Research Article

“End-of-Life Care? I’m not Going to Worry About That Yet.”
Health Literacy Gaps and End-of-Life Planning Among Elderly Dialysis Patients

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Abstract

Purpose: Between 2000 and 2012, the incident dialysis population in the United States increased by nearly 60%, most sharply among adults 75 years and older. End-of-life (EOL) conversations among dialysis patients are associated with better patient-centered outcomes and lower use of aggressive interventions in the last month of life. This study examined how health literacy may affect engagement, comprehension, and satisfaction with EOL conversations among elderly dialysis patients.

Design and Methods: Qualitative/descriptive study with semi-structured interviews about health literacy, EOL conversations, and goals of care with 31 elderly dialysis patients at 2 centers in Boston. Themes were interpreted in the context of Nutbeam’s health literacy framework.

Results: Despite high mortality risk in this population, only 13% of patients had discussed EOL preferences with physicians, half had discussed EOL with their social network, and 25% of participants explicitly stated that they had never considered EOL preferences. Less than 30% of participants could correctly define terminology commonly used in EOL conversations. Analyses yielded 5 themes: (1) Misunderstanding EOL terminology; (2) Nephrologists reluctant to discuss EOL; (3) Patients conforming to socially constructed roles; (4) Discordant expectations and dialysis experiences; and (5) Reconciling EOL values and future care. Patients had limited understanding of EOL terminology, lacked of opportunities for meaningful EOL discussion with providers and family, resulting in uncertainty about future care.

Implications: Limited health literacy presents a substantial barrier to communication and could lead to older adults committing to an intensive pattern of care without adequate information. Clinicians should consider health literacy when discussing dialysis initiation.

Keywords: End-of-life, Health literacy, End-stage renal disease, Decision-making, Dialysis, Advance care planning, Geriatrics
Medicare beneficiaries with life-limiting illnesses (Wong, Kreuter, Curtis, Hall, & O’Hare, 2015; Wong, Kreuter, & O’Hare, 2012). During their final month of life, nearly 50% of elderly dialysis patients are admitted to an ICU and only 20% receive hospice at time of death, compared with 24% and 55% of cancer patients, respectively (Report to the Congress: New Approaches in Medicare, 2004; Wong et al., 2012). Medicare covers most adults over 65 years old in the United States and all persons with end-stage renal disease (ESRD). Although ESRD affects fewer than 2% of Medicare beneficiaries, they comprise nearly 9% of spending, Medicare’s single largest expenditure (Collins et al., 2014).

In January 2016, Medicare began reimbursing doctors for EOL conversations to discuss how patients want to live their last stage of life and goals for medical care. For many elderly patients, EOL conversations may include discussion about dialysis (Marczak & O’Rourke, 2016; Medicine, 2014; Morrissey, Herr, & Levine, 2015). Despite clinical guidelines and patient preferences supporting EOL discussions, (Ladin et al., 2016; Singh, Germain, Cohen, & Unruh, 2014) discussion of dialysis initiation is seldom coupled with EOL planning (Davison, 2010; Goff et al., 2015; Song et al., 2015; Tamura, Tan, & O’Hare, 2012). Thus, elderly patients offered dialysis may make what are effectively EOL decisions without adequate EOL discussions (Davison, 2006; Goff et al., 2015; Moss, Renal Physicians, & American Society of Nephrology Working, 2000; Singh et al., 2014; Tonkin-Crine et al., 2015; Wachtlerman et al., 2013).

EOL discussions are associated with improved patient satisfaction (Amro, Ramasamy, Strom, Weiner, & Jaber, 2016), reduced use of discretionary invasive treatments, fewer in-hospital deaths, and improved quality of life among patients and survivors (Detering, Hancock, Reade, & Silvester, 2010; Emanuel & Emanuel, 1994; Fries et al., 1993; Heyland et al., 2009; Song, Metzger, & Ward, 2016). Although considerable scholarship has focused on the communication skills and preferences of physicians (Fine, Fontaine, Kraushar, & Rich, 2005; Schell, Green, Tulsky, & Arnold, 2013), gaps remain in understanding how to best carry out EOL conversations in the context of dialysis decision-making, and especially the role of health literacy, which is often limited among older patients (Goff et al., 2015; Song et al., 2015; Tonkin-Crine et al., 2015).

Low patient health literacy is often cited as a key barrier to EOL conversations (Cavanaugh et al., 2010; Medicine, 2014; Volandes, Barry, Chang, & Paasche-Orlow, 2010; Volandes et al., 2008; Waite et al., 2013), and is associated with lower rates of advance directives completion, higher rates of aggressive treatment in the last month of life, and death in hospitals (Volandes et al., 2008). Elderly ESRD patients with low levels of health literacy are especially vulnerable, experiencing higher mortality and greater utilization of emergency services than higher literacy patients (Cavanaugh et al., 2010; Green et al., 2013). In healthcare settings, patient health literacy can support patient engagement and empowerment to make and carry out plans (Nutbeam, 2008; Zarcadoolas, Pleasant, & Greer, 2005). Health literacy is multidimensional, involving the intersection of patient skills and physician skills, and literacy demands imposed by the clinical environment (Kindig, Panzer, & Nielsen-Bohlman, 2004; Walker et al., 2016). Clinicians can support health literacy by reducing literacy demands through patient-centered communication and processes (Koh, Brach, Harris, & Parchman, 2013). Nutbeam’s (2000) frequently used health literacy framework is composed of three components: functional, interactive, and critical literacy. In clinical settings, functional literacy involves understanding words and numbers, interactive literacy relates to provider–patient communication and active patient engagement, and critical literacy reflects patients’ ability to achieve and express individual decisions concordant with preferences (Nutbeam, 2000). Few studies have examined patient comprehension of EOL terminology (functional literacy) (Volandes et al., 2010; Volandes et al., 2008), and none have employed a multidimensional health literacy framework to examine how interactive and critical literacy affect elderly ESRD patients’ experiences of EOL planning (Schell et al., 2013; Waite et al., 2013). We used semi-structured interviews with older dialysis patients to address this gap in the literature.

Design and Methods
Population
We completed 31 semi-structured interviews with patients at two dialysis clinics in Greater Boston between August 2014 and June 2015. A nephrologist (D. E. Weiner) screened potential participants for inclusion criteria including: receiving maintenance outpatient dialysis (> 1 month), age 65 years and older, English-speaking, and capacity to consent. Educational attainment and sociodemographic data were obtained from medical records. Research assistants trained in qualitative interviewing consented participants and purposively sampled by sex, age (65–70s, 80s, and 90s), dialysis vintage (time on dialysis), modality, and race/ethnicity to ensure diversity in demographics and potential patient experiences (Patton, 1990). Recruitment was conducted in conjunction with analysis and continued until new interviews did not yield new insights (Hamberg, 1994). The study was approved by the [blinded] Institutional Review Board.

Interviews
K. Ladin and S. Koch-Weser, social and behavioral scientists with expertise in qualitative methods, and D. E. Weiner, a nephrologist, developed the semi-structured interview guide. Open-ended questions explored patient experiences and preferences for EOL conversations and goals of care, including whether patients discussed preferences for...
resuscitation with clinicians or loved ones. Probes were used to encourage participants to expand about health literacy, comprehension, and conversation dynamics. To examine patient understanding of EOL terminology, an indication of functional literacy, we identified terms that occurred frequently in education materials routinely provided to dialysis patients and in clinical encounters (National Institute of Digestive Diseases and Kidney, 2015). Terms related to treatment (“hemodialysis, peritoneal dialysis, alcohol in moderation, low-fat low-salt diet, chronic”) and EOL decision-making (“prognosis, hospice, intervention, and quality of life”) were included. In the U.S. context, hospice refers to compassionate care for people facing a life-limiting illness or injury. Interviewers assessed comprehension of each term separately.

K. Ladin and S. Koch-Weser trained research assistants in qualitative interviewing, coding, and theme development. Interviewers completed multiple practice interviews with the investigators, were observed during their first interviews, and met weekly with K. Ladin to review interviews. Interviews were conducted privately, face-to-face at dialysis facilities and lasted approximately 1 hour. Interviews were audiorecorded and transcribed verbatim.

Analysis
K. Ladin and S. Koch-Weser created a preliminary codebook based on the question structure. K. Ladin and S. Koch-Weser then independently coded the first three transcripts using line-by-line coding (Saldaña, 2012). Coding differences, refinement, and emergent codes were documented, and consensus was reached through discussion. The revised codebook was then used by two research assistants/interviewers who read and independently coded the initial three, and an additional random selected five transcripts. The team discussed coding discrepancies and amended descriptions using a team-based consensus process. This final codebook was then applied iteratively to the remaining transcripts. These codes were organized into themes through iterative deliberation led by S. Koch-Weser, K. Ladin with D. E. Weiner and interviewers/coders (Saldaña, 2012). We followed the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007) Nvivo version 10 (QSR International) was used for coding and analysis.

To analyze terminology, K. Ladin, S. Koch-Weser, and D. E. Weiner created a guide based upon established definitions of terms and their meaning in the ESRD/EOL context. Responses were deemed correct or partially correct if they reflected at least a partial understanding, versus incorrect (lack of comprehension) if they did not align with the definition, were inappropriate in the context of care, or if the respondent did not know. Two trained coders/interviewers and K. Ladin independently determined correctness. Interrater reliability (IRR) was 92% reflecting agreement in determining correctness. Disagreements were resolved through discussion and consensus was reached.

Results
Thirty-six patients were approached, and five declined (86% participation rate); one participant started but did not complete the interview. Sixteen were women, seven received peritoneal dialysis (PD), 23 received in-center hemodialysis (HD), and one received home HD (Table 1). All lived at home; 29 were retired either due to age or disability, whereas two still worked. Dialysis vintage ranged from 2 months to 10 years. Only 13% of patients had not completed high school and 33% completed college or graduate degrees.

A quarter of participants explicitly stated having never considered EOL preferences. Despite high risk of death, only 13% had discussed EOL preferences with clinicians, 20% could articulate conditions for dialysis withdrawal, half had discussed EOL with their social network, and only 30% had a will or advance care plan. Patients described few opportunities to discuss EOL with nephrologists.

Analyses yielded five major themes: (1) Misunderstanding frequently used EOL terminology; (2) Reluctant physicians; (3) Patients conforming to socially constructed roles; (4) Discordant expectations and dialysis experiences; and (5) Reconciling EOL values and treatment (Figure 1). The themes were interpreted using Nutbeam’s health literacy framework and are presented using the sequential levels of health literacy in the framework. Theme 1 addresses functional literacy. Themes 2 and 3 relate to EOL discussions with clinicians and social networks, providing insight into interactive literacy and illustrating barriers to EOL discussions in the clinic. Themes 4 and 5 relate to identification of values and decision-making, reflecting critical literacy.

Functional health literacy involves understanding words and numbers used in the clinical context.

Theme 1: Misunderstanding Frequently Used EOL Terminology

Prognosis
Most patients (67%) could not define prognosis. Many patients (30%) misunderstood prognosis to mean diagnosis—“what’s wrong with you” or “it tells you your symptoms.” Additional misconceptions included: becoming healthy enough to discontinue dialysis, being cured as long as dialysis was continued, and transplant eligibility. Ten participants (33%) understood that prognosis involves the future course or outcome, responding: “what will happen with my disease.” When asked if they received information about how dialysis may affect how long they could expect to live, only 10% reported receiving prognostic information from nephrologists. A man in his 90s said, “They never told me how long I’d live...on dialysis. How long that will be?”.

Hospice
Many (62%) could not correctly define hospice. Of those offering correct definitions, nine (31%) defined it as a place
instead of a type of care (coded as partially correct). Many also responded emotionally: “That doesn’t make me feel good... I don’t like that word.” Participants with prior hospice experiences responded positively: “It helps people, especially when you’re dying”, and “more people should know about hospice”.

Quality of life
Many (83%) thought that the term was important and wanted more information, but could not offer a definition. Some described quality of life as symptoms: “There are limitations, but they go with the ailment.” Few described family and social participation, which were recorded as correct “Life is comfort ...enjoyable” and “Being able to do for yourself.”

Interventions
Five patients (14%) understood the meaning in the context of ESRD care. Many interpreted intervention as a planned discussion meant to persuade the patient to change undesirable behavior. “I think of intervention as being something that one does if someone has an addiction. I don’t know quite how it applies in this context.” Approximately half wanted to learn more; however, patients who misinterpreted the meaning did not share this desire.

In presenting information about dialysis initiation, treatment choices, and implications for later-life care, nephrologists often relied on terms that patients did not understand. Although most patients had encountered the terms either during clinic visits or in literature provided, few could define them or understand their meaning in context. For “prognosis” patients confused the meaning, whereas for “intervention,” confusion stemmed from the context. “Hospice,” although often misunderstood, evoked strong emotions.

Table 1. Sample Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Hemodialysis (HD)</th>
<th>Peritoneal Dialysis (PD)</th>
<th>Total (n = 31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>77.7 ± 9.8</td>
<td>70.9 ± 5.8</td>
<td>76.2 ± 9.4</td>
</tr>
<tr>
<td>Female sex</td>
<td>N = 12.50%</td>
<td>N = 4.57%</td>
<td>52%</td>
</tr>
<tr>
<td>Dialysis vintage (months)</td>
<td>24 (13, 54)</td>
<td>25 (16, 32)</td>
<td>25 (13, 49)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>N = 18.75%</td>
<td>N = 5.71%</td>
<td>23.75%</td>
</tr>
<tr>
<td>African American</td>
<td>N = 5.21%</td>
<td>N = 1.14%</td>
<td>6.19%</td>
</tr>
<tr>
<td>Asian</td>
<td>N = 1.4%</td>
<td>N = 1.14%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Hispanic ethnicity</td>
<td>N = 2.8%</td>
<td>N = 0%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Primary cause of ESRD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>N = 13.57%</td>
<td>N = 3.43%</td>
<td>16.52%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>N = 4.17%</td>
<td>N = 2.29%</td>
<td>6.19%</td>
</tr>
<tr>
<td>Return from transplant</td>
<td>0%</td>
<td>N = 2.29%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Other</td>
<td>N = 6.25%</td>
<td>0%</td>
<td>7.23%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>N = 2.8%</td>
<td>N = 2.29%</td>
<td>4.13%</td>
</tr>
<tr>
<td>College degree</td>
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<td>N = 2.29%</td>
<td>8.26%</td>
</tr>
<tr>
<td>High school degree</td>
<td>N = 13.54%</td>
<td>N = 3.43%</td>
<td>16.52%</td>
</tr>
<tr>
<td>Less than high school degree</td>
<td>N = 3.13%</td>
<td>0%</td>
<td>3.10%</td>
</tr>
<tr>
<td>Laboratory results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Albumin (g/dL)</td>
<td>3.8 ± 0.4</td>
<td>3.7 ± 0.3</td>
<td>3.8 ± 0.3</td>
</tr>
<tr>
<td>Hemoglobin (g/dL)</td>
<td>10.6 ± 0.7</td>
<td>11.4 ± 1.3</td>
<td>10.8 ± 0.9</td>
</tr>
<tr>
<td>Phosphorus (mg/dL)</td>
<td>5.1 ± 1.2</td>
<td>4.7 ± 1.1</td>
<td>5.0 ± 1.2</td>
</tr>
</tbody>
</table>

Note: ESRD = end-stage renal disease. One HD patient performed home HD. All data are mean ± SD, median (25th to 75th percentile), or percent.

Figure 1. Conceptual model of emergent themes interpreted using Nutbeam’s health literacy framework.
Patients demonstrated greater comprehension of terms related to dialysis modality. Nearly all correctly defined HD and PD, and most explained “low-fat, low-salt diet” and “alcohol in moderation.” However, only 30% offered an accurate definition of “chronic” (even in the context of “chronic kidney disease”), perhaps reflecting limited insight into the persistent nature of their condition. Indeed, some patients mistakenly understood dialysis as curative, and questioned when they would be well enough to discontinue treatment. Some patients had not understood that dialysis involved a needle-stick every session, and were confused about needing surgical fistula placement.

Interactive health literacy reflects opportunities for patient engagement and active patient participation in discussions with providers and families. For elderly dialysis patients, limited opportunities for engagement constrained patients’ ability to clarify points of confusion and understand trade-offs associated with their treatment options. Despite interest in discussing EOL, few had the opportunity.

Theme 2: Reluctant Physicians

Nephrologists’ avoidance of EOL conversations posed a significant barrier to patient engagement in EOL conversations. Only 13% of patients reported discussing EOL with clinicians, although, when asked, 80% expressed interest in discussing EOL. Only two patients had been given EOL planning documents, both from primary care physicians. Barriers identified by patients included: perceived physician discomfort discussing EOL, not wanting to jeopardize the doctor–patient relationship, and perceiving EOL discussions as irrelevant.

Those who may have had higher levels of interactive literacy and interest in EOL discussions described sensing physicians’ discomfort at discussing EOL and having to press physicians to engage in conversation. Patients felt stymied by an inability to get clear responses. “I’ve tried doctors, and they’re literally closed mouth! You ask a pointed question, I like pointed answers. Doctors are more uncomfortable with the fact that somebody’s going to pass on than anybody else. They don’t like discussing it.” Linking interactive literacy to decision-making, which involves critical literacy, the patient added, “The only way I’m able to cope is to have knowledge, which [doctors] think, if you don’t know, that’s how you’re going to be able to cope.” Patients voiced a desire to collaborate with physicians and loved ones in making EOL decisions, but were dependent on the willingness of providers. “Nobody has ever discussed that kind of stuff [EOL] with me so I don’t know… I always ask [and] they tell me I’m stable.” Another man responded: “We were talking about starting things, not ending them”. Patients wanted to maintain the doctor–patient relationship through their treatment choices, with one stating, “[physician] thinks it’s wonderful that I made up my mind to come [to dialysis]. Took me a long time… They all wanted me to come here… and they’re glad that I’m here.”

Some patients interpreted physician hesitation to discuss EOL as validation that EOL planning was unnecessary and that EOL concerns did not pertain to them. Some became confused about the need for an EOL conversation: “What’s to talk about, if this is the end of life?” Perceived hesitation among physicians reinforced patients’ trepidation related to discussing EOL care.

Theme 3: Patients Conforming to Social Roles

Patients conforming to socially constructed roles presented another barrier to active participation in decision-making (interactive literacy). Two sub-themes emerged: patient role and family role.

Role as Patient
In an attempt to uphold their “good patient” role, patients avoided challenging physicians, concerned that they could harm the physician–patient relationship and emphasizing that they could not push the physician into discussions. A woman in her 80s explained: “I’m accepting everything as it goes along because there’s nothing I can do to control it. So I’m accepting everything they tell me. There’s nothing more I can do.” Patients frequently felt shut-down by physicians when asking about implications of dialysis for quality of life and prognosis. Initiating discussions with clinicians places significant demands on patients. Most did not initiate discussions, in deference to physicians, or because of their own personal discomfort and the perception that EOL did not apply to them.

Role in Family
Perceived reluctance of loved ones’ to discuss EOL also presented a significant barrier. One participant said, “My kids don’t want to talk about it, I know that. Especially my oldest son - he wants me around forever. My daughter, she’s too emotional about it.” Similarly, patients who engaged in EOL discussions also voiced hesitation in expressing their true preferences. For example, one man described his EOL conversations as “mostly with my wife [but] we don’t say anything that would upset each other.” Many reserved their most deeply held beliefs about EOL care, and at points of confrontation acquiesced to family’s wishes.

Conversely, factors facilitating patient engagement in EOL conversations included: speaking with persons with poorer health status and speaking with those at least one-step removed from caregiving. Knowledge about health care and greater functional health literacy also facilitated EOL conversations.

Critical health literacy, predicated upon functional and interactive literacy, reflects the ability to synthesize information and use it in decision-making. Limited understanding of EOL terminology and lack of opportunity for EOL discussions with clinicians rendered patients with...
informational gaps feeling that treatment was discordant with their preferences, and unsure about future EOL care options.

Theme 4: Discordant Expectations and Dialysis Experiences

Patients experienced dialysis as intensive and somewhat invasive; and often described this as discordant with their preferences. Patients frequently cited lack of discussions and information (interactive and functional literacy) resulting in less than optimal decision-making for some. A PD patient said, “I was working up until I started [dialysis]. My time was busy but, I could always make time for the things I wanted to do. I thought [with PD], I could …go to work. But it takes too much out of you… I miss working… Being home is killing me…” A HD patient in his 90s responded, “Initially, I did not want to do it. I was quarreling with my physician, because he was really… interested in having my dialysis. They didn’t give me very much information [about dialysis].”

Surprised by unexpected burdens, some regretted not considering EOL preferences when starting dialysis. They described disappointment, loss of purpose and identity, isolation, feeling constrained, and social and mobility limitations. One woman explained, “I’m limited with everything. Usually the off days I have other doctors’ appointments… everything is filled up, it’s overwhelming.”

Theme 5: Reconciling EOL Values and Plans for Future Care

Limited understanding of EOL terminology and lack of opportunity for EOL discussions with clinicians (functional and interactive literacy) rendered most patients unable to articulate circumstances under which they would elect to discontinue dialysis. A woman in her 80s said, “End of life care? I’m not going to worry about that yet”.

In the absence of discussions with nephrologists, the intensive nature and shared social experience with their fellow patients in the dialysis unit shaped patients’ EOL plans (interactive literacy). Confronted with deterioration of peers in the clinic, a patient remarked that he would stop dialysis before “…com[ing] into dialysis on a gurney” as he had seen others do. However, he did not share this preference with clinicians. For others, needing to switch modality, developing life-threatening comorbidities, and losing independence were critical factors influencing potential withdrawal.

Only three patients (10%) placed the greatest value on extending life at all costs. Few patients discussed these preferences with physicians. One patient explained, “I’m near the end of my life now … so if I should get real sick, I don’t want them to revive me.” Another noted, “There’s nothing worse than being hooked to a machine when you’re trying to decide what to do with yourself.” Others described less specific preferences: “depending on circumstances, and how sick I am, I don’t want any heroics…let me go in peace.” Patients had difficulty reconciling EOL values with their preferences for care. Most important to patients were: staying home for as long as possible, not burdening or disappointing loved ones, driving, traveling, independence, and comfort.

Discussion

Fewer than 50% of severely or terminally ill patients documented an advance directive in their medical records (Kass-Bartelmes & Hughes, 2003). Although new Medicare reimbursement for advance care planning may increase EOL discussions with patients, our findings suggest that low patient health literacy may limit the effectiveness of these conversations when they occur, as well as patients’ ability to use basic health information to make treatment decisions that align with their EOL preferences. Elderly ESRD patients had limited understanding of EOL terminology (functional), lacked opportunities for meaningful EOL discussion with providers and family (interactive literacy), resulting in uncertainty about future care (critical literacy). Despite high mortality in this population, only 13% of patients had discussed EOL preferences with physicians. Interactive literacy was constrained by lack of opportunity to discuss EOL issues, likely due to clinicians not initiating EOL conversations regularly. Given patient uncertainty about terminology, it would be difficult for patients to introduce the topic. This is consistent with data showing that fewer than 10% of ESRD patients had a discussed EOL with their nephrologist in the previous year (Amro et al., 2016; Davison, 2010). As the emergent themes reflect, failure to attend to health literacy by creating opportunities for patients to learn terminology and discuss EOL preferences may result in poor quality care and treatment discordant with patient preferences among older patients facing dialysis. It is also possible that some patients’ grief and coping strategies may include avoidance of these discussions (Papen, 2009). However, low interactive health literacy (i.e., lack of clinician engagement) may have contributed to the unrealistic expectations that dialysis is curative or at least is effective in keeping the patient alive long-term. Communication was hampered by physician use of EOL-specific terminology without explanation; patient misunderstandings of prognosis, hospice, and transplantation likelihood; and lack of conversations with physicians.

Among dialysis patients, limited health literacy is associated with higher mortality and worse patient-reported outcomes, including regret of treatment choice (Cavanaugh et al., 2010; Davison, 2006, 2010; Green et al., 2013; K Ladin & Weiner, 2015). We expand upon prior studies by demonstrating how failure to create a setting that supports health literacy may contribute to these undesirable outcomes. Several studies have found that patients do
not perceive a choice to start dialysis, and feel rushed and pressured into treatment and experience regret (Davison, 2006, 2010; Ladin et al., 2016; Wachterman et al., 2013). Although previous studies also find regret among some dialysis patients (Davison, 2010), our findings clarify the relationship between lack of EOL conversations and regret in the context of health literacy. Patients who did not discuss EOL and goals of care did not realize that dialysis would constrain their ability to choose EOL treatment consistent with their values, and to participate meaningfully in the last stage of life.

Patients had low functional literacy of EOL terminology, with only one-third of patients able to define prognosis. Low health literacy may impede patients’ ability to comprehend complex medical concepts such as fistula placement, dialysis, and resuscitation preferences. Despite repeated requests, few patients reported receiving prognostic information. Patients with low functional literacy are more likely to interpret words literally, confuse the meaning, skip key words, misunderstand context, and tire out quickly in both reading and conversations (Doak, Doak, Friedell, & Meade, 1998; Doak, Doak, & Meade, 1996; Subramanian, Doak, & Doak, 2006). Our findings also illustrate that commonly used terms can be interpreted differently by different people. For example, although nephrologists meant “intervention” as indicating an invasive procedure, patients often interpreted “intervention” as an action meant to usurp patient autonomy in the context of addiction or harmful behavior. Emotional responses to terms like “hospice” and misinterpretations may involve mistrust, reinforcing barriers to EOL conversations. Especially for older patients, clinicians should lower literacy demands in explaining prognosis and treatment options, and inquire about patient-centered outcomes, tailoring the conversation to outcomes most important to each patient and avoiding ambiguous use of terms like “intervention” (Melhado & Bushy, 2011; Waite et al., 2013).

Health literacy deficits extend beyond functional literacy. Patients’ perceived physicians’ reluctance to discuss EOL as a signal that EOL planning did not apply to them and increased trepidation for some. Consistent with prior studies (Davison, 2010; Fine et al., 2005; Holley, Finucane, & Moss, 1989), we too found that patients overwhelmingly wanted to engage in EOL discussions, however, only if they understood the need and had a clear opportunity (interactive and critical literacy). Although some patients were interested in discussing EOL with physicians and families, they deferred to others for fear of damaging relationships or appearing “pushy” in a clinical setting. These limits on interactive and critical health literacy actions keep patients from adequately engaging in shared decision-making. Discussions that did occur often neglected outcomes important to patients, such as implications for daily life and well-being, highlighting the how discussions may largely address providers’ priorities (longevity) (Tong et al., 2015; Urquhart-Secord et al., 2016).

Although our semi-structured interview process was designed to develop comfort at the outset with sensitive questions were interspersed to enable participants to candidly reflect on EOL experiences, our findings should be interpreted in the context of these limitations. First, despite our best attempts, it is possible that some patients may not have shared the entirety of their experiences due to the sensitivity of topics discussed. Second, although we used a quota sampling strategy to enroll diverse patients and interviewed until thematic saturation, our sample is from an area with significant healthcare market competition with high education levels. Additional themes may emerge in other settings. However, the themes we identified related to limited communication and understanding, are likely to occur even more frequently among patients from underserved areas outside of Boston who may be less equipped to discuss EOL with clinicians. Finally, we do not have data on clinicians’ or caregivers’ perspectives. Future studies should examine those perspectives, as well as health literacy implications for disparities in EOL discussions (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Kuttner, Greenberg, Jin, Paulsen, & White, 2007; Lora et al., 2011; Melhado & Bushy, 2011; Volandes et al., 2008; Waite et al., 2013; website.).

Low health literacy disproportionately affects African Americans and Hispanics, persons of lower socioeconomic status, and older adults, partly explaining high use of aggressive EOL treatment in these populations (Dewalt et al., 2004; Kuttner et al., 2004; Lora et al., 2011; Melhado & Bushy, 2011; Volandes et al., 2008; Waite et al., 2013). In 2012 in the United States, prevalence of advanced chronic kidney disease was fourfold higher among blacks and 60% higher among Hispanics compared to non-Hispanic whites (United States Renal Data System, 2014). Miscommunications stemming from literacy gaps can exacerbate distrust, especially among racial and ethnic minorities who experience lower rates of health literacy (Volandes et al., 2008). Health literacy implications for disparities should be examined in future studies.

Our results have important clinical implications, suggesting the need for evidence-based communication strategies for EOL discussions with older ESRD patients. Clinicians should reduce literacy demands and communicate clearly so that patients of all functional literacy levels can fully engage in care. The Health Literacy Universal Precautions Toolkit, developed by AHRQ, provides concrete ways for clinicians to improve communication with patients of all health literacy levels (Hibbard, Peters, Dixon, & Tusler, 2007). Our findings suggest that physicians should assume limited health literacy among elderly ESRD patients. Where physicians want to confirm literacy status some evidence suggests that identifying patients with more limited literacy and specifically addressing their needs can be effective. This was accomplished among PD patients by asking, “How confident are you filling out medical forms by yourself?” using the cut-off “Somewhat” to identify patients with
limited health literacy (Jain, Sheth, Bender, Weisbord, & Green, 2014; Jain, Sheth, Green, Bender, & Weisbord, 2015; Wilkie, 2015). Among all patients facing dialysis, decision-aids may improve the quality and effectiveness of EOL communication by clarifying decision points, patient preferences, prompting discussion and documentation with clinicians and families, and by offering patients insights about what to expect from treatment (Jain et al., 2015; Volandes et al., 2010; Volandes et al., 2011). Additionally, clinical training should include training in communication, avoiding medical jargon when communicating with patients, and using techniques like “teach back” to assess for the patient’s comprehension (Schillinger et al., 2003). Given additional affect of progressive cognitive impairment associated with ESRD on health literacy capabilities and the large role of proxy decision-makers (Pruchno, Lemay, Feild, & Levinsky, 2005), it is vital that clinicians have EOL discussions with patients earlier on.

Conclusions

Providers and health systems can reduce health literacy demands on ESRD patients, improving patient-centered care by assessing health literacy and tailoring their approach to meet patients’ needs. Providers should anticipate emotional responses and should be prepared to address patient misunderstandings.

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