



Advance Care Planning: Opportunities for Clinical Social Work Leadership

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Abstract

As our population ages, providing person-centered, family-focused, culturally congruent, quality care becomes ever more important. Advance care planning (ACP) conversations seek to elicit a person's values, beliefs and preferences and to identify who might be a surrogate decision-maker for a person if they are unable or unwilling to speak for themselves. These nuanced conversations provide the foundation for the delivery of personalized goal-concordant care. Yet, despite the many benefits associated with ACP, it remains underutilized. Clinical social workers are well positioned to take a leadership role in ACP. This paper highlights a range of ACP roles and resources for clinical social workers within healthcare and in the community.

Keywords Clinical social work · Advance care planning · Advance directives · Social work leadership · POLST · Palliative care

Regardless of setting, clinical social workers (CSWs) engage with issues of mortality. Whether working in private practice, child welfare, specialized substance use clinics, with the incarcerated or those on probation, with veterans or those in service, with the aged or infirm, or within the varied fields of health social work—skilled social workers are needed to assist and support people as they grapple with issues of mortality. People die and loved ones grieve. The choices that people make regarding their care at end of life have broad repercussions and lasting implications. And because CSWs are themselves mortal and have loved ones who will need care at end of life, CSWs in all settings benefit from an understanding of the importance of advance care planning (ACP). Yet, many report a lack confidence for this work and see ACP activities as being in the province of specialized palliative social workers (Glajchen et al. 2018).

ACP is the explicit elicitation of a person's values, beliefs and preferences related to the treatments that they might receive if they were unable or unwilling to directly communicate with their healthcare team regarding a future health state (Denny 2013). ACP typically consists of several distinct steps:

1. The identification of a *surrogate decision maker*, who would act as the patient's advocate and spokesperson to relay the patient's wishes related to treatment decisions if they were unable to speak for themselves. This person might also be called a healthcare agent or proxy. Appropriate documentation of a surrogate decision maker appoints this person as the patient's *durable power of attorney for healthcare*.
2. The patient discusses their values, beliefs, wishes, goals for care and treatment preferences with the surrogate decision maker and all others who might be involved in care decisions.
3. These choices and preferences are documented in an Advance Directive (AD) and/or a POLST form and this information is provided to the patient's healthcare providers, with copies of this form shared with all who might be involved in the patient's care or eventual decision making.

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4. Periodically updating this information and revisiting choices whenever the patient's circumstances change (due to marriages, divorces, changes in health status, etc.). Regularly reviewing the form also ensures that the surrogate's contact information is accurate and up to date.

ADs vary from state to state and organization to organization. Typically, an AD will have a place to identify the name and contact information for a primary healthcare agent and indicate if there are secondary agents—should the first be unavailable or unwilling to act in this role, as well as an area where a person may choose to record specific future healthcare treatment preferences. To be valid, the AD must be signed and dated and in most cases either witnessed or notarized. There may be additional provisions required for those who reside in a skilled nursing facility. ADs can vary greatly in length, tone and content and may be independently completed on a physical document or virtually online (see [Recommended Resources](#) for various examples), or with the aid of an attorney—often when one is doing estate planning (American Bar Association Commission on Law and Aging 2018), or with the guidance and support of a healthcare provider. Individuals who are medically fragile or seriously ill may also benefit from having a conversation with their healthcare providers about their specific medical wishes should their condition worsen. These conversations may result in the completion of a medical order form that in some states may be called “Physician Orders for Life Sustaining Treatment” (POLST), which guide first responders on the level of medical interventions the person desires.

Yet despite these tools, too often the gap between the interventions that people report that they want and the interventions that they actually receive can be wide. Recent Institute of Medicine Reports (2013, 2015) present ample evidence that our current healthcare system is poorly designed to meet the needs of our rapidly aging population. Quality care is not equitably accessible, and too often diverse patient populations receive disparate care. Access to necessary medical and psychosocial support services is a function of having health insurance, is mediated by socioeconomic status, varies by region, is influenced by individual and family attitudes and beliefs about the need and efficacy of such care, and is impacted by personal and institutional attitudes and practices of care providers and facilities. Differential access to societal resources and institutionalized bias/discrimination lead to inequalities and variation among these factors, resulting in an unequal burden of illness in the United States.

As the healthcare system has become ever more bureaucratized, care has become more fragmented and regimented. Too often we treat the *disease*, and not the *person*. Interventions are often based upon standardized protocols, which may lead to impersonal “default” treatment plans that don't

take into account an individual patient's specific values, beliefs and preferences. This has contributed to increasing numbers of people receiving burdensome interventions in settings that may not be desired, may increase regret for the survivors, and which increase costs associated with end-of-life care. For example, many people die in intensive care units or while receiving chemotherapy in the last days and weeks of life, when they would rather be home with their loved ones.

ACP conversations that are carefully documented and reliably retrievable when needed are associated with a higher likelihood that a person's treatment wishes will be honored at the end of life (Beavan et al. 2013) and are correlated with less remorse and regret by surviving family members, and with greater patient and family satisfaction. Decreased costs follow as many patients would prefer to avoid prolonged hospitalizations at the end of life. Perhaps not surprisingly, interest in expanding ACP activities is increasing globally (Jimenez et al. 2018), as is attention to the potential economic impact (O'Hanlon et al. 2018). It is important to emphasize that ACP activities are not limited to those who are seriously ill, but ideally occur over a lifespan.

Yet, despite the many benefits associated with ACP, there remain numerous barriers to clinicians adequately and reliably engaging in these conversations (Blackford and Street 2016). Too few providers have been systematically trained to engage in these nuanced conversations and despite widespread understanding of the importance of ACP, few organizations have prioritized the development of ACP programs. Although there is now a separate Medicare billing code for ACP conversations, it is considered by many to be too meager to fully off-set the extra time required for the careful exploration of a patient's wishes, fears and expectations regarding treatment choices, and few physicians consistently engage in these complex conversations with their patients. Clinicians involved in delivering interventions not perceived to be aligned with the wishes of patients report increased instances of moral distress (Rushton et al. 2013). Clinicians note this as a significant source of strain, increasing the risk for compassion fatigue, decreased job satisfaction and premature exodus from the field.

Given these challenges, there have been movements that seek to re-humanize and personalize the delivery of healthcare. Efforts to improve population health, increase patient satisfaction and lower the costs associated with healthcare address what's been described as the “Triple Aim of Healthcare” (Berwick et al. 2008). Palliative care and ACP activities lay the foundation to the provision of goal-concordant care which helps us not only address the Triple Aim (Meier and Morrison 2012), but also the *Quadruple Aim* (Boenheimer and Sinsky 2014), whereby we increase the satisfaction rates of healthcare providers. Clinicians, perhaps not surprisingly, report less stress when they feel confident that they

have engaged in goal-concordant care where the interventions they provided were consistent with the wishes, values and preferences of their patients.

The Affordable Care Act was a recent U.S. attempt to shift our payment model from a “fee-for-service” system to a “value-based” payment system that would begin to incentivize whole-person care. The fields of hospice and palliative care explicitly remind practitioners of the importance of contextualizing care and the need to see the family as the unit of care. Advance care planning can be seen as a necessary first step for the reliable delivery of such person-centered, family-focused and culturally-congruent care. Developing an infrastructure that standardizes assessing and addressing the physical, social, psychological and spiritual concerns of patients will require a major culture change in the delivery of American healthcare.

The field of palliative care has risen in prominence in part to address these challenges. Palliative care can be seen as the larger umbrella field within which hospice and end-of-life services are but a part. Palliative care services are specifically designed to address the quality of life concerns of seriously ill people. Introducing palliative care at the point of diagnosis of a serious illness is recommended as the early integration of palliative care is associated with better quality of life and improved patient, family and provider satisfaction (NCP 2018). Palliative care specialists are trained to provide tailored communication that seeks to understand the values, beliefs and preferences of each individual that they serve (Altilio et al. 2008). The primary principles of palliative care include: a relational perspective, a collaborative team approach to address the multidimensional aspects of suffering, contextualized care that looks at the family as the unit of service, exquisite attention to pain and symptom management, a focus on quality of life and improved function and sensitive communication as a key intervention. These constructs make palliative care providers ideally suited as leaders who model and mentor ACP activities (Stein et al. 2017).

Roles for Clinical Social Workers in Advance Care Planning

Guided by professional standards of care and a code of ethics, social workers must personally and professionally embrace the imperative to deliver and sustain meaningful advancements in the delivery of quality person-centered care (National Association of Social Workers 2016). Persons facing serious illness require competent and compassionate care throughout a continuum of illness, across multiple and varied treatment settings and throughout the lifespan, and there are numerous CSW opportunities and roles all along this continuum. CSWs are well positioned to develop, facilitate and participate in ACP across settings (Otis-Green 2008).

With proper education and support, CSWs can engage patients in having meaningful conversations that lead to completed ADs and provide detailed documentation of the values, beliefs and preferences that led to their recorded decisions (Bekelman et al. 2018). As non-prescribers, CSWs have an important role to remind colleagues that the person’s *goals for care* should guide all treatment decisions, as too often, ADs can become just a “check box” exercise, without careful consideration of how these potential interventions actually serve to meet the patient’s individual values and preferences.

The purpose of ACP is to support people in receiving personalized care that best supports their goals for an acceptable quality of life. Assisting people in exploring what a “good day” looks like, identifying what brings joy and meaning and exploring what future conditions may be incompatible with an acceptable quality of life, requires sensitively determining if there might be conditions or future health states that a person would find unacceptable. This nuanced dialogue provides the important information that best drives treatment decisions and ideally results in shared goals of care. Meaningful ACP conversations also explore preferences related to where care is to be provided (in a home-like environment vs a hospital or skilled nursing facility), how one’s spiritual or religious beliefs influence care, thoughts about care at end of life, what constitutes “dying well” and post-death decisions such as decision regarding the final disposition of the body and if there are any specific rituals that should be observed.

Ideally, ACP conversations occur organically over a lifetime, with ADs being completed by all adults and updated periodically as one’s life circumstances change (Volandes 2015). In many states, ADs are valid until changed, so establishing “prompts” to remind people of the need to review and potentially revise ADs can be useful. Driver’s license renewals might be a useful memory jog, as many states ask about whether the driver wants to participate in organ donation at that time. Reminding people to review their ADs when there is a change in relationship, the birth or death of a loved one, when there is a move, at retirement or a change in employment, or when there is a diagnosis of a serious illness or change in prognosis is recommended. It is important to remember that people’s needs, wishes, preferences and contact information may change as circumstances evolve, and a new AD form can be completed at any time. For this reason, it is important to recommend that people keep track of where previous forms have been distributed, so that the new ones can be provided—and the old forms destroyed to minimize confusion.

ACP programs are systematically designed to ensure that patients have multiple opportunities to engage in ACP conversations. Historically, providers have been reluctant to initiate ACP conversations until a medical crisis necessitates a “code” discussion. ACP is too often seen as “too early”

until it's "too late." Like buying insurance, there is a human tendency to delay actions about an unwanted future state until after an unfortunate event occurs, resulting in regret and missed opportunities. Too many elderly patients develop dementia without anyone proactively discussing the person's wishes and preferences leaving adult children in the unenviable situation of needing to "guess" what their parent might have wanted at end of life. Innovative programs that recognize diminishing cognitive capacities have been developed to assist families in having these important conversations while there is still time for meaningful choice (for an example, see [Recommended Resources](#) EndofLifeWA.org).

CSWs can help people in choosing the most appropriate healthcare surrogate. Surrogate decision makers need to understand that they are *not* being asked to decide what they might want for themselves, but to be the voice relaying the preferences and desires of the patient who is now unable to speak for him/herself. Therefore, it is important that healthcare providers encourage people to explicitly discuss their wishes with their selected surrogates, so that they are better prepared to speak on the patient's behalf should the need arise. Differing states may have restrictions upon who is eligible or excluded from this role, and what types of decisions they are allowed to make. Typically, the surrogate decision maker has the authority to choose the physician or facility that provides care, review medical records, authorize or refuse organ donations, approve an autopsy and make other post-death arrangements (deciding about cremation, burial, funeral services, etc.). CSWs should be aware of their own state's laws and regulations regarding these matters.

The CSW also has an important role in supporting the surrogate if they are asked to make decisions for another. Unsurprisingly, surrogates may struggle if they feel unable to accommodate the patient's stated wishes, such as to "die at home,"—when for a myriad of potential reasons this might not be feasible. Best practice is to include the surrogate decision makers in the initial and subsequent goals of care discussions with their loved one. Recommended practice is to have a primary surrogate named as well as an alternate in case the primary is unavailable, but having a "committee" with equal decision-making authority is to be avoided. CSWs can support the patient in considering alternatively important roles for all loved ones to mitigate concerns about hurting someone's feelings if not selected for the surrogate role. Other vital tasks might include being selected to have responsibility for finances, providing physical care, keeping others apprised of the patient's condition, or coordinating logistic/practical needs such as providing transportation, arranging meal delivery, supporting caregivers, attending to pets or providing respite care.

Surrogates might be asked to make medical decisions using "substituted judgement" ("*what would the patient be telling us if they could speak right now?*"), and the CSW

can support the surrogate in asking meaningful questions to aid in more fully comprehending the implications of the decision options. Such questions might include:

1. "*What are the probable short-term and longer-term benefits/risks/side effects of this option?*"
2. "*What might the patient's quality of life be like with this option?*"
3. "*What type of suffering is associated with this choice, and how might it be managed?*" The surrogate might then consider if this is likely to be a condition/situation that the patient had indicated that they would find tolerable/acceptable.

Choices related to ACP may include decisions about specific treatment options. The CSW may support the use of decision aids (Stacey et al. 2017) to assist with comprehension of complex medical choices. Decisions regarding the use of cardiopulmonary resuscitation, mechanical ventilation, and artificial hydration or nutrition can be especially daunting for a non-medical professional to fully understand. Reviewing these terms and concepts to ensure a better comprehension of the potential benefits, risks and unintended consequences of such complex treatment options help the patient and/or surrogate decision maker have truly informed consent (see [Recommended Resources](#) for examples). CSWs have the communication skills needed to elicit concerns and identify misunderstandings so that medical interventions are better understood. It is important that the CSW not aim to influence the person's decisions, though using the CSW's expertise to support the patient through the process of complex medical decision making is appropriate. CSWs support patients in understanding their options and in exploring how a potential intervention is related (or not) to their desired treatment goals. CSWs recognize the importance of cultural and spiritual beliefs and rituals and have a role in ensuring that these are known and respected throughout the shared decision making process (Bullock 2011).

CSWs should be aware of their state's version of what are commonly called "Physician Orders for Life Sustaining Treatment" (POLST) forms. Although different states may have different names for these documents, they are medical orders that are specifically designed to follow people across settings providing guidance to first responders regarding the level of medical intervention to be provided. Patients who have a serious illness, who are medically fragile and who a provider wouldn't be "surprised" if they were to learn had died within the next several months are appropriate candidates for a POLST conversation. CSWs can help to ensure that the patient and family understand the differences between an AD and a POLST form and how they are designed to complement one another. The AD is designed to guide future health decisions, while a POLST form is a medical order

related to a present condition. The CSWs role may be to recommend the use of a POLST or facilitate the POLST discussion, but only medical providers—as determined by the various states—can authorize the actual medical order.

Because ACP and POLST discussions may be emotionally fraught, the role of CSWs is especially important. CSWs can support the patient and their loved ones in exploring these potentially challenging topics, offering support, anticipatory guidance and empathy. CSWs can help normalize the conversation and place it in a context that is meaningful and culturally sensitive. Assisting patients and their families in increasing their tolerance for the ambiguity associated with prognostic uncertainty can be tremendously helpful. And, acting as part of an interprofessional collaborative team, the social worker can support colleagues in engaging in these complex discussions. The CSW may serve as a model and mentor to co-workers in developing and enhancing their ACP skills.

CSWs may be critical in integrating the values, beliefs and preferences of the patient into the care planning process to specifically address the patient's quality-of-life concerns. Social workers might be involved in skillfully reframing the reluctance that many people feel in initially engaging in ACP conversations as a “gift” to minimize the guilt and anxiety that families might otherwise feel if asked to make medical decisions without having information from the patient to guide their decisions. Skilled CSWs may find Motivational Interviewing techniques useful in preparing patients and surrogates for the process of shared decision making (Fried et al. 2018).

CSWs assist patients in goal setting and might find that using tools such as “Go Wish” (see [Recommended Resources](#)) are useful to engage patients in exploring and prioritizing their values, which can subsequently be useful to guide medical decision making. Resources such as these are helpful in normalizing the experience of exploring and expressing one's wishes and values. Encouraging patients to consider creating a recording (perhaps using a smartphone) that explains their choices and preferences and how they made their decision can neutralize potential family turmoil and perhaps prevent future misunderstandings. Providing anticipatory guidance in this circumstance may help to minimize a family's regret and family conflict over differing interpretations of a patient's wishes.

CSWs serve an important role in family conferences as translators of medical information, coordinators, and advocates for the patient and family (Fineberg 2010). Evidence suggests that family-conferencing is a potent and effective intervention for family decision making (Fineberg et al. 2011). CSWs have the ability to help patients and their families better understand and cope with serious illness and assist in communicating decision options. Social workers also play an important quality assurance role in ACP by ensuring that ADs and POLST forms are accurately completed. They might assist with periodic chart reviews and

provide education, mentoring and support to colleagues to raise the standard of documentation.

CSWs in the community have a role to play related to ACP as well, as they might offer community educational events, assist with education and outreach to community partners to provide information on ACP where people live, learn, work, play and pray. They might be sourced as “content experts” who can assist with sharing information and resources through social media and be tapped for interviews with the press related to notable community events. In collaboration with local faith communities and others (and using resources such as those available through the Coalition for Compassionate Care of California website—see [Recommended Resources](#)), CSWs in the community can actively support the understanding and completion of ACP documents.

CSWs might collaborate in the coordination of a wide range of ACP events. Participating in *National Healthcare Decisions Day* efforts (which are held annually each April 16th), integrating ACP activities into book clubs, civic events, and community forums all help to normalize ACP conversations and raise awareness of the importance of proactively addressing these topics with one's family and health providers. CSWs bring a systems-based perspective to ACP that positions them to broaden where ACP activities typically occur (Jacobsen 2018). And as palliative care services become more widely available in the community, social workers have the opportunity to engage in these discussions with patients in their home environment.

Additional CSW Leadership Opportunities in ACP

CSWs can demonstrate leadership in this area through the creation and coordination of an organization's ACP program to ensure that treatment decisions are truly informed and customized to each individual's needs, wishes and preferences. Culturally nuanced assessments are needed to explore how a person's ethnic, cultural and spiritual beliefs impact medical decision making. CSWs recognize that there is tremendous diversity in how people make decisions, how much information that they may want to receive, their level of medical literacy and their preferences for medical guidance (Menon et al. 2018). Some people prefer to actively participate in all aspects of decision making, others prefer to defer to family or esteemed community members to decide, while still others prefer to more passively follow the recommendations of medical experts. In recognition of these differences among individuals, CSWs can assist people in identifying the appropriate ACP process, tools and forms that best meets their needs (Lum et al. 2018).

CSWs who work within the healthcare field may have expertise in developing, promoting, and implementing an institutional

ACP program. CSWs practice in a wide array of settings and provide an extensive range of mental health services to patients and their families. Interprofessional care improves quality health outcomes for patients and reduces health-related distress and other psychosocial barriers to health outcomes (Blacker and Deveau 2010). Highlighting and reinforcing social workers' teamwork and communication skills promotes improved collaboration with team members and enhances effectiveness in implementing ACP services. CSWs bring crucial skills in contextualizing patient needs and offering insight into factors that impact patient quality of life and health decision making. CSWs play a critical role in advocating for patients and reducing barriers to desired outcomes, particularly with disenfranchised and vulnerable populations (Bullock 2011).

A robust ACP program lays the foundation for the provision of contextualized care through shared decision making. Quality programs ensure that all those with a serious illness receive tailored information about the potential benefits and anticipated risks and side effects of the proposed treatment options, as well as an understanding of what might occur should the patient forego the recommended interventions. Efforts are continually expanding to assist patients to more fully imagine future health states to guide goals of care (Childers and Arnold 2018).

To be successful in changing an organization's culture regarding how care is discussed and ultimately delivered, a sustainable program will need to align with an organization's strategic initiatives. For example, many healthcare organizations pride themselves in offering leading edge technical care to those they serve. Framing ACP efforts as necessary for the realization of an organization's initiatives related to developing leadership in the emerging field of precision medicine might then be seen as an effective strategy to establish the integration of ACP activities as a necessary step in the customization of individualized care planning.

The collaborative nature of ACP offers opportunities for CSWs to serve as role models, mentors and ACP champions for colleagues within and across disciplines. Despite widespread agreement on the importance of ACP, many providers lack confidence in their abilities to skillfully conduct ACP conversations (Fulmer et al. 2018). CSWs might be tasked to educate colleagues on best practices related to ACP activities. These best practices may include:

- Normalizing the ACP conversation process regarding concerns and encouraging questions
 - Empathically responding to concerns related to the confrontation of mortality
 - Tailoring the conversation to address the patient's and family's specific needs (explicitly exploring for spiritual and cultural concerns)
 - If appropriate, assisting with the completion of the document (identifying witnesses or a notary, answering questions, providing support materials, scheduling a subsequent visit)
 - Copying the forms and distributing them as needed
 - Appropriately documenting the interaction
 - Following up as needed.
- Planning the conversation
 - Scheduling the appointment to include the key participants
 - Setting the stage and clarifying expectations
 - Asking permission to proceed
 - Determining the preferred communication style of the patient/family
 - Ensuring that you have access to the necessary support materials, forms and decision aids

The building and maintaining of an organization-wide program that normalizes ACP conversations and integrates ACP activities into the system of care offers numerous additional opportunities for CSWs leadership (see "Appendix" section for an example of an Advance Care Planning Scenario). Educating staff about the importance of ACP, collecting quality improvement data related to the completion of ADs and the provision of goal-concordant care, assisting in the standardization of the electronic record documentation process, identifying gaps in service, creating strategies to address these gaps, and developing meaningful metrics to evaluate the effectiveness of the ACP efforts, are all possible roles for innovative social work leadership (Kezirian et al. 2019). Strategic involvement in rapid cycle quality improvement activities related to ACP services can identify problem areas that require additional attention, such as identifying gaps in services for other-than-English speaking patients. Creating programs that nimbly serve diverse patient populations requires recognition of the different ways people deal with concepts such as "truth-telling," and how they might define "dying well." CSWs are needed to determine a patient's "explanatory model" and to discover how they understand their illness and its expected trajectory (Smolinski 2019). CSW's can sensitively tailor their ACP conversations to meet the needs of culturally and linguistically diverse populations (McDermott and Selman 2018).

CSWs might be involved in assisting their organizations with activities related to employee engagement to normalize ACP conversations. Many healthcare organizations have incentives in place to encourage employees to complete ADs. CSWs in supervisory positions can work with Human Resources staff to integrate ACP expectations into job descriptions and annual evaluations. CSWs might introduce ACP into support groups or integrate these concepts into other educational events. CSWs benefit from support to negotiate the complex political climate so as to maximize their leadership role as advocates for institutional enhancement (Otis-Green et al. 2015). Although CSWs may be well

versed in the importance of communication, they, like all healthcare professionals, benefit from continuing education to refine these specialized skills to enhance team practice and engage more competently in effective ACP conversations (Back et al. 2009).

CSWs may also be involved in a broad range of research activities related to the integration of ACP conversations throughout a healthcare system. CSWs may have roles in assisting in the collection of data and the dissemination of findings through professional presentations and publications. CSWs can also assist in the development of appropriate messaging that is tailored for the diverse populations that one's organization serves.

Exemplar ACP Program in a Large Urban Quaternary Health System

UCLA Example: *ACP Initiative*

Recognizing the common misalignment between the medical care that seriously ill people want and the care that they too often receive, the health system (including four hospitals and over 100 community clinics), developed an ACP Initiative to better align care delivery with patient preferences system-wide. Early efforts were the standardization of the ACP process and development of the electronic health record infrastructure to accommodate “Goals of Care” notes across sites. They created an innovative, customized AD tailored to their specific patient populations that incorporated evidence-informed best practices and was sensitive to literacy issues. They developed a training mechanism, using simulated patients (actors) with tailored scenarios for differing specialty practices (i.e., cardiac transplant services and oncology). Importantly, they identified both process and outcome measures that allow evaluation of the system to drive quality improvement efforts.

They developed the following vision statement: *The ACP Initiative aims to create and foster culture, skills and infrastructure that support effective and compassionate communication and the reliable documentation of goals and preferences to deliver high-quality, personalized, end-of-life care.*

Novel interventions included embedding a dedicated ACP social worker within the heart transplant service. This specially trained palliative social worker is tasked with evaluating all cardiology patients being considered for transplant and left ventricular assist devices/mechanical circulatory support as well as elevated risk surgical candidates to elicit preferences concerning future health states, adverse outcomes, and their acceptable quality of life. These preferences are then documented in an

enduring advanced directive. The ACP social worker has been well received, with other specialty services requesting their own dedicated social worker. The CSW has been integrated throughout the program's activities and is now seen as a role model, mentor and ACP Champion throughout the hospital.

Summary

CSWs understand how barriers to health are impacted by culture, community, discrimination and disenfranchisement. Using skills in cultural humility and cultural awareness, CSWs are well positioned to support patients and families through the ACP process. Recognizing the tremendous variability regarding communication and decision making styles across cultures requires attention by skilled practitioners as a necessary component of competent healthcare in our diverse society.

ACP activities lay the foundation for personalized, goal-concordant care throughout the continuum of illness. The collaborative nature of ACP creates important leadership opportunities for CSWs both within healthcare organizations, and in the community. CSWs have an opportunity to act as system change agents seeking to improve the delivery of care for the traditionally underserved, for example, creating ACP services to meet the needs of other-than-English speaking patients within their institution or addressing the ACP needs of those with impaired cognitive capacity. ACP offers an opportunity for social workers to begin to address the barriers impeding the reliable delivery of person-centered, family-focused, culturally-congruent quality care.

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Appendix

Advance Care Planning Scenario

Mr. H is a 58-year-old gentleman with end stage heart failure who is being considered for a high-risk cardiac procedure. The CSW was consulted by the cardiac surgeon to guide this patient and family in a discussion regarding goals of care regarding future health states and adverse outcomes, and to support the patient in completing an advance directive. The CSW arranged a meeting with the patient and his family.

Prior to the meeting the CSW met with her social work field placement intern to provide anticipatory guidance regarding the upcoming family meeting. Together the CSW and intern reviewed the patient's medical history and checked to see if an advance directive or POLST form had been completed in the past. The CSW used this pre-meeting as an opportunity to remind the intern that some patients and families have cultural or religious beliefs that may make them reluctant to make decisions regarding their goals, preferences, and/or end-of-life care. These may include concerns that:

- If you discuss preferences related to care at the end of life, the patient may die sooner.
- If you discuss a patient's advancing illness, they may "lose hope," give up "fighting" and die sooner than they would have otherwise.
- Since God has the ultimate say in when death will occur, participating in advance care planning is ultimately pointless.
- Making end-of-life decisions isn't useful, as people have no control over how they will die.
- An individual may not want to be involved as they tend to defer to their family regarding decision making.

The CSW and her intern then met with Mr. H, his spouse, his parents, and his two adult age children. During this meeting the CSW and her intern:

- Explained the social work role to the patient and family and the purpose of the meeting.
- Requested permission to begin the advance care planning process.
- Elicited the patient and family's understanding of the patient's current medical condition and expected outcomes of the medical treatment.
- Explored if the patient and family had previous discussions regarding their preferences for medical interventions should there be a medical emergency.
- Gently provided education regarding possible future health states and adverse outcomes.
- Introduced the concept of an advance directive document, answered questions regarding the form and offered education and support in completing the directive.
- Assured the patient that they did not need to answer all the questions at this time, but if the patient was comfortable in proceeding, offered assistance to the patient in completing the form.
- Explored who the patient might select to be his medical decision makers and clarified the role and responsibilities of this position.

- Arranged for notary or witnesses to sign the completed document.
- Made copies of the advance directive for the family and medical providers, returning the original document to the patient.
- Summarized the plan of care and next steps.

Following the meeting, the CSW and intern met again to debrief the meeting. The CSW reminded the intern that if the patient was unable or unwilling to participate in the discussion the meeting would still be beneficial, as the discussion helps build rapport with the family and plants the seed for further discussions regarding goals of care. The process of asking permission and allowing the patient to have control over what information they share builds a strong relationship and allows for more open and honest discussions in the future. The CSW and intern then communicated any pertinent information from the discussion with the medical team and documented the discussion in the "Goals of Care" note in the patient's electronic medical record.

Recommended Resources

Advance Care Planning Decisions

<https://www.acpdecisions.org/>

Angelo Volandes (author of *The Conversation*) offers videos and resources to guide understanding of complex healthcare decisions at end of life.

Aging with Dignity (*Five Wishes*)

agingwithdignity.org

www.fivewishes.org

The non-profit Aging with Dignity provides people with the practical information, advice and legal tools including the popular, low cost and easy to use *Five Wishes* Advance Directive, which is available for purchase in multiple languages, including Braille.

American Bar Association

americanbar.org/groups/law_aging/resources/consumer_s_toolkit_for_health_care_advance_planning.html

<http://ambar.orgagingtoolkit>.

Toolkits for approaching and completing Advance Directives, with links to state-specific Advance Directives.

American Society of Clinical Oncology (*ASCO Answers: Advanced Cancer Care Planning*)

http://www.cancer.net/sites/cancer.net/files/advanced_cancer_care_planning.pdf

A free decision-making booklet for patients and families facing serious illness with information and resources about care options, communication tips and coping at end of life.

Ariadne Labs (*Serious Illness Care*)

ariadnelabs.org/areas-of-work/serious-illness-care

Ariadne Labs consolidates evidence-supported videos, tools and resources to support decision making for the seriously ill including a downloadable “*Serious Illness Conversation Guide*.”

Begin the Conversation.org

begintheconversation.org

Learn how to take the first steps to begin an ACP conversation. Workbook and toolkit available with information to support community engagement and empowerment.

California State University Institute for Palliative Care

<https://csupalliativecare.org/programs/advance-care-planning/>

Extensive ACP education and materials (including virtual, self-paced courses) for health professionals.

Center to Advance Palliative Care (CAPC)

<https://www.capc.org/>

CAPC provides a wealth of information to support organizations and clinicians in improving the delivery of palliative care. Educational content regarding ACP is available for CAPC members.

Chinese American Coalition for Compassionate Care (Heart to Heart)

cacc-usa.org

Heart to Heart cards are a bilingual (Chinese/English) communication activity designed to make it easier to understand what people might prefer when their lives are threatened by injury or disease.

Coalition for Compassionate Care of California (CCCC)

<http://coalitionccc.org/tools-resources/advance-care-planning-resources>

Widely used curricula supporting culturally congruent care, ACP and Physician Orders For Life Sustaining Treatment (POLST). Many free and low-cost resources are available, including decision aids, tips for starting ACP conversations, information for professionals and consumers (with tailored resources for pediatrics, faith communities, skilled nursing facilities and long term care facilities), often in different languages. CCCC is involved in public policy, offers educational programs and provides consultation and coalition-building related to ACP and POLST.

Coda Alliance (Go Wish)

gowish.org

Offers a fun and non-threatening way to explore people’s preferences for care when seriously ill.

Consumer Reports (Advance Care Planning)

<http://consumerhealthchoices.org/wp-content/uploads/2017/04/CarePlanningCCCC-ER.pdf>

Free, downloadable patient ACP booklet available in English and Spanish.

Common Practice (Hello/Gift of Grace)

commonpractice.com/hello

Information on the evidence-based conversation game Hello (formerly Gift of Grace) to assist people in discussing what matters most to them.

The Conversation Project Toolkit

theconversationproject.org/starter-kit/intro/

Resources and discussion guide for people who want to talk with their loved ones about end-of-life wishes (available in multiple languages).

Institute for Healthcare Improvement (The Conversation Project)

theconversationproject.org

Stories for sharing, tools, and tips for initiating ACP. The primary focus is to help people overcome barriers to planning and to start talking to family and loved ones.

My Directives.com

<http://mydirectives.com>

Free web-based service with guidance for completing an “Advance Digital Directive” with a smartphone app.

National Hospice and Palliative Care Organization (Caring Connections)

caringinfo.org

Free resources to help people make medical decisions, with links to Advance Directives for all 50 states.

National Institute on Aging (Advance Care Planning Tips)

<https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives>

Free information on ACP in an easy to read format with links to local *Agencies on Aging* and to Advance Directives for all 50 states. Printable wallet card.

National POLST (Physician Orders for Life-Sustaining Treatment) Paradigm

www.POLST.org

Information and patient resources on each state’s POLST efforts with recommendations for best practices.

Palliative Care Network of Wisconsin (Fast Facts)

<https://www.mypcnow.org/>

Over 350 “Fast Facts” are available as teaching tools, offering clinicians a wide range of information to support ACP conversations.

Prepare for Your Care

prepareforyourcare.org

A website designed to empower people to make decisions, talk with providers and get medical care that is right for them. Prepare for Your Care walks people through the basic steps in ACP and provides prompts and videos to help them get started.

Respecting Choices

gundersenhealth.org/respecting-choices/

Evidence-informed training program and resources to promote person-centered care and ACP.

Stanford Letter Project

<http://med.stanford.edu/letter>

Provides “*What Matters Most*” and “*Who Matters Most*” letter templates to share with healthcare providers and family members.

Social Work Hospice and Palliative Network (SWHPN)

<https://www.swhpn.org/>

Palliative and hospice social work organization that offers a variety of educational opportunities related to ACP skill development.

UpToDate

<https://www.uptodate.com/home>

Vast array of evidence-based, clinical decision resources to support medical decision making and ACP activities.

Vital Talk

<http://vitaltalk.org/>

Evidence-based communication skills-building programs to support physicians in having more effective conversations with those facing serious illness.

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