

DEVELOPING A DIGNITY INSTRUMENT TO MEASURE THE OUTCOMES OF PALLIATIVE HOME-BASED CARE

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ABSTRACT

This research sought to develop a palliative care measurement tool that could track and measure the rendering of care by informal caregivers to dying persons across the diversity of South African cultural and religious groups. This mixed method research led to the development of an instrument consisting of a one-dimensional domain, eight sub-items and 56 scores against which care can be numerically quantified on a radar graph. It is recommended that this tool be utilised to provide objective indications about the quality of home-based palliative care rendered to terminally ill patients.

KEYWORDS: end-of-life care, informal caregivers, measurement tool, outcomes management, palliative care

INTRODUCTION AND BACKGROUND INFORMATION

The South African Medical Research Council (MRC) reported that 65 925 people in South Africa died of cancer in 2000 (Bradshaw et al., 2004). The Cancer Association of South Africa (CANSA) published on its website (CANSA, 2009) its vision being "... to lead the fight against cancer in South Africa and to save lives" by being "the preferred not-for-profit leader to enable research, to educate the public and to provide support to all people affected by cancer". Started in 1931 by a group of medical professionals concerned about the high incidence of cancer, CANSA has grown to become the leading cancer non-government organisation in South Africa with 45 offices and more than 6 800 volunteers and 388 staff members (CANSA, 2009). In 2006 CANSA concluded that, although it is committed to the prevention of cancer and life-saving interventions for most people affected by cancer, it is not doing well in supporting those 65 925 people dying of cancer annually and for whom its services came too late. CANSA took a re-look into palliative care in order to extend palliative care as a third core service of CANSA (CANSA, 2009). This service requires a management plan but the principle that "you cannot manage if you cannot measure" remains a barrier. CANSA commissioned

the South African Database for Functional Medicine (SADFM), a research-based organisation, to develop a measurement instrument for evaluating the outcomes of palliative care (Loubser, 2007).

In this article, palliative care refers to those end-of-life services allowing dying persons not only to “die in comfort” but also to “die in peace” (Loubser, 2009). CANSA relies on the services of volunteers as well as informal caregivers from the Department of Health to provide this care. Volunteers are mostly trained to do the menial tasks related to the “die in comfort” part of palliative care, and the “die in peace” part is reserved for skilled counsellors of whom there is a dire shortage in South Africa (CANSA, 2009). While some cancer victims might be dying in relative comfort, they might not be “dying in peace”. This study is CANSA’s response to address this issue, and CANSA made available its most experienced caregivers to explore the “die-in-peace” concerns of its clients.

THE PURPOSE OF THE STUDY

The purpose was to study the die-in-peace phenomena and to produce a measurement tool to be used routinely by informal caregivers to quantify the value they are adding through their services. The study was therefore designed to explore, identify and define the domain (what is to be measured) of end-of life care, its sub-items (which contribute to the domain) and the scores (of the sub-items).

OVERVIEW OF THE LITERATURE

A literature search for existing objective end-of-life measurement instruments - at caregiver level - was conducted using the following key words: palliative care, measurement instrument, objective assessment and routine assessment. No evidence of such an instrument could be found, although the need for such an instrument is evident from the literature (Jocham et al., 2006).

The challenge of developing the theory, such as end-of-life care, into a measurement instrument was reviewed in the literature, and there seems consensus that that this phenomenon needs to be explored to produce a measurement tool (Freeman, 2006). The need for such research to be conducted across different cultures, belief systems, and racial divides was emphasised by Halcomb et al. (2007). Although benchmarking the quality of end-of-life care is vital, this is not yet supported or accepted by service providers as it cannot be measured (Ellis, 2006).

The basic tenets of palliative care are mostly reported from a service delivery paradigm and the existing measures are used to manage quality assurance of all the services to secure a “holistic physical, spiritual, psycho-social, and physical care and comfort service rendered to terminally ill patients and their families, including a bereavement programme after death” (Cochinov, 2002; Walsh & Kawanko, 2002). Patients seem

more interested in the preparation for death (Aspinal et al., 2006), while the family and professional caregivers prioritise symptom management and physical comfort. Although Clayton et al. (2005) identified a framework whereby a structured discussion between the palliative worker, the dying person and the family could take place, they fell short of producing a measurable framework.

The view of Valderas and Alonso (2008) is that a patient-related outcomes measure is an instrument that can consistently measure the minimum points a patient has achieved upon admission and again upon discharge. The difference between the admission and discharge totals represents the outcome scores achieved on the measurement instrument. Statements by Hack et al. (2004) were useful towards understanding the core issues involved in a multifaceted society like South Africa.

RESEARCH METHODOLOGY

This study comprised both a qualitative and quantitative approach. Explorative unstructured focus groups were used to collect descriptive data to reveal the domain, sub-items and scores for the measurement tool. The tool was then implemented to collect information about the clients. Analysis of the patient data revealed the psychometric properties of the proposed measurement tool.

Qualitative sampling and data collection

Informal, experienced, CANSA caregivers were selected as focus group participants to reveal their personal and collective observations of the dying process. Care was taken to ensure representation of the total South African population as far as race, ethnicity, culture, and religion were concerned. The minimum criteria for participation included guidance of more than ten dying-persons on their end-of-life journey; a track record of dedication through volunteerism in palliative care; providing palliative care for five years or longer; only practical experience (as previous formal training might put this study's validity and reliability at risk); a member of one of the eleven South African cultural groups with in-depth knowledge and experience of that group's customary routines, beliefs and behaviours pertaining to the dying process. The researcher led 18 focus group sessions. Six caregiver groups were identified across South Africa with six to ten participants per group. Three rounds of four hour visits were made to each group one month apart.

First round focus groups

The first focus group round was used for building a cohesive interactive working group that understood the objective of exploring the domain of end-of-life care. Questions posed to participants attempted to determine what is meant by palliative care; why they were involved in providing palliative care; what they hoped to achieve; and, how they would know that they were successful in what they attempted out to do? With all the responses listed on a flipchart, participants were asked to consider and indicate the most

important and essential reason why they rendered palliative end-of-life care. A singular measurable objective (domain) of palliative care was thus established.

Second round focus groups

In this discussion the objective was to reveal the contributing factors (sub-items) that impact positively or negatively on the outcomes of palliative care. Furthermore, probing was done to encourage participants to reveal how they would recognise these positive factors to secure better outcomes and, having recognised them, how they would enhance those factors. The same was done with negative factors and how they could be negated.

The second round was also used to analyse, validate and rank the collective responses obtained from other focus groups. Each focus group had an opportunity to reflect on, and verify the relevance of the national data obtained from all focus group meetings. From their own background they had to evaluate the relevance of all responses within their own culture, belief system, racial grouping, socio-economic status, care setting and age grouping. If no, or little relevance was evident, the particular response item was removed from the list.

Participants also had to verify the relevance of the collective knowledge in relation to the domains, sub-items and scores. They were prompted to evaluate responses through open debate. This helped to verify and define the items that finally remained on the list. Following this, participants had to collapse similar response items on the list. Finally, they had to rank the items to identify the sub-items.

The open debates on issues raised were helpful as they produced additional background knowledge to the response items and provided a more in-depth understanding of other issues involved. The debates also assisted in identifying the layers of an operational model by clarifying nuances, meanings and contexts of the response items from the perspective of different cultural groups. They also contributed towards the knowledge of words and phrases used by informal caregivers. Palliative care situations that occurred commonly and the standard responses to some basic interventions were also identified. Finally, similarities and differences across the South African cultural, racial, religious, and belief systems became evident. The second round provided refined information which assisted in the design and drafting of a measurement tool for the diverse South African population.

Third round focus groups

A week before the third focus group round took place, all participants were provided with a draft of the proposed palliative care measurement tool. Participants were requested to familiarise themselves with the proposed instrument in an effort to raise their comments during the third round of focus groups.

Consideration was given to possible similar trends or comments which might indicate strengths or weaknesses in the design. The reliability, validity and clinical utility value

of the instrument were scrutinised by asking whether the information fit the diverse cultural perspectives of South Africa; was technically correct; the difficulty level was appropriate for operationalising the measurement instrument for informal caregivers' utilisation; and the language was universally understood by caregivers. The third round resulted in a measurement tool approved by the focus groups' participants.

Quantitative sampling and data collection

Quantitative data were collected by making use of the measurement tool. Participants were subjected to a test during the third focus group round to qualify them as credentialled users of the tool. They were requested do a cross-sectional score of their existing clients. As the instrument was designed to measure generically across the diverse South African population, the study did not exclude any cancer grouping and no willing participant (dying person) was refused participation in the study. The only eligibility criteria used in the selection of "dying patients" were they had to be 20 years of age or older; be cognitively aware; have a terminal irreversible illness; and were predicted to die within six months. After two weeks, 260 sets of client scores were received by the researcher on hard copy. The data were entered into an Excel spreadsheet and were used to calculate the Cronbach alpha coefficient for internal consistency (reliability).

ETHICAL CONSIDERATIONS

Permission to conduct the study was obtained from the Research and Ethics Committee, Department of Health Studies, University of South Africa. CANSA provided permission to interview CANSA caregivers to explore their experiences in caring for dying persons and to collect, analyse and interpret such information. Participants were briefed on their role in this study and were given the option to reconsider their participation at any time. Experiences of participants were presented anonymously. All data collected were recorded as confidential. Only the researcher had access to the identifying data.

PRESENTATION AND DISCUSSION OF DATA

Members of the focus groups agreed about their reasoning for being involved in palliative care. They concluded that their all-embracing effort was directed to support the dying person's ability to maintain or improve his/her dignity. They were all of the opinion that *"Dignity is not something you just give to a person; it is something the person earns ... our job is to put it within the dying person's reach."*

Another point of consensus was that the *"dying person's last functional activity on this earth was his/her reaching out to dignity."* Participants reported that if they failed to *"put dignity inside the reach"* of the dying person, they would be failing in their task. Improving the dignity of the dying person would be the indicator that they had succeeded in their task. Therefore dignity became the domain of the proposed measurement tool, which soon became known as the "dignity tool" amongst the participants. Through

elimination, collapsing, and ranking, eight sub-items were identified to support the dignity of the dying person. In the dying process these eight sub-items were all found to be interdependent, meaning that they were linked to one another.

The eight sub-items identified by the participants were communication, family harmony, fear, letting go, unfinished business, wishes, basic care and nursing care. Good communication was seen by participants as the *“best instrument to start re-arranging the dying person’s flowers of dignity”*. Without honest communication *“one would never be able to pick up the cotton threads that left a trail into the dungeons of the patient’s dignity underworld”*. Another construct is the harmony between the family and the dying person. If the loved ones were not *“in sync”* with the needs of the dying person, then the dignity of the dying person would be severely affected. The stigma attached to cancer in the rural communities, and denial of the dying process amongst the Western communities, were the most relevant issues ranked under family harmony.

Equally relevant, was the fear of the unknown at the *“end of the tunnel”*. The fear sub-item was very highly ranked by mostly white Christian communities, while black rural communities seemed to have little fear or conflict during their end-of-life journey to join their ancestors. The phenomenon of letting go was equally supported by all racial and cultural groups. Saying goodbye forever is never easy, more so for younger parents who had to leave their children behind. The unfinished business construct was experienced with equal intensity by all groupings. The achievement of settling old disputes *“is like cutting into an abscess, painful the lancing, but the peace it created echoes forever”*. Wishes have many dimensions, but all relate to the same underlying construct. All dying people must come to a decision about what should happen to their assets and relationships.

The sub-item of basic care concentrated on the apparent need by dying people to die at home amongst their loved ones and to receive physical care by those persons they respected and loved most. Pain, discomfort and physical distress on the other hand were grouped under the need for professional nursing care to provide relief for such symptoms. While white Christian communities gave pain and discomfort management the highest priority during the dying process of cancer patients, black rural communities did not prioritise pain management amongst the top five needs amongst their clients.

A definition was formulated for each of the eight constructs. These definitions contextualised the sub-items and many of the item responses previously eliminated through collapsing and ranking, now found their way into the sub-item definitions. Initially, the responses between the different cultural, racial and belief groups were difficult to include but, in the end, the groups overcame the cross-cultural issues by collapsing and ranking the diverse issues into constructs that were fundamental in nature and were shown that they could apply to all South Africans.

Table 1: Sub-items and their definitions

Constructs	Definitions
Communication	Measurement of the client's ability to communicate his/her daily needs and feelings through open, clear, frank, honest and meaningful communication.
Family harmony	Measurement of the person's ability to ensure that his/her loved ones react emotionally appropriately to his/her dying process; such as family withdrawal (due to stigma or denial or family that could not face the decline) or an overbearing family (not allowing privacy, space and respect) to allow a peaceful death.
Fear	Measurement of the client's ability to find comfort in his/her spiritual and/or religious beliefs during the dying process.
Letting go	Measurement of the client's ability to say goodbye to his/her children, family, friends, property, status, job and other earthly belongings.
Unfinished business	Measurement of the client's ability to settle old outstanding disputes, regrets, blames, forgiveness, conscience qualms and secrets, with him/herself, family, friends or community.
Wishes	Measurement of the client's ability to finalise all his/her wishes (wills, policies, bequests, agreements, funeral arrangements) to ensure that those left behind were informed and/or taken care of.
Basic care	Measurement of the client's ability to find comfort and satisfaction in his/her: <u>care environment</u> (<i>home, clinic, hospice, hospital</i>); <u>assistance with daily activities</u> (<i>eating, grooming, bathing, toileting, bed/chair transfers</i>); and <u>living conditions</u> (<i>cleanliness, bedding, temperature</i>).
Nursing care	Measurement of the client's ability to find comfort and satisfaction with the nursing care to alleviate discomfort, such as: <u>physical pain control</u> ; <u>vital organ support</u> (<i>breathing, ulcer management, bladder, bowel management</i>); and <u>symptom relief</u> (<i>nausea, diarrhoea, odours, rashes and itches</i>).

The scores represent the degree of “acting out” when a dying person’s dignity was affected. The “acting out” might represent a conscious or sub-conscious behavioural act to express the emotional conflict experienced by the dying person. The caregivers reported that these behavioural responses were easily observed and recognised as “acting out” and could readily be recorded.

Table 2: Scores and their descriptions

Scores	Acting out
Score 1	<i>"Not discussed or not responding"</i> (0%)
Score 2	<i>"Start talking"</i> (1–49%)
Score 3	<i>"Discussing or debating"</i> (50%–80%)
Score 4	<i>"Accepting or resolving "</i> (81%–100%)
Score 5	<i>"Working on family co-operation"</i>
Score 6	<i>"Only follow-up support needed"</i>
Score 7	<i>"OK"(the family is a unified team managing the dying process)</i>

During the qualitative research process there were strong feelings among participants that the role of the family (or loved ones) had to be incorporated into the measurement tool. Scores 5, 6 and 7 represented this notion. Caregivers reported that their task included the process whereby the dying persons and their loved ones became a highly functional team who experienced the end-of-life journey together. The term "die-in-peace" could be equated to "die-at-home-in-the-bosoms-of-loved-ones".

PSYCHOMETRIC STUDIES

The Cronbach alpha coefficient analysis is an estimate of an instrument's internal consistency. This calculation establishes an instrument's ability to measure what it purports to measure, namely its "true value". In a perfectly designed instrument the sub-items should all contribute equally to the "true value" and, thereby, render an ideal coefficient of one. It is therefore an indication of how consistently the sub-items contributed to the domain (Allen & Yen, 2002). The Cronbach alpha value for the designed eight sub-item instrument (see table 3) was 0.915, being an acceptable value for internal consistency (reliability). This means that the eight constructs contribute to the total score in a highly consistent manner. A stepwise regression analysis (exploring how each of the eight constructs contributes to the total score) shows an even contribution of each construct. Principal component analysis showed that the instrument had a single main component, with each of the constructs contributing fairly strongly to this component. This finding supports the instrument's high internal consistency (Van Deventer, 2008).

Table 3 indicates that the "letting go" construct is nearest to the "dignity" domain, with the "nursing care" domain being the weakest contributor. The content validity of the instrument, based on the ongoing peer review methodology used to verify the data during the descriptive data collection process, was considered to be substantial.

Table 3: Constructs with their contributions towards the dignity domain

Construct	Contributions	Construct	Contributions
Communication	0.706	Unfinished business	0.854
Family harmony	0.847	Wishes	0.822
Fear	0.848	Basic care	0.729
Letting go	0.892	Nursing care	0.607

A CASE STUDY

The following fictitious case study of Simon (55), dying of bronchial carcinoma and being cared for at home by his family with the help of Anne (a CANSA caregiver), illustrates the use of the “dignity instrument”. The scores 1–7, over time, are in brackets.

Communication

Initially Simon refused most of the time to discuss his feelings and needs (2), but now he is discussing his dying process with his family members, who are not yet comfortable with his attempts to have open and frank discussions (5).

Family harmony

In the beginning he discussed his family’s denial of his dying process only with Anne and he acted out against his family members from time to time (3), but now he does not act out anymore and is prepared to help them come to terms with his condition (4).

Fear

Simon spoke to Anne about his fear of dying (3), and she arranged for a pastor to attend to his and his family’s spiritual needs. Simon and his family are now functioning as a team with the pastor guiding them (6).

Letting go

Simon is too emotional to say goodbye to his 14-year old son (2), but now he is working with his son and wife towards a life for them without him (5).

Unfinished business

As Simon indicated that he would like to see his brother whom he had not seen for 10 years (4), his wife is now arranging a visit (5).

Wishes

He postponed all decisions regarding his financial affairs (3), but Anne has arranged for his attorney to visit him and take care of his estate. The attorney is working with him and his family to sort out all his affairs (6).

Basic care

Simon was in a hospice and wanted to go home (1). Anne is now facilitating his basic care with his family and he is contented but his wife must still adjust to him being at home (5).

Nursing care

Simon had no pain but needed oxygen from time to time which he controlled himself (4). His wife is now learning to manage his medication. (5).

The dignity outcome of the above case study was graphically charted on the “dignity tool radar graph” showing Simon’s levels of dignity improving and his family supporting him towards a peaceful demise.

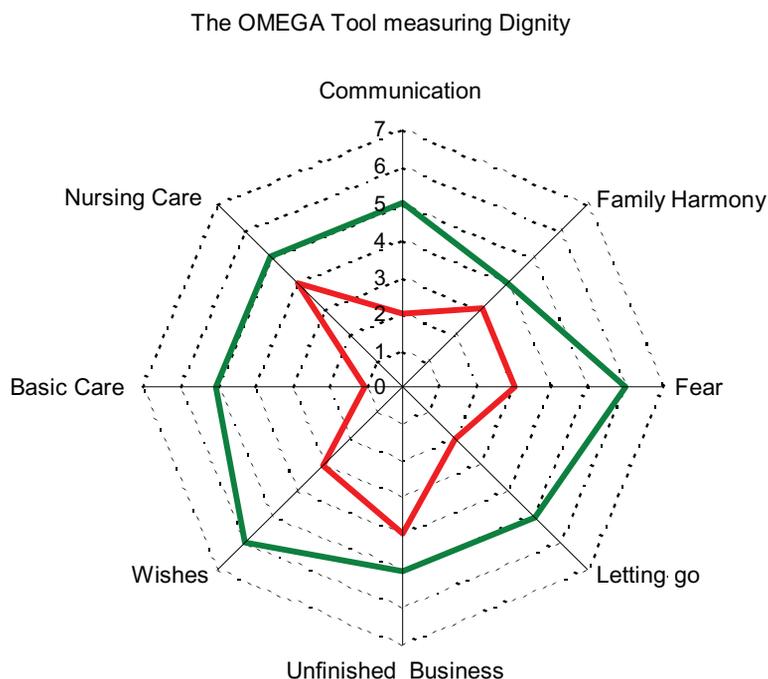


Figure 1: Graphic illustration of a case study’s results

CONCLUSIONS

In general terms, the nebulosity of the dying process has been demystified for the caregivers. A structure has been created to revitalise the support to dying persons with a uniform language to measure and track quality of care. Caregivers reported that the use of the tool had an invigorating and positive effect on them. They felt, for the first time, in control of a difficult situation. It seems possible that “burn-out” due to emotional stress might be reduced if assessments are replaced by a structured objective approach. Managers of the CANSA’s caregivers responded positively to the tool. They believed that it would help them separate those caregivers who were able to support a client’s “die-in-peace” needs from those that would better be left with the “die-in-comfort” needs.

The dying person should receive the appropriate support to die with dignity. The family of dying persons should have a better understanding of letting a loved one “die-in-peace”. Caregivers are empowered with knowledge and skills to identify and assess the components of the dying process and address it with confidence.

CANSA supervisors of caregivers using the dignity tool should now manage with focused, clear-cut questions and their responses can be to the point, precise, and truthful. The uniform language of the instrument can help caregivers to formulate problem statements and help supervisors to find more accurate solutions.

The training and development of caregivers should move into higher levels of understanding of the dying process and how to facilitate the process. CANSA can use the tool to demonstrate to funding groups the value they are adding to the end-of-life process of dying patients. The healthcare funding industry is moving towards an outcomes-based system and this instrument could facilitate the palliative care phase in the healthcare continuum.

RECOMMENDATIONS

Further research should be conducted regarding the ranking differences observed between black rural and white Christian communities. Black communities ranked the need for “family harmony” the highest and “pain” and “fear” of death the lowest, whereas white Christians ranked it inversely. Substantial evidence also became available that active inclusion of loved ones in the dying process may substantially reduce the need for bereavement programmes after death. This observation requires further research.

There was evidence that two groups of caregivers are doing their work for ulterior motives, namely the fundamentalist Christian-based caregivers who see it as their task to “*prevent the dying person going to hell by offering them last-minute-salvation*”, and the basic stipend seekers who saw their task only as manual support to provide basic chores, such as washing, cleaning, and taking care of children. Should caregivers feel

uncomfortable with the use of the “dignity tool” they should be identified and excluded from implementing the tool.

CANSA should use the data collected by the tool in a web-based research platform to track and manage palliative care processes nationally. The instrument has been translated into isiXhosa and Afrikaans with promising results. It is recommended that it be translated into other indigenous languages and tested in other communities as well.

LIMITATIONS

The dignity tool was not designed to replace the existing profession-based instruments used by professional counsellors for therapeutic use, but as an instrument to manage the rendering of optimal end-of-life palliative care to dying persons by caregivers. The tool was developed and tested only in South Africa and should be pre-tested in specific communities before its implementation.

The instrument should only be used on persons over the age of 20 who are cognitively alert and interactive and who are fully aware that they have an irreversible fatal ailment.

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