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Experiences and Perspectives on Advance Care Planning among Individuals Living with Serious Physical Disabilities

Suzanne E. Mitchell, MD,[1] Gabriela M. Weigel, BS,[2] Sabrina K.A. Stewart, BS,[3]
Morgan Mako, BA,[4] and John F. Loughnane, MD[5]

Abstract

Background: Despite frequent encounters with the healthcare system and high risk for secondary conditions, it is unclear how frequently individuals living with serious physical disabilities document advance directives (AD) or engage in advance care planning (ACP). Their perspectives on these topics are largely unknown.
Objective: We aimed to characterize the perspectives of individuals with serious physical disabilities receiving care from two different healthcare delivery settings on the value of AD and ACP.
Design: Key informant interviews were conducted, audiorecorded, transcribed, and analyzed using thematic analysis and constant comparative analysis.
Subjects: Twenty-five adults with serious physical disabilities were interviewed.
Results: Five organizing themes emerged as follows: (A) AD is a right versus responsibility, (B) past medical experiences influence ACP engagement, (C) ACP requires relationship-centered decision support, (D) concerns for care after death, and (E) suggestions for improving ACP experiences. Participants wished to engage in a relationship-centered approach to ACP, yet voiced hesitation due to experiences of significant medical bias and mistreatment, typically surrounding judgments of their quality of life.
Conclusions: Better health professional training in ACP and heightened awareness of the unique ACP considerations pertaining to people with disabilities are recommended.

Keywords: advance care planning; advance directive; disability; shared decision making

Introduction

Twenty percent of Americans report living with a disability, 35% of whom have ambulatory disabilities, which is defined as having serious difficulty walking or climbing stairs.[1–4] While medical advances have enabled individuals to survive one's fatal medical conditions and live with now manageable chronic diseases or disabilities, people with disabilities (PWD) experience on an average 4 to 13 secondary conditions per year, some of which may be life-threatening and require intensive medical care.[5,6] Despite this, the prevalence of PWD who have documented healthcare advance directives (AD) to ensure that they receive medical care that meets their personal values, in the event they encounter a life-threatening illness and/or are unable to communicate their preferences, remains unclear. This study refers to AD as legal, written documents that comprised a living will detailing instructions for end-of-life care and designation of a healthcare proxy to direct medical care if the patient is unable.[7] Since the passing of the Patient Self-Determination Act in 1990, which requires healthcare facilities receiving federal funds to inform and educate patients on their healthcare decision-making rights, the process of advance care planning (ACP) has become more widely known and available to patients.[8–10] Still, only 18%–36% of Americans report AD documentation.[11]

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[1] Boston Medical Center, Boston University Medical Center, Boston, Massachusetts.
[2] Department of Family Medicine, Boston Medical Center, The University of California, San Francisco School of Medicine, Boston, Massachusetts.
[3] Department of Family Medicine, Boston Medical Center, The University of Nottingham Medical School, Nottingham, United Kingdom.
[4] Department of Family Medicine, Yale University School of Nursing, Boston Scientific, Orange, Connecticut.
[5] Commonwealth Community Care, Commonwealth Care Alliance Medical Group, Lawrence, Kansas.
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The prevalence of documented AD for PWD is insufficiently researched and remains uncertain; current studies are severely limited by sample sizes[12] or fail to distinguish between PWD and individuals with chronic disease or long-standing illness.[13] Even more unknown are the perspectives of PWD on the value of ACP.[14] To better understand the perspectives of individuals living with serious physical disabilities on ACP, we used a qualitative research approach to characterize common viewpoints on ACP and AD among members of this community; we aimed to identify barriers and facilitators to effective ACP and documentation of AD.

Methods

To explore if healthcare system characteristics influence views on ACP, we recruited participants from two healthcare models as follows: (1) an integrated healthcare practice dedicated to PWD, where patients receive coordinated medical and behavioral healthcare and social services from teams of providers in office, hospital, or home-visit settings and (2) traditional, nonintegrated health systems, where clinicians neither typically specialize in PWD nor provide home visits or integrated behavioral health and social services. These participants were recruited through announcements and flyers at a local center for independent living. Clinicians from the integrated healthcare system recruited participants from this group. Individuals were eligible if diagnosed with an irreversible serious mobility impairment (spinal cord injury, paraplegia, quadriplegia, amputation, cerebral palsy, and progressive neurological diseases). All participants provided informed consent and received gift cards as compensation.

Using our interview guide (Table 1), we conducted 25 key informant interviews with individuals in Greater Boston living with serious ambulatory disabilities to elicit their experiences discussing AD with healthcare professionals, preferences for learning about and deciding on AD, and what individuals deemed important to the ACP process. Theme saturation was achieved at this sample size.[15–17] Interviews were audio-recorded, transcribed verbatim, coded by a minimum of three independent coders trained in qualitative research, and analyzed by thematic analysis with constant comparative analysis between participants from the integrated versus nonintegrated healthcare systems (Table 2).[18–21] The qualitative data management software, NVivo 9.0, was used.[22] The Boston University School of Medicine IRB approved this study protocol.

Table 1. Key Informant Sample Interview Questions

Describe your thoughts and experiences with making medical decisions. How do you usually make decisions about healthcare?
What is your preference for being involved in decision making?
Describe a time when you faced an important healthcare decision.
Describe your thoughts about AD and ACP.
Describe a time when you talked with a doctor, nurse, or other health professional about AD or life-sustaining treatment.
What were important considerations for you in making decisions about life-sustaining treatment?
What could have been done to improve communication of healthcare providers concerning advance directive?

ACP, advance care planning; AD, advance directives.

Table 2. Phases of Thematic Analysis[18]

Phase	*Description of the process*
1. Familiarizing team with the data	Transcribing the data with dual review of transcripts; rereading the data; noting initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic manner across the entire dataset; codebook created, and data relevant to each code collected. Transcripts coded by minimum two reviewers.
3. Searching for themes	Collating codes into potential themes.
4. Reviewing themes	Examining the fidelity of the themes in relation to the coded extracts and the entire dataset.
5. Naming and defining themes	Refining each theme to develop an overall framework for the data; generating concise definitions and names for each theme.
6. Interpreting results	Final analysis; selection of evocative, detailed extract examples; final analysis of selected extracts, relating the analysis to the research question and literature.

Results

Twenty-five individuals living with serious physical disabilities were interviewed; 15 from the integrated care system and 10 receiving nonintegrated care. Table 3 reports their sociodemographics. Participants receiving integrated care had higher rates of nominating healthcare proxies and documenting AD than those receiving nonintegrated care. Five overarching themes emerged from the data as follows: (A) AD is a civil right or responsibility, (B) past medical experiences influence willingness to engage in ACP, (C) effective ACP requires relationship-centered decision support, (D) concerns for dignity after death, and (E) suggestions to improve ACP (Table 4). Individuals from different healthcare systems held similar perspectives on four of the five themes (A, B, D, E), but held different views on the appropriate person to facilitate ACP decisions.

Advance directives as right or responsibility

All participants viewed AD as salient meaningful documents. Some participants believed AD constituted a personal responsibility to their family members and friends and were concerned about the financial or emotional burden their loved ones could confront if charged with making decisions around life-sustaining care for the individual. One participant noted, ‘‘It's probably a more peaceful mind…knowing that you wouldn't be putting anyone else in burden…it's…your responsibility…either to take care of it [yourself] or to have a discussion with family, so they won't be tormented…how

Table 3. Sociodemographics of Key Informant Interview Participants by Healthcare System

Self-reported measures	*Integrated care* (n=*15)*	*Nonintegrated care* (n=*10)*	*All participants* (n=*25)*
Gender, *n* (%)			
Male	9 (60)	5 (50)	14 (56)
Female	6 (40)	5 (50)	11 (44)
Age			
Average age	48	59	54
Age range	25–70	48–76	25–76
Reported healthcare proxy, *n* (%)			
Yes	10 (67)	6 (60)	16 (64)
No	0 (0)	3 (30)	3 (12)
Not sure	5 (33)	1 (10)	6 (24)
Reported advance directive (healthcare proxy and living will)	8 (53)	3 (30)	11 (44)
Racial and ethnic background, *n* (%)			
White	9 (60)	6 (60)	15 (60)
Black	4 (27)	2 (20)	6 (24)
Hispanic	2 (13)	1 (10)	3 (12)
Asian	0 (0)	1 (10)	1 (4)
Annual household income, *n* (%)			
<$5000	0 (0)	1 (10)	1 (4)
$5–9999	1 (7)	2 (20)	3 (12)
$10–14,999	2 (13)	1 (10)	3 (12)
$15–19,999	0 (0)	2 (20)	2 (8)
$20–29,999	5 (33)	0 (0)	5 (20)
>$30,000	0 (0)	1 (10)	1 (4)
Do not know or refused	7 (47)	3 (30)	10 (40)
Highest level of education, *n* (%)			
Less than high school	0 (0)	1 (10)	1 (4)
Some high school	0 (0)	1 (10)	1 (4)
High school graduate	7 (47)	1 (10)	8 (32)
Trade school	0 (0)	1 (10)	1 (4)
College: associates	0 (0)	1 (10)	1 (4)
College <2 years	2 (13)	1 (10)	3 (12)
College graduate	3 (20)	2 (20)	5 (20)
Postgraduate/no degree	1 (7)	0 (0)	1 (4)
Postgraduate/degree	1 (7)	2 (20)	3 (12)
No answer	1 (7)	0 (0)	1 (4)
Marital status, *n* (%)			
Single w/out partner	10 (67)	1 (10)	11 (44)
Single w/partner	0 (0)	1 (10)	1 (4)
Divorced or separated	2 (13)	6 (60)	8 (32)
Married	3 (20)	2 (20)	5 (20)

dare [people without AD] leave their family… and their kids like that? They didn't take responsibility for their things.''

By contrast, other participants felt AD constituted a responsibility to themselves, a healthcare right necessary to protect: ''[AD] are…a big part of self-determination for people with disabilities. People with disabilities must have a voice in all aspects of their lives…especially when your active voice is silent…[more] people with disabilities are leading productive lives than ever before …and they still get…undermined in the doctor's office.''

For this individual, AD represented asserting agency over his care. When probed further, the discordance between the perception of the importance of AD and the subsequent willingness to document AD seemed largely shaped by past medical encounters and discrimination experienced by participants.

Influence of past medical experiences on willingness to engage in advance care planning

Regardless of the healthcare system, all participants shared cautious approaches to ACP, concerned with confronting further stigma and discrimination due to past medical experiences. Many participants felt medical practitioners considered the lives of PWD less valuable and therefore did not trust them to make care decisions aligning with their best interests: ''I don't trust the medical system to do what's best for me… that's my experience overall so… when I'm in a medical setting [I] make sure…decisions are in my best interest…because when you go into the hospital, that means you could die. But it's the idea that the medical system can have control over me…that's sort of denial of human

Table 4. Dominant Themes from the Data and Representative Quotes

Themes	*Representative quotes*
(A) AD is a right vs. responsibility	*AD as a right:* ''[AD]are…a big part of self-determination for people with disabilities. People with disabilities must have a voice in all aspects of their lives… they still get…undermined in the doctor's office.'' *AD as a responsibility:* ''It's probably a more peaceful mind…knowing that you wouldn't be putting anyone else in burden…it's…your responsibility…either to take care of it [yourself] or to have a discussion with family, so they won't be tormented.''
(B) Past medical experiences influence ACP engagement	''I don't trust the medical system to do what's best for me… that's my experience overall so… when I'm in a medical setting [I] make sure…decisions are in my best interest…because when you go into the hospital, that means you could die.'' ''[Previously], we didn't have any doctors that understood disabilities, it was sort of scary… [now] our [medical] group is very experienced working with them… The minute we got on that group, we felt safer…they think we have a very good quality of life.''
(C) ACP requires relationship-centered decision support	*Support from healthcare providers:* ''They [my healthcare provider] will have my back no matter what. If I can't talk or something, I already put what I needed on a piece of paper…I think it [ACP] should be one-on-one with a nurse or a doctor.'' *Support from peers:* ''I think [PWD could discuss AD] with friends. With peers. I think this issue should start entirely with your best friend with disabilities who understands you and yourself understands them. I think that's where the conversation starts.''
(D) Concerns for care after death	*Concerns for consequences to family:* ''…it's very selfish to leave decisions about end of life to family who is already in a very emotional situation… it can cause a lot of divisions in the family… It's so selfish to say, 'Oh well, I don't care. Do whatever you want with me.'… It could really hurt their relationship with each other.'' *Concerns for self-determination:* ''Some people don't want to be cremated. And someone with a disability, if they don't say that, we may cremate them and that's not their wishes… If you don't get [life insurance] then you will be [taken] by the state and the state will have no problem cremating you.''
(E) Suggestions for improving ACP experiences	*Changing conversations around ACP:* ''The way we deal with death in this culture is really poor…. by the time someone turns 21 and they walk into the doctor's office, there should be conversations… if [ACP] became part of your regular medical exam, people would talk about this with their family…at some point one has kids, and a family, and a partner or whatever and they're going to say, ''…I do need to start thinking about this stuff.''

PWD, people with disabilities.

rights…If I thought about how powerless I was, I'd be paralyzed. I don't want my disability to paralyze me.''

Another participant echoed this sentiment, explaining, ''Some of these doctors, they say, 'Oh, you're handicapped. It doesn't matter what happens.' But it does.'' These participants spoke from a deep sense of vulnerability felt by many PWD in healthcare settings, resulting in apprehension to engage in end-of-life conversations for fear that care may be withheld due to a perceived lesser quality of life.

When asked about their own lives, however, participants expressed they have ''wonderful,'' ''absolutely fabulous,'' and ''excellent'' quality of life. One participant even thought his quality of life was better than when he was nondisabled. One woman explained quality of life as: ''a little different with the disability community than the nondisabled community… we have a different perspective… People will [say], 'Oh, you poor thing,'… because I can't do certain things or because I'm in pain… So for them, the quality of life would be like, 'Oh, just let me go.' Well I'm glad… that didn't happen because … I wouldn't have … gotten married, I wouldn't have my kids… Quality of life…it's so subjective.''

Despite overwhelming feelings of discrimination, some participants in the integrated health system did believe that their current providers appreciate them: ''[Previously], we didn't have any doctors that understood disabilities, it was sort of scary… [now] our [medical] group is very experienced working with them… The minute we got on that group, we felt safer…they think we have a very good quality of life…they'll say, 'you girls are very healthy.' And we laugh, we are very healthy. We just can't breathe and can't walk.''

What this participant thought differentiated her current providers from previous providers was the high value they assigned to the quality of life of PWD. What followed from this trust was a desire by participants from the integrated health system to engage in ACP with their provider.

Relationship-centered decision support

Participants enrolled in the integrated care system commonly reported a trusting relationship with providers as a prerequisite to ACP discussions. Despite a history of negative medical encounters, these participants often wanted to engage in ACP with their trusted healthcare provider. ''They [my healthcare provider] will have my back no matter what. If I can't talk or something, I already put what I needed on a piece of paper…I think it [ACP] should be one-on-one with a nurse or a doctor.''

By contrast, the majority of participants from nonintegrated health systems wished to conduct ACP conversations with peers who were highly aware of their needs and who may offer trusted advice: ‘‘I think [PWD could discuss AD] with friends. With peers. I think this issue should start entirely with your best friend with disabilities who understands you and yourself understands them. I think that’s where the conversation starts.’’

Others felt clinicians’ biases on the quality of life of PWD impact their ability to provide decision-making support. One participant with nonintegrated healthcare suggested, ‘‘Maybe they [clinicians] should [talk about AD] in the house. They can see how we live and what we can do around the house. They think we’re just living in the bed all the time, but we’re not. We’re out in the community.’’

Concerns for dignity after death

For some participants, life insurance and after-death arrangements were of substantial importance, raising the question of whether ACP should involve discussions of after-death preferences, a topic not typically covered currently. Many expressed concerns about financial and emotional burdens their families may experience if after-death arrangements were absent: ‘‘…it’s very selfish to leave decisions about end-of-life to family who is already in a very emotional situation… it can cause a lot of divisions in the family… It’s so selfish to say, ‘Oh well, I don’t care. Do whatever you want with me.’… It could really hurt their relationship with each other.’’

There was also the fear that without explicitly stated directions on treatment preferences at the end of life or once they had died, their preferences would not be honored. One participant explained anxiously: ‘‘Some people don’t want to be cremated. And someone with a disability, if they don’t say that, we may cremate them and that’s not their wishes… If you don’t get [life insurance] then you will be [taken] by the state and the state will have no problem cremating you.’’

Suggestions for ACP

Participants voiced suggestions to improve ACP specifically for PWD, and two overarching recommendations emerged. First, participants insisted on increased training for healthcare professionals in patient communication, the process of dying, and caring for PWD. Many thought this training should be taught in medical school for doctors, and one participant suggested requiring healthcare professionals to complete their own process of ACP to better understand the patient’s experience.

Second, participants thought conversations concerning ACP and AD should be extended, both in time and in frequency. For those who had engaged in ACP, they felt the typical 10 minutes allotted by physicians to cover this topic was insufficient. After the initial discussion of AD, they wanted these documents to be revisited yearly to ensure they still aligned with their wishes. One participant called for a holistic approach to ACP: ‘‘The way we deal with death in this culture is really poor…. by the time someone turns 21 and they walk into the doctor’s office, there should be conversations… if [ACP] became part of your regular medical exam, people would talk about this with their family…at some point one has kids, and a family, and a partner or whatever and they’re going to say, ‘‘…I do need to start thinking about this stuff.’’ …it’s an evolutionary process… changes depending on what’s going on in the person’s life…We just need a paradigm shift in society so that death becomes part of our life experience as opposed to just sending people to a hospital to die and just being shocked when they do… instead of getting the proper palliative hospice care.’’

Discussion

All participants strongly supported self-determination and AD in the event of life-threatening illness. Our participants and disability advocates alike, however, feel that the end-of-life care reform movement has largely ignored the concerns of the disabled community,[3,11,23,24] perhaps resulting from a sharp divergence between those living with disabilities and the nondisabled on what constitutes a satisfactory life and dignified end-of-life care.[6,8,25,26] The perspectives of PWD on their quality of life are not necessarily driven by the extent of their disability; while some participants did believe physical limitations would diminish their quality of life (e.g., inability to breathe or eat), others thought factors such as keeping a sense of humor and being with family were more important. Despite differing perspectives, participants agreed that measuring quality of life is highly subjective and may change during the course of one’s life, compatible with prior research measuring quality of life for people with spinal cord injuries.[27]

Still, discussions between clinicians and patients about wishes for life-sustaining treatment often focus whether an acceptable quality of life can be achieved despite physical limitations. This approach to discussing life-sustaining treatment is clearly inappropriate for individuals who already live with serious disabilities; one participant reflected that the medical technology he depends on as daily care is often regarded by providers as life-sustaining equipment, a reliance on which would diminish quality of life. Confining end-of-life discussions to physical capabilities fails to account for other ways of determining a valuable life and implies to a patient with a disability that the healthcare system may not deem his/her life as valuable.[24] Our participants, however, noted highly satisfactory quality of life, alluding to the distinction between disability and sickness.[3,28] Although our participants thought AD were important, for some, the discussion seemed premature, as they are healthy and capable despite disabilities. This calls into question when is the right time to engage in ACP and how the discussion should be framed to avoid devaluing the lives of PWD.[29]

Shared decision making between patients and clinicians about wishes for life-sustaining treatment can be a challenge for individuals with disabilities, racial and ethnic minorities, and other communities with historical evidence of discriminatory treatment in healthcare settings.[30] The majority of our participants expressed some level of fear of differential treatment by medical providers between disabled and nondisabled individuals, and some feared this would translate into care being withheld at the end of life. One participant believed this anxiety has to do with pressing political concerns about what legalization of physician-assisted suicide may mean to PWD.[31] This man noted that many PWD see a fine line between AD, physician-assisted suicide, and palliative care,[26,28] stemming historically from the health system’s lack of value and respect for PWD. ‘‘Euthanasia [used interchangeably with physician-assisted suicide by participant]… takes away from agency. In the medical system that exists, the doctor becomes the expert, and it's not really the person making the choice… my strong feelings against euthanasia are in large part a reaction to this jump from illness to 'kill myself,' as opposed to saying, 'There will be suffering, but you will have control and we can offer these services to you.'…We miss palliative care… and hospice as a more dignified way.''

Mistrust is particularly acute among PWD who worry that the healthcare system will fail to provide and support goal-concordant care in the face of a life-threatening event. The history of systemic inequality in care for the disability community makes it formidable for the persons living with a disability to muster the confidence that the healthcare system will truly abide by their medical care wishes.[32] All of the participants reported prior experiences of perceived medical discrimination. However, most participants from the integrated healthcare system contended their relationships with their healthcare providers were so trusting that they actually preferred to engage in ACP with these professionals over peers. Despite the seemingly insurmountable barrier of historical medical discrimination, the continuity of care model appears to offer a compelling mechanism for fostering trust between PWD and providers to facilitate AD discussions through relationship-centered care. By contrast, individuals receiving care from nonintegrated systems typically felt more comfortable having these conversations with peers. While individuals from the integrated health system saw their providers as attentive to the specific needs of PWD and meaningfully engaged with this community, those from nonintegrated health systems did not cite this same level of trust in their providers; this may help explain why those from the integrated system documented AD at a higher rate than those receiving nonintegrated care. In the absence of a trusting relationship with a long-term physician, ACP discussions may be more meaningful and appropriate with other healthcare professionals, including social workers, nurses, chaplains, and attorneys, or with family and friends.[33,34]

Participants offered recommendations for ACP, stressing the importance of medical professionals learning to better communicate about end-of-life issues, specifically for PWD. One participant believed her physician is uncomfortable discussing this topic, alluding to insufficient training and familiarity with ACP among healthcare professionals. Numerous studies name an urgent need for more physicians to be board certified in hospice and palliative care and for more nurses and social workers to complete specialty certification programs in this field to become better able to communicate compassionately and appropriately with patients about the end of life.[3,23,35,36] Moreover, participants supported a holistic approach to ACP, rather than brief, infrequent encounters. Many wished providers would discuss this topic more comprehensively, and one thought end-of-life considerations must be integrated into our cultural framework. The Institute of Medicine's report, *Dying in America,* echoes these recommendations, believing ACP should be part of periodic, comprehensive discussions starting at any age or state of health.[35] In addition, for many participants, a dignified death was as important as dignity in dying, and therefore, burial arrangements and life insurance were seen as essential components to include in ACP.

Given the qualitative data, causal associations cannot be made. We also acknowledge that AD documentation may be contingent upon physician prompting, and individuals interested in this topic were more likely to participate in the study; however, this does not discount participant's guidance for future development of the ACP process. Information on health status and healthcare utilization was not collected, yet these factors may have influenced participants' perspectives toward ACP. Our study is neither a representative of all disabled people or communities nor does it explore the potential confounding factors to disability such as race, gender, age, religion, and LGBT status that may influence one's experiences and perspectives.

Ultimately, the unique voices from the disability community are largely absent in existing literature and deserve to be heard to protect the values and agency of PWD in medical decision making.[33] Further research is warranted to understand the optimal implementation method of ACP and design of AD, specifically for individuals with disabilities.

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Address correspondence to:
Suzanne E. Mitchell, MD
Boston Medical Center, Dowling 5
Boston University Medical Center
771 Albany Street
Boston, MA 02118

E-mail: suzanne.mitchell@bmc.org