Letter from the Chair

“I feel extraneous in my own life.”

My client is an 87-year-old, upper-middle-class white woman who still lives in her own home but has recently started experiencing serious decline. She’s had a few falls. She’s become more forgetful and confused. When she failed to show up for her regular Pilates class, she informed her concerned instructor that her husband had phoned earlier that day to cancel her appointment. Her husband died four years ago.

That was the alarm bell for her family. For several years, she had had a caregiver come to her house four days a week to drive her, assist her with chores, and provide companionship. Now her three sons, none of whom live nearby, hired round-the-clock in-home care and arranged for a geriatric evaluation at a local day hospital. They come for more frequent visits, largely to check up on her.

My client tries to be grateful for their attentiveness, but mostly she is angry. She doesn’t understand why they are making such a commotion. She feels as if she is not being allowed to perform the basic activities of daily living. She feels as if she has lost all sense of purpose. “I start to do something, like take napkins out the drawer to help set the table, and my caregiver says, ‘I can do that. You sit down.’ Why can’t I help set the table? I feel extraneous in my own life.”

“My body is old, but I’m not old.”

This client is a 92-year-old retired academic who is proud of her PhD. She is physically compromised after a stroke, but mentally sharp. She has begrudgingly moved into an assisted living facility and accepts help. But she resents being treated as if she has no original thoughts or interests beyond the walls of the building. An old-school Southern lady, she is too well mannered to speak her mind, but inside she seethes.

These older women are fortunate to have financial resources and supportive families. They have the privilege of being able to make choices about where to live and what kind of care to employ. This is not true of many older adults who have to cope with profound changes in their lives—physical, social, mental, psychological, economic—with limited options. These changes represent what is probably the biggest set of adjustments since adolescence; but unlike adolescence, these changes are characterized by diminution rather than gain.

A crucial role for any social worker working with older adults is to listen. To not assume you know who your client is or has been, or what they are thinking. Or that they are happy with what you think is best for them. These clients require empathy. I learned a lot about aging when I earned my master’s degree from University of Southern California, USC School of Gerontology, but I have learned a lot more from listening to my clients.

Richard Gollance, LCSW, MSG
Terminally ill clients may be in a fragile emotional state as they face change and uncertainty at the end of life. Dealing with end-of-life issues can cause anxiety, fear, and despair but also feelings of hope and gratitude (Bern-Klug, Gessert, & Forbes, 2001). Psychological distress can affect a client’s quality of life, including physical health. Yet in spite of these physical and psychological challenges, many clients experience growth toward self-actualization at the end of life, inspiring those around them in the process (Herbst, 2004; Zalenski & Raspa, 2006).

End-of-life care studies have focused largely on the management of physical symptoms via medical interventions; however, client quality of life is enhanced when care providers attend to biopsychosocial-spiritual needs as the end of life approaches (Waldrop, 2008). Generally, the literature lacks information about the emotional well-being of terminally ill clients, neither does it address how to care for their “emotional” quality of life (Prost, 2014). Emotional support interventions with the terminally ill have not been widely researched (Candy, Holman, Leurent, Davis, & Jones, 2011; Prost, 2014; Reese & Raymer, 2004). So, how can a social worker meet the emotional and psychological needs of a client who is terminally ill?

Research on the psychosocial care preferences of older adults has noted the importance they place on pleasurable and personally meaningful activities (Carpenter, Van Haitsma, Ruckdeschel, & Lawton, 2000). The crucial component for an activity to be deemed beneficial is that it conforms to the older person’s individual wishes. Equally significant is personal choice and the desire to remain in control over one’s life. Following a terminally ill client’s expressed preferences gives him or her control over his or her life, and this sense of control has a positive effect on physical and emotional health, as it produces feelings of self-efficacy and agency (Carpenter et al., 2000).
Many terminally ill clients continue to focus on living and remain engaged in activities while simultaneously dealing with the physical challenges of managing their illness (Wrubel, Acree, Goodman, & Folkman, 2009). Those who remain actively engaged in living report lower scores on illness symptoms, pain, suffering, depression, and illness-related anxiety (Wrubel et al., 2009). Unfortunately, at the same time in life when terminally ill clients need to continue such enjoyable activities and hobbies, they experience a decreased ability to do so (Arnold, Artin, Griffith, Person, & Graham, 2006).

What are some ways to improve terminally ill client’s emotional well-being?

END-OF-LIFE CLIENT-CENTERED ACTIVITIES

There has been recent interest in such end-of-life activities as legacy projects, creative activities, and customized client-centered events, which can provide terminally ill clients with emotional relief from their problems, increase their self-esteem, and improve their quality of life. Legacy projects are designed to help clients participate in a life review that results in a product that can be enjoyed by family after the client’s death. Life review is a universal process of looking back on a person’s life story to bring an understanding to the present (Life Review Project, n.d.). Many hospice agencies offer some form of legacy project to their clients and families. Examples might include oral history interviews, writing stories or letters, and family activities, such as examination of family pictures and other memorabilia, all culminating in the creation of a scrapbook (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008).

Engagement in creative activities has been found to allow clients to cope with declining abilities and to “create connections to life” (La Cour, Josephsson, & Luborsky, 2005). The most commonly used creative activities are arts and crafts, and gardening (La Cour et al., 2005). The individual often uses the creative activity to re-create part of his or her story, enabling him or her to “share” by doing rather than by talking. The crafts themselves often communicate a message and allow the terminally ill person an opportunity to express feelings of self-acceptance and transcendence. An example of this type of symbolic communication through creative activity is in the report of a woman with terminal cancer who made as a present for her daughter soap containing an angel figure (La Cour et al., 2005).

Emotional support may be provided through a customized client-centered event. For example, one hospice agency invites each newly admitted client to imagine and describe a “perfect day” that he or she would enjoy. Then the interdisciplinary staff members—social workers, nurses, volunteer coordinators—work together to create the perfect day and gift it to the client. Sometimes the perfect day is filled with simple, personally meaningful things, such as...
and “never stopped thinking teaches and love for children.”

Activities and interventions that teacher who had a “zest for something great to anticipate. illness, and to give clients quality of life. enhances their emotional clients extra attention that to celebrate the clients’ life, to take the focus off his or her illness, and to give clients something great to anticipate.

Activities and interventions that address client emotional needs at end of life are vitally important. Because each client has unique goals and wishes for his or her remaining time, social workers shape each care plan to fit that individual client’s unique preferences. Helping terminally ill individuals identify priorities for the end of life should be an integral strategy in developing client-centered care plans (Vig & Pearlman, 2003).

**RECOMMENDATIONS**

From the review of the literature, the following recommendations are offered.

- **Assess the clients’ emotional state.** Psychosocial-spiritual distress at the end of life is understandable, and each client needs to be asked about his or her level of emotional distress (Carpenter, 2014). Assessing and monitoring emotional well-being (i.e., depression, anxiety, stress) can be as straightforward as asking one question: How would you rate your emotional well-being over the past week on a scale of 0 to 10, where 0 = as bad as it can be and 10 = as good as it can be (Locke et al., 2007)?

- **Provide emotional support.** Emotional support is a fundamental piece of biopsychosocial-spiritual care (Bradley, Frizelle, & Johnson, 2010). Terminally ill clients are coping with the challenges of terminal illness, loss, and uncertainty. Social workers address each client’s unique stressors at end of life and offer emotional support and therapeutic interventions (McNnis-Dittrich, 2014).

- **Individualize end-of-life care.** A comprehensive assessment can help social workers evaluate client preferences in order to individualize care. Clients have unique desires about the care they would like to receive as they become more dependent on others. Tailor end-of-life interventions using the clients’ values and goals in decision making in order to provide individualized care that may bring emotional benefits (Carpenter et al., 2000).

- **Include clients in their care plans.** Terminally ill clients need to maintain a sense of mastery and control over their lives for as long as possible. This can be accomplished by including them in end-of-life treatment choices. Listen to the client’s wishes and desires with empathy, and, where possible and feasible, include them in the plan of care. Allow clients to exercise control in their environments and in integrating personal preferences into their care to increase their satisfaction and quality of life (Carpenter et al., 2000).

- **Make use of unique end-of-life activities and services.** Finally, providing terminally ill clients and families such activities as legacy projects, creative activities, and customized client-centered events requires a greater time commitment to plan, implement, and evaluate. Yet these activities offer clients the opportunity to have meaningful, positive, enjoyable experiences that are emotionally beneficial and that could improve or maintain emotional state and quality of life.

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**REFERENCES**


I do wish we had been saving more and had a good insurance policy in place. I will be in serious financial problems if my husband passes away before I do.” This was the heartfelt concern shared by a 72-year-old wife and caregiver of a hospice patient who was dying from advanced cancer. Unfortunately, her experience is not uncommon. Many families report mounting medical debt, reduced income, and other sources of financial burden when coping with a life-threatening illness. In fact, nearly a third of U.S. families dealing with an end-stage illness report having spent all or most of their savings. Furthermore, when compared to residents of other industrialized countries, Americans have the highest out-of-pocket costs for end-of-life care and rank poorly in terms of financial burden on patients (31 out of 40 countries; Economist Intelligence Unit, 2010).

Although economic stress and strain felt by families during terminal illness is widely recognized as a common problem by social workers and other health care providers, few studies have focused on the financial burden experienced by families—and no research has rigorously tested an intervention to minimize such burden. These gaps in the evidence base have led researchers at the University of Maryland School of Social Work to examine the complexities of financial burden at the end of life and to develop an intervention to reduce this burden.

Dr. John Cagle, the study’s principal investigator, approaches his research as a former social work practitioner with nearly a decade of experience as a hospice social worker. Through this clinical work, he was involved with countless patients and families teetering on the precipice of financial devastation. These encounters led him to explore financial burden in a more systematic way through the present research project. The overarching goals of this project are twofold: first, to identify factors that impact financial security of households at the end of life; and second, to develop a pragmatic, translatable intervention to identify and support families at risk for financial burden. To accomplish these goals, Dr. Cagle assembled a venerable research team—which includes interdisciplinary representatives from social work, medicine, nursing, law, pharmacy, and economics—to gather and analyze information from four data sources: a large national survey, a systematic review of the scholarly literature, practitioner interviews, and an environmental scan of existing tools and resources. The project is supported by a Pilot & Exploratory Interdisciplinary Research Grant from the University of Maryland, Baltimore, and the University of Maryland School of Social Work’s Financial Social Work Initiative. The project encompasses five phases over a 3-year period: understanding the problem, identifying key variables, developing the intervention prototype, refining the intervention, and pilot testing. Findings from the aforementioned four data sources are part of the first two phases of the project and are described in detail below. Preliminary findings from these data sources are also summarized.

DATA SOURCE #1 – The Health and Retirement Survey
Research team members analyzed the Health and Retirement Survey, a nationally representative dataset of adults ages 50 and older in the United States. By pooling two waves of data collected from 2006 and 2008, the team isolated two variables pertaining to economic outcomes: financial satisfaction and difficulty paying bills. For the first outcome, a total sample of 13,764 was identified, and for the second, 13,670 (with substantial overlap between samples). Through statistical analysis of these data, the research team found that widowhood, having been divorced, or otherwise being single were linked with greater financial burden. Women were also more likely to suffer financial burden than men, perhaps owing to gendered roles and disparities (e.g., differences in income). Financial burden was also higher among younger members of the sample. Not surprisingly, minorities and those at the lower end of the socioeconomic spectrum were at greater risk for financial burden. These findings may help practitioners identify financial risk factors when working with older patients and their families.

DATA SOURCE #2 – A Systematic Review of the Literature
The Maryland research team also conducted an extensive systematic review of the literature. Using search terms...
related to financial burden and terminal illness, they scoured recent peer-reviewed articles from six large electronic scholarly databases for all relevant research conducted since 2007. After the team evaluated a total of 1,162 initially identified articles, only 16 articles met the criteria for inclusion (e.g., samples involved participants from the United States; empirical evidence was reported in the article). These 16 articles included both quantitative and qualitative studies, and consisted of patients and families from a variety of health care settings, including parents of pediatric patients and patients/families dealing with cancer and cardiovascular disease, for example. The review reinforced findings from the Health and Retirement Survey analysis, suggesting those at risk for financial burden include minority populations, those with lower income, individuals with worse mental health or physical impairment, females, younger persons, those who are single/unmarried, the uninsured, those with greater numbers of clinic visits, those receiving life-sustaining treatments, and those diagnosed with late-stage cancer. For protective factors, the systematic review showed that assistance from governmental programs, including Medicare, Medicaid, and income derived from Social Security programs was beneficial. Other protective factors included higher levels of education and greater frequency attending religious services.

**DATA SOURCE #3 – An Assessment of Current Practices**
The principal investigator and his research team also interviewed social workers and other end-of-life professionals in five health care settings (hospice, ICU, long-term care, oncology, and dialysis) to explore how they screen for, assess, and intervene with issues of financial burden. They interviewed five practitioners within each setting and asked questions like: In your practice, how are financial concerns brought up? What financial concerns come up? What do you do when these concerns come up? Regarding an intervention, what is needed? What are obstacles to addressing financial needs for families? And what kinds of tools, information, or resources would be helpful? Using a qualitative content analysis, the researchers found that not all social workers are screening or assessing for financial burden, and, unsurprisingly, that issues related to money are often difficult to bring up in clinical conversations. Differing levels of skill in addressing financial burden were also noted. Social workers talked about the importance of fostering trust and rapport with family members when discussing household finances and money-related concerns. Much of the interview discussions also revolved around accessing resources for patients and families—including resources for emergency needs like housing, utilities, and food—but noted that there are huge gaps in policies, services, and funding for meeting these needs. From the interview data, researchers also identified numerous potential dilemmas and competing economic motives on the part of both patients/families and practitioners (e.g., working in the best interest of the client versus serving the best interest of the agency). Practitioners also indicated differing levels of job satisfaction and frustrations when addressing financial burden as a critical component of clinical work. The researchers are currently conducting follow-up focus groups with these social workers to confirm their findings and to refine the planned intervention.

**DATA SOURCE #4 – An Environmental Scan**
As the final data source for this project, the principal investigator and his team completed an environmental scan of online tools, technologies, resources, and other programs that practitioners can employ in their work to address financial burden. These can be used as a component of the work or as stand-alone features. Ideas gleaned thus far include Internet-based programs that can aid in budgeting, screening for benefits eligibility, financial planning, and end-of-life communication, as well as resources and policies that are useful in understanding particular needs and issues faced by certain groups of patients and families.

**CONCLUSION & NEXT STEPS**
At this point in the project, Dr. Cagle and the research team are compiling results from all four data sources to begin to flesh out the intervention for end-of-life professionals helping patients and families with potential financial burden. Critical components to consider include implications for psychosocial and financial risk screening, and associated assessment and interventions activities. Additionally, awareness of existing resources (local, regional, and national) is key. Communication between and among health care professionals, patients, and families is also critical, as communication impacts financial planning and treatment decisions. Communication between patients and family members, along with care providers, related to advance directives and preferences for end-of-life care is yet another undeniable factor. It is hoped through this research that a comprehensive intervention—one that fully appreciates and addresses the complexities of financial burden on families—can be developed and implemented to support people at this most vulnerable time in life.

Christine Callahan, PhD, MSW, has been with the University of Maryland School of Social Work Financial Social Work Initiative since July 2012. Dr. Callahan is the principal investigator, co-investigator, and/or study coordinator on a number of funded projects in the initiative including studies focused on financial burden at the end of life.

John G. Cagle, PhD, MSW, is an Assistant Professor at the University of Maryland, School of Social Work. His current research focuses on ways to improve care and support for dying patients and their families. His work is informed by nearly a decade of practice as a hospice social worker.

**REFERENCE**
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