

## Research

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# Initial Impressions and Review of Literature Concerning Factors Affecting the Use of Palliative Care Assessment Tools in an African Setting

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## ABSTRACT

**Introduction:** Quality palliative care encompasses early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>1</sup> Despite the importance of symptom assessment in palliative care, use of assessment tools in practice is limited.<sup>2</sup> The aim of this study was to assess factors that influence use of symptom assessment tools.

**Methodology:** 1:1 interviews were conducted using a guideline developed by the researcher. Ten participants who met the inclusion criteria were interviewed. The data was recorded and then transcribed with topics and issues being isolated and grouped together into themes.

**Findings:** The themes were perception of palliative care, communication, practical concerns and emotions associated with use of assessment tools, spirituality and cultural compatibility with assessment tools, resources, policies and training.

**Conclusion:** Lack of quality education in palliative care coupled with incompatibility of current tools with cultural and religious practices is a major hindrance to use of assessment tools. Poor communication among clinicians negatively affects use of assessment tools.

**KEYWORDS:** Palliative care; Measures; Assessment tools; Palliative care practice.

**ABBREVIATIONS:** WHO: World Health Organisation.

## INTRODUCTION

The philosophy of “whole person care” coupled with assessment of patients’ symptoms is the mainstay of modern palliative care.<sup>3</sup> Uses of assessment tools increase the likelihood of meeting patients’ goals as well as improving symptom control.<sup>4</sup>

Studies on development and utilization of assessment tools in palliative care have been carried out but none have been carried out on the factors affecting their use in the African setting.<sup>5,6</sup> Lack of standardization in assessment of symptoms in palliative care pose a challenge for care providers in determining appropriate treatment.<sup>7</sup>

There is often conflict between nurses and physicians regarding communicating patients’ health status and symptom management. Use of assessment tools identified by a palliative care team would minimize this conflict.<sup>8</sup>

Cultural beliefs and parameters guide relationships and communication between health care workers, patients, families and the society in general. Kagawa-Singer, et al.<sup>9</sup> found out that culture influences patients’ and community’s perception and satisfaction with symptoms control and quality of care being provided.

**METHODOLOGY**

In this qualitative study, palliative care practitioners included doctors, clinical officers who are physicians' assistants, social workers and nurses. The participants have experience of working in palliative care settings for at least 3 months since this is adequate working duration to have used or discussed use of an assessment tool. They have also attained a diploma in palliative care at least 3 months before the study commencement date. The participants are registered with their respective professional bodies.

The study participants who comprised 2 males and 8 females were aged between 33 and 53 years (mean=47 years). They included two (2) doctors, five (5) nurses, two (2) clinical officers) and one (1) social worker who have practiced health care between 3 to 16 years (mean=7 years). Their initial qualifications were certificate in nursing (n=3), diplomas in nursing (n=2), diplomas in clinical medicine (n=2), degrees in medicine and Surgery (n=2) and diploma in social work (n=1). There were 3 participants from 2 palliative care settings each and 4 from the third setting.

Individual semi structured interviews were conducted using a guide designed by the researcher. The interviews were in English and took place at the participants' places of work i.e 2 hospices and 1 palliative care unit located in various geographical sites in Kenya. Some of the interview questions were:

- 7)a) Can you tell me about any assessment tools you use in your practice?
- b) Discuss which tools you use, how often and why you use them?
- c) Can you talk about why you do not use assessment tools in your practice?
  
- 8) Do you think assessment tools are useful in your practice setting? Discuss.....
  
- 9) a) Is there any time you have felt that use of assessment tool(s) would have eased the acquisition of information from a patient?
- a) Yes ( ) No ( )
- b) Why do you feel so? Expand on this .....
- c) Why were assessment tools not used ?.....
  
- 10) a) Who are some of the members of your palliative care team?

  - Nurse
  - Doctor
  - Social worker
  - Clinical officer
  - Others, please name.....

Responses to the interviews were recorded and then transcribed. The responses were thoroughly examined, connections between several messages from all the interviews identified and then clustered together into themes. The predominant themes formed the basis of the data.

**DATA ANALYSIS**

The following themes were identified:

1. Perception of palliative care practitioners about assessment tools
2. Communication
3. Spirituality and cultural compatibility with assessment tools
4. Practical concerns and emotions associated with use of assessment tools
5. Resources, policies and training

In most tools, symptoms are numbered 0-10 with 0 being no symptom/ distress and 10 being the most severe. The patients and /or families are supposed to mark the number that best expresses the level of the patient's distress. However, most tools do not give guidance on the intervention to be undertaken.

The symptoms are already indicated and numbered... After you assess, it is a dead end... no guidelines on the way forward, how to treat. Participant V.

Doctor-nurse conflict was singled out as a big impediment towards the goal of assessment of patients.

I no longer use assessment tools... When I called the doctor with my findings, he repeated the whole process, I felt very embarrassed and today I leave assessment for the doctor. Participant D.

Collusion between doctors and families not to inform patients their diagnosis and prognosis is a common occurrence in this setting as well as avoiding the use of assessment tools with an aim of not passing information to the patients.

In this case, the son was very angry with us... We had broken an agreement he had with their doctor. Participant M.

The lack of adaptability of the assessment tools indifferent cultural settings is cited as a leading cause of inconsistency in their use.

Some are the age of my father, how can I talk to them about sex with their wives, who are my mother's age? Participant X.

They are pastoralists and they keep on moving from one area to another... They don't have much time to answer questions. Participant N.

The assessment tools do not address the most pressing

needs of patients.

They request money for food, school, transport and other home necessities... This is what distresses them most ... The assessment tools do not factor in this. Participant Z.

The assessment tools use language that is not compatible with local terms and expressions.

The tools are difficult to understand... Depression, anxiety, how do you translate these words into a local language? Participant S.

The limited number of palliative care practitioners in relation to the large number of patients and families that require the service is a critical factor in the use of assessment tools.

Being the only nurse trained in palliative care in the hospice... I know I can use these tools but there are very many patients to be seen and I feel pressured for time, I ask about their recurrent symptom and make reference to the clinical notes. Participant V.

Unavailability of medical necessities was regarded as detrimental to the overall quality of care and full patient assessment.

I could see the patient was in pain, the way he walked, we did not have drugs in our store... I did not ask about her pain. Participant S.

Palliative care is not integrated in the mainstream health care training and also the palliative care training being offered currently at the diploma level is not adequate for practical use of assessment tools.

Palliative care module is not part of the training offered in our training. Participant X.

## DISCUSSION

### Perception of Palliative Care Practitioners about Assessment Tools

The low utilization of assessment tools is attributable to the many challenges facing this field in Africa that ranges from understaffing, lack of knowledge and skills and financial constraints. Greenhalgha, et al.<sup>10</sup> noted that inadequate utilization of assessment tools is a significant challenge in palliative care. In addition, the current training in palliative care is not comprehensive and there are cultural and spiritual challenges meaning that holistic assessment of patients is a daunting task for practitioners. Due to the late referral to palliative care, assessment is usually carried out at the end of life stage and in an incomplete manner.

## Communication

There is poor, untimely, insensitive communication with patients and families regarding symptoms and effects of different treatment modalities. Studies by Gunten and Weissman<sup>11</sup> found out that untimely, incomplete and insensitive communication with the patient from the time a diagnosis is made is a major cause of failure to utilize assessment tools globally.

It is a big challenge for doctors when there is a shift from cure to palliation which limits their communication skills at end of life since their training is not focused on this state of affairs. This in turn leads to a failure of utilization of assessment measures.<sup>12</sup>

Poor doctor-nurse relationship is a significant factor in medical practice. Nurses choose consciously or otherwise to preserve and protect physicians "superior" status by always deferring to them and undertaking their instructions without even critiquing the same, Gamondi, et al.<sup>13</sup>

Furthermore, collusion occurs between doctors and families preventing practitioners from using assessment tools as by so doing they might raise issues that were not meant to be discussed with patients. Palliative care practitioners therefore find it difficult to use assessment tools in such scenarios as the patients do not have adequate information about their illnesses and as such will not give proper feedbacks, Dunne<sup>14</sup> and Hudson, et al.<sup>15</sup>

Discussing prognosis is a complex communication question that hinders use of assessment tools in end of life care. Because prognosis is a major topic in assessment tools used at end of life, practitioners avoid utilizing assessment measures as a way of keeping off this sensitive topic, Orioles, et al.<sup>16</sup> and Manalo.<sup>17</sup>

## Spirituality and Cultural Compatibility with Assessment Tools

When use of assessment tools conflict with cultural practices, beliefs and norms of the society, the health care workers withdraw and do not pursue issues further. This is because culture is regarded to be supreme and hence resulting to a missed opportunity to assess the patients. For example discussion around death is regarded a taboo due to the fact that death transition is culturally considered an unwelcome occurrence.<sup>17</sup>

It is inappropriate to discuss sexuality with elderly patients as culture demands that this can only happen among peers. Tools which assess this parameter are therefore not used in palliative care settings locally. Orioles, et al.<sup>16</sup> found out that clinicians are unwilling to discuss and assess sexuality as this is thought to be a less important aspect for the patient and also as a result of cultural barriers.

It emerged that spirituality is an important way of life in this society where it is seen to be the same as religion. Being this important to the ways of life of this society, assessment of spirituality should therefore be part and parcel of quality assessment. However, spiritual consideration is a major factor missing in common assessment scales and this contributes to failure to utilize assessment tools. Hardings, et al.<sup>2</sup> and Kagawa-Singer, et al.<sup>9</sup> made similar findings.

#### **Practical Concerns and Emotions Associated with Use of Assessment Tools**

Time used to complete the assessment tools is considered by practitioners as being too much and takes time away from patients. Time is usually limited due to increased workload, few practitioners and the fact that family members who bring in the patient need to go back to work and continue with their income generating activities.

The multiplicity of symptoms reported by patients is a significant turn off to practitioners when they consider use of assessment tools as this is thought to be a huge load. Rhondali, et al.<sup>17</sup> and WHO<sup>1</sup> made similar observations.

#### **Resources, Policies and Training**

Poverty, lack of basic resources and the strained nature of the health care system significantly impede use of assessment tools by palliative care practitioners. Evidently, these factors combined are a big source of distress and burnout to those in palliative care practice and are reported as significant hindrances to the use of assessment tools.<sup>18</sup>

Education, skills and knowledge on palliative care practice is not broadly available to health care professionals hence leaving big gaps in the availability and accessibility of this crucial service and failure to assess patients. Similar findings are reported by Jazieh<sup>7</sup> and Weissman and Meier.<sup>19</sup>

This study found out that lack of nationally agreed and recognized conglomerate of assessment tools is a big impediment to their utilization or usefulness as different settings use different approaches and tools thus sharing of data and analysis of the same is not nationally feasible. Richardson, et al.<sup>20</sup> and Durand, et al.<sup>21</sup> made similar findings.

#### **CONCLUSIONS**

Despite the impressive growth and progress made in palliative care, Marete<sup>22</sup> and Weru,<sup>23</sup> widespread adoption of measurement tools is not common in palliative care settings as highlighted in this study.

Lack of training and education in palliative care for

health care and non-health care professionals coupled with lack of practical placements compounds the poor use of assessment measures. It is noted that current tools do not take into consideration the culture, norms, religious beliefs and traditional practices of the society. Further, the language used in the tool is not translatable and understandable to all those concerned and thus it is not easy to interpret the findings.

Poor communication between patients/ families and clinicians coupled with collusion between patients and doctors has also been reported as a strong determinant of the use of assessment scales. Nurse-Doctor Conflict is reported as a big impediment in the provision of quality care and utilization of assessment tools. Palliative care being multidisciplinary will require nurses and doctors to work collaboratively and the way they relate and communicate with each other need to be improved.

A major concern is the practical applications of tools; the questions in the scales, how to record and document the findings, time factors in filling out the tools and the actual benefit the tools offer to the quality of patient care. Poverty and the overall cost of acquisition and application of assessment measures hinder their use. The general lack of basic medical necessities such as drugs and dressing materials limits assessment activities in palliative care.

#### **RECOMMENDATIONS**

There is a need for better scientific evidence of palliative care assessment tools clinical utility in this setting as the current available assessment tools do not appear to be applicable, in their current state, in this setting as evidenced by this study. A thorough review of nursing, medical and palliative care curricula should be undertaken to ensure the content of these modules provide adequate, relevant and appropriate information and subsequently equip clinicians to effectively assess patients who need palliative care.

Tools need to be translated into a language that is easily understandable by clinicians, patients, families and other stakeholders. It is also recommended that nationally acceptable standards and guidelines for assessment measure and unified approach to patient needs assessment are developed.

It would be worthwhile to start documenting assessment findings bit by bit to full completion with multiple visits. This way, time will be saved and the end result will be high quality information. To be able to do this, patients should be referred for palliative care early.<sup>24</sup>

At the same time, assessment needs to be carried out at the key moments of a patient's illness trajectory which are diagnosis, commencement and completion of treatment, time

of recurrence, time incurability is identified, when death is imminent.<sup>25</sup>

Report of symptoms need to be via digital media and face-to-face communication. The increased use of electronic media for exchange of information means there is need of development and use of electronic assessment tools and decision-making systems in palliative care. Mobile telephony has tremendously grown and can be used for assessment purposes. For this to work best, the guidelines thus developed will need to be widely disseminated and implemented.<sup>20</sup>

The author recommends that professionals are trained together on the aspects of communicating with each other and how well to avoid conflicts. Conflicts can be avoided through regular nursing/ medical meetings, regular nurses and physician's surveys for feedback on communication challenges, team building meetings where there will be increased nurses-physicians' interaction. There should be standardized protocols for nurses to communicate with physicians about patients and at the same time institutions need to have laid down procedures of resolving conflicts and punishing those who are culpable.<sup>26</sup>

The researcher would also recommend a collaborative study between different service providers from different countries in Africa so as to assess the issues affecting use of palliative care assessment tools in practice.

#### LIMITATION OF THE STUDY

One of the limitation of this study is that few people, ten participants, were studied hence making it difficult to generalize the findings.

It is more difficult to determine the validity and reliability of data realized using qualitative research methodologies as supported by Payne<sup>27</sup> and Morse.<sup>28</sup>

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