

Introducing a Supportive Care Team for Advance Directive Education in a Neurological and Neurosurgical Patient Population

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Abstract

Background: Patient-centered care includes delineation of patient treatment values (ie, advance care planning [ACP]). Advance care planning often includes advance directive (AD) completion and is underutilized, particularly among neurology and neurosurgery patients. Implementation of a supportive care team (SCT) in outpatient clinic settings may offer opportunities for AD education and completion. **Objective:** This study assesses the effectiveness of an integrative SCT composed of hospice volunteers and undergraduate quality improvement interns in their efforts to provide ACP education in neurological and neurosurgical outpatient clinics. Assessment includes a description of different types of SCT-patient encounters, as well as patient interest in and completion of ADs after interacting with the SCT. **Results:** Across the data collection period, 2770 encounters were initiated. The majority of encounters resulted in patient ACP education. Some patients completed ADs during their SCT encounter (3.45%) or after their SCT encounter (10.18%). **Conclusion:** The SCT effectively enhances ACP education in this patient population. The utilization of trained interns to assist with ACP is beneficial and practical in clinic workflow.

Keywords

advance care planning, advance directive, medical decision making, patient education

Advance care planning (ACP) is central to patient-centered care, involving clarifying patient treatment preferences in advance of limiting health conditions (1). Advance care planning aims to decrease the use of futile treatment, promote palliation when needed to prevent hospitalizations, and increase compliance with patients' end-of-life wishes (2). The use of ACP increases patient and family satisfaction with care and has been demonstrated to decrease symptoms of post-traumatic stress, depression, and anxiety among family members (3). Patients who participate in ACP report higher satisfaction with their level of care involvement, and their families feel more prepared to comment on their medical treatment plan when required (3). Although benefits of ACP are clearly delineated, critiques of ACP emphasize that lack of education and support available to individuals as they consider, document, and revisit their recorded values may lead to unintended distress for patients and families (4,5). Best practices for effective and timely ACP remain somewhat unclear.

Advance care planning requires that patients explore life values and hold intimate conversations with their care team (1), in part to guide completion of an advance directive (AD). Advance directives typically include living will and health care surrogate documents which, when completed and incorporated into patient's medical records, provide formal

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instruction to medical teams regarding care patients wish to receive if they are unable to participate in medical decision-making (6). Inclusion of an AD in a patient medical record has been deemed one major marker of successful ACP (7). Advance directive completion helps to satisfy the parameters of the patient self-determination act, a federal law that requires health providers to inquire about patients' AD status and communicate with them about health care decisions (8).

While 92% of adults have heard of an AD, only 36% have completed one. Many patients remain in a state of precontemplation or lack of consideration of ACP (7,9). A diverse patient population, however, results in varying degrees of patient education about ACP (10). Previous studies have demonstrated, for example, that age, education level, patient experience, and diagnosis can affect patients' awareness of ACP, likely impacting their engagement in ACP (11,12).

Advance care planning is particularly important for patients with life-limiting or terminal conditions. This includes neurology and neurosurgery patients, who often have progressive cognitive decline, risk of dementia, impaired speech, or motor disability (13). These symptoms can limit an individual's capacity to understand and make independent ACP decisions or communicate and document decisions. As such, neurological and neurosurgical patients with advanced diseases urgently need early, individualized ACP support (14). To date, patients with neurological conditions are grossly lacking such support (15,16).

To improve opportunities for ACP in this patient population, a supportive care team (SCT) was initiated and integrated into neurology and neurosurgery clinic flows. The goal of the SCT is to provide opportunity for ACP, normalizing discussion of care values and encouraging continued contemplation outside of the clinic visit. One way that team members do this is to present patients with an AD.

The SCT is comprised of community volunteers affiliated with a local hospice organization, as well as pre-health learner undergraduate Quality Improvement interns. Historically, undergraduate pre-health learners have rarely been incorporated into structured ACP initiatives. The majority of pre-health learner students are not formally educated about ACP until they enter graduate or professional programs (17). Earlier training in patient-centered components of care (e.g., ACP) through involvement with initiatives such as the SCT may be beneficial to pre-health learners while providing needed resources to drive initiative success.

Objective of Current Study

The primary goal of this study was to assess the effectiveness of the SCT in increasing ACP education in outpatient neurological and neurosurgical clinic settings. A secondary goal was to demonstrate the ability of trained undergraduate Quality Improvement interns to provide such education. To this end, the study had 3 aims: (a) establish the extent to which Quality Improvement intern SCT members experienced successful encounters with clinic patients, (b) describe

types of successful encounters Quality Improvement intern SCT members can have with a clinic patient, and (c) determine how often encounters for all SCT members resulted in patient motivation to complete ADs.

Methods

Participants

The current work was approved through the institutional review board's Quality Improvement Project Registry (Project ID: 466). This study utilizes information from SCT encounters with patients seen in neuromedicine outpatient clinics (see Table 1 for clinic details). Demographic information about patients seen by SCT members across these 2 clinical settings is included in Table 2. Systematic Quality Improvement methodology (18) was used to develop the SCT program and included iterative Plan-Do-Study-Act (PDSA) cycles, which are detailed in Table 3.

Materials

Advance directive packet. The SCT used a state-approved AD packet created by the medical center where this study took place. The packet includes forms for Healthcare Surrogate Designation, Living Will, and Organ Donation (<https://ufhealth.org/sites/default/files/media/Advance-directives/2018-advanced-directives-packet.pdf>). The packet also contains an educational description of each form. Patients were also provided with instructions for uploading their AD to their electronic health record (EHR) at home.

Encounter survey. Quality Improvement interns completed an encounter survey after each patient encounter using REDCap, a secure web application for data collection. See Table 4 for survey items and guidelines intern SCT members used when completing the survey. For this preliminary study of the effectiveness of the SCT, encounter data were collected only from intern SCT members, and not patients, to ensure that time spent with patients and families could be dedicated to ACP support.

Procedure

SCT member training. The SCT consists of hospice volunteers and undergraduate Quality Improvement interns. Team members visited patients in each of the 2 clinics, regardless of their diagnosis or experience with ACP, during regular clinic hours. All team members were provided with a formal orientation to the program, including ACP education, training in navigating ACP conversations with patients during encounters, and online module training opportunities through Emmi Solutions (eg, <https://www.emmisolutions.com/>; Advance Directives module). The SCT members were also familiarized with AD components and the AD completion processes. The SCT members were trained to begin encounters with patients by asking questions to gauge patients' understanding of ACP, such as "Have you ever heard of an Advance Directive?" or

Table 1. Clinic Site Details.^a

	Clinic site 1	Clinic site 2
Type of clinic	Mixed service neurology and neurosurgery clinic	Neurology clinic specializing in movement disorders and other neurological diseases
Common diseases of patient population	Epilepsy, stroke, brain tumors, among others	Parkinson's Disease, multiple sclerosis, dementia, traumatic brain injury, among others
Number of providers in 2019	78	41
Number of patients seen in 2019	32 039	13 643

^aThis study was conducted at 2 clinic sites, both of which are part of an academic medical center located in the southeastern United States.

Table 2. Demographic Information of Patients Seen by SCT Members.^a

Measure	N/M	%/SD
Age	60.10	16.49
Sex		
Female	1361	49.13%
Male	1330	48.01%
Unknown	79	2.85%
Race		
White	2304	83.18%
Black/African American	243	8.77%
Asian	15	0.54%
American Indian/Alaskan Native	6	0.22%
Native Hawaiian or Pacific Islander	0	0.00%
Other	103	3.72%
Unknown	99	3.57%

Abbreviation: SCT, supportive care team.

^aThis data span encounters from intern SCT members and hospice volunteer SCT members occurring during the period that this study took place.

“Have you filled out an Advance Directive before?” These probing questions allow interns to assess patients’ familiarity with ADs. The project managers of SCT demonstrated patient encounters using standard protocol while the new SCT member observed, followed by project managers observing while interns worked with patients.

Data pertaining to hospice volunteer–patient SCT interactions were derived from brief descriptions of encounters recorded by volunteers during June 2017 to September 2019. Data pertaining to Quality Improvement intern–patient SCT interactions were derived from encounter surveys completed during August 2018 to September 2019 (ie, following PDSA 3). During the data collection periods, SCT members initiated 2770 patient encounters.

Hospice volunteers. At the inception of the SCT, hospice volunteers were utilized as SCT members. Volunteers were selected based on previous experiences in patient support roles (ie, retired nurses).

Undergraduate Quality Improvement interns. Well-qualified interns were selected from a pool of applicants to become SCT members. These interns were selected based on

Table 3. Plan-Do-Study-Act Timeline for SCT Development.

PDSA cycle number	Updates to the supportive care team program
1	June 2017–December 2017 Former health care providers who currently volunteer at a local hospice met patients of 1 outpatient neuromedicine provider during 1 day of the week
2	January 2018–July 2018 Volunteers began seeing patients of multiple neuromedicine providers
3	August 2018–September 2019. Quality Improvement interns were introduced to the SCT and began assisting patients of all neuromedicine providers during all days of the week

Abbreviation: PDSA, Plan-Do-Study-Act.

experience and comfort working with ACP, hospice, or end-of-life care as well as availability.

In a typical encounter with a patient, the Quality Improvement intern SCT member begins by stating that they are meeting with all clinic patients to reduce the patient’s assumption that they are being “targeted” for end-of-life discussion. The team member then asks the patient if they are signed up for the medical center’s online patient portal and offers to assist them with activation. This serves to establish the intern’s role as a patient advocate. The intern then initiates an ACP conversation. If the patient completes the AD packet with an intern, the intern uploads it into the patient’s EHR. After this ACP discussion, the intern introduces another support service which assists patients and visitors with finding their destination within the hospital. After concluding the visit, the intern fills out the Encounter Survey. An SCT encounter typically averages around 10 minutes.

Results

Data were analyzed using IBM SPSS Statistics version 25. To address aim 1, data from 1427 responses pertaining to intern SCT member encounters were included. To address aim 2, only the 1203 encounters deemed successful by intern SCT members were included. To address aim 3, data from all

Table 4. Encounter Survey for Quality Improvement Intern SCT Members.

Item number	Survey item	Response options
1	Intern SCT member Name	[Open-ended text field]
2	Appointment Date	[Day-Month-Year]
3	Appointment Time	[Hour: Minutes]
4	Patient First Name	[Open-ended text field]
5	Patient Last Name	[Open-ended text field]
6	Did you have a successful patient encounter?	<p>Yes</p> <p>An encounter is successful if one or more of the following occurs:</p> <ul style="list-style-type: none"> – The patient received ACP education – The patient accepted AD materials to review and consider at a later time – The patient completed an AD with you – The patient already has an AD and you confirm that it is on file in their Medical Record and/or offer to help them update it <p>No – Patient declined</p> <p>This selection applies if:</p> <ul style="list-style-type: none"> – Upon the intern’s entering, the patient expressed that they did not want to speak with them – After hearing the intern’s initial introduction, the patient does not wish to discuss ACP/ADs <p>No – Interruptions (ie, provider entered room)</p> <p>This selection applies if:</p> <ul style="list-style-type: none"> – The provider entered the room and the SCT member defaulted, cutting the encounter short <p>No – Other</p> <p>If the SCT member selects this option, an open-ended text field appeared. This option may be selected if:</p> <ul style="list-style-type: none"> – The patient was visibly distressed and the intern chose not to conduct the discussion – The patient was distracted by their imminent visit with their provider – The patient was unable to communicate because of a neurological issue, language barrier, or other reason
7	Is the AD already in the patient’s EHR?	Yes No
8	Does the patient have an AD? (patient self-report)	Yes No Maybe/Unknown
9	Was the patient interested in completing an AD?	<p>Yes</p> <p>The patient may be determined to be interested if:</p> <ul style="list-style-type: none"> – The patient actively listens while the intern provides education and acknowledges that they find the information helpful – The patient states that they would like to complete an AD but first need time to think about their goals of care/ discuss with their family, and accepts the AD materials to review later – Patient starts or completes an AD with the intern <p>No</p> <p>The patient may be determined to be uninterested if:</p> <ul style="list-style-type: none"> – The patient relays that they are not interested or willing to discuss or consider ADs – The patient declines to take AD materials–The patient already has an AD and does not wish to review or update it
10	Did the patient complete an AD with you?	Yes No
11	Did the patient take home an AD packet?	Yes No
12	Additional notes about the encounter:	[Open-ended text field]

Abbreviations: ACP, advance care planning; AD, advance directive; SCT, supportive care team.

2770 encounters across intern and hospice volunteer SCT members were reviewed.

Successful Encounters Among Intern SCT members

Intern SCT member survey responses to the item “Did you have a successful patient encounter?” were reviewed (see

Table 4). Intern SCT members reported 1203 successful encounters (84.30%). Encounters were unsuccessful in 223 instances (15.63%) due to the patient declining interaction with the SCT member (41 encounters, 2.87%), the SCT member being interrupted before beginning (149 encounters, 10.44%) or “other” reasons, which included the patient being unwell or unable to communicate (33 encounters, 2.31%).

Types of Successful Encounters Among Intern SCT members

Across intern SCT member encounters, 175 (14.55%) patients had an AD on file. These patients engaged in a discussion with the SCT member about ACP, including potential verification that their AD was in their EHR. An additional 446 patients (37.07%) thought they had an AD or might have an AD, but it was not on file in their EHR. These patients were provided with a new packet and education. Of those patients who had successful encounters but did not have an AD on file in their health record already ($n = 1028$), 750 (72.96%) patients showed interest in learning more from the SCT member.

Completion of Advance Directives

The SCT interns recorded which encounters resulted in a patient taking home an AD packet or filling out an AD packet with the intern. Of the relevant successful encounters (ie, where the patient did not already have an AD on file; $n = 1028$), 766 (74.51%) patients took home an AD packet and 53 (5.16%) patients completed the AD during the visit with the intern.

A total of 252 (18.76%) patients seen by hospice volunteers had an AD in their health record before the visit. Although hospice volunteers did not record additional information about patients who took a packet home, volunteers documented completing an AD with 28 patients (2.08% of those who did not already have an AD on file).

In addition to reviewing data reported by the SCT, the EHRs of all patients encountered by SCT members were retrospectively reviewed. Of the patients who did not previously have an AD on file in their EHR and did not complete one with the hospice volunteer ($n = 1063$) or intern SCT member ($n = 1199$), 282 (10.18%) patients later had a completed AD scanned into their EHR. The number of study-relevant clinic patients who later scanned an AD into their EHR did not vary due to the type SCT member who they interacted with (ie, hospice volunteer, Quality Improvement intern; $t = -0.23$; $P = .65$). Patients who self-reported that they had an AD, despite it not being in their EHR, were more likely to later have an AD scanned into their EHR ($r = 0.07$; $P < .01$) than patients who self-reported never having an AD.

Discussion

Increased awareness about the importance of ongoing ACP support (19) motivated the establishment of the SCT. This study demonstrates the effectiveness of an SCT in clinics serving neurology and neurosurgery patients, both in promoting ongoing ACP conversations and providing opportunities for completion of ADs. Results can be used to guide effective ACP education in neuromedicine patient populations and with other patients who may need ACP.

Successful SCT Encounters

This study demonstrates that the majority of the SCT encounters were successful in that they led to opportunities for patient ACP education and support. Although direct assessment of patients' stages of ACP was not conducted, interns initiated encounters through questions which assessed patients' knowledge of ACP, helping to tailor each encounter to observed patient stages of ACP awareness and participation (7). Providing ACP education and support to clinic patients from varied age groups and backgrounds may have helped to dissolve patient misconception that AD completion is only for the elderly (20) or for those who are very ill (21).

This study found that, despite having dedicated SCT members in clinics to provide appropriate ACP information, some encounters were unsuccessful due to time constraints. Because SCT members approach patients and caregivers while they are waiting to meet with their providers, the time SCT members have to spend with patients is dependent on clinic flow and room availability. Implementation of SCT services in clinics with more limited time between rooming and provider encounters would thus require alternative strategies for enough time to provide ACP education.

Quality Improvement Interns as SCT Members

The high rate of success of Quality Improvement intern SCT members offers evidence that conversations about ADs and ACP education do not have to be restricted to those with formal medical training. Indeed, recent research suggests that, while nearly all physicians believe ACP is important, the vast majority do not engage patients in ACP, in part because they do not feel they have the appropriate training (22). Research also suggests that providers, including those working with seriously ill neurological patients (23), often feel uncomfortable, unprepared (24), or too restricted by time constraints (25) to have conversations with patients about ACP. Quality Improvement interns often have the time, adequate training, and resources to overcome barriers to patient ACP caused by time restraints, low patient health care literacy, and patients' lack of access to ACP resources (26,27). Physicians have reported being more interested in having ACP conversations with patients who demonstrate that they value such discussions (22). We speculate that ACP education and support initiated by intern SCT members may lay the foundation for future conversations, initiated by patients, with their providers or loved ones.

Increasing ACP Discussions and AD Completion

Incorporating ADs to patients' health records remains an important marker in the ACP process. Although the Patient Self-Determination Act made AD documentation a requirement in some settings, inquiry about AD status during clinic visits is historically hastily done, if it is done at all (28).

Ultimately, patients are often not presented with the option to complete an AD until they are in a perioperative setting or after disease progression (29). This means that patients regularly have little opportunity to consider or discuss the AD until they are facing serious medical concerns. Such ACP decisions have the potential to create unintended negative consequences (29). The SCT members initiate ACP conversations with patients before their disease progresses to the point of needing serious medical attention or imminent surgery, allowing for more time during which the patient can carefully consider values and care options.

This study found that 13.63% of patients completed an AD during or following their SCT encounter. Patients who reported being confident that they had previously completed an AD were more likely to later upload an AD to their EHR than those who were confident they had never completed one. As such, the SCT may be particularly effective for patients in the latter stages of ACP (ie, action and maintenance) (7). The SCT members may serve as a catalyst for these patients who have already considered their health care goals, to ensure that goals are documented in their EHR (30).

Due to the multifaceted process of ACP, education initiatives should not focus solely on AD completion, but rather align with patients' readiness to participate in ACP (1). Many patients need time to review their life values, consider their options, and speak with loved ones before they formalize ACP decisions (19). The study found that the majority of patient encounters resulted in patients bringing an AD packet home, and most patients who scanned ADs into their EHRs did so in the time following their SCT encounter. Best practices for encouraging AD completion should be developed with recognition of the time patients may need to explore, discuss, and record treatment preferences after initial exposure to ACP initiatives.

Limitations and Future Directions

Data collection focused on global assessment of SCT program success, prohibiting a full exploration of patient traits (eg, awareness of prognosis, perspectives on ACP). Patients' perspectives on the quality of their encounters with SCT members are thus currently unknown. As this study was the first step in assessing the effectiveness of the SCT initiative, patient and family perspectives were intentionally not collected. In addition, data primarily came only from Quality Improvement intern SCT members. REDCap surveys were initiated and integrated into the SCT program to assess the effectiveness of Quality Improvement interns in the role of SCT member. Hospice volunteers were affiliated with a third-party organization, and thus the project managers were unable to require that they adapt to the survey and hold them to the same level of accountability as the interns. Volunteers also lacked the credentials that interns used to access protected health information, which limited their ability to complete all survey items.

Intern SCT members likely lack in-depth ACP knowledge and medical expertise to address complex questions or concerns from patients. Though any member of the SCT can recommend resources to further educate patients or motivate patients to speak with their families and providers about more complex issues, some SCT encounters may ultimately feel dissatisfying to patients who hoped to have specific issues addressed. Program refinement could include a clearly defined communication mechanism for ensuring patients remain connected to providers to address any unresolved questions or concerns. In addition, while initial support for program success was demonstrated in the current study, future work should include follow-up with patients to encourage continued ACP and explore patients' potential barriers to AD completion.

Conclusion

Effective ACP education helps ensure patient-centered care by empowering patients to plan for their future and consider their care values. The SCT has shown substantial initial success in engaging patients in ACP conversations and motivating AD completion, even in challenging patient populations. Quality Improvement interns are promising members of the SCT, demonstrating success in most encounters. As our population ages on a global level, prioritization of ACP demands innovative solutions to existing barriers. The SCT is a valuable asset in guiding patients through the ACP process.


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