influence the perception of Palliative Care, 46(82.1%) strongly agree that respect for individual cultural values, beliefs and practices is critical to palliative care, 37(66.1%) strongly agree 19(33.9%) agree that age, gender, ethnicity, traditional beliefs and spirituality can influence the assumption of cause of illness and treatment plan and also 33(58.9%) agree and 23(41.1%) strongly agree that patients and families should be told the truth irrespective of their cultural orientation

***Awareness of the presence of social workers***

The study wanted to find out whether the participants were aware about the presence of the social workers in the Aga Khan University Hospital. The findings of the study are show in the table

***Presence of social workers***

	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>
0	2	3.6	3.6
yes	54	96.4	96.4
<b>Total</b>	<b>56</b>	<b>100.0</b>	<b>100.0</b>

*Source; researcher 2018*

From the findings of the study in the table 4.9, 96.4% of the participants are aware of the social workers. At the Aha Khan University hospital there are social workers.

In this study the health care givers were asked whether they understand the role of social worker in The Aga Khan University hospital. The findings are summarized in the table

***Understanding the role of social worker in a hospital***

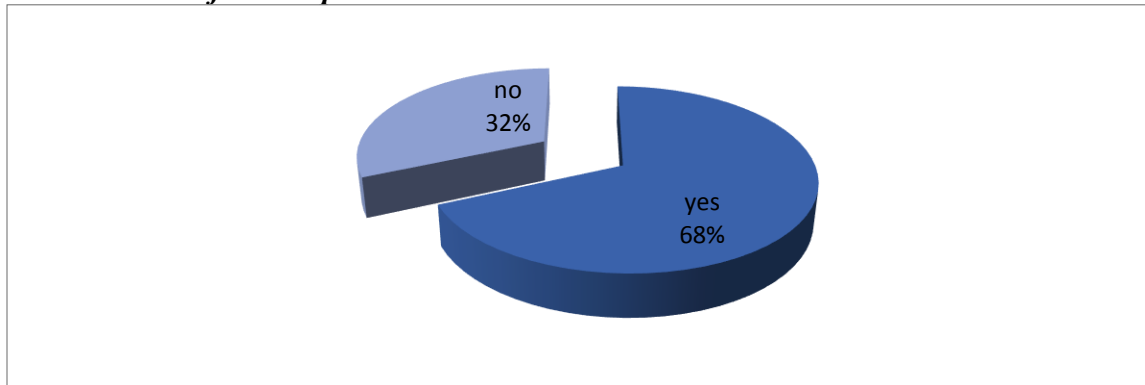
	Frequency	Percent	Valid Percent
waive bills	5	26.3	26.3
psychosocial assessment and interventions	14	73.7	73.7
<b>Total</b>	<b>19</b>	<b>100.0</b>	<b>100.0</b>

*Source; researcher 2018*

From the findings of the study, 73.7% of the participants show that the role of social workers is psychosocial assessment and interventions and 26.3% of the participants show that the role of social workers is to waive bills. This finding show a significant percentage of 26.3% of health care givers who does not understand the role of social workers. The role of social workers at Aga Khan University Hospital is psychosocial assessment and interventions and waiving the bills.

***Consulted or referred a patient to a social worker***

Participants were asked to show if they have ever consulted or referred a patient to a social worker. The figure gives the summary of these findings

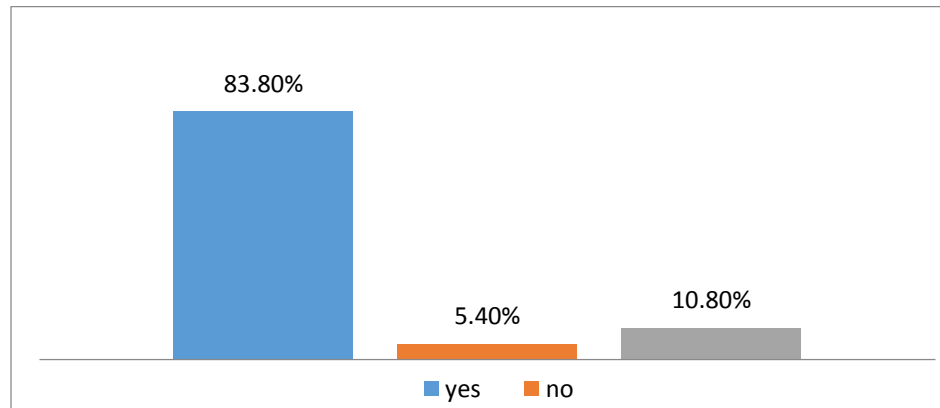
***Consulted or referred a patient to a social worker***

*Source; researcher 2018*

The participants in the study show that they have consulted or referred a patient to a social worker as indicated by 68% and 32% have not. At the Aga Khan University hospital, health care givers have consulted or referred a patient to a social worker.

***Interacted with a social worker***

The study wanted to know whether the participants have ever interacted with a social worker as shown in the he findings

***Interactions with a social worker***

*Source; researcher 2018*

At the Aga Khan university Hospital, quite a significant number are aware of the presence of a social worker and have even interacted or referred patients. The study findings reveals that 83.8% of the participants have interacted with a social worker and 5.5% have not. The reason for the interaction with a social worker include; psychosocial support, discharge processing and Financial Issues as illustrated in the table

***Reasons interaction with a social worker***

		Frequency	Percent	Valid Percent
<b>Valid</b>	0	4	10.8	10.8
	psychosocial support	24	64.9	64.9
	financial issues	7	18.9	18.9
	Discharge processing	2	5.4	5.4
	<b>Total</b>	<b>37</b>	<b>100.0</b>	<b>100.0</b>

*Source; researcher 2018*

**1.9 Conclusion**

Working together provides the best quality of care and encourages sharing of information and coordination in the team which is critical. Social work integration and inter-professional collaboration facilitate multidisciplinary team meetings to share pertinent patient details and goals of care. Need assessment to include pain, depression, anxiety, nausea, fatigue and wellbeing is of utmost importance. Communication between the team, patient and family is essential in the end of life care. Socio-cultural practices in palliative care include; spiritual issues, perception, cultural values, beliefs and practices. Social cultural issues also include Age, gender, ethnicity, traditional beliefs and spirituality which influence the assumption of cause of illness and treatment plan.

**1.10 Recommendations**

Social work integration should be encouraged in all multidisciplinary teams outside palliative care. Needs assessment must be ongoing throughout the continuum for all patients with life limiting conditions and during end of life. Besides, patients and families should be told the truth irrespective of their cultural orientation. Socio-cultural practices must be understood and

respected in order to achieve the goals of palliative care.

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