

**STATUS OF PALLIATIVE CARE PRACTICE AMONG HEALTH CARE
PROVIDERS WORKING IN HEALTH CARE SETTING OF JIMMA TOWN,
SOUTH WEST ETHIOPIA.**

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**JIMMA UNIVERSITY INSTITUTE OF HEALTH, FACULTY OF HEALTH SCIENCES
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SOUTH WEST ETHIOPIA .**

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ABSTRACT

Background - People with serious illness and their families receive substandard medical care, including untreated symptoms, unmet psychosocial needs, severe caregiver burden and low patient and family satisfaction. Palliative care addresses these shortcomings through a coordinated, team approach that results in better communication with the patient and the patient's family, and better community support.

Objective - To examine status of palliative care practice among health care providers working in health care settings of Jimma town.

Methods & materials - An institutional based qualitative case study was conducted from April 11 to June 2017 among purposively selected 27 health care providers working in health care setting of Jimma town, by using semi structured in depth interview guide & focused group discussion guide. Atlas ti 7 to assist and analyzed thematically & ethical clearance was obtained from Jimma university institutional review board.

Result - the analysis revealed that physical care, psychological care, spiritual care, practical and social care are identified under scope of palliative care, availability of training, Individual related factors and disease related factor are identified under enabling factor and unavailability of drug, unconducive working environment, patient related problems and lack of recourse are identified as a barrier to provide palliative care.

Conclusion and recommendation - The result of this study suggested that the health care providers are motivated to provide the best possible scope palliative care and to add life on the day of their patients. Nevertheless, due to barriers they fail even there were enablers. Therefore the organizations should work to tackle those obstacles to provide palliative care.

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ACRONYMS

AIDS - Acquired Immuno Deficiency Syndrome

ART - Anti Retro viral Therapy

BSC- Bachelor of Science

CDC- Center of Disease Control

FGD- Focus Group Discussion

HIV - Human Immuno Deficiency Virus

IDI - In depth Interview

IRB – Institutional Review Board

JUMC - Jimma University Medical Center

MSC - Master of Science

NCD - Non communicable Disease

NHRE - National Health Research Ethics

OSSHD- Organization for Social Service Health and Development

WHO - World Health Organization

WPCA - Worldwide Palliative Care Alliance

CHAPTER ONE; - INTRODUCTION

1.1 Background

Palliative care is 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 means of early identification and impeccable assessment, treatment of pain, distressing symptom & other problems (physical, psychosocial and spiritual) (1).

Palliative care improves the survival and quality of life as compared to usual care among patients with cancer or other disease and helps ensure care is concordant with patient preference (2). Palliative care arose as a response to patient experiences of poor quality dying. Following a long period of evidence building, the benefit of palliative care in improving quality of living and dying are now relatively robust (3). Palliative care is integral to the management of all patients with non-communicable, communicable diseases, injuries and trauma (4).

Worldwide palliative care alliance also recommends that all governments to integrate palliative care into their country's health system alongside curative care(5). At a minimum, palliative care should be provided even when curative care is unavailable (6)

To effectively integrate palliative care into a society and change the experience of patients and families, all four components of the world health organization (WHO) Public Health Model must be addressed. There must be appropriate policies, adequate drug availability, education of health care workers and the public, and implementation of palliative care services at all levels throughout the society (7). The scopes of palliative care are disease management, physical care, social care, psychological care, loss and bereavement, spiritual care, practical

and end of life care (8).

1.2 Statement of Problem

Annually worldwide 54 million people die (all causes), 30 million people die from progressive organ failure other degenerative disease, 8.5 million people die from cancer & 1.5 million people die from HIV/AIDS. With technological advance in public health and health care provision, life expectancy is increasing rapidly in many parts of the world & currently almost 1 in 10 people are over 60. By 2050, this proportion will have risen to 1 in 5 an aging population brings with it arise in chronic condition and multiple co morbidity and an increased need of palliative care (9)

Non communicable disease (NCD) kills more than 36 million people every year. About 80% of NCD related deaths (29 million) occur in low- and- middle income countries. More than 9 million NCD related deaths occur before 60 years of age. Four common NCDs (cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes) account for 80% of all NCD related death (10). The current magnitude of NCDs is a reflection of exposure to the risk factors a couple of decades ago (11).

According to a verbal autopsy study on burial surveillance in Addis Ababa, 51% of deaths were attributed to non- communicable diseases followed by 42% died of communicable disease & 6% died due to injuries (12). Despite of high death rate due to chronic disease in Ethiopia, the health system not yet well equipped to address the challenges of chronic diseases until Health Sector Development Program– IV (13).

Globally, 35 million people experience pain and suffering caused by old age or by life-limiting conditions such as cancer, AIDS, and other chronic diseases (7).

Sub-Saharan Africa has the greatest unmet need for pain relief, with 837,000 untreated deaths in pain from HIV or cancer (14). Developing countries consume only about 9% of the world's morphine, even though they account for 83% of the world's population(15) So providing palliative support globally is also likely to benefit the approximately 70 million families or voluntary caregivers who are helping those affected (16).

According to the Global atlas of palliative care report an estimated 40 million people worldwide need palliative care every year, of those, about 21 million people need palliative care at the end of their lives, above 90% of them as a result of non-communicable diseases. However estimated 42% of countries have no palliative care services whatsoever, while a further 30% have limited service delivery that reaches only a small percentage of the population (17).

According to the Global Atlas of Palliative Care at the End of Life, palliative care is still at its infancy in Ethiopia(17).. The latest economic intelligence unit quality of death index also ranked Ethiopia 70 out of 80 countries assessed further proof of the need to improve palliative care delivery in the country (18). Insufficient training of health professionals in low and middle income countries, both before and after they begin practice, is a major obstacle to the widespread provision of palliative care (19).

The need for palliative care is expected to escalate over the next several decades. The world's population continues to grow and many countries will see increases in their older age group. This means the number of individuals who will experience illness, either chronic or life-threatening conditions, live longer with their life-limiting illness because of advances in science and technology, and die from their disease, is anticipated to rise significantly (20). Patients suffering from a chronic life-threatening disease are eligible to receive palliative care (1). People with serious illness and their families receive substandard

medical care, including untreated symptoms, unmet psychosocial needs, severe caregiver burden and low patient and family satisfaction (21).

Palliative care addresses these shortcomings through a coordinated, team approach that results in better communication with the patient and the patient's family, and better community support. Palliative care team's lower overall healthcare costs by preventing clinical complications, facilitating discharge planning and reducing preventable hospitalizations, re-admissions and emergency room visits(22).

Despite an increased burden of chronic disease & palliative care need; very limited research has been conducted on the topic, especially from the perspectives of health care providers in general in our country and palliative care is a good strategy aimed to provide comfort and maintain the highest possible quality of life as long as life remains for the increase premature NCD related deaths; so, the purpose of this study is to explore the current status among health care providers.

1.3 Significance of the study

The study benefit for health care settings to address for those patients of all ages that needs palliative care from life threatening to chronically ill patients. This study will provides fertile ground to continue working of palliative care and it will benefit to the health care providers to see them and respond accordingly. Benefits patients in terms of by improving the quality of life if identified barriers are tackled. Also the findings of this study will serve as a base for other researchers who want to study about palliative care in advance & it will also helpful for policy makers and health care planners to expand their understanding of current practice of palliative care service and inform future policy development and helpful to add literature gap on palliative care in our country especially qualitative studies.

CHAPTER TWO; - LITERATURE REVIEW

2.1 Scope of palliative care

A study conducted to explore public perception of palliative care in United Kingdom showed that Holistic services like focus on physical care, the need to consistently address psychological, spiritual, emotional and practical needs are expected from health professionals who are providing palliative care (23).

A study done United State of America on how to provide optimal end-of life care for critically ill patients showed that controlling physical symptoms, psychological and cognitive symptoms, economic and care giving needs, social relationships and spiritual care are essential to have a good death (24).

2.2 Barriers to provide palliative care

A qualitative done to asses' structural challenges of providing palliative Care for Patients with Breast Cancer in Tehran, Iran result showed that participants in the study believed, that the care providers' lack of adequate knowledge and awareness of palliative care, nonexistence of clinical guidelines and protocols in primary care and education, fuzzy and vague job descriptions, and weak

teamwork skills are among those structural barriers to providing effective palliative care (25).

A study done to identify barriers and facilitators in five European countries result showed that professionals in Italy, described that there is a general lack of awareness about palliative care, and professionals in the Netherlands stated that their managers considered palliative care unimportant, because they were not aware of what palliative care actually is (26).

A study done to asses' physicians' and Nurses' perceptions about palliative care in coronary unit central Sweden result showed that the informants thought that their knowledge and education about palliative care was, generally insufficient. Staff nurse believed they had little or no education on palliative care and were thus not competent to deal effectively with either patients or relatives. Furthermore, Staff nurse noted that their knowledge often was deficient to support relatives adequately (27).

A qualitative study done to asses barriers to provide palliative care for older people in acute hospitals of United Kingdom result showed that barriers to palliative care provision for older people includes attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources. And also differing in understandings of whose responsibility it was to provide palliative care for older people, and uncertainly over the roles of specialist and generalist palliative care providers in acute hospitals (28).

A study done to identify barriers to the provision of high-quality palliative care for people with dementia in England result showed that ambivalence towards the systematization of palliative care, disconnection between services, different assumptions about training needs and negotiation of risk are among barriers to the provide high-quality palliative care among health professionals (29).

Cross-country comparison study done to asses' barriers and facilitators to care for the terminally ill in Canada, England, Germany, and the United States result

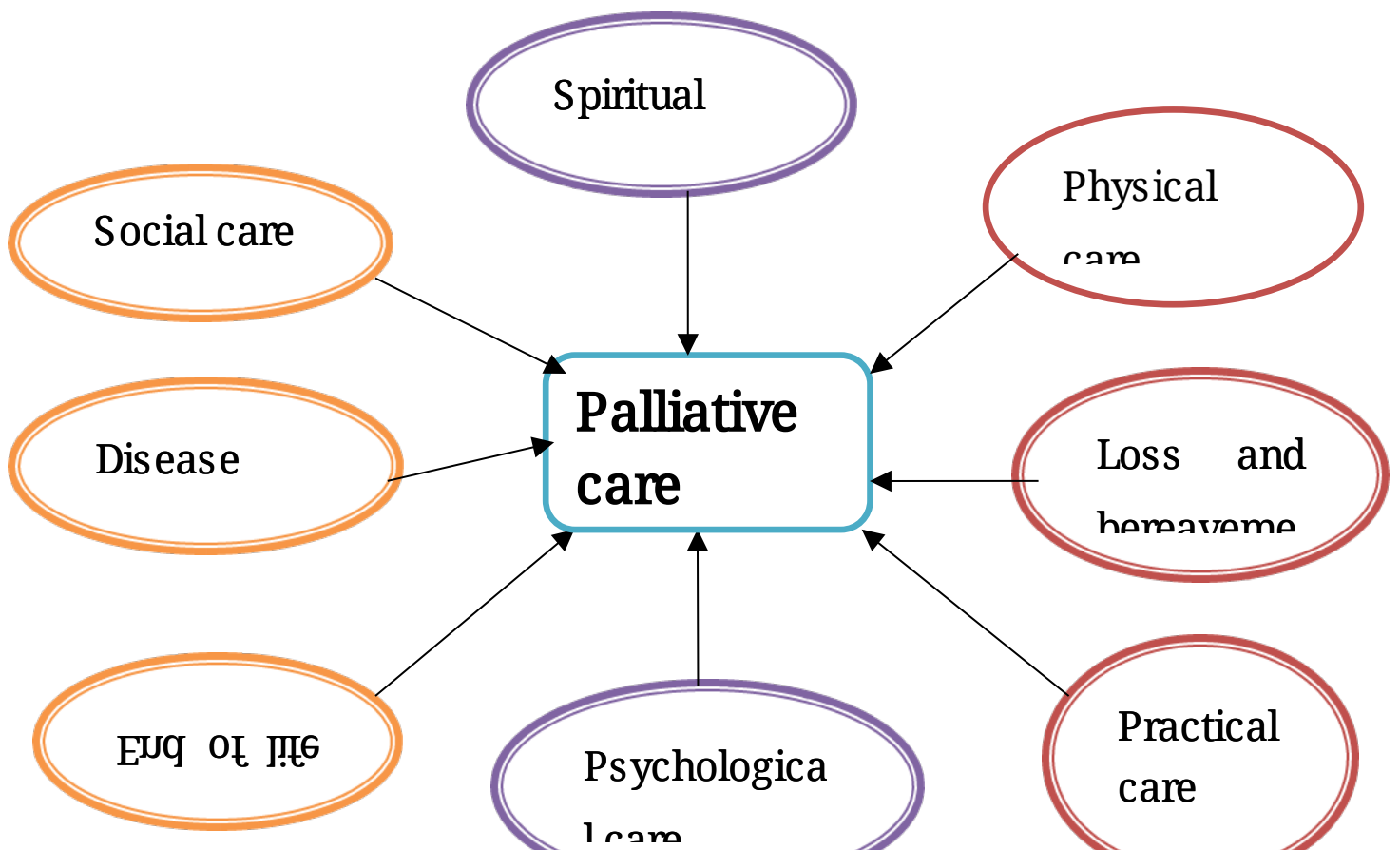
showed that limited availability of opioid analgesics was not identified as an issue in any country for pain management, education and training toward their use as well as prescribing (and, to a lesser extent, dispensing) were described as a challenge (30).

2.3 Enablers to provide palliative care

Cross-country comparison study done to assess barriers and facilitators to care for the terminally ill in Canada, England, Germany and the United States result showed that dedicated and stable funding and having standards of practice and guidelines was identified as facilitators (30).

In summary different literature showed that lack awareness of palliative care, nonexistence of clinical guidelines, protocols and education, vague job descriptions, and weak teamwork were among those structural barriers to providing effective palliative care & like having dedicated and stable funding and having standards of practice and guidelines were facilitator to provide palliative care.

2.4 Conceptual model of the study



Palliative care model of palliative care adopted from department of Health, Western Australia (8).

UNIT THREE: - OBJECTIVES

3.1. General objective

- ❖ To examine palliative care practice among health care providers working in health care settings of Jimma town, 2017.

3.2. Specific objectives

1. To determine the scope of palliative care among health care providers working in health care settings of Jimma town.
2. To identify enablers to practice palliative care among health care providers working in health care settings of Jimma town.
3. To identify barriers to practice palliative care among health care providers working health care settings of Jimma town.

CHAPTER FOUR; - METHODS AND MATERIALS

4.1 Study Area / period

Based on the 2007 Census conducted by the Central Statistical Agency of Ethiopia this Zone has a total population of 120,960, of whom 60,824 are men and 60,136 women.

Jimma town was 352 km far from Addis Abeba. There are six public health institutions of them two are hospitals & four are health center.

Currently three health care settings, Jimma university medical center, Shenan Gibe hospital & Organization for social service health and development provides palliative care by the health professionals and .

According to 2016 organization report, organization for social service health and development (OSSHD) is nongovernmental organization located in Jimma town providing palliative care to the community by dividing the town into Tana and Bocho bore out let. By three health professionals and 197 care givers divided

into 16 'edir'. Those care givers has 20 patients under them, by going to their home they provide palliative care. Additionally there are 24 peer groups they provide service similarly for the clients.

4.2 Study design and selected case

Institutional based qualitative case study design was employed to explore status of palliative care practice in Jimma university medical center, Shenen Gibe hospital & Organization for social service health and development from march 1- april 30 2017 on status of palliative care practice to identify the scopes and factors enabling and hindering to provide palliative care by using palliative care model of Australia (8).

4.4 Study participants Selection procedures

Criterion based purposive sampling was used. Any health care providers who had experience on caring patients with chronic life threatening disease were selected as study participant. For in depth interview health professionals and for focused group discussions peer groups were selected.

4.5 Data Collection Procedures

4.5.1 Data collection tool / instruments

A semi structured interview guide containing open-ended questions were used to produce data from selected participants.

In depth face to face interview & focused group discussion was conducted to explore the views of the participants and probing question was used. During data collection voice recorders and field-notes was used to capture the information obtained from the interview & discussion. The interview took 35- 55 minutes and the discussion took 1; 30 – 1; 45 hours.

4.5.2. Data Collectors/ Personnel

Two data collectors having BSC degree and MSC degree & having an experience on qualitative data collection was selected.

The principal investigator was given one day full training prior to data collection. The session of the training included the objective of the study, techniques of interview and discussion and transcription rules. As well as the role and responsibility of data collectors was described. The principal investigator & the data collectors were transcribed, collected and coded the data.

4.6 Data Analysis and Management

On completion of interviewing the participants of each day; audio recordings were listened carefully and transcribed verbatim. Then translated into English language, data organized and exported directly into ATLAS.ti7.1 and familiarization with the data was done. Then the data were analyzed by thematic analysis, by using both an inductive and deductive coding approach. Pre-existing coding framework was used and then category and subcategories are developed into themes for each participant and across different participant and finally the meaning of each theme was interpreted.

4.7 Trustworthiness

The question was commented by expert.

The interviews and discussion were carried out in places and at times chosen by the respondents to avoid any distortions that might creep into data. Respondents with different educational status & professional background were selected for the interview & discussion, regular debriefing meetings and review of data collection forms was held daily. Iterative questioning to get in in-depth information, peer scrutiny/ examination of the research project by colleagues, peers and academics & feedback at any presentation were welcomed, digital recorder & note taker used to capture the information. The respondents were asked similar questions in the same way and the steps of analysis were followed. The interviews & discussion was transcribed into word, in the language of respondent by principal investigator & assistant interviewer then translated to English language for analysis. The

transcription was proof-read against the audio file by both the assistant interviewer and the researcher to check for accuracy, identify any missed or misheard words and to clarify any areas of confusion or unclear terminology. Member check was done. Qualitative research experts were consulted during data collection, analysis and report writing. First the interview conducted then the focused group discussion. The categories identified in this research were transferable to similar groups of respondents.

4.8 Conceptual definition

- ✓ **Barrier of palliative care** - any factor (physical, environmental, organizational, and personal) that hinders to implement palliative care.
- ✓ **Enabler of palliative care** - any factor which enables or helps to implement palliative care in your organization as the standard.
- ✓ **Health care provider**- any individual involved in the provision of palliative care, like physician, Nurses, Pharmacists, Physiotherapist and etc.
- ✓ **Health care setting**- any facility involved in the provision of health service for the community.
- ✓ **Scope of palliative care**- any service provided for patients with chronic disease besides to medical service until death.
- ✓ **Peer educator** - are HIV/AIDS positive individual who are trained to provide palliative care for patients in the hospital and/or community setting voluntarily.

4.9 Ethical considerations

Ethical clearance and approval to conduct the research was obtained from Jimma University institutional review board (J U IRB) letter was secured from the university to respective hospital management to gain support for the study; objectives of the study was explained to the participants & their participation was voluntary. The field team was briefed in the ethical guidelines of the National Health Research Ethics (NHRE). All notes and audio files will be kept with the field worker/note taker at all

times. Names of interviewees was not be used at any stage of the data collection process. Pre-determined identification numbers were used on data collection form (topic guide and notes). An audio recording was not being started until the interviewee has given consent and didn't record their name. All typed records was kept in password protected computer and back-up drive. Finally after entering to computer for analysis recorded audio tape was discarded.

4.1.1 Dissemination of Research Findings

Upon completion the results will be disseminated to Jimma university institute of health science, faculty of health science school of Nursing and Midwifery, Jimma University Medical Center & Shenen Gibe hospital management and Nursing service director office, organization for social service health and development, Jimma zonal health office. Also it will be presented on seminars, workshops and conferences & finally efforts will also be made to publish on peer reviewed scientific journal.

CHAPTER FIVE; - RESULTS

5.1 Socio- demographic characteristics of the study participant

A total of 27 health care providers from two public hospitals and one local nongovernmental organization; fourteen of them are health professionals and thirteen are peer educators (1 for in depth interview 12 for focused group discussion) were participated in this study as described in the table below (table 1).

Table 1; - The socio demographic characteristics of the health care providers working in health care settings of Jimma town, Ethiopia 2017 (n= 27)

| Characteristics | | Frequency |
|-----------------------|--|-----------|
| Sex | Male | 7 |
| | Female | 20 |
| Professional category | Nurse | 8 |
| | Physician | 3 |
| | Pharmacist | 2 |
| | Midwifery | 1 |
| | Peer educators | 13 |
| Institution | Jimma university medical center | 13 |
| | Shenen gibe hospital | 7 |
| | Organization for social service health and development | 7 |
| Educational status | General practitioner | 3 |
| | Msc degree | 1 |
| | Bsc Degree | 7 |
| | Diploma | 3 |
| | Below diploma | 13 |

5.2 Main themes and categories

From the analysis of the interviewee and focused group discussion 149 primary codes are identified, and then the codes are examined for similarities. Then after similar codes were merged and finally 65 main codes were extracted; in later stages, they are described in thirteen categories and three main themes as mentioned in the table below (table 2).

Table 2 Main themes and categories emerged from data analysis of the health care providers working in health care settings of Jimma town, Ethiopia 2017

| Main theme | Category | Subcategories |
|--------------------------|---|--|
| Scope of palliative care | Physical care, Psychological care, Spiritual care, practical, Social care | <ul style="list-style-type: none"> - pain management - psychological support - care giver support - spirituals support - discharge planning |

| | | |
|-------------------------------------|--|--|
| Enablers to provide palliative care | <ul style="list-style-type: none"> - availability of training - Individual factors | <ul style="list-style-type: none"> - training of palliative care - training of pain management - life experience |
| Barriers to provide palliative care | <ul style="list-style-type: none"> - unavailability of drug - work environment related problems - health care provider related problems - Patient related problems - funding/ resource related problems | <ul style="list-style-type: none"> - lack of team approach - lack of anti pain drugs - unconducive working area - interruption of support - patient resistant |

5.3 Scope of palliative care

The result of this study indicated that there is no guidelines concerning palliative care in the health institution; which obligates the health professionals to provide palliative care for the patient; but they are aware of palliative care service and provide it for the patients with chronic disease by calling ‘comfort care’ but as they reported they didn’t provide all scopes for one patient rather by assessing the patient condition, they select the scope which is appropriate for that particular patient. Among those physical cares, psychological care, spiritual care, practical care & social care were mentioned by the participants.

5.3.1 Physical care

In spite of its subjective nature, most pain in patients with chronic disease is associated with tissue damage and functional impairment of body systems. As reported by most of the study participants, patients may have a lot of complain due to the disease process but pain is not ignored symptom.

Regarding this 30 years old, general practitioner interviewee said that *“...watching people in pain are something that I don't like to work with; this just doesn't exist for me, so I have to asses and provide anti pain.”*

Also another participant mentioned that patients complain pain due to the

disease severity as a result they manage it accordingly.

A female oncology nurse interviewee said that *“cancer has severe pain ... I asses the pain level and manage it, starting from paracetamol to morphine”*

5.3.2 Psychological care

According to report of participants, building relationships that enable discussions to take place with the patient helps to cope from fear full emotions at the end of their life by gaining of trust from the patient and also having people to talk to, to help reflect on one’s life, or simply to have fun with is an important

A 28 years old general practitioner interviewee said that *“Most of them (patient) have fear of dying ..., I spend most of my time dealing with them”*

Another participant reported that non verbal communication can convey a great relief from terrible feeling or sense of belongingness provides a way for the patient to resolve from stressful conditions related to impairment of his/ her health condition.

A 27 years old male staff Nurse interviewee said that *“...you doesn’t have always to talk (...) sitting at his/her side is sometimes enough, the patient may find some peace or some way to cope with his own emotions”*.

5.3.3 Spiritual care

Traditional healing is an influential community-based resource that impacts utilization of drugs as discussed by focus group discussants as a result they advise to use both concurrently.

“After starting the medication, they (patient) say “HOLY WATER “, “PRAY”, “DUA” will heal us. But we teach them to not stop taking the medication and to use both together“

5. 3.4. Practical care

In order to bring change to health care practice and to have good compliance on their life styles of the patient continuous provision of services practically has an importance. As mentioned by focused group discussants they go where the eligible patient available is and provide services directly.

“We provide health education for the patient in the morning, we see patients admitted in the wards and counsel them, if new patient is got, we link it to our clinic.”

5.3.5. Social care

As described by study participant’s social care provided for patients and his/her families, to make kinship ties strong and build relationships as family with the care providers especially when they ill seriously and suffer economically.

A 34 years old male manager interviewee said that *“We provide social support for the patients... due to most patients suffer economically besides ill health”*.

5.4 Enablers to provide palliative care

All health care providers participated in this study pointed out different factors which helped them in their role of palliative care service including availability of training individual factors and disease related factor.

5.41 Availability of training

Most of the study participants mentioned they have training on physical care and psychological care among the scopes of palliative care.

5.4.1.1. Training of palliative care

Regarding this the interviewee participants described that due to complexity of nature of chronic disease and less chance of being cure the need for training is must.

A 46 years old, female key informant said that *“.. chronic disease are incurable, so we have to give service for those patients, this done through training, so before providing the service, I took training of palliative care.”*

As reported by most of health professionals, there is lack of training on palliative care, which hindered them to provide for the patient.

A 36 years old female key informant said that *“I am providing the service ,*

due to I have an experience, as I told you as served many years as health professional, so the main barrier for me is I haven't took training on palliative care."

Similarly a general practioner mentioned the essentiality and need of training to meet complex need of the patient.

"To provide better care for patients, we need training..because patients with chronic diseases have complex needs and training has great importance to manage the situation."(28 years old male general practitioner)

5.4.1.2. Training of pain management

As mentioned by the participants' pain is a major part as very rarely seen in patient with chronic disease, having protocols helped them to effectively treat or not miss managing it.

A 30 years old male physician said that *"...mostly pain in patients with chronic disease are ignored but, we have pain management protocols, by using that I asses and manage it."*

5.4.2 Individual factors

The health care providers' experience like sense of humanity, motivation and life experience helped them to provide palliative care.

FGD discussant described that they are providing the service in the community besides to health care institution, because of feeling as self diseased or needing help.

The participants of FGD discussant said that "Additionally we provide palliative care in the community, not due to payment, but due to humanity."

Similarly another participant described due to sympathy they manage patient symptoms or provides a way to relief of pain.

A 29 years old Bsc Nurse interviewee said that "I feel; (...) you don't leave

patient die due to pain. “

5.4.2.1 Motivation

As reported by some of the participants motivation comes first to provide palliative care.

A 36 years old diploma key informant said that *“My mind obligates me... I have motivation, even you trained, if you don't have motivation, you can't do anything”*

Internal motivation to help people has an importance to be effective in the service provision; yet providing care tiresome in community setting as described by FGD discussants.

“When you become a volunteer, you are taking responsibility... even it is tiresome, we want to contribute what we can to stop the disease. That is why we are providing the service in the community.”

5.4.2.2 Life experience

The support provided while some one is ill, creates strong commitment while providing the service for those who need it similarly and through time it becomes just experience, as described by FGD discussants nongovernmental organizations help them while they were ill.

“...Religious institution and red cross helped us to provide the service..that is why we are providing the service that we got previously.”

As mentioned by participant an having experience of caring critical patients and life experience has a great impact to easily bring change on patient disease prognosis

A 30 years old key female informant said that *“The major one is my life experiences, human being by nature do what he looks, if someone live or pass with that condition or life; he is able to got acceptance from others, so I am providing palliative care what I have already lived and living and I have experience of caring critical patients.”*

5.5 Barriers to provide palliative care

Different barriers are identified from the data; which were associated with working environment (unconducive working environment, shortage of room,) others are associated with the patient themselves (frequent changing of address, name, resistant to stay in the hospital), resource/ funding related (interruption of support, unavailability of drug) and barrier related to health care provider (lack of team approach and shortage of staff).

5.5.1 Problems related with the working environment

Most participants mentioned the environment where the service provided should be comfortable as much as possible and the lack of privacy exposes the patient to have unnecessary effect of the disease prognosis.

A 27 years old male Nurse interviewee said that *“The room is not comfortable, better to say it a corner, (...) privacy not kept for patient, you are unable to discuss freely with them, and patient don’t feel free.”*

Additionally the participants mentioned that the importance of palliative care unit to provide the service freely in order to have a desired outcome on patient life and also to discuss confidently with the patient to attain his need.

Similarly a 35 years old female key informant said *“When I advise patient someone enters to the room and our discussion interrupts, because we don’t have separate room for palliative care... the patient don’t feel free to discuss all the issues. “*

But few participants reported that the even there is no room for palliative care but available area where they provide the service is conducive for the patients to discuss freely and to provide the service as well as the staff relationship have favorable while providing palliative care.

Regarding this a 31 year old female diploma nurse interviewee said that *“The working environment is comfortable and the staffs are willing to share what they know”*

5.5.2 Problems related to patient

FGD discussants described that, due to social stigma in the community the patient conceal their status by frequently change their name and address; as a result they faced difficulty when they go to patient home while they vanishes the service.

“When the patient defaults treatment we go to their home; due to the patients change their name & address...You stay all the day searching for her, but she is there , when you ask her, she say “such kind of woman not living here.”.

While other patients not voluntary to be visited by the health care providers as described by FGD discussants.

“Some patient throw stone on us, untie their dog, when we go to their home”

Several respondents described that families are influenced by denial of palliative care, including hope for a miracle or consideration of treatments unlikely to confer benefit. The emotional difficulty of bringing up the possibility of death combined with denial on the part of patients and families served as an important barrier to perceiving palliative care as an option, much less initiating it.

Regarding this 28 years old male general practitioner interviewee said *that “... if they (the attendant) know they the patient is diagnosed with chronic disease, they hesitate to initiate palliative care discussions and interventions.”*

5.5.3 Unavailability of drug

As reported by health care providers patients with life limiting conditions frequently have multiple symptoms as a result access to pain medication is one component of palliative care but inaccessibility and unaffordable to the medication made difficult to manage pain symptom.

A male oncology nurse interviewee said that *“... there is financial problem... the drugs are expensive, some patients unable to pay for...patients are*

suffering due to pain. “

A female oncology Nurse interviewee said that *“Last year we face big challenge to manage pain...but now there is problem related to supply... due to diclophenac is contraindicated for children less than twelve year, we provide morphine by decreasing the dose.”*

A 32 years old male pharmacist interviewee supported the idea and said that *“..currently morphine is preferable drug for severe pain management, but for pediatrics the suspension form is not currently available in our hospital.”*

5.5.4 Resource related problems

Continuous support for the palliative care patients in material or in kind has a temporarily means to resolve from their illness, by decreasing psychological burden being economically weak. As described by study participants sometimes there is interruption of material supports provided from the nongovernmental organization for patients who need palliative care.

A 34 years old male manager interviewee said that *“When supports are interrupted, we face difficulty; actually everyone should be economically independent but little support is needed for those who are critically sick.”*

The FGD discussants also mentioned the impact of economical support on the acceptance of care by the patients.

“Due to interruption of support provided from the organization, when we go to patients home, they (patient) say “why you came without material support.”

5.5.5 Problem related to health care providers

According to the analysis, most participants mentioned that all health care providers are responsible to provide palliative care and the essentiality different discipline in solving different problems of the patient and to appeal to for a better solution.

A 30 years old male general practitioner interviewee said that *“Sometimes things become very complicated, (...) when the patient caught by chronic*

disease, it is related with almost all system so, I have to discuss with other medical staffs to provide medical service.”

Similarly a 26 years old male pharmacist interviewee said that *“...Every health service is provided in team, if one of the team is missed, and the service wouldn't be adequate.”*

Even they agree the essentiality of multi- disciplinary/team approach in the provision of palliative care, but

As reported by study participant every health care providers absence of bringing together diverse disciplinary points of view to meet patient need or doing his own duty while providing palliative care service by stating the contradiction of the theory and practice.

A 27 years old male Bsc nurse interviewee said that “During training we thought palliative care is provide in team but, practically different ; the physician order medication and left the patient (...) comes and asses again (..) Writes order and go.”

The participants also described that disproportional between patients to health care provider ratio while providing palliative care for the patient as a challenge.

Regarding this a 48 years old, key informant said that *“Sometimes patient flow increases, during that time (...) we didn't provide the palliative care for patients, because of shortage of health professionals”*

CHAPTER SIX; - DISCUSSION

All health care providers have a role in the delivery palliative care throughout the illness. In this section, palliative care practice in hospital and community setting is discussed focusing on three main themes extracted from analysis of interviews and focused group discussions, which are “scope of palliative care”, “enablers to provide palliative care” and “barriers to provide palliative care”.

Much of the available literature (26-31) on palliative care focuses on enablers and barriers to practice palliative care without identifying the scopes, which are the base for palliative care provision, however, this study focused exclusively and dig out those scopes, to understand the real situation of the practice.

Having experience of caring critical patients has a great impact on the provision of palliative care. In contrast to study conducted in five European countries (26). The findings of this study showed that, almost all participants have experience of caring critical patients.

Palliative care has been started for about a decade, it is not yet known as routine care and in this study provided mostly in outpatient department only and very limited in inpatient unit, besides this resource used to deliver the care is deficient, in contrast the study done on Canada, England, Germany and the United States(30) this leads to decrease quality of life of the patient (2).

An observational study showed that patients with cancer who had unmet spiritual concerns were more likely to have significantly worse psychological quality of life than those whose spiritual concerns were addressed(31).

According to this study spiritual care provided by health care providers is not in line with the components spiritual care like value, belief and practices, existential and transcendental issues (8).

At diagnosis, half of all people living with cancer experience anxiety and depression sufficient to impair their quality of life and impacts upon not just quality of life, but survival (32). In this study psychological support is provided by trained health care providers.

One of the important aspects of palliative care is the availability and possibility of utilizing medical resources and financial support. In this study social support is provided by nongovernmental organization and the eligible patient is determined by the health professionals and referred to.

But most of the patients doesn't get the support timely as a result they severely ill and go to catholic mission and the missionaries helps the patients for while and let them by offering immediate support. Due to the support is very limited, the patients again suffer economically and discontinue the medication and finally they either die or go to second line drugs which are very expensive and with many side effects similar with study done in United Kingdom (28).

In order to increase the quality of life and to decrease frustration due to fragmented and disjointed care for patients with life limiting illness the service should have continuity, which is associated with the option of further home care provided by health care providers and the care provided in one unit must be continues, if the patient go to other unit for further service. In this study service unavailability or inaccessibility, especially the treatment of opportunistic infections at night and on weekends challenged people living with HIV/ AIDS.

To have mutual trust between the patient and the health care providers, the service should be provided in both setting either by one health care institution or by having network with other organization who provide similar service in the community, but in this study palliative care is provided separately in both setting and the service not as recommended by world health organization (7).

Effective pain and symptom control is the foundation of palliative care and is best achieved through a holistic approach to address the problems of psychological, social, spiritual and physical needs of a patient and their family; the result of this study indicates that having pain management protocols enabled them to assess pain but to lesser extent problem related to prescription identified as a barrier in which contrast with finding of qualitative study conducted in Canada, England, Germany, and United State (30).

But also effective pain relief depends not only on the availability, accessibility or affordability of pain relieving drugs but also on the health sectors capacity to use those drugs efficiently. In this study there is problems related to supply of anti pain drugs; which are most preferable for patients who are receiving palliative care in contrast to study done in Canada, England, Germany, and the United States (30).

This study and other have observed obstacles that health professionals perceive as preventing provision of palliative care. The results of this study point out that work environment related problem, drug unavailability and patient related factor are significant which they encounter when they perform their duty; which is similar with study conducted in England (28).

Non-disclosure is an important public health problem that affects individuals' access to treatment and care (33). In this study this issue mostly seen during palliative care provision in the community by the social worker. Some of them provide palliative care only in the community, while others provide both in the

community and health care institution; in both settings interrelated obstacles were identified.

Those working in the health care institution provide palliative care for their own clients in the community; these clients are already disclosed themselves and use the service but while they provide palliative care in health care institution, some of the clients vanish using the service; going and searching such patients are the responsibility of them; due to health extension workers busy, they go to patients home lonely, even though they are searching the whole day, but the patients conceal themselves even though they are searched.

In case of community, they already know the address of their clients, but the problem is, the patients conceal their status to prevent stigma and discrimination by the house renters. Due to this the community palliative care providers keep secret of their client's status. This social discrimination may result in increased distribution of the disease even than before.

The hospital environment, which encompasses the physical surroundings and the social interactions with hospital staff, can impact on the quality of palliative care experienced by patients(34). In this study uncondusive working environment and lack of palliative care unit are identified which may impact on quality of life of the patient.

Strength and limitations of study of the study

The strength of the study was this was a novel qualitative study that collected data from multiple sources to understand the contexts and factors involved in implementation of palliative care. Data analysis was rigorous and was assisted by software. As a limitation, with a sample size of 27 health care providers, there are obvious limitations to the representativeness of the findings and it doesn't explore patient view directly.

UNIT SEVEN: CONCLUSION AND RECOMMENDATIONS

7.1 Conclusions

The result of this study suggested that the health care providers are motivated to provide the best possible scope palliative care and to add life on the day of their patients. Nevertheless, due to barriers they fail in their intentions from providing palliative care fully than they are providing now; even they have enablers to provide.

7.2 Recommendation

In this study different obstacle were identified to provide palliative care. In order improve the quality of palliative care and to meet the patient need, the following recommendations were forwarded for different concerned bodies.

For Jimma university medical center and Shenen Gibe hospital

- ✓ To give palliative care training for all health professionals.
- ✓ To open palliative care unit separately.
- ✓ To create conducive work environment.

The Jimma town woreda health office

- ✓ They should prepare in-service training for health care providers to improve their skill.
- ✓ They should strengthen the existing service provision and develop new mechanisms to develop palliative care practice.

For organization for social service health and development

- ✓ To further support community based palliative care
- ✓ To create network with health care institution in order to have better palliative care service.

For health care providers

- ✓ Should work in a team.

For researchers

- ✓ To conduct further study using triangulated study design to address the unreached problems like patient view directly.

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ANNEX 1;- IN DEPTH INTERVIEW GUIDE & CONSENT FORM

Verbal consent form

I want to thank you for giving the time to meet with me today. My name is _____ and I would like to talk to you about status of palliative care practice among health care providers working in health care settings of Jimma town, the interview will take less than an hour. I will be taping the session because I don't want to miss any of your ideas. Although I will be taking some notes during the session. Because we're on tape, please be sure to speak up so that we don't miss your ideas. All responses will be kept confidential. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time. Are there any questions about what I have just explained?

Are you willing to participate in this interview?

Date _____

WRITTEN CONSENT FORM

In signing this document, I am giving my consent to participate in the study titled “status of palliative care practice among health care providers working in health care settings of Jimma town, south west, Ethiopia.” I have been informed that the objective of this study is to explore status of palliative care practice health care providers working in health care settings of Jimma town, south west, Ethiopia 2017. I have understood that participation in this study is entirely voluntarily & my voice will be recorded. I have been told that my answers to the questions will not be given to anyone else and no reports of this study ever identify me in any way. I understood that participation in this study does not involve risks except the time spent for completing the interview.

I understood that S/r TIWABWORK TEKALIGN is the contact person if I have questions about the study or about my rights as a study participant. The following is his contact address.

Address of principal investigator Tiwabwork Tekalign

Tel: +251-916185005/+251-945011550 E-mail: tiwabworkt@gmail.com

Participant's signature: _____ date: _____

Date ----- place interviewer -----

ANNEX 2- INTERVIEW GUIDE

In depth interview guide developed for health care providers working in health care settings of Jimma town.

General Information

1. Position (responsibility) _____
2. Work experience in the area _____
3. Educational status _____
4. Sex _____
5. Age _____

Part one- status of palliative care practice related question.

1. How do understand palliative care? Probe why, Whose responsibility is providing palliative care ? , When do you provide it? What really it look like of caring patients with critical condition ? Can you tell me your experience Do you give attention to patients' feeling? ,
2. Can you describe the scope of palliative care you are providing for the patients? Probe, what else, can you describe any activities that you are not providing due to different reason?

3. What sort of things do you think help you in your role of palliative care?

Probe - What else? , How? , What about the patient need?

4. What sort of things do you think difficulty in providing palliative care? Probe - What else? , Probe: availability of drugs, training, lack of multi-disciplinary approach, funds/donors related issue, Reason? Do you tried to avoid such barriers & how? , Which barrier do you think needs urgent solution? Why?

Part two; - Feature recommendation

1 What do you recommend for the feature? What else? , How can responsible body handle such issue? , What about you?

❖ Is there anything more you would like to add?

I'll be analyzing the information you and others gave me and submitting a final result to your organization. I'll be happy to send you a copy at that time, if you are interested.
Thank you for your time

Data Collector name _____ Signature_____

ANNEX 3- FOCUSED GROUP DISCUSSION GUIDE & CONSENT FORM

Verbal consent form

How are you? My name is _____thank you for your willingness to participate in these discussion today. We are here to talk about the status of palliative care practice among health care providers working in health care settings of Jimma town. This discussion will take at least one hour and half. The discussion will provide invaluable information to your hospital about, how can to offer better palliative care services in the future. In this discussion there is no right or wrong answers. We want to hear from everyone in the room. We will be keeping a record of this discussion & take notes. I will not refer to any participant by name in the reports I prepare. The information will be kept confidential and used only by research team members.

Remember, you don't have to talk about anything you don't want to and you may end the discussion at any time.

Are there any questions about what I have just explained?

Are you willing to participate in this discussion?

I will be moderating the session.

Let's start by going around the circle.

ANNEX 4- FGD QUESTION

Focused group discussion guide developed for health care providers working in health care settings of Jimma town

Part one- status of palliative care practice related question.

1. How do you understand by palliative care? Probe, whose responsibility is to provide?

When should be provided for whom?

2. Can you describe the scope of palliative care? What else? Why only those? Is there any scope that you are not providing to the patient?

3. What are the main factors facilitating you in the provision of palliative care? Probe, What else?, how that facilitated you?

4. What are the main factors that hinder you to not provide of palliative care service to the patient ? What else? Which one the most difficult? Why?

5. What do you recommend for the future?

Thank you for your time!!!

ANNEX 5- AMHARIC VERSION OF THE TOOL

የጥልቅ መጠይቅ መመሪያ እና የስምምነት ውል

በቅድሚያ ጊዜዎን ሰጥተው ሊያገኙኝ ስለፈቀዱ እያመሰገንኩ _____ እባላለሁ። በጅም ከተማ በሚገኙ የጤና ተቋማት የሚሰሩ የጤና አገልግሎት ሰጪዎች ጋር ሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት የትግበራ ሁኔታን በተመለከተ ጥልቅ የሆነ ቃለ መጠይቅ ለማድረግ እፈልጋለሁ ። ቃለ መጠይቁ ቢያንስ አንድ ሰዓት ይፈጃል። የትኛውም ምላሽዎ እንዳያመልጠኝ ድምፅን እቀዳለሁ። ማስታወሻም እወስዳለሁ። የሚሰጡት መልስ ሚስጢራዊነቱ የተጠበቀ ነው። የማይፈልጉትን ነገር ያለመናገርና በየትኛውም ሰዓት ቃለ መጠይቁን የማቋረጥ መብትዎ የተጠበቀ ነው ።

ማብራሪያ በሰጠኋቸው ጉዳዮች ላይ ግልፅ ያልሆነ ነገር አለ?

በቃለ መጠይቁ ላይ ለመሳተፍ ፈቃደኛ ነዎት?

ቀን _____

የፀሎፍ የስምምነት ውል

ከተማ በሚገኙ የጤና ተቋማት የሚሰሩ የጤና አገልግሎት ሰጪዎች ጋር ሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት የትግበራ ሁኔታ በሚል ርዕስ በሚደረገው ጥናት አለማውን ተረድቼ፣ ተሳትፎ በሙሉ ፈቃደኝነቴ ላይ የተመሠረተ እንደሆነ አውቄ ፣ ድምፃዬ የሚቀዳ መሆኑን፣ በዚህ ጥናት ውስጥ የምሰጠው መልስ ከጥናት ቡድኑ በስተቀር ለማንም እንደማይሰጥ፣ በዘገባው ማንነቴን የሚገልፅ ነገር እንደማይኖር፣ መሳተፊ ጊዜዬን ከመውሰዱ ውጪ ምንም አይነት ጉዳት እንደማይደርስብኝ እና እንደ ጥናቱ ተሳታፊነቴ ስለ ጥናት ፅሁፉም ሆነ ስለ መብቴ የጥናቱ ባለቤት የሆነችውን ሲ/ር ትዋብወርቅ ተካልኝ መጠየቅ የምችል መሆኑን ተረድቼ መሳተፊን በፊርማዬ አረጋግጣለሁ።

ስልክ +251916185005 / +251945011550, email, tiwabworkt@gmail.com

ቀን _____

ቃለ መጠይቁ የተደረገበት ቦታ _____

በጅማ ከተማ በሚገኙ የጤና ተቋማት ለሚሰሩ የጤና አገልግሎት ሰጪዎች የተዘጋጀ ጥልቅ መጠይቅ

አጠቃላይ መረጃ

አሁን ያለዎት የስራ ሀላፊነት _____

የሥራ ልምድ _____

የትምህርት ደረጃ _____

ፆታ _____

ዕድሜ _____

ክፍል አንድ - ሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት ሁኔታ ጋር የተያያዙ ጥያቄዎች

- 1) ሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎትን እንዴት ይረዱታል? የማን ሀላፊነት ነው? መቼ ነው አገልግሎቱን የሚሰጡት? በፅኑ ሁኔታ ያሉ ህመማን መንከባከብ ምን ይመስላል? የእርስዎን ልምድ ሊነግሩኝ ይችላሉ? ለህመማን ስሜት አፅንኦት ይሰጣሉ?
- 2) - የሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት አገልግሎቶች ምን ምን ናቸው? ሌላስ?
- 3) ሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት ውስጥ የእርስዎ ሚናን እንዲወጡ የረዳዎት ምንድነው ብለው ያስባሉ? ሌላስ? እንዴት ረዳዎት? የህመማን ፍላጎትስ? የህመማንን ፍላጎትን እንዴት ነው የሚያሟሉት?
- 4) ሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት እንዲይሰጡ ያገደት ነገር ምንድነው ብለው ያስባሉ? ሌላስ? ምክንያቱስ? እነዚህን እንቅፋቶች ለማሰወገድ ሞክረዋል? እንዴት? አስቸኳይ መፍትሔ የሚፈልገው እንቅፋት የቱ ነው? ለምን?

ክፍል ሁለት- ለወደፊት የሚያሳስቡት

ለወደፊቱ ምን ያሳስባሉ? ሌላስ? የሚመለከተው አካል እነዚህን ጉዳዮች እንዴት መወጣት አለበት ይላሉ? እርሶዎስ?

መጨመር የሚፈልጉት ነገር አለ?

እርስዎና ሌሎች የሠጡኝን መረጃ አጠናቅቆ ለመስሪያ ቤትዎ የማቀርብ ይሆናል ፍላጎትዎ ከሆነ ግልባጩን እልክሎታለሁ።

ጊዜዎን ስለሰጡኝ አመሰግናለሁ።

መረጃ ሰብሳቢ _____ ፊርማ _____

የቡድን መወያያ መመሪያ እና የቃል የስምምነት ውል

እንዴት ናችሁ ? ስ ሜ _____ ይባላል። በዛሬው ወይይት ለመሳተፍ ፈቃደኛ ስለሆናችሁ በጣም አመሰግናለሁ። በጅም ከተማ በሚገኙ የጤና ተቋማት የሚሰሩ የጤና አገልግሎት ሰጪዎች ጋር ሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት የትግበራ ሁኔታን በተመለከተ ለአንድ ሰዕት ተኩል ለማይበልጥ ጊዜ እንወያያለን ። ወይይታች ለወደፊት በሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት መሻሻል የላቀ አስተዋፅኦ ያበረክታል። በውይይታችን ትክክል የሆነ ወይም ያልሆነ መልስ የለም። ስለዚህ የሁላችንም ሀሳብ እንፈልገዋለን። ውይይታችን የሚቀዳ እንዲሁም ማስታወሻ የሚያዝ ይሆናል ። የሚሰጡት መልስ ሚስጢራዊነቱ የተጠበቀ እና እርስዎ መላሽ እንደሆኑ የሚገልፅ ምንም አይነት መረጃ አይኖርም። የማይፈልጉትን ነገር ያለመናገርና ፣ በየትኛውም ሰዓት ውይይቱን የማቋረጥ መብትዎ የተጠበቀ ነው ።

ማብራሪያ በሰጠኋቸው ጉዳዮች ላይ ግልፅ ያልሆነ ነገር አለ?

በውይይቱ ላይ ለመሳተፍ ፈቃደኛ ነዎት?

እኔ ውይይቱን እመራዋለሁ

በጠረጴዛ ዙሪያ እንቀመጥና እራሳችንን በማስተዋወቅ እንጀምር።

የቡድን መወያያ የፀሐፍ የስምምነት ውል

በጅም ዩኒቨርሲቲ ሜዲካል ሴንተር እና በሸነን ጊቤ ሆስፒታል ለሚሰሩ የጤና ባለሙያዎች በሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት በሚል ርዕስ በሚደረገው ጥናት አላማውን ተረድቼ፣ ተሣትፎ በሙሉ ፈቃደኝነቴ ላይ የተመሠረተ እንደሆነ አውቄ ፣ ድምፄ የሚቀዳ መሆኑን፣ በዚህ ጥናት ውስጥ የምሰጠው መልስ ከጥናት ቡድኑ በስተቀር ለማንም እንደማይሰጥ፣ በዘገባው ማንነቴን የሚገልፅ ነገር እንደማይኖር፣ መሳተፊ ጊዜዬን ከመውሰዱ ውጪ ምንም አይነት ጉዳት እንደማይደርስብኝ እና እንደ ጥናቱ ተሳታፊነቴ ስለ ጥናት ፅሁፉም ሆነ ስለ መብቴ የጥናቱ ባለቤት የሆነችውን ሲ/ር ትዋብወርቅ ተካልኝ መጠየቅ የምችል መሆኑን ተረድቼ መሳተፊን በፊርማዬ አረጋግጣለሁ።

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ቀን _____ ቃለ መጠይቁ የተደረገበት ቦታ _____

ፊርማ _____ ገገገ፣ _____ ገገገ፣ _____ ገገገ፣ _____ ገገገ፣
_____ ገገገ፣ _____

በጅም ከተማ በሚገኙ የጤና ተቋማት የሚሰሩ የጤና አገልግሎት ሰጪዎች የተዘጋጀ የቡድን መወያያ መመሪያ

ክፍል አንድ - የሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት ሁኔታ ጋር የተያያዙ ጥያቄዎች

- 1- ሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎትን እንዴት ይረዱታል?
- 2- - የሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት አገልግሎቶች ምን ምን ናቸው? ሌላስ?
- 3- የሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት ለመስጠት የረዳዎት ምንድነው? ሌላስ?
- 4- የሁለንተናዊ የህመም ክብካቤና የማስታገስ አገልግሎት እንዲይሰጡ እንቅፋት የሆነቦት ነገር ምንድነው? ሌላስ?

ማጠቃለያ

ጊዜዎን ስለሰጡኝ አመሰግናለሁ!!!

ANNEX 6 - ATLAS Ti OUT PUT

All current quotations (309). Quotation-Filter: All (extended version)

HU: atlas I wish

File: [C:\Users\USER\WAR\ATLAS\atlas I wish.hpr7]

Edited by: Super

Date/Time: 2017-06-14 14:04:01

P 3: transcription 44.rtf - 3:5 [advise them to use bed net, to..] (20:20) (Super)

Codes: [behavioral modification - Family: physical care] [ITN utilization - Family: physical care] [nutritional assessment - Family: physical care]

No memos

advise them to use bed net, to avoid drinking alcohol, chewing chat , and to eat any kind of food that is gotten in their home and to take the drug after meal.

P 3: transcription 44.rtf - 3:6 [My mind obligates me ?, so I h..] (22:22) (Super)

Codes: [motivation - Family: individual factors]

No memos

P12: transcription 59.rtf - 12:25 [Palliative care is a care which..] (9:9) (Super)

Codes: [comfort care - Family: palliative care awareness]

Memos: [genera research on palliative care practice]

Palliative care is a care which is provided for patient with critical condition. Or one of care provided for the patients with incurable disease or for any disease with low healing probability in order to promote peaceful death.

Memos:

MEMO: genera research on palliative care practice (Super, 2017-04-30 21:43:17)

Type: Commentary

21/ 08/09 4.30 AM

even I am late , today I started by reading some of the interview and giving free quotation, and writing comments to understand full of my interview.

for instance one of the participant said the following about palliative care

There are opportunistic infections, if prevented; it is one of the palliative care services. Also patient may have urgent problems, if he gets the medical service for that problem that is, also palliative care and (..)

WHO recommends patient with chronic life threatening disease have eligible to get palliative care, but the adherence supporters sees beyond that, they say every one coming to hospital should get palliative care

"Anyone coming to hospital in need of help, not for refreshment. So palliative care should be given for all patients".

Some of the participants believe the eligibility to receive palliative care is disease severity, one of the FGD participant said that

"now a day's compared to other disease HIV/AIDS is severe, because it attacks our immune system. So, palliative care must be provided for our clients. But, if other patient get palliative care it is essential."

EXPERIENCE OF CARING CRITICAL PATIENTS

Maybe due to different barrier the health professional may not provide palliative care even they have an experience of caring critical patient or may be their experiences enable to provide emotional care which is under psychological care.

"Now a days I feel as normal, because I try all my best to save patient life, (..) I discuss with the clinical colleagues, the medical staff, about his condition, so if the patient dies, it is the will of God." (GP male 30 yrs old

Team approach is one of the essential pillar of palliative care, but it is obvious every health care is provided in a team, lack of team approach may lead fragmentation of the service.

One pharmacist mentioned team approach in this way when asked is you responsible to provide pc *"Yes the pharmacist is responsible to dispense the drug, the patient don't heal without taking drugs, (..) every health service is done in team, if one of the team is missed, the service wouldn't be adequate."*

Codes- quotations list

Code- Filter: All

HU: atlas l wish

File: [C:\Users\USER\WAR\ATLAS\atlas l wish.hpr7]

Edited by: Super

Date/Time: 2017-06-15 09:14:41

Code: absence of PC guideline {1-0}

P14: transcription manually.docx - 14:16 [you should have written guide..] (38:38) (Super)

Codes: [absence of PC guideline]

No memos

“You should have written guidelines for palliative care, not only for scopes but also about what is the significance of palliative care. Everyone has to be made aware of the significance of palliative care”.

P 5: transcription 47.rtf - 5:6 [I will listen their problems c..] (27:27) (Super)

Codes: [being available - Family: psychological care]

No memos

I will listen their problems carefully, then after (...), I will provide the service accordingly.

Code: changing of name {1-0}~

P15: FGD.rtf - 15:44 [the patients change their name..] (74:74) (Super)

Codes: [changing of name - Family: patient related] [lack of common address - Family: patient related]

No memos

“The patients change their name and their address, in order to find job and to rent house. Let us tell you what happened to me, my house renter don't know my status, then I think someone told her, about my status and she come to my home early in the morning and said me “leave my house with in twenty four hour”. So because of this patient their name and address frequently.”

ASSURANCE OF PRINCIPAL INVESTIGATOR

The undersigned nursing student declare that this thesis is my original work and not done

before for similar purpose. All participants of this study also are respected and acknowledged indeed.

Declaration

Name of the student: _____

Date. _____ Signature _____

APPROVAL OF THE FIRST ADVISOR

Name of the first advisor _____

Date _____ Signature _____

APPROVAL OF THE SECOND ADVISOR

Name of the second advisor: _____

Date _____ Signature _____