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A Structured Approach to End-of-Life Decision Making Improves Quality of Care for Patients With Terminal Illness in a Teaching Hospital in Ghana

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Abstract

Purpose: To determine whether a structured approach to end-of-life decision-making directed by a compassionate interdisciplinary team would improve the quality of care for patients with terminal illness in a teaching hospital in Ghana. **Findings:** A retrospective analysis was done for 20 patients who consented to participate in the structured approach to end-of-life decision-making. Twenty patients whose care did not follow the structured approach were selected as controls. Outcome measures were nociceptive pain control, completing relationships, and emotional response towards dying. These measures were statistically superior in the study group compared to the control group. **Conclusions:** A structured approach to end-of-life decision-making significantly improves the quality of care for patients with terminal illness in the domains of pain control, completing relationships and emotional responses towards dying.

Keywords

palliative care, interdisciplinary team, end-of-life decision making, quality of care, terminal illness, outcome evaluation, teaching hospital in Ghana

Introduction

Despite the growing evidence that early end-of-life care planning is beneficial when administered as part of routine care,[1] end-of-life decision making continues to be challenging for many clinicians because of barriers such as lack of communication skills in breaking bad news, fear of upsetting patients, a focus on curative care even when the patient is dying, and limited time and space for end-of-life decision making.[2] Because of these barriers, most clinicians perform this task poorly or avoid it completely. There is evidence that the quality of care delivered to terminally ill patients is rarely optimal.[3] Suboptimal end-of-life care is prevalent in all life-limiting conditions but is particularly worrisome in cancer care, where most patients must contend with symptoms and treatments that may worsen their quality of life.

Ghana, with estimated cancer deaths of 10 700 in 2012,[4] is particularly challenged when it comes to palliative care in patients with cancer. Due to low awareness of cancer in Ghana, a large proportion of patients with cancer present with advanced cancers that are incurable at the time of diagnosis.[5] For these patients, often the only realistic goal of care is palliative. However, due to the unavailability of such services many patients who could have benefitted from palliative care die without the needed support. Four pillars are central to the World Health Organization's public health palliative care strategic response to this problem which include[6] government policy and national strategy to improve access, education for health workers and the public, drug availability, and implementation of palliative care throughout health care systems. Recently, investigators from the Palliative Care, Policy and Rehabilitation Unit of Kings College London working together with investigators from the African Palliative Care Association proposed a fifth pillar, generation of locally

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relevant research evidence to support the public health strategy for palliative care.[7] The fifth pillar is dependent on the availability of locally validated, patient-reported outcome measures. However, evaluation of palliative care in Africa in terms of outcomes and effectiveness is grossly lacking. Harding and Higginson, in a review, found that of 26 service organizations identified on the continent, only 8 provided any form of monitoring or evaluation.[8] The 4 pillars are operational in Ghana but like most African nations, the fifth pillar is largely nonexistent.

At the Korle Bu Teaching Hospital (KBTH) in Ghana, suboptimal end-of-life care for patients with cancer has been a recurring problem, resulting in complaints from patients and families in several instances. Although "end-of-life conversations need to become a routine structured intervention...,"[9] they are not. The KBTH established a palliative care team (PCT) in May 2012 to address these deficiencies in the quality of care delivered to terminally ill patients. The PCT instituted a structured approach to end-of-life decision making to improve the quality of care for patients with terminal illness.

The PCT's palliative care intervention commenced in August 2012. The current study lays the foundation for setting up the fifth pillar in Ghana and provides the first evaluation of the PCT's use of a structured end-of-life decision-making process. The authors are unaware of previous studies reporting the adoption of such a structured approach to end-of-life care on the African continent. It was hypothesized that the structured approach to end-of-life decision making directed by a compassionate interdisciplinary team would improve the quality of care for patients with terminal illness and would be consistent with a more ethically justifiable patient-centered approach for end-of-life care.

The Structured Approach to Palliative Care Consultation

The PCT's approach is based on Fins' "Goal-Setting: a strategy for effective palliative care."[10] The structured approach developed in this study is a 4-step process by which patients and families are engaged in the palliative care process. These steps are determining triggers, gathering information, articulating goals of care, and building consensus for goals of care. The approach provides a framework for thinking about and working through a range of problems that arise in the provision of end-of-life care. Such issues include the transition from restorative care to palliative care, emotional responses to death and dying, symptom (particularly pain) control, and completing relationships. Prior to this intervention, end-of-life care was left in the hands of the patient's primary physicians. The PCT's intervention was thus a novel one in KBTH.

Determining Triggers

Patients with advanced disease prefer frank discussions on their prognosis and end-of-life care with their clinicians early in the course of their disease,[11] in the outpatient setting.[1] Thus, to facilitate end-of-life decision making, clinicians need to recognize triggers for initiating end-of-life discussions with patients and/or family. Triggers include spontaneous (or elicited) requests for end-of-life discussions by the patient or the family, perception that the patient is dying, when end-of-life decisions such as withholding or withdrawing life-sustaining treatments have been made and when there is a significant clinical development such as a worsening of the clinical course in a patient with life-threatening illness,[1] especially one needing intensive care unit admission and refractory end-of-life symptoms. One of our patients, a 44-year-old woman with widespread metastatic breast cancer, sought prognostic information from her oncologist after noticing new growths in the skin. In spite of her query and clinical deterioration, the oncologist did not initiate end-of-life discussion, feeling the patient was not ready. The palliative care referral came only 2 days prior to the patient's death. The triggers to initiating end-of-life discussions in this case were regrettably overlooked by the oncologist.

Gathering Information

The patient's clinical and narrative data are needed to formulate the care plan. While clinical data may be readily available in patient's charts, talking to others involved in the patient's care can be a source of valuable information. In addition, "listening" to the patient and family's narrative brings the relevant psychosocial, spiritual, and existential issues to the fore; good end-of-life care is context specific. Master Q was a 3-year-old boy diagnosed with embryonal rhabdomyosarcoma of the bladder when he was 8 months old. He had received 12 cycles of first-line chemotherapy prior to surgery. However, the cancer recurred less than a month after surgery, with rectal involvement. Palliative radiotherapy did not result in any improvement. In the PCT's process of gathering information, it became obvious that in spite of prior discussion with the pediatric oncology team, the mother did not fully understand her son's clinical situation. She was unaware of the implications of the recurrence and why the second line of chemotherapy was terminated after only 3 cycles. The PCT explained the nature of the son's condition, the poor response to treatment, and why the second-line chemotherapy was terminated. Only then did it become clear to the mother that the son's condition was terminal. That understanding was crucial for formulating and articulating the care plan for the patient.

Articulating Goals of Care

As the patient's clinical picture and narrative picture emerge, the goals of care become clearer. Goals of care are not static; they change with the patient's condition. They may progress from a cure, through restoring function, prolonging life, to palliative and comfort care. Because hardly any patient chooses palliative care as a first choice in goals of care, it is a choice that only becomes acceptable with time.[10] This usually occurs when patients accept the terminal nature of their illness. At this point, it becomes important to clearly articulate what is achievable in terms of symptom control, level of consciousness and its likely deterioration with time, the need to have important end-of-life conversations with family, and legal discussions regarding the patient's will so as to facilitate the process of developing a care plan.

Building Consensus for Goals of Care

Once the goals of care have been articulated, the clinician should suggest a care plan to the patient and family, ensuring that all the key players understand what the next steps are. This often means getting other services such as palliative care, hospice, spiritual care, psychological care, social work, and clinical ethics involved in the patient's care.

Because conflict over end-of-life treatment decisions is an important ethical challenge for the society,[12] it is important to build consensus with other key players in the patient's care when developing a care plan for the patient. If this is not done, it can lead to a potential conflict when the patient is unable to state his or her position. Although a surrogate increases the chances of a patient's wishes being carried out,[13] having a surrogate does not rule out a potential conflict when the patient becomes incapacitated. Conflicts can be especially difficult to resolve when it has to do with futile treatments as one case illustrated. A 74-year-old man with metastatic cancer of the stomach had been seeing the PCT for a few months. On the last home visit, it was discovered that the patient had been semiconscious for 5 days. He had stopped eating but the family caregiver had been force-feeding him with juices. Although the PCT had been having end-of-life discussions with the patient and his family and he had articulated his goals of care, specifying that he wanted to die at home and did not want any heroic measures, his wife, who was his surrogate, and his children were having difficulty coming to terms with the patient's wishes. The family was concerned that the patient was semiconscious because he had not been eating. They wanted a nasogastric (NG) tube passed so the patient could be tube fed. The PCT's opinion was that the patient was dying and passing the NG tube would be futile. As a compromise, an intravenous infusion of dextrose was set up, and a plan made to review the patient the following day. If there was significant improvement, the NG tube could possibly be passed. This was acceptable to the patient's family. However, when the patient was reviewed the following day, it had become obvious to the family that the patient was dying. They no longer wanted the NG tube and the patient died peacefully that night. As recommended by Workman,[3] a treatment trial deescalated and resolved a potential conflict between the patient's family and the PCT about futile care.

Methodology

Study Design

This study was a retrospective chart review of patients who died. The office in charge of research at KBTH determined that this study was not humans research due to the anonymous nature of the review and the use of deceased patient records. The sample size was 40 including 20 cases and 20 controls.

The study is a retrospective analysis of outcomes of 20 consecutive terminally ill patients and their families who consented to participate in the structured approach to end-of-life decision making between December 2012 and April 2014 at the KBTH and for whom complete follow-up data were available. Outcome measures of interest were nociceptive pain control, completing relationships, and emotional response toward dying. Twenty terminally ill patients and their families whose care did not follow the structured approach and for whom complete follow-up data were available were selected as controls. Patients in the control group declined the structured approach to care, preferring not to engage the team in discussing their terminal illness. Their focus was on symptom control. All control and study group patients were dead at the time of the study.

Study Setting

The KBTH is a 2000-bed tertiary academic institution in Accra, Ghana. The Oncology Center of the Hospital sees over 1100 patients per year.[5] This number is exclusive of patients with cancer seen in other departments of the hospital. The core palliative care service interdisciplinary team is made up of a pediatric oncologist, 2 family physicians with international fellowships in palliative care, a physician clinical psychologist and bioethicist with special interest in end-of-life care, a clinical pharmacist, 2 general/palliative care nurses, a public health nurse, and 2 community health nurses. The team has access to a radiotherapist, a chaplain, a social worker, a clinical and radiation oncologist, and a surgeon.

Definitions

Pain control. Assessment of nociceptive pain control as judged by the patient was scored on a 5-point scale: poor (no pain relief) = 1, fair (slight pain relief) = 2, good (moderate pain relief) = 3, very good (mild residual pain) = 4, and excellent (no residual pain) = 5.

Completing relationships. Byock's description of "completing relationships" was adopted in this study. "We are complete in our relationships when we feel reconciled, whole, and at peace. People say they feel complete when, if they were to die tomorrow, they'd have no regrets—they would feel they had left nothing undone . . . or unsaid."[14] According to Byock, 4 simple phrases—"Please forgive me," "I forgive you," "Thank you," and "I love you"—carry enormous power to mend and nurture relationships. All patients demonstrated aspects of their relationship with significant others where they needed to seek or grant forgiveness and express gratitude and/or love. We scored "completing relationships" on the basis of expressing the following 4 phrases to significant others: poor (expressing none) = 1, fair (expressing 1) = 2, good

Table 1. Malignancies in Terminally Ill Patients.

Study group, N = 20		Control group, N = 20	
GIT malignancies	5	GIT malignancies	5
Breast cancer	4	Breast cancer	3
Pancreatic cancer	2	Hepatocellular cancer	2
Ovarian cancer	2	Ovarian cancer	1
Head and neck cancer	2	Head and neck cancer	2
Osteosarcoma	1	Osteosarcoma	1
Malignant melanoma	1	SCC of face	1
Gall bladder cancer	1	Gall bladder cancer	1
Cervical cancer	1	Leukemia	1
Bladder cancer	1	Prostate cancer	1
		Kidney cancer	1
		Testicular cancer	1

Abbreviations: GIT, gastrointestinal; SCC, squamous cell carcinoma.

Table 2. Outcome Measures.

	Study group	Control group	*P* value
Age, years	53.7 ± 17.5	41.9 ± 17.9	.062
Pain control	3.9 ± 0.7	3.3 ± 0.6	.004
Completing relationships	3.7 ± 0.8	1.2 ± 0.4	<.001
Emotional responses toward dying	4.6 ± 0.7	2.3 ± 1.3	<.001

(expressing 2) = 3, very good (expressing 3) = 4, and excellent (expressing all 4 phrases) = 5.

Emotional response toward dying. The Kubler-Ross description of emotional responses of the terminally ill toward dying[15] was adopted. The stage of acceptance represented the most appropriate response, while denial was considered the least favorable and most difficult to influence by targeted intervention. The Kubler-Ross stages formed the basis for scoring as follows: denial = 1, anger = 2, bargaining = 3, depression = 4, and acceptance = 5.

Statistical Analysis

Data for the study and control groups were analyzed for differences in the scores for pain control, completing relationships, and emotional responses toward dying. The scores for the groups were expressed as mean ± standard deviation. Differences in the mean scores were compared between groups by independent samples 2-sided Student *t*-test assuming equal variance; a *P* value <.05 was considered statistically significant. Statistical analysis was performed using Microsoft Excel 2007 software Microsoft Corporation.

Results

In both groups, there were 11 females and 9 males. All patients were referred on account of end-stage malignancies. The spectrum of malignancies was similar between the 2 groups (Table 1). Although the control group tended to be younger, the ages of the 2 groups did not differ in a statistically significant manner (Table 2). As indicated in Table 2, the outcome measures were demonstrably superior in the study group compared to the control group.

Discussion

This study hypothesized that a structured approach to end-of-life decision making directed by a compassionate interdisciplinary team improves the quality of care for patients with terminal illness and is consistent with a more ethically justifiable patient-centered approach for end-of-life care. The results show that patients who had the structured approach to end-of-life decision making had significantly better outcomes in the measures assessed. The most appreciable differences in outcomes between the groups were seen in completing relationships and emotional responses toward dying. In these outcome measures, the study group averaged 3 and 2 times the scores for the control group, respectively. The results of other workers endorse these findings, indicating that patients are more satisfied with the quality of care they receive when they are actively engaged in their medical decisions.[16] Several studies have shown the efficacy of various interventions that can improve end-of-life care.[17,18] Although pain control was statistically superior in the study group, the clinical difference between the groups was less than a unit score of perceived pain relief. The Scottish Intercollegiate Guidelines Network on the control of pain in adults with cancer indicates that patients with cancer experience improved pain tolerance when they are encouraged to express emotions and understand the meaning and significance of the pain.[19] Possibly, the superior pain scores observed in the study group is attributable to such factors that were generally lacking in the control group. Additionally, other factors that contribute to an individual's perception of pain, notably, existential issues, interruptions in around-the-clock analgesia, and breakthrough analgesia were more readily addressed in the study group because of more frequent PCT visits.

Although not directly assessed, it was noted that the structured approach decreased the need for ethics consultations. This is not surprising since many ethics consultations result from conflicts about end-of-life decision making. Conflicts can be especially difficult to resolve when it has to do with futile treatments. As recommended by Workman,[3] a treatment trial can often deescalate and resolve a potential conflict between patients and their families and clinicians about futile care.

It is well documented that palliative care improves the quality of care for patients.[20,21] However, despite findings that early integration of palliative care in patients' treatment plans gives patients better quality of life,[20] PCTs are often involved late in the patient's disease trajectory. Some investigators have suggested that late involvement of palliative care makes no significant difference in the quality of care experienced by patients with cancer,[22] but other reports indicate that caregiver satisfaction, including caregiver attitudes toward palliative care, consistently improved even with late referrals.[23] In this study, caregivers who were part of the end-of-life discussions with patients reported more satisfaction than those who were not part of such discussions. During bereavement visits by the PCT, caregivers who had been part of the end-of-life conversations with the died patients were less distraught and appreciative of the services rendered. Caregivers who had not been part of such conversations were less eager for bereavement visits from the PCT.

Although there are guidelines on advanced care planning for terminally ill patients expected to die within a year,[24] the longest time a patient has been under the care of the PCT from the time of referral to the time of death has been 9 months. To date, all the patients with cancer who have been referred to the PCT have been referred late. However, the findings of this study show that even late referrals still benefit from palliative care if a structured approach is followed; end-of-life discussions are better late than never. Other workers have found that late discussions about prognosis with patients help with advanced care planning and make patients more satisfied with end-of-life care, especially when their family members are involved.[25]

Palliative care is a great resource for helping patients with end-of-life decision making.[26] End-of-life decision making is more manageable and satisfying for all involved when supervised by a compassionate interdisciplinary team, using a framework of shared decision making with patients and/or their families.[27]

Limitations

This study suffers from small sample size limitations. Its ability to determine significant differences between outcome measures assessed is therefore restricted. Additionally, the study is retrospective and therefore errors due to confounding and bias could have influenced the outcomes. Since patients in the control group declined the structured approach to care, our results may be biased by the fact that the study group may have been predisposed to engaging in end-of-life discussion, while the control group was less inclined to do so. This is a major limitation of this study.

It has been documented that willingness to discuss end-of-life care is predicted by older age.[28] The control group was significantly younger than the study group, and this age difference between the groups may account for different attitudes toward palliative care and end-of-life decision making. This may explain why the control group declined the structured approach to end-of-life care and suggests that future work will be necessary to ensure that this structured approach can be adopted by patients of all ages and that it is equally effective for patients regardless of age.

However, it is important to note that this work is the first attempt to study and measure the impact of a structured approach to end-of-life care in Ghana. Despite these limitations, this work is essential to establishing the feasibility and importance of instituting an interdisciplinary PCT in Ghana. These preliminary results suggest that patient outcomes are dramatically improved by the establishment and use of these teams. Future research will address these limitations by random case selection or trying to control for these factors.

Conclusion

This study aimed to evaluate the outcomes of a structured approach by an interdisciplinary PCT in a teaching hospital in Ghana and found that the approach significantly improved relevant outcomes for end-of-life care.

The improvements occurred in the domains of pain control, completing relationships, and emotional responses toward dying. In these domains, the greatest improvements were seen in completing relationships, emotional responses toward dying, and pain control in decreasing order of magnitude.

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Declaration of Conflicting Interests

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