

# DS-ACP: A care plan that goes beyond directives and proxies

Disease-specific advance care planning delivers greater patient satisfaction and provides greater clarity about preferences, improving end-of-life care.



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**A**dvance care planning (ACP) discussions are not sufficiently incorporated into the care of oncology patients. Studies have consistently found that patients with late-stage cancer have a low rate of completing advance directives (ADs). Yet even the completion of ADs or appointment of proxies may be insufficient to address end-of-life decision making needs that may arise. Disease-specific advance care planning (DS-ACP) was developed to address many of the weaknesses of current end-of-life planning methods. Initial studies have suggested that DS-ACP can improve the experience of patients with chronic conditions. This article describes DS-ACP and how it can benefit oncology patients, their proxies, and their health care providers.

## **ADVANCE CARE PLANNING**

Following the implementation of the Patient Self-Determination Act (PSDA) in 1990, ACP programs began to focus on promoting and evaluating the impact of advance directives. The early assumption was that if more people were made aware of their right to complete ADs, end-of-life care would then match patients' goals and values.<sup>1</sup> However, providing patient-determined care near the end of life has proven to be much more complex.<sup>2</sup>

### **Low participation, availability, and specificity**

Research on ADs has determined that the rate of

completion of directives is low, physicians lack awareness of directives when patients do complete them, and the inclusion of vague instructions makes decision making difficult. A summary of research funded by the Agency for Healthcare Research and Quality (AHRQ) indicates that less than 50% of the severely or terminally ill patients studied had an AD in their medical record; between 65% and 76% of physicians whose patients had an AD were not aware that it existed; having a directive did not increase documentation in the medical chart regarding patient preferences; and language in the directives was often not specific enough to provide clear instructions.<sup>3</sup> A national study of ADs conducted 10 years after ratification of the PSDA found that people who died in nursing homes or at home with hospice care were more likely to have completed ADs compared with those who died in hospitals.<sup>4</sup> Respecting Choices, the systematic ACP program initiated in La Crosse, Wisconsin, is one exception to national AD trends of low-use, low-availability in medical records, and low-specificity in guiding clinical decision making. This program has consistently documented and sustained high levels of ADs available in medical records among residents who die. It has also documented high compliance with patients' wishes.<sup>5</sup>

In studies of cancer patients, the availability and usefulness of ADs remain low. A recent review of the medical records of 1,186 patients with incurable pancreatic cancer found ADs were present in the medical records of only 15% of patients. Of those who did have a directive, 42% had a different person designated as their health care agent in their AD than the individual who appeared as the primary contact person in the medical record.<sup>6</sup> Another study of 75 consecutively admitted patients with cancer found only 41% had completed an AD.<sup>7</sup> Other studies have found low levels of ADs among patients with advanced cancer or terminal illness.<sup>8,9</sup> When directives did exist, the language may not have been specific enough to guide clinical decision making. For example, directives often focus on life-sustaining treatment and incorporate generic language that may not provide enough guidance for the wide array of decisions people with cancer and their loved ones face. Among 125 proxies of advanced cancer patients who had completed ADs, the proxies reported they found the AD to be helpful in decision making only about 50% of the time.<sup>10</sup>

### COMMON BARRIERS TO ACP

**Proxies** The appointment of proxies (eg, power of attorney for health care) is a recommended component in the

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completion of an AD, but even this may be inadequate to guide and ensure patient-determined care. Research on the use of proxies indicates they are often not present to make decisions or are too emotionally upset to offer balanced and thoughtful guidance.<sup>3</sup> Other research has demonstrated that proxies are often not capable of accurately predicting the desired choices of the patient and frequently lack enough information to serve as capable decision makers.<sup>11,12</sup> A review study found proxies incorrectly predicted patients' treatment preferences in one-third of cases and that efforts to improve surrogate understanding of patient preferences

### Case Scenario 1: A family member makes decisions without advance care planning

Mr. S. is a 67-year-old divorced male who has a history of prostate cancer and lung cancer with metastases to the brain and bone. Since his diagnosis in 2007, he has undergone five cycles of chemotherapy as well as whole brain and gamma knife radiation therapy. He has gone from living independently to living in an assisted living facility because of periods of confusion and frequent falling. He presents with a decreased level of consciousness and an inability to take in food or fluids, and he is bed bound, confused, and delirious. After thorough testing, the confusion is determined to be a result of the progression of his cancer and the side effects of radiation leukodystrophy. Despite attempts to reverse the confusion, his condition worsens and he is likely to die in the next days to weeks. Mr. S. has two adult sons who have helped him over the past several years with his treatments and living situation. Mr. S. is full code and has no health care directive. As legal next of kin, his eldest son is the medical decision maker. When the son was asked whether he and his dad had discussions about treatment preferences and health care wishes, he replied, "We never talked about those things." With great emotional pain, the son discontinued life-sustaining treatments and chose comfort care for his father.

were unsuccessful.<sup>13</sup> A recent study of decedents older than 60 years documented that substitute decision makers were needed in approximately 30% of deaths.<sup>14</sup> These findings provide compelling evidence of the need to better prepare and assist proxies for their duties as decision makers.

**Communication gaps** A lack of communication between providers and patients is another commonly identified barrier to successful ACP. Many professionals are uncomfortable with and lack appropriate training to initiate complex end-of-life decision-making discussions.<sup>15</sup> Studies of physician communication with cancer patients have identified certain communication skills and discussion topics related to ACP

that may increase patient depression and anxiety levels if they are not included when discussing prognosis and planning for further treatment.<sup>16,17</sup> Poor communication with patients about ACP may have detrimental effects on the patient's and caregiver's mental health.<sup>18</sup>

### **DISEASE-SPECIFIC ADVANCE CARE PLANNING**

DS-ACP is designed for patients with chronic progressive illness who have begun to experience decreased functional status, increased comorbidities, more frequent hospitalizations, or a higher risk for complications that might leave them unable to make their own health care decisions. The in-depth planning

## **Case Scenarios 2 and 3: Experiences with disease-specific advance care planning**

While research has yet to be conducted on the use of disease-specific advance care planning (DS-ACP) with cancer patients, the process is done as a part of practice in two health care systems. These two case scenarios demonstrate the benefits of DS-ACP for these patients and their proxies.

### **Scenario 2**

Mrs. G. has pancreatic cancer and has been told she does not have much time left. She is currently in a "wait and see" period about whether to have another round of chemotherapy. The side effects from the first round of chemotherapy were not too bad, but she has not regained her energy. Additional tests are planned in a month or two to determine whether she will have another round of treatment. DS-ACP discussions allowed Mrs. G. and her daughter to openly discuss worries and fears they had about her illness, future treatment preferences, and feelings about how they may impact her quality of life. "I am really glad we were able to have someone help us discuss these things, as I have not felt comfortable bringing up these topics even though I have been thinking about them for quite some time," Mrs. G. said. She was able to discuss with her daughter her feelings about the type of care she might want if she became so ill that she was no longer benefiting from the treatments she received. The DS-ACP facilitator was able to give Mrs. G. and her daughter information about planning for future care. Several months later, Mrs. G. called and requested another advance care planning session to re-clarify her goals and treatment preferences. This allowed her and her daughter to again openly discuss her wishes and care needs in addition to updating her advance care planning documents.

### **Scenario 3**

Mr. J. was a retired physician with gallbladder cancer diagnosed in the past year and was recently given a 6- to 12-month prognosis. His meeting with a DS-ACP facilitator included his wife, three daughters, and son-in-law. The patient chose his son-in-law as his health care agent, a decision supported by the other family members. The value of this group discussion became evident almost immediately. The patient shared the overwhelming admiration and love he had for his family; his family shared how proud they were of their father's courage through his cancer experience. Although Mr. J. was given a time-limited prognosis, he had accepted a trial of another round of chemotherapy. "What if they are wrong about my prognosis?" he said. With further discussion, he clarified his goals for this chemotherapy trial. His son-in-law heard him articulate what an unacceptable outcome would be (eg, if he lost his mental functioning or ability to take care of himself) and when he would want life-sustaining treatment stopped. His family was thankful for this clarification. During the CPR discussion, he was interested in specific information about the success of CPR. While surprised about the low success rate of CPR, he decided he should attempt it based on his goals related to the chemotherapy treatment. However, if the chemotherapy was not successful, or he became more ill, he directed his son-in-law to change his CPR request. He agreed to revisit his CPR decision after he completed his chemotherapy treatment. Too often we look for a "yes" or "no" decision from patients regarding such interventions as CPR. In reality, the decision is more complicated and requires a more thorough clarification of the risks patients are willing to bear and the goals they expect.

process should include the patient, the appointed proxy (and other family members), and a trained facilitator. Tailored to the patient's specific disease and potential complications, this patient-centered intervention aims to uncover gaps in understanding, clarify the patient's goals for future medical care, and improve communication between all involved parties.

**DS-ACP interview** Specifically, the DS-ACP structured interview with the patient and proxy includes

- Assessment of the patient's and proxy's understanding of the patient's disease, symptoms, and possible complications
- Discussion of the patient's values, worries, and fears regarding illness, quality of life, coping strategies, and past and present experiences with the end of life
- Review of previously expressed patient preferences from existing documents and discussions with family
- Review of the purpose of ACP and the role of the proxy
- Discussion of complications and scenarios related to the patient's disease trajectory (this stage uses a Statement of Treatment Preference form to guide the discussion and assist the patient in clarifying goals for treatment)
- Review of the patient's decisions, including the proxy's understanding of and ability to honor the choices the patient makes
- Follow-up activities, including further discussions with the patient's physician, arranging needed services, additional ACP discussions, and completion of appropriate written advance care plans such as the Health Care Agent, Health Care Directive, Statement of Treatment Preferences, and Provider Orders for Life Sustaining Treatment. Copies are filed in the medical record and given to the patient and the proxy, and the facilitator follows up with the provider about the decisions they have made.<sup>19</sup>

**Certified facilitators** A key component of the program is the use of certified facilitators during the DS-ACP discussion. The Respecting Choices DS-ACP Facilitator Certification Program identifies and reinforces a set of skills to help engage patients with chronic, progressive, and life-limiting illness, and their families, to make timely and informed health care decisions specific to the complications they are likely to face in the future. The program also aims to open the channels of communication between the patient, family, and health care providers. Facilitators complete a rigorous, competency-based communication skills training program that includes an online course to be completed before the classroom experience. In the intensive 2-day classroom experience, participants are exposed to an identified set of interview and communication competencies through video demonstration, individual and group role-play practice activities, and group discussion. A competency checklist of expected facilitator

behaviors is used to clearly define the expectations of performance and to evaluate role-play activities. Participants are required to submit a video role-play demonstration 2 to 3 weeks after the classroom course. Individual performance is evaluated through the use of the competency checklists, and feedback is provided on areas needing improvement. Certification ensures the DS-ACP intervention is delivered in an effective, consistent, and reliable manner.

### OUTCOMES OF THE DS-ACP MODEL

The Respecting Choices DS-ACP was tested for immediate outcomes in four randomized trials of patient-proxy pairs. Three small studies with patient-proxy pairs conducted among patients with congestive heart failure, end-stage renal disease, cardiac surgery, and HIV (adolescents only) all found that the DS-ACP intervention was associated with increased congruence in decision-making between patient and proxy on the statement of treatment preferences and demonstrated reduced decisional conflict among patients in the DS-ACP group as compared to the standard treatment patients. Two

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of the studies found a positive association with the quality of provider communication.<sup>19-21</sup> A larger trial involving 313 patient-proxy pairs with congestive heart failure or end-stage renal disease found a significantly higher degree of understanding of patient goals among intervention surrogates.<sup>22</sup> A separate trial in Australia examined facilitated ACP, which includes the same basic elements as DS-ACP, in elderly patients and their proxies. Among patients who died, those who had completed the ACP process were much more likely to have their wishes known and adhered to as compared to the usual care group. Family members of ACP participants also had less stress, anxiety, and depression compared to those in the usual care group.<sup>23</sup>

### POTENTIAL BENEFIT OF DS-ACP IN ONCOLOGY PATIENTS

A review project suggests that the pain and delirium often experienced by cancer patients toward the end of life provide a strong rationale for integrating ACP into oncology care. The project also notes that cancer patients often receive

aggressive treatment near the end of life, precisely a time when they might benefit from or prefer more comfort-oriented care.<sup>24</sup> Most research on ACP indicates the majority of patients will choose to forgo aggressive treatment near the end of life, opting instead for palliative care.<sup>24</sup> In interviews conducted during one study with 342 patients, some with advanced cancer, more patients chose to forgo the more invasive long-term treatments such as mechanical ventilation and feeding tubes.<sup>25</sup> Another study found that older patients with metastatic cancer would choose artificial tube feeding less frequently than physicians use it in their practice.<sup>26</sup>

## Evidence exists that patients want to be informed and are receptive to health care providers initiating advance care planning discussions.

Another observational prospective cohort study of terminally ill cancer patients found that having end-of-life discussions was associated with lower rates of ventilation, resuscitation, and ICU admission and with earlier hospice enrollment. The study also found an increased quality of life for both patients and their caregivers when less aggressive treatments were provided. Caregivers of patients who underwent aggressive treatment were more likely to experience mental health problems such as depression and feelings of regret after the patient's death.<sup>18</sup> Given these findings, being aware of and honoring a patient's choices would likely result in fewer hospitalizations, increased hospice use, and better quality of life for oncology patients. While research has yet to be conducted on the use of DS-ACP in cancer patients, the process is currently practiced among cancer patients in two health care systems. The initial experience, as illustrated in the Case Scenarios that accompany this article, suggests that the process was useful for cancer patients and their proxies.

**Questions to be answered** Devising effective strategies for engaging individuals in ACP activities can be challenging, but compelling evidence exists that patients want to be informed, are receptive to health care providers initiating planning discussions, desire information about the benefits and burdens of life-sustaining treatment, and gain great benefit from advance care planning.<sup>27-29</sup> However, implementation of DS-ACP for cancer patients will require consideration of some of the possible differences in the illness experience of cancer patients as compared to patients with chronic progressive illness:

- Patients with chronic, progressive illness often learn to adapt to their condition and situation over time and may experience a change in goals of care. Patients with a new cancer diagnosis are still learning about their disease and identifying treatments with a goal of curing their cancer.
- A potential barrier to implementation of DS-ACP is the misperception that ACP and end-of-life discussions will raise anxiety and decrease hope in patients struggling to manage their complex medical situations. However, research and clinical experience to date with DS-ACP indicates that patients and families find the process to be satisfying and helpful.
- DS-ACP is initiated for patients with chronic, progressive illness when they experience complications from their illness, more frequent hospital or ED visits for exacerbation of symptoms, or when they identify a desire to shift their goals of care. Since most patients realize they are getting sicker, the DS-ACP conversations are timely and well-received. However, the most appropriate timing for the DS-ACP conversation is less clear for cancer patients, and it may be that patients with certain forms of cancer are more likely to benefit from DS-ACP.
- The qualifications and experience of the DS-ACP facilitator has proven to be very important in establishing trust and positive communication with patients and families. Which types of professionals are best suited for the role of DS-ACP facilitator for cancer patients and what the role of the oncologist should be in this process remains unclear.

**A promising approach to end-of-life care planning** The Respecting Choices disease-specific advance care program addresses many of the problems identified with prior AD initiatives, proxy use, and communication. Through DS-ACP, patients are encouraged and enabled to consider and clarify their care preferences in worst-case scenarios, facilitating timely and proactive health care decisions based on accurate information of benefits and burdens. Proxies become educated about the preferences of their loved ones and are better prepared to make substitute decisions if needed, thus lessening the burdens of decision making. Patients and their families find this planning approach to be satisfying and helpful. DS-ACP also provides medical record documentation of patients' goals for treatment that are specific to their



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Disease-specific advance care planning  
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disease. These preferences are communicated directly with providers and promote conversation about future choices and desires. As with chronic disease, patients with cancer and their families may face important decisions about their medical care if their disease progresses or if they suffer complications from treatment. DS-ACP is a valuable mechanism by which patients can exert control over their health care needs and preferences, clearly communicate their wishes, and purposefully direct their individual end-of-life care experience. ■

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