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Transitions Regarding Palliative and End-of-Life Care in Severe Chronic Obstructive Pulmonary Disease or Advanced Cancer: Themes Identified by Patients, Families, and Clinicians

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Abstract

Background—Classic trajectories of illness at end of life (EOL) suggest different care needs for patients with cancer versus chronic obstructive pulmonary disease (COPD) and may lead to different experiences of transitions over the course of a life-limiting illness. Patients may experience transitions in different ways than clinicians. No prior studies have examined this issue from patients', families', and clinicians' perspectives.

Objectives—We sought to explore transitions, defined as experiences that patients and family members viewed as milestones in the evolution of their illnesses and therapies, and compare these perceptions with the perspectives of the patient's physician and nurse to provide insights about communication concerning EOL care.

Methods—We conducted a qualitative study using grounded theory to examine participants' perspectives on the experiences of key transitions in the context of living with advanced COPD or cancer. In-depth interviews with patients, family members, nurses, and physicians were conducted by experienced interviewers.

Results—Six themes were identified regarding participants' experiences with transitions. Themes that defined transitions among both patients with COPD and those with cancer included: new or different treatments and no more treatments available. Themes unique to patients with

COPD were activity limitations due to functional decline and initiation of oxygen therapy. One theme unique to clinicians was acute exacerbation of illness or hospitalization.

Conclusions—This study identified differences in the meaning of transitions for patients versus clinicians and for patients with COPD versus those with cancer. These findings may offer clinicians the opportunity to provide a more patient-centered approach to communication about end-of-life care by acknowledging and addressing transitions in palliative care from the perspective of the patient and family.

INTRODUCTION

Metastatic cancer and chronic obstructive pulmonary disease (COPD) are life-limiting illnesses with different trajectories of functional decline and different care needs for patients at the end of life.¹ Cancer trajectories typically have a long maintenance period of good function with a rapid decline in clinical status, while patients with COPD often experience a slow decline in physical capacities marked by acute exacerbations, followed by a limited number of improvements near but not quite reaching their prior baseline.² These trajectories of illness identify critical points in a patient's illness and may provide helpful markers for clinicians. Hence, they often frame transitions in palliative and end-of-life care from the perspectives of clinicians. However, patients and family may experience transitions in different ways or at different times. Comparing patients' and families' experiences of transitions with clinicians' perspectives may provide insight for and facilitate a more patient-centered approach to communication about end-of-life care.

Patients with life-limiting illnesses undergo many transitions as their illness progresses. In order to assist patients and their family in making adjustments through times of transitions, clinicians must first recognize how transitions are experienced. Transitions in clinical care are often associated with changes in services that promote the timely transfer of patients from one level of care to another, such as the transition from curative treatment to palliative care.^{3,4} However, in the context of this paper, transitions in palliative care were defined more broadly as events or perceptions that patients, family members, and clinicians viewed as milestones in the evolution of their illnesses and therapies.

We sought to explore transitions regarding palliative and end-of-life care from the perspectives of patients with severe COPD or advanced cancer, their family members, physicians, and nurses, using semi-structured interviews. Understanding patients' and family members' experiences of transitions may be important for providing patient- and family-centered care and may allow clinicians to target end-of-life communication interventions based on patients' needs.

METHODS

Design

The qualitative design utilized in-depth interviews about participants' perceptions of hope and prognostic information in the context of life-threatening illness. During individual interviews, patients and family members were asked to discuss transitions or sentinel events that occurred during the course of their illness that may have affected their outlook or hope

for the future. Physician and nurse participants were asked to discuss transitions within the context of the specific patients. The design and recruitment has been reported elsewhere in this issue.⁵ Data were collected between January 2003 and December 2006. All study procedures were approved by the Human Subjects Division of the University of Washington.

Participant recruitment

Physician participants—To sample different approaches to palliative care, physicians were recruited first, and patients, family members, and nurses were subsequently recruited for each physician participant. The recruitment strategy was designed to sample physicians with a spectrum of attitudes toward with palliative care. To identify physician participants, the investigators selected an “expert panel” of physicians in two cities (Seattle and Tacoma) from three specialties (oncology, pulmonary, and general medicine). Each panel member was asked to identify physicians whom they judged to be “thought leaders” and to classify each physician into one of three categories: focused on curative or life-prolonging treatment, focused on palliative care, or “in the middle.” Physicians were then randomly selected from each category, stratifying by specialty. Eligibility criteria for physicians were: (1) 50% time spent in clinical practice and (2) ability to identify at least four eligible patients (with the goal of recruiting two patients).

Patient participants—Enrolled physicians were asked to identify patients using two eligibility criteria: (1) diagnosis of advanced cancer (metastatic solid cancer or non-operable lung cancer) or severe COPD (forced expiratory volume in 1 second [FEV₁] < 35% predicted and oxygen dependent) and (2) the physician “would not be surprised if the patient died from any cause in the next year.”⁶ Patients were excluded if they did not speak English sufficiently well to participate in an interview.

Family and nurse participants—Patients identified a family caregiver or a close friend who was involved in their care. Inability to name a person in this role did not exclude a patient from participation. Patients identified nurses involved in their care and with whom the patient had interacted. If patients did not identify a nurse, study staff asked the patient’s physician if he or she worked with a nurse who was involved in the patient’s care.

Data collection

Semistructured interviews were conducted by two experienced interviewers who received training by investigators. Interviewers completed 5 hours of observation before conducting solo interviews. Investigator-trainers sat in on interviews periodically for quality-control purposes. Follow-up interviews with patients were conducted at two points in time: 4–6 months after study entry and 12 months after entry. We planned to interview three quarters of the patients at 6 months and one-third at 12 months. The interviews were audiotaped and transcribed verbatim.

Qualitative analysis

We used a limited application of grounded theory for these analyses.^{7,8} The investigators represented medicine, nursing, health services research, educational psychology,

anthropology, social work, and hospice care. Investigators were initially grouped into pairs; each pair included one clinician and one non-clinician.

For this paper, we completed three analytic steps: open coding; axial coding; and selective coding. Open coding involved the development of a coding framework designed to capture the meaning of participants' speech. Axial coding was used to identify relationships between codes. Selective coding was used to develop theoretical constructs using open and axial codes. The research team reviewed transcripts from all interviews associated with 10 patients including a physician, family, and nurse. The team developed an iterative list of codes related to the research topics of communication about hope and prognostic information. These codes were then applied to all remaining interviews by investigators, who worked in pairs for 50% of the remaining interviews and individually for the other 50%.

One of the codes developed during the open coding process was a code titled transitions, defined by the team as "the discussion of times or events salient to the participant that may denote transitions or shifts in needs from clinicians or a shift in the participant's outlook on their illness or treatment." The analyses reported in this paper focused on examining the characteristics of transitions identified by this code; one of the investigators (L.F.R.) examined data from codes that were related to the transition code. These additional codes were examined to more fully understand the categories and properties of transitions regarding palliative and end-of-life care. Last, selective coding was completed, during which the single core concept of transitions and related categories were built from the open and axial codes. This analytic step was completed on transcript sets for eight patients (four with COPD and four with cancer) in which all participants (patient, physician, family, nurse) were represented. The interviews ($n = 32$) were examined to ensure that the *transition* concept and categories that emerged during the open coding process accurately reflected information from the entire interview and from the perspective of all participants associated with a given patient.

Trustworthiness for transitions coding was established by: (1) initial review of the transitions coding scheme by the entire multidisciplinary team; (2) reexamination of the transition coding scheme for a quarter of the transcripts; and (3) recoding of a random sample of 30 transitions passages into the transitions coding scheme by a second investigator blinded to the initial coding results. Results of the recoding exercise yielded 90% agreement and a κ statistic of 0.85, both representing excellent agreement.⁹

RESULTS

Description of participants

Expert panel members identified 129 physicians for potential participation, 123 of whom were actively practicing in the Seattle–Tacoma area. Of those approached, 84 physicians met eligibility criteria and 49 agreed to identify patients for the study. Thirty-one physicians identified at least one patient who participated and completed at least one study interview. Thus, the physician participation rate was 37% (31/84).

Participating physicians identified 67 eligible patients, and 55 consented to participate (82%; 55/67). Of the 55 enrolled patients, 42 identified a family member or friend, and 36 of these individuals consented to participate (86%, 36/42).

Twenty-five nurses participated (100% of those approached).

Overall, we interviewed 31 physicians, 55 patients, 36 family members, and 25 nurses. Demographic characteristics of patients and families are shown in Table 1 and characteristics of the clinicians are shown in Table 2. Of the 55 patients, 24 had oxygen-dependent COPD, 30 had advanced cancer, and 1 had both COPD and cancer. Two patients were enrolled in hospice at study entry, and seven patients entered hospice during study follow-up. Twenty-one patients died within the first six months of the study. Second interviews were completed by: 22 (71%) physicians; 38 (69%) patients; 27 (75%) family; and 6 (24%) nurses. Third interviews were completed by: 7 (32%) physicians; 16 (42%) patients; 10 (37%) family; and 1 (17%) nurse.

Overview of the themes identified regarding transitions in palliative care

Transitions identified by patients, families, physicians, and nurses are described in Table 3. Some of these were similar across COPD and cancer and others were unique to their particular diseases. Physicians and nurses seemed aware of the transitions experienced by patients, but often assigned different meanings to them. Some transitions were significant for clinicians, but not described by patients.

Themes regarding transitions common to patients with COPD and cancer as well as their clinicians

Theme: new or different treatments—For patients with COPD or cancer, transitions were associated when new or different treatments were believed to be possible or were offered by a clinician. For patients with cancer, this often meant new chemotherapy regimens, while for those with COPD it usually meant a new bronchodilator option. Discussion of new or different treatments was often accompanied by statements from the patient or family of a renewal of hope. A patient with COPD said:

She (the physician) mentioned this new pill and she said they've been testing it for over a year, so that gives me a lot of hope. I kind of think [the medication is] helping a little . . . that's part of the hope, I mean. I'd eventually like to go to the golf range and swing a few.

A family member of a patient with cancer described a change in treatment:

They put in a port in his chest for access and he's doing very well on this particular combination of drugs, so things are looking very good, at the moment. They've come up with so many new treatments that weren't available when he first got this disease. So there's always hope out there.

Clinicians recognized that offering new or different treatments could instill hope in their patients. One physician caring for a patient with COPD reflected:

We've talked about interventions with regards to other surgical procedures and things like that. I think he was hoping there'd be something else coming up . . . both in the sense of medications and technologies.

The potential of new or different treatments throughout a patient's illness trajectory was recognized by both patients and clinicians as positive milestones associated with hope for improvement in the patient's disease status and prognosis.

Theme: no more treatment/curative to palliative care—Patients with cancer and those with COPD described a transition when they realized there were no further treatment options as “there's nothing more they can do” or “no more treatment,” while providers viewed lack of treatment options as the time to transition from curative to palliative care. A patient with COPD discussed what he feared as the last resort of his treatment plan:

I can't imagine anything more severe than prednisone . . . I have a real fear of prednisone as the sort of last pitch deal . . . and maybe that's the thing. What's next? I have no hope beyond prednisone.

Family members also recognized no more treatment as a transition time. One family member voiced, “She couldn't tolerate that chemo and so that was the last thing that he had in his little bag of tricks there. So he actually told her, there's nothing more he could give her right now.”

Clinicians similarly acknowledged the lack of treatment options as a transition but, for them, the transition was marked as a time to shift from curative to palliative care.

An oncologist captured this shift by stating:

Hospice comes in when you've decided there is not more effective therapy or every time you give the therapy, you about kill the patient and it's really not worth it. Or sometimes it comes from the patient saying, ‘I just can't take anymore,’ and sometimes it comes from the physician saying, ‘I just don't have anything that will make it better.’ Then the goal is to have the best quality life and live to the fullest.

Themes regarding transitions unique to patients with COPD and their clinicians

Theme: activity limitations/functional decline—For nearly all patients with COPD, significant milestones were often associated with activity limitations or functional decline. This theme was not described by patients with cancer or their families in our dataset. Patients with COPD used language such as, “I can't do the things I used to do” to describe the activity limitations they faced; clinicians used the language of activity limitations but also the more clinical language of functional decline to describe these changes. A patient expressed these challenges in the following manner:

I used to dance and travel; then I was diagnosed with COPD and oxygen therapy, everything stops – it's like you are on a leash, tied to a regimen. I feel sad I can't do the things I would like to do with my kids . . . go to the horse races. I haven't done anything I like to do.

Family members of patients with COPD acknowledged these activity limitations:

He went to the store and when he came home, walked the driveway, up the basement steps, up to the main floor, and he was just purple . . . he was gray. And uh, he stood and put his oxygen on . . . and uh, he looked at me (deep breath—voice breaks) and he said “The emphysema’s winning.”

Clinicians caring for patients with COPD recognized these activity limitations and functional declines as important transitions for their patients with lung disease. One physician commented on the patient’s functional decline saying, “Her exercise tolerance and functional status have dropped and she is not able to care for herself.”

Theme: initiation of oxygen therapy—The initiation of oxygen therapy, or in the words of many patients “starting on oxygen”, was a key milestone in the COPD disease trajectory. Often patients viewed oxygen therapy negatively because it further restricted their activity level and reflected declining disease status.

Originally, I thought I would [eventually get] off the oxygen, when I first got on it, and I’m sure [the physician] knew I wouldn’t, but he never said. But . . . I don’t know . . . It’s just been a gradual thing, you know, this is the way it’s going to be.

Physicians also recognized the initiation of oxygen therapy as a milestone in a patient’s condition, but often focused more on its clinical benefits than on its restrictive or prognostic implications. One physician described prescribing oxygen by saying, “The initiation of oxygen therapy was just one more therapy that might help.” However, a few physicians discussed the transition to oxygen therapy as the time they began to think about end-of-life issues for the patient.

Themes regarding transitions unique to clinicians for patients with COPD

Theme: illness exacerbation or hospitalization—Clinicians caring for patients with COPD identified illness exacerbation or hospitalization as a sentinel clinical event that defined an important transition for their COPD patients:

It’s like a seminal event, you know, sort of some critical event that then, snaps a trigger, for both of us, the patient and me, about where you are in life. Because often, a lot of the folks I have just kind of putter along, kind of at the same sort of reasonable functional level, but not great. And then they . . . have a rapid decline or a hospitalization and that often is the time where people’s quality tends to start changing.

Some physicians used illness exacerbations or hospitalizations in their COPD patients as a time to initiate discussion of future treatment options with patients, “It’s hospitalizations or acute events that precipitate the need to actually say ‘you know, you just went through this horrible time in the hospital, what do we want to do if that ever happens again?’” By contrast, neither clinicians caring for patients with cancer nor patients in either disease category were likely to identify illness exacerbations or hospitalizations as an explicit time of transition.

Themes regarding transitions unique to patients with cancer

Theme: improvement from illness—Patients with cancer discussed the hope of improvement from illness as a period of time when the patient's overall health would improve because their disease was stable or their symptoms were improving. This theme was not present among the patients with COPD, perhaps reflecting the nature of the disease process. Talking about improvement from illness was often accompanied by statements of hope such as this patient describing her posttreatment recovery, "The radiation finally killed the cancer and then they went in and put a stent in and then they removed the tubes from my body and there I was . . . free once again."

A family member of this same patient acknowledged this positive milestone saying:

I can see she's getting better. When she goes in for treatments and her body goes down so far that she gets really sick and then, when she goes off of the treatments, then her body starts building back up, which she is doing right now.

DISCUSSION

Our findings suggest that there are some important differences regarding transitions in palliative and end-of-life care between patients with COPD and those with cancer and that these transitions often involve more than a "one-time" transition from curative care to care focused on "comfort measures only." Instead, these transitions were different for different individuals covering a range of issues including changes in therapeutic options but also changes in symptoms, quality of life, and functional status. In addition, patients and their families differed in their perspectives on some of these transitions compared with physicians and nurses. Identifying individual perspectives and the differences in perspectives between patients and clinicians broadens the common definition of "the transition from to palliative care" used by clinicians. Understanding patients' experiences of transitions in palliative care may provide clinicians an opportunity to support patients and family members not only in their physical health, but with the psychosocial dimensions that accompany life-limiting illnesses. An individualized approach may also provide an opportunity for clinicians to focus on the unique experiences and needs of individual patients and families in a way that is congruent with the principles of a patient- and family-centered approach to palliative and end-of-life care. Based on our findings, we hypothesize that interventions utilizing an individualized approach to understanding and addressing transitions in palliative care will result in increased patient and family satisfaction with end-of-life care, decreased fear and anxiety, and an overall improved dying experience.^{10–12} Further studies will be needed to test these hypotheses.

A theme found exclusively in COPD patients focused on oxygen therapy, which imposed further restrictions on activities. Wearing oxygen can be accompanied by social stigmas and lead to social isolation.¹³ A study of patients living with severe, oxygen-dependent COPD found that patients described oxygen therapy in negative terms.¹⁴ Physicians in our study recognized the initiation of oxygen therapy as a transition phase for patients, but discussed the initiation of oxygen more as an effective treatment to promote survival and improve quality of life. Discussions about transitions associated with oxygen therapy may help

patients manage the difficult emotions associated with living with a chronic, debilitating disease and to accept treatments that require adjustment in their daily lives.

Our findings also illustrate how patients and clinicians may identify the same transitional milestones but may respond differently to those milestones. For example, when further curative therapy was exhausted, patients described this transition point as, “there is nothing more they can do.” By contrast, clinicians framed this transition as a shift from curative to palliative care; clinicians talked about what they could offer in place of cure. One explanation for this difference may be physicians’ discomfort acknowledging that there is “nothing else” that might prolong patients’ lives. In one study, caregivers reported that when physicians told patients that nothing else could be done, the patient’s sense of hopelessness increased.¹⁵ Another explanation for the difference in perspective may be that although physicians believe they can provide palliative care with a focus on symptom control and quality of life, rather than on cure,¹⁶ patients have a different perspective because this information is not adequately explained to patients or is difficult for patients to accept. Regardless of the reasons for these different views, clinicians should recognize this time as a milestone for patients and proactively address this topic. To help patients and families accept this transition, clinicians may benefit from skills for framing discussions about the availability of no more treatments and emphasizing symptom management.^{17–19} A recent systematic review outlined evidence-based recommendations on communication methods for health care providers who rarely discussed transitions from curative care through palliative care.²⁰

Another finding that highlights the difference between clinicians’ and patients’ perspectives was the relevance of illness exacerbation or hospitalization. Clinicians caring for patients with COPD viewed exacerbations or hospitalizations as a time of transition for patients. Some clinicians in this study capitalized on these clinical events to provide information on changes in prognosis or to hold discussions about end of life. This use of hospitalizations by clinicians has been described previously.²¹ However, few patients and family members in our study talked about these events as transitions. This may be related to the complexity of these exacerbations not affording the patient or family the opportunity to reflect on the possible long-term implications. Furthermore, patients and families often suggested that physicians should bring these issues up prior to a clinical deterioration when patients may be better prepared to make critical decisions.

This study has several limitations. First, the study was designed to identify patient, family, and clinician perspectives, but was not designed to describe the prevalence of the perspectives identified or the prevalence or timing of the transitions in palliative care that we have described. Further studies will be needed to address these issues. Second, generalizability may be limited since the study was conducted in one geographic region and patients had one of two life-limiting diseases. However, these two illnesses account for more than one-quarter of deaths among Americans aged 65 or older.²² Third, the rate of physician refusal to participate was relatively high; therefore findings may not fully represent all physicians’ perspectives or ways of addressing transitions. Finally, the study was originally designed to explore how participants balance the need for prognostic information and hope

and not specifically to explore transitions. However, the importance of transitions emerged early in the qualitative analyses.

We have defined and described transitions regarding palliative and end-of-life care from the perspectives of patients with severe COPD or advanced cancer along with their family and clinicians. The findings highlight some differences between experiences of patients with COPD compared to patients with cancer. Patients with COPD experienced transitions related to the gradual losses that coincide with living and dying with a chronic illness, whereas patients with cancer experienced transitions focused more around anti-cancer treatment initiation or completion. Patients and family members also described transitions differently than their clinicians did. Differences in perspectives between patients and clinicians are common, as evidenced by several studies that explored other aspects of patients', families', and clinicians' perspectives of living with chronic disease or cancer.^{11,15,23–25} Identifying these differences regarding transitions may give clinicians the opportunity to acknowledge and address the transitions that are most important to the patient and family, and facilitate support for a patient-centered approach to improving the dying experience.

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Table 1

Characteristics of Enrolled Patients and Family Members

	Patients (<i>n</i> = 55)	Family or friend caregivers (<i>n</i> = 36)
Mean Age (SD)	67.3 (11.4)	60.3 (15.8)
# Female (%)	33 (60%)	18 (50%)
# Ethnicity (%)		
Caucasian	43 (78.2)	29 (80.6)
African American	9 (16.4)	5 (13.9)
Asian	2 (3.6)	2 (5.6)
Hispanic or Latino	0	0
>1 ethnic identity	1 (1.8)	0
# Diagnosis (%)		
COPD	24 (43.6)	NA
Cancer	30 (54.5)	
COPD and cancer	1 (1.8)	
# In hospice care at some point during study (%)	9 (16.4)	NA
# Died during study (%)	21 (38.2)	
COPD	5 (9.1)	
Cancer	15 (27.3)	
COPD and cancer	1 (1.8)	
Length of relationship with physician, median, in years (IQR)	2.0 (0.83, 6.00)	NA
# Living setting (%)		
Private home	48 (87.3)	NA
Assisted living	3 (5.5)	
Skilled nursing/long term care	4 (7.3)	
# Family's relationship to patient (%)		
Spouse/partner	NA	20 (55.6)
Relative (adult child, sibling, in-law)		12 (33.4)
Friend		4 (11.1)

SD, standard deviation; COPD, chronic obstructive pulmonary disease; IQR, interquartile range; NA, not applicable.

Table 2

Characteristics of Enrolled Study Clinicians

	Patients (<i>n</i> = 31)	Nurses (<i>n</i> = 25)
Average Age (SD)	48.7 (7.9)	46.6 (8.6)
# Female (%)	11 (35.5%)	23 (92%)
# Ethnicity (%)		
Caucasian	28 (90.3)	20 (80)
African American	0	2 (8)
Asian	2 (6.5)	2 (8)
Hispanic or Latino	1 (3.2)	1 (4)
>1 ethnic identity	0	0
# M.D./R.N. specialty (%)		
Pulmonary	11 (35.5)	11 (44)
Oncology	12 (38.7)	14 (56)
Internal medicine	8 (25.8)	NA
# RN Education		
4 year degree (%)	NA	17 (68.0)
# M.D. with academic affiliation (%)	15 (48.4)	NA
# Without training in end-of-life care	19 (61.3)	19 (64)
Mean years in practice (SD)	21.0 (7.7)	19.3 (8.9)

SD, standard deviation; M.D., physician; R.N., registered nurse; NA, not applicable.

Table 3

Comparison of Transition Themes

Themes	<u>Patients/families</u>		<u>Clinicians</u>	
	COPD	Cancer	COPD	Cancer
New or different treatments	X	X	X	X
No more treatment/curative to palliative care	X	X	X	X
“Can’t do the things I used to do”/activity limitations	X		X	
“Starting on oxygen”/initiation of oxygen therapy	X		X	
Exacerbations, hospitalizations			X	
Improvement from illness		X		

COPD, chronic obstructive pulmonary disease.