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Development of Home-Based Palliative Care Assessment Tool Preliminary Study

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ABSTRACT

Background: One of the ways to ensure optimum care of patients with terminal illnesses at Home-Model of Palliative Care settings in Nigeria is to ensure the use of accurate and systematic ergonomic home assessment tool that takes into consideration the holistic factors in Palliative care practice, the Culture and Spiritual beliefs of Nigerians. **Aim:** This study was designed to develop, an ergonomic home-based palliative care assessment tool for the management of patients with terminal illnesses in Nigeria. **Material and Method:** 30 participants in this study were patients with terminal illnesses recruited from the home model of pain/palliative care centre of the University of Ilorin Teaching Hospital. Constructs that were relevant assessment indicators for the Home-Based palliative care assessment tool for patients with terminal illnesses were identified from a review of published literature. A total of 120 items were identified from the literature search. **Results:** The final tool consisted of 55 items divided into 7 major domains (social class assessment, Assessment of level of consciousness, current activities of daily living assessment, patient insight into illness, spiritual assessment, home assessment and bereavement support). **Conclusion:** This study developed a home-based palliative care assessment tool for patients with terminal illnesses in a home-based model of pain/palliative care which will be useful clinically in a home-based model of palliative care in Nigeria.

Keywords: Terminal Illness, Holistic Factors, Home-Based Patients, Home-Based Palliative Care Assessment Tool.

INTRODUCTION

The Worldwide prevalence of patients with terminal illnesses has continued to increase dramatically. Addressing the suffering of patients with terminal

illnesses involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. According to the World Health Organization (WHO), this includes addressing practical needs, providing bereavement counselling and offering a support system to help patients live as actively as possible until death. [1] Medical care for patients with terminal illnesses should not only be provided by specialized palliative care clinics but also in general care facilities, such as community-based care facilities including nursing and home care. Terminal diseases are the diseases which can lead to death of the patient, such as Cancer, HIV, Heart disease, Diabetes, Neurological conditions etc. Most chronic, usually incurable diseases, which have the effect of considerably limiting a person's life expectancy and reduced quality of life.[2]

It has been proposed that care should be based on a holistic perspective, which requires a supportive care environment in which non-medical interventions, such as meaningful activities are of great importance for quality of life.[3] Enabling meaningful activities is a way to enhance the quality of life and support clients to live with dignity despite a reduced ability to be active.[4] Hence, regardless of the client's stage of life, Physiotherapists should support clients in finding strategies to deal with social isolation to redefine their roles and to enable activity by adjusting the client's environments.[5]

Terminal diseases are chronic, usually, a terminal illness for whom curative treatment is no longer an option [6]. Patients suffering from such diseases require or are likely to require special care or services.

An estimated 56.4 million people passed away worldwide in 2015 and 68% of them were due to diseases that progressed slowly [7].

The most commonly used screening instrument in the ergonomic home assessment tool is the Occupational Therapy Initial Assessment form.[6] However, this instrument has problems associated with understanding how the dying process affects physical, psycho-social and spiritual components, and considering environmental context with specific end-of-life occupations of patients with terminal illnesses in Nigeria [8] appropriate assessment tools which incorporate the cultural and social factors in each environment

should be used in the management of patients with terminal illnesses, considering the fact that the environment and culture of countries in Africa, particularly Nigeria and morbidity/mortality rates of these diseases of patients with terminal illness vary considerably with other clinical conditions. Ergonomic home assessment tools developed for such countries and other chronic diseases that are not terminal diseases would not be effective in Nigeria and palliative care settings.

There is therefore a need to develop ergonomic home assessment tools that will take into consideration the culture and spiritual beliefs in Nigeria, in addition to physical suffering/bereavement support with social factors of the Palliative care setting. To effectively manage patients with terminal illnesses at home, it is of high importance that Physiotherapists and other health care Professionals in the Palliative care team use an appropriate and ergonomic home assessment tool in order to enhance the quality of life (QoL) of these patients. The Occupational Therapy Initial Assessment Tool (OTIAT) is the only validated home assessment tool in use but is not appropriate for palliative care settings because the content is not in line with palliative care principles. This study was therefore designed to develop a palliative care home assessment tool to enhance the quality of life of patients with terminal illnesses at home.

MATERIALS AND METHODS

The study was carried out in three (3) stages. The three (3) stages addressed the development of a Home-Based Palliative Care Assessment tool for the management of patients with terminal illnesses.

Stage 1: Selecting Items for Inclusion in the Home-Based Palliative Care Assessment Tool (HPCAT).

Literature on Home-based Management of Patients with terminal illnesses was reviewed and relevant assessment indicators for ergonomic assessment tools were identified. Articles and validated ergonomic assessment tools were identified through a search of PubMed, Google Scholar, Medscape, PEDro, Hinarii Medline databases and Research Gate. The search terms "terminal Disease", "Ergonomic Home Assessment Tool", "Home-Based Management of Patients with terminal illnesses", "Occupational therapy end-of-life care", and "Spiritual and Psycho-social

issues in Palliative Care" prospective cohort studies" were used. A list of constructs for potential inclusion was compiled, in line with the existing occupation therapy initial assessment tool.[9] A total of 120 items were identified from the literature search and these were classified under the constructs of home assessment, social class assessment, spiritual/psychologic al assessment, bereavement support. This categorization of 120 items into various domains is in line with palliative care principle of holistic approach in treatment of patients with terminal illnesses. A series of item reduction processes to eliminate redundancy and duplicity was carried out using principal component analysis which is a variable reduction technique and this brought the 120 items down to 65.

Stage 2: Expert Panel Review

An expert panel consisted of Palliative care specialist including Palliative Care Physicians, Consultant Physiotherapists, Consultant Psychiatrist, Palliative Care Nurses, Occupational therapists and the Researcher was constituted.

The expert panel review took place in the Physiotherapy Department and Palliative Care Unit of the University of Ilorin Teaching Hospital and was conducted for four sessions. Each session was anchored by a moderator, notes were developed and taken from video recordings of the sessions. Items on the list of identified constructs were taken one after the other, each item was deliberated based on deductive thematic analysis, experts' opinions and a review of the items generated through semi-structured data from the focus group discussion via transcription of recording videos were structured into themes and patterns that were relevant to research questions. Final themes were solidified and decisions were made by consensus within the panel. The expert panel further reduced the 65 items to 55 items through the removal of duplicates and redundancies. The items considered non-modifiable or rare or that were likely to be inappropriate targets for intervention were excluded. The best-performing items were deliberated on till a consensus was reached by the panel. Through consensus within the panel, the final constructs were chosen using information on strength, independence, consistency of association with outcome and perceived face validity. Items 28, 29, 40, 42, 54 and 55 were reconstructed to

broaden application and improve respondent comprehension. The item response categories and wording were also standardized by the panel.

Stage 3: Pilot study

Copies of the final draft of the newly developed Home-Based Palliative Care Assessment Tool (HPCAT) were administered to 30 participants purposely selected with terminal illnesses receiving palliative care treatment at home in Offa, Kwara State. The aim of the pretest was to ensure that the items were comprehensible, unambiguous and not double-barreled (i.e. ask only one question). There was no modification made to the final copy of the tool since the items in the tool were understood by the Participants.

Inclusion Criteria

Participants Included in this Phase of the Study Were:

Participants with terminal illnesses attending the home-based model of Pain/Palliative Care Centre,

University of Ilorin Teaching Hospital. The participants were diagnosed with the following clinical conditions; Cancer, HIV, Renal failure, Heart Failure, Diabetes, and Lower Respiratory tract Infection.

Exclusion Criteria

Participants excluded from this phase of the study were patients with life-limiting illnesses attending the home-based model of palliative care of UITH. Patients with life-limiting illnesses are cerebral palsy, sickle cell disease, muscular dystrophy etc.

Ethical Consideration

Ethical approval was obtained from the Health Research and Ethics Committee of the University of Ilorin Teaching Hospital. Written informed consent was also obtained from participants by completing the consent form while assuring them of confidentiality and the voluntary nature of their participation in the study.

Instrument

The newly developed Home-Based Palliative Care Assessment tool (HPCAT).

Description of Instrument

The Home-Based Palliative Care Assessment Tool (HPCAT): The newly developed HPCAT consisted of 55 items. These items were grouped into 8 domains, major domains (Section A-H) which have direct relevance and Importance to the construct of the Study (Appendix 1). The research instrument was an interviewer-

administered questionnaire and ergonomic assessment of the participants' houses by the researcher.

RESULTS

Expert Panel Review

The tool had 55 items after the expert panel review. Eight domains were identified which were the diagnosis and medical history of the participants, social class assessment, assessment of level of consciousness, activities of daily living (ADL), Patient insight, spiritual assessment, home assessment, home accessibility and bereavement support. All items on the tool had consistency in wording and response format.

Pilot Study

The result of the pilot study showed that the items are comprehensible, unambiguous and not double-barreled. All the items were relevant in assessing 30 participants and their home environment. All the items in the tool were understood by the participants.

Socio-demographic Data of Participants for Pilot Study

The average age of the respondents used for pretext was 62±14.5. 10 (33.3%) of them are in the age group 70 to 79. More than half 19 (63.3%) are males and less than half of the respondents 11 (36.7%) have cancer (Table 3).

More than half of 20 (66.7%) of the participants own a house and at least a vehicle. Some of them 12 (40.0%) are into small business. Some 13 (13.3% of them are university graduates. Less than half 13 (43.3%) have one out of four support and a look into the social class of respondents revealed that 10 (33.3%) belong to the social class two and three (Table 4).

More than half of the respondents 17 (56.7%) had eye-opening spontaneous responses and had the best verbal response Oriented to time, place and person while close to half 10 (33.3%) moved to localized pain. The average glass glow COMA scale was 13.7 with a standard deviation of 1.1 (Table 5).

Patients' insight into the cause of their illness shows that 18 (60.0%) know and understand that their illness is treatable, out of which all of the participants who feel it is treatable are on drugs and 18 (100.0% others are also on drugs and Physiotherapy (Table 6).

The majority 29 (96.7%) of the participants felt that the illness has affected their relationship

with their immediate family members. 3 (10.0%) are of the opinion that it is a terminal illness that they have while a few 2 (6.7%) are worried about their inability to walk (Table 7).

An assessment of participants' houses shows that 28 (93.3%) were at their houses along 19 (63.3%) owned the houses (Table 9).

An assessment of the homes of participants shows that some 13 43.3%) have the front access accessible and some 10 (33.3%) also have the back entrance accessible while less than half 15 (50.0%) have the interior accessible (Table 10).

The desired burial site according to participants shows that a little less than half 14 (46.7%) proffered their own home to be the burial site. Among the 14 who would like to be buried in their houses, 4 (28.6%) prefer the front view (Table 11).

Many of the issues identified from observation include medical by 30 (100.0%), social issues 15 (50.0%), and psychological issues 29 (96.7%) Table 12.

Table 3: Socio-Demographic Characteristics of Respondents for Pilot Study N=30

Variables	Frequency	Percentage
Age groups		
< 40	2	6.7
40 – 49	5	16.7
50 – 59	5	16.7
60 – 69	7	23.3
70 – 79	10	33.3
≥ 80	1	3.3
Mean ± SD	62 ± 14.5	
Gender		
Male	19	63.3
Female	11	36.7
Diagnosis		
Cancer	11	36.7
HIV/AIDs	3	10.0
Diabetes	3	10.0
Stroke	3	10.0
LRTI	0	0.0
Kidney Disease (CKD)	2	6.7
Ischemic heart diseases	3	10.0
CVD	5	16.7
Diarrhea	0	0.0
COPD	0	0.0

Table 4: Socio-Demographic Characteristics of Respondents for Pilot Study N=30

Variables	Frequency	Percentage
Housing and Transportation		
Houses and vehicle	0	0.0
A house and a vehicle	20	66.7
Renting house	9	30.0
Renting a house with less than 4 rooms	1	3.3
Occupation		
Professional	10	33.3
Professional with middle-class	8	26.7
Small business	12	40.0
Peasant farmer	0	0.0
Level of education		
University tertiary	13	43.4
Post-secondary/Non-university	7	23.3
Secondary	7	23.3
Primary	3	10.0
Family support		
3 out of 4 support	9	30.0
2 out of 4	8	26.7
1 out of 4	13	43.3
Social Class		
Social Class 1	9	30.0
Social Class 2	10	33.3
Social Class 3	10	33.3
Social Class 4	1	3.4

Table 5: Assessment of Level of Consciousness using Glassgow COMA Scale (Pilot Study)

Variables	Frequency	Percentage
Eye opening response		
Spontaneous	17	56.7
To speech	12	40.0
To pain	1	3.3
No response	0	0.0
Best verbal response		
Oriented to time, place and person	17	56.7
Confused	11	36.7
Inappropriate word	2	6.7
Incomprehensible sound	0	0.0
No response	0	0.0
Best motor response		
Obeys command	17	56.7
Moves to localized pain	10	33.3
Flexion withdrawal from pain	3	10.0
Abnormal flexion	0	0.0
Abnormal extension	0	0.0
No response	0	0.0
Mean glassglow Coma Scale ± SD	**13.7 ± 1.1**	

Table 6: Patient Insight (Knowledge and understanding of illness) Pilot Study

Variables	Yes (%)	No (%)
Knowledge of cause of illness	12 (40.0)	18 (60.0)
Illness is treatable	18 (60.0)	12 (40.0)
Treatment options	**n=18**	
Drugs	18 (100.0)	0 (0.0)
Physiotherapy	18 (100.0)	0 (0.0)
Surgery	7 (38.9)	11 (61.1)
Radiotherapy	1 (5.6)	17 (94.4)

Table 7: Worries about the Illness (Pilot Study)

Variables	Frequency	Percentage
Inability to walk/Disability	2	6.7
Body weakness/paralysis	1	3.3
Pain	4	13.3
No sign of recovery	1	3.3
Weakness	1	3.3
Dependent on others	0	0.0
Terminal	3	10.0
Weight loss	2	6.7
Chronic nature	6	20.0
Difficult breathing	3	10.0
Slow recovery	4	13.3
Others	3	10.0
Illness has affected close relations		
Yes	29	96.7
No	1	3.3
Don't know	0	0.0

Table 8: Spiritual Assessment (Pilot Study)

Variables	Frequency	Percentage
Believe in God /Almighty being		
Yes	29	96.7
No	1	3.3
Previous religion		
Islam	19	63.3
Christianity	11	36.7
Current Religion		
Islam	18	60.0
Christianity	12	40.0
Religion is important		
Important	27	90.0
Not important	2	6.7
Don't know	0	0.0
Prayers		
Yes	26	86.7
No	4	13.3
Illness has affected my relationship with God		
Yes	22	73.3
No	8	26.7
Assessment of current relationship with God		
Good	22	73.3
Fair	5	16.7
Poor	3	10.0

Variables	Frequency	Percentage
Spiritual obligation		
Yes	23	76.7
No	7	23.3
At peace with family		
Yes	29	96.7
No	1	3.3
At peace with God		
Yes	29	96.7
No	1	3.3
Don't know	0	0.0

Table 9: Home Assessments (Pilot Study)

Variables	Frequency	Percentage
Housing type		
House	28	93.3
Hostel	0	0.0
Nursing home	2	6.7
Ownership		
Owned	19	63.3
Rented	9	30.0
Government	0	0.0
Boarding	0	0.0
Others	2	6.7
Personal Alarm		
Yes	14	46.7
No	16	53.3

Table 10: Home Accessibility (Pilot Study)

Variables	Accessible (%)	Not accessible (%)
Front access	13 (43.3)	17 (56.7)
Back access	10 (33.3)	20 (66.7)
Interior	15 (50.0)	15 (50.0)
Bathroom	12 (40.0)	18 (60.0)
Toilet	11 (36.7)	19 (63.3)
Bedroom	7 (23.3)	23 (76.7)
Seating	15 (50.0)	15 (50.0)

Table 11: Bereavement Support (Pilot Study)

Variables	Frequency	Percentage
Burial Site		
Owned home	14	46.7
Rented home	0	0.0
Public cemetery	16	53.3
Location in home	**n=14**	
Front view	4	28.6
Internal	2	14.3
Side view	5	35.7
Back view	3	16.7

Table 12: Issues Identified from Observations (Pilot Study)

Variables	Yes (%)	No (%)
Medical	30 (100.0)	0 (0.0)
Social	15 (50.0)	15 (50.0)
Psychological	29 (96.7)	1 93.3)
Spiritual	25 (83.3)	5 (16.7)
Home modification needed	30 (100.0)	0 (0.0)
Bereavement support	30 (100.0)	0 (0.0)

DISCUSSION

This study was conducted with the aim of developing a tool for Home-Based Palliative Care assessment of patients with terminal illnesses, in the home model of Pain/Palliative Care settling. The high percentage (100%) of participants that needed one form of home modification or the other from this study suggests that efforts geared towards developing a Home-based palliative care assessment tool are worthwhile. The results of this study revealed (100%) of participants needed home modification. This finding is in agreement with the commonly reported trend in the literature. According to Peoples *et al* [10], in their various studies, reported that the physical environment may pose barriers to performing daily routines and valued occupations; physical modifications may promote autonomy, enhance their QoL, reduce disability and sustain engagement. The average Glasgow coma scale was 13.74 $\pm$1.24, this implies that the participants were fully, conscious of their home environment and mentally alert. The study also revealed that the participants at a ratio 2:1 needed social support. This is in congruence with findings reported by previous studies.[11]

A HPCAT was developed which put into cognizance, the holistic factors in the home model of pain/palliative care of patients with terminal illnesses and cultural factors in pain/palliative care settings (pain/palliative care ethos). The development followed the holistic factors synonymous with pain/palliative care and was divided into seven domains namely: Social Class assessment comprising Housing and Transport, Occupation, Education comprising, Family Support; current activities of daily living compromising personal care, mobility, transfer, bathing, toileting; psychological factor patients understanding of illness and goals of care; Spiritual assessment was reflected by the items: Do you believe in God,

How Important is religion and spiritual to you right now; and bereavement factor were reflected by item on burial site, location. There has been no previous tool which included these items thereby limiting comparison. The Occupational Therapy Initial Assessment Tool (OTIAT) Gold Standard has a psycho-social sub-scale which consists of items on social situations, although OTIAT had a psycho-social sub-scale. This sub-scale is reflected in an open-ended format. However, the newly developed tool (i.e HPCAT) included additional domains in line with the holistic approach in palliative care namely; Spiritual and Bereavement factors. This is particularly important in Nigeria where spiritual and bereavement factors are of great importance e.g. a person may indicate where and how to be buried while alive in line with his/her faith system. This is shown by the finding of this study to enhance quality of life. These items have not been investigated by earlier studies hence comparison could not be made.

The finding of the study showed all the variables of the newly developed HPCAT were found to enhance quality of life. These variables were housing, family support, activities of daily living, cause of illness, the goal of care, and how important is religion and spirituality to you right now? Home accessibility was found to show a statistically significant contribution towards enhancing quality of life. This finding corroborates the findings [12] that for terminal patients, who face death, spiritual and religious comfort may be even more important than physical and psychological health and physical modifications of the home environment with a holistic factors approach promote autonomy and sustained engagement.[13] The other items "Home accessibility, modification safety and Bereavement" the finding of the study also significantly enhances the quality of life of the participants. This is in concordance with previous findings on the association between home accessibility and modification that enhances quality of life.[14]

This study provides a guide for clinicians in pain/palliative care settings on which holistic factors to measure and target in practice. This will enable clinicians to allocate patients with terminal illnesses to the right type of ergonomic home assessment in intervention targeted at modifiable holistic factors. In view of the serious consequences of patients suffering from

terminal illnesses on individuals and society, it is imperative to use the tools that are capable of enhancing the quality of life of patients receiving treatment at home model of pain/palliative care settings. To the researcher's knowledge, this HPCAT tool is the first attempt at providing home assessment tool for patients in a home model of pain/palliative care that puts into cognizance the peculiarities of the Nigerian culture, pain/palliative care ethos and environment. Thus, this study provides a clinically applicable HPCAT suitable for use by clinicians in home models of pain/palliative care setting both in Nigeria and Africa. These peculiarities in culture, holistic factors in pain/palliative care and Socioeconomic factors are similar to most African countries. This new HPCAT may be effective in clinician decisions in the management of patients with terminal illnesses in the home model of pain/palliative care setting, perhaps in other African countries.

The newly developed HPCAT had seven domains; Social class assessment, Assessment level of consciousness, Activities of daily living assessment, Patient insight into illness, Spiritual assessment, Home assessment and Bereavement support. The concept of the new HPCAT having several domains is in line with guidelines on HPCAT which says that holistic approach in terms of psycho-social care, spiritual care as well as support in the activities of daily living should be provided for patients with terminal illnesses at home model of pain/palliative care. [15]

CONCLUSION

This study developed a home-based palliative care assessment tool for patients with terminal illnesses at the home-based model of pain/palliative care which will be useful clinically in a home-based model of palliative care in Nigeria.

RECOMMENDATIONS

The newly developed HPCAT is recommended for use in a home-based model of pain/palliative care in Nigeria and other African Countries in order to enhance QoL of patients with terminal illnesses because the assessment tool capitalizes on environmental resources to facilitate end-of-life occupational participation.

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APPENDIX 1

Communalities

	Initial	Extraction
HousingTrans	1.000	.632
Occupation	1.000	.831
EducationalLevel	1.000	.728
FamilySupport	1.000	.402
SocialClass	1.000	.939
SocialSupport	1.000	.411
FriendsSupport	1.000	.502
NeighboursSupport	1.000	.475
GovmntSupport	1.000	.500
WelfareSupport	1.000	..237

Extraction Method: Principal Component Analysis.

Communalities

	Initial	Extraction
SecECauseofIllness	1.000	.613
Treatable	1.000	.704
IfTreatableOptionsDRUG	1.000	.897
CauseofDisease	1.000	.444
WorryaboutDisease	1.000	.511
Thinktoomuchaboutillness	1.000	.512
Treatableillness	1.000	.426
Burdenedbycondition	1.000	.497
Physiotherapy	1.000	.743
Surgery	1.000	.779
Radiotherapy	1.000	.786
WhatisyourgoalofCare	1.000	.408
HowIllnessaffectcloserelationship	1.000	.605

Extraction Method: Principal Component Analysis.

Communalities

	Initial	Extraction
SectionDBedMobility	1.000	.793
Transfer	1.000	.888
N06MobilityBalance	1.000	.931
Telephone	1.000	.772
MovesAround	1.000	.511
Business	1.000	.431
Visiting	1.000	.490
House chores	1.000	.325
Feeding	1.000	.500
Beddings	1.000	.613
Drugs	1.000	.700
WheelChair	1.000	.310
Washing	1.000	.419
CuttingofGrass	1.000	.512
WashingofPlates	1.000	.417
WashingofClothes	1.000	.389
WashingofFloor	1.000	.499
GeneralCleaning	1.000	.387
PersonalCareeating	1.000	.211
PersonalCareEating	1.000	.395
Grooming	1.000	.938
Bathing	1.000	.928
Toileting	1.000	.941
SelfMedication	1.000	.864
DomesticMealPrep	1.000	.894
Housework	1.000	.811
Laundry	1.000	.825
Garden	1.000	.825
N09CommDriving	1.000	.767
Finance	1.000	.848
Shopping	1.000	.863
Writing	1.000	.827
Work	1.000	.770
Leisure	1.000	.859

Extraction Method: Principal Component Analysis.

Communalities

	Initial	Extraction
SecFSpiritualDoUbelieveinGOD	1.000	.517
PreviousReligion	1.000	.918
CurrentReligion	1.000	.944
ImportanceofReligion	1.000	.590
CurrentBelieveSystem	1.000	.444
Religionisimportnat	1.000	.390
AtpeacewithBelievesystem	1.000	.501
Likestopray	1.000	.404
Prayerisimportnat	1.000	.308
DiseaseAffectsme	1.000	.318
RelatrionshipwithGodisPerfect	1.000	.219
AtPeacewithChildren	1.000	.399
AtPeacewithLovedones	1.000	.470
AtPeacewithneighbours	1.000	.436
DoUpray	1.000	.730
Hasthisillnessaffectedyourrelationship	1.000	.603
Howiscurrentrelationshipwith God	1.000	.613
Anyspiritualorreligiousobligation	1.000	.630
AtPeacewithfamily	1.000	.739
AtpeacewithGOD	1.000	.752

Extraction Method: Principal Component Analysis.

Communalities

	Initial	Extraction
SectionGHousetype	1.000	.815
Ownership	1.000	.800
PersonalAlarm	1.000	.648
LeasingHome	1.000	.457
Bell	1.000	.611
Rings	1.000	.472
N013HomeAccessibilityFront	1.000	.782
BackAccess	1.000	.544
Internal	1.000	.630
Bathroom	1.000	.751
Toilet	1.000	.641
Bedroom	1.000	.707
Seating	1.000	.426
Innerroom	1.000	.635
Backyard	1.000	.561
FronView	1.000	.437
BoysQuaters	1.000	.512
Varander	1.000	.459
Passage	1.000	.367

Extraction Method: Principal Component Analysis.

Communalities

	Initial	Extraction
OverallIssuesIdentifiedMEDICAl	1.000	.330
Social	1.000	.283
Psychological	1.000	.513
Spiritual	1.000	.664
LeasingCemetry	1.000	.555
HomeAssessmentModificationNeeded	1.000	.771
bereavement support	1.000	.715

Extraction Method: Principal Component Analysis.

The initial variables were 120 and variable reduction techniques were applied using principal components analysis (PCA). The variables that I feel most likely represent the construct were selected from the questionnaires and these were the ones that were highly correlated. The questionnaires were shortened to remove more than one item that measured the same construct. The researchers choose to remove the ones with extraction less than 0.500.

APPENDIX 2

APPENDIX 1: Screening Tool After Expert Panel Review

DEVELOPMENT OF HOME-BASED PALLIATIVE CARE ASSESSMENT TOOL

Name:……

DOB:……

Affix Patient Identification Label here.

SECTION A

Admission Date:…/… Contact Date:…/…. Physiotherapist/Palliative Care Clinician……	
DIAGNOSIS:	**MEDICAL HISTORY:**

SECTION B: SOCIAL CLASS ASSESSMENT CHART GUIDE

HOUSING AND TRANSPORT

1	2	3	4	5
≥ house, own vehicle (s)	1 house + /- vehicle	Renting house ≥ 3 rooms, + /- No vehicle	Renting house with ≤ 3 rooms No vehicle	No house & No vehicle

OCCUPATION

1	2	3	4	5
Professional with 1st class job, Prominent business owner, senior government officer, etc	Professional with middle class job, senior religious leader, ordinary business owner, etc	Small business owner, junior religious leader etc	Peasant Farmer, pretty trader, etc	Destitute

EDUCATION LEVEL

1	2	3	4	5
Tertiary or University Education	Post-Secondary (Non-University) Education	Secondary Education	Primary Education	Non Formal Education

4. FAMILY SUPPORT (Supports are Financial, Moral, Social and Spiritual)

1	2	3	4	5
Total Support	3 out of 4 support	2 out of 4 support	1 out of 4 support	No support at all

SCORRING INDEX OF SOCIAL CLASS ASSESSMENT

Parameters	Patient Score	Comments/Recommendation
Housing & transport means		
Occupation		
Education Level		
Family Support		
Total		
Average		
Patient social class (Round to whole number)		

(5) SECTION C: ASSESSMENT OF LEVEL OF CONSCIOUSNESS (USING GLASSGOW COMA SCALE)

Behavior	Response	Score
Eye Opening Response	Spontaneously	4
	To speech	3
	To pain	2
	No response	1
Best Verbal Response	Oriented to time, place, and person.	5
	Confused	4
	Inappropriate words	3
	Incomprehensible sounds	2
	No response	1
Best Motor Response	Obeys Commands	6
	Moves to localized pain	5
	Flexion withdrawal from pain	4
	Abnormal flexion (decorticate)	3
	Abnormal extension (decerebrate)	2
	No response	1
Total score:	Best response	15
	comatose client	8 or less
	Totally unresponsive	3

SECTION D: ACTIVITIES OF DAILY LIVING (ADL) ASSESSMENT

Key: 1 = Independent A = Assistance required D = Dependent

		Previous Status		Current Status	
	(6) MOBILITY				
9	Bed Mobility				
10	Transfers				
11	Mobility/Balance				
	(7) PERSONAL CARE ADL				
12	Eating				
13	Grooming				
14	Dressing				
15	Bathing				
16	Toileting				
17	Self Medication				
	(8) DOMESTIC ADL				
18	Meal Preparation				
19	Housework				
20	Laundry				
21	Garden/Home Maintenance				
	(9) COMMUNITY ADL				
22	Driving/Transport				
23	Financial Management				
24	Shopping				
25	Writing/Telephone				
26	Work:				
27	Leisure:				

(10) SECTION E: PATIENT INSIGHT (KNOWLEDGE/UNDERSTANDING OF ILLNESS)

	PATIENT UNDERSTANDING OF ILLINESS AND GOALS OF CARE	
28	Do you know the cause of your illness? – Yes/No	
29	Do you think is treatable? - Yes/No	
	If it's treatable what are the treatment options (i) Drug (ii) Physiotherapy (iii) Surgery (iv) Radiotherapy	
30	What is your worry about this illness?	
31	What is your goal of care?	
32	How has this illness affected any close relationship?	

(11) SECTION F: SPIRITUAL ASSESSMENT

33	Do you believe in God or a supernatural/holy/Almighty being?	
34	What religion were you raised in?	
35	What is your current religion or faith system? If different explore reasons/circumstances for changing	
36	How important is religion & spiritual to you right now?	
37	Prayer: Do you pray? Does it help? Would you like prayer with team/others?	
38	How has this illness affected your relationship with God?	
39	How is your current relationship/belief/spiritual communication with God	
40	Are there any spiritual or religious obligation/rituals/ sacraments etc that are important to note	
41	Are you at peace with your family?	
42	Are you at peace with God?	

(12) SECTION G: HOME ASSESSMENT

43	Type: ☐ House ☐ nit ☐ Hostel ☐ Nursing Home ☐ other:.....
44	Ownership: ☐ Owned ☐ Rented ☐ Government ☐ Boarding ☐ other:.....
45	Personal Alarm: ☐ Yes ☐ No

(13) HOME ACCESSIBILITY

		Accessible	Not accessible	Modifications/Corrections to be made
46	Front Access:			
47	Back Access:			
48	Internal:			
49	Bathroom:			
50	Toilet:			
51	Bedroom:			
52	Seating:			
53	Other:			

(14) SECTION H: BEREAVEMENT SUPPORT:

54 A. Burial Site: Owned Home ☐ Rented Home ☐ Government Home ☐ Public Cemetery ☐ Other ☐

55 B. Location: Front View ☐ Internal ☐ Side View ☐ Back View ☐ Other ☐

SUMMARY

ISSUES IDENTIFIED	GOALS/PLAN