WHO DEFINES MY QUALITY OF LIFE?:

Perspectives from Disability-Advocates and Caregivers

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Background

The Office of Developmental Primary Care facilitated two discussion groups in order to learn more about the experiences of people with disabilities and their families in accessing the health care system. Discussion topics included communication, personal life values, changes in or loss of function, medical decision-making, and end of life care conversations. Our ultimate purpose was to uncover how these interactions impact patient care, including goals of care and end of life conversations.

A number of steps were taken in both groups to create safe, welcoming, accommodating environments, and to ensure that each participant felt respected and heard. The goal was to foster an atmosphere of trust where potentially sensitive, difficult topics could be openly discussed. Participants were told that all personal information shared during the session would remain anonymous. They also agreed to keep the information shared by others confidential. Participants were given the option of not answering emotionally difficult questions, and could leave the room if they needed time and space away from the group.

The first group met in a wheelchair and transit-accessible location in downtown Oakland. This group consisted of seven, adult advocates with disabilities representing a variety of genders, ethnicities, developmental disabilities, and other health conditions. The group was facilitated by two advocates with disabilities.

At the start of the session, each participant shared their name, preferred gender pronoun, and any anticipated access needs. Two skilled attendants were available to help meet any physical and communication needs during the two-and-a-half-hour session. Lunch was served, and assistance with eating was provided as requested. Several of the participants have communication disabilities. The attendants and other group members helped participants by revoicing their responses. Revoicing is the practice of a supporter restating what a person has said to ensure understanding of unclear speech.

The second group met for dinner in a conference room within the Department of Family and Community Medicine at University of California, San Francisco. This caregiver group consisted of four mothers of adults with complex disabilities. Two of the mothers had direct experience with end of life medical care. Their daughters had passed away within the last five years.

Both facilitators were mothers of children with disabilities. One had direct experience with end of life medical care for her child. The combined groups included one mother-daughter (with a disability) pair. Their accounts of specific situations and interactions contained a significant amount of overlap. Two parents who were not able to attend the caregiver group were interviewed by telephone at a later date. Their feedback was incorporated into this report.

Key Issues and Recommendations

Participants offered a number of recommendations to better support patients with disabilities and their caregivers. These recommendations, as well as quotes from both groups describing their experiences, are included in each section below.

1. Communication and Decision-Making

From Advocate Group

> "When I have brought others, especially my parents, the providers tend to direct their questions to them, and not to me. They take them more seriously. It's frustrating."
>
> "I go with help now. I make it clear that the helper is there to help me, not the provider."

From Caregiver Group:

> "I brought in her communication device and they were shocked that she could do anything like that. They had assumed that she was a little lump."
>
> "He [my son] is usually, at this point, the person who makes the decision that it's time to go to the emergency room."
>
> "Because they discriminate against people who have intellectual disabilities, and if you have a speech disability they treat you like you have an intellectual disability, they're not really taking what she's saying very seriously."

Participants in the advocate group spoke of their frustration when medical providers directed questions and comments about their health to caregivers or family members. Many of these participants went to medical appointments without support in order to force clinicians to speak to them directly. Participants in the caregiver group also experienced frustration when clinicians failed to acknowledge the autonomy of their loved ones.

In most cases, people with disabilities are competent to make medical decisions with the right support. Patients with disabilities may have unique ways of understanding and communicating information, making medical decisions, and expressing specific wants and needs. As with all patients, presuming that patients have unique, individual perspectives, and can learn and communicate is respectful. It helps reduce barriers to participation that can arise when abilities are underestimated. Inquiring and supporting effective communication methods builds provider-patient communication.

For visual readers, use visual aids or bullet-pointed lists. Some low vision patients may need information in Braille and descriptions of pictures or other graphics. Another modified communication exchange may include slowing down the conversation and giving patients extra time to relay information or ask questions. Some people with developmental disabilities have strong receptive language skills. They understand language in a preferred format, but have greater challenges with expressive language. It may be helpful to present information in a respectful, easy-to-read, plain language format. This doesn't mean watering down information. Rather, plain language refers to using clear, straightforward communication that ensures language is accessible, and can be easily understood by the listener.

Leaving patients out of conversations about their health care denies them personal control over what happens to their own bodies. Many individuals with disabilities have a long history of not having a say over their medical care. Other people have made decisions about their bodies. Some of these decisions have had negative, life-altering consequences. In medical situations, patients with disabilities need as much autonomy over their bodies as possible.

This sense of control is especially important when making end of life decisions. When appropriate, patients should be encouraged to ask a trusted supporter (a caregiver, family member, spouse, or friend) for help weighing their options, but if at all possible, follow and honor the decisions made by the person with the disability.

2. Intersecting Identities

From Advocate Group:

> "Being disabled doesn't disqualify us as multi-faceted beings that experience the effects of race, sexuality, socioeconomic status, gender, etc."
>
> "My primary nurse practitioner sees me as a whole person, including my disability, sexuality, social life, and other medical needs unrelated to my disability."

From Care Provider Group:

> "Our difficult experiences have always been with people who haven't gotten to know him. So in the hospital, if it's not the team who knows him, it becomes more difficult."
>
> "We had pictures up all over the room to show what she was when she wasn't in bed bald, you know? What her other life looks like. And so, that helped."

Disabled people are complete individuals with a lifetime of intersecting identities, personal goals and fears equal to those of their nondisabled peers. Both advocates and caregivers asked that clinicians acknowledge and respect them as whole people when considering the impact of potential treatment. For some people, disability is a cultural experience. This cultural identity gives them a shared history and a sense of pride, purpose, and belonging. Yet even the lives of the members of this powerful community do not solely revolve around their disabilities or health care needs. They have relationships, other cultural identities, professional responsibilities, and a variety of gender and sexual orientations.

One woman in a power wheelchair spoke of how her clinicians failed to convey that a specific course of treatment would affect her ability to conceive. As a result, she proceeded with the treatment offered, and is now unable to have biological children. She believed that the clinicians failed to share this information due to the common assumption that a disabled woman would not want to have, or could not have, children. Other group members described how they attempted to get clinicians to see them as whole people.

3. Avoiding Assumptions

From Advocate Group:

> "Stop using compliments like, 'You're doing so good in life!' or 'I could never live with a disability!' It's like they think they're making my day by saying these things. It shows that they have a super low impression of my quality of life. I have to show off just to get basic health care. I deserve the best health care."

> “When I go [to a medical appointment] and speak up for myself, I think about how to challenge their assumptions.”
>
> “I wish medical students had to work in the community so they can see for themselves what our lives can be. I would like them to see ‘life.’ That it’s not all medical; we have fun.”

From Caregiver Group:

> “You know, if I brought my [non-disabled] son in here with the exact same issue, I wouldn’t be having this discussion.”
>
> “Like this is the status quo, and this is what it always looks like. As opposed to making the assumption they have this really rich, great life in the community doing all sorts of neat things. They’re not always this sick. Not always unable to communicate in their own way. It then puts the burden on us and the person who is not feeling great to paint that picture in some way."
>
> “Their mission is to cure somebody and they can’t cure disability. So they would wash their hands of it. And in turn, wash their hands of her.”

People with disabilities want clinicians to avoid basing treatment options on assumptions about their quality of life. Clinicians sometimes assume that people with significant disabilities and their caregivers have a poor quality of life. These personal judgments can have dangerous side effects, including the premature withdrawal of life-saving care. False assumptions about a patient’s prognosis can lead to self-fulfilling prophecies. On average, people in both groups are generally satisfied with their lives. Life with a disability may look different, but disabled people still have deep connections to friends, family, and their communities. In cases where patients or caregivers are feeling stressed or isolated, take the time to assess their service and support needs.

Negative messages regarding the perceived life-quality of people with disabilities can be found in abundance in popular literature, the media, and the medical community. When news stories use phrases like “confined to a wheelchair” or “suffers from a disability,” the nondisabled public hears the message that having a disability or health condition must be horrible. In some instances, society sends the strong message that death is a better option than living with a disability.

This bias is also found in some written forms of medical literature. Certain pieces of information show strong biases against living with the assistance of medical devices, and can, in turn, devalue living with a significant impairment. Some spoken language used in healthcare settings conveys value judgments about certain conditions. Words such as burden, suffer, hopeless, dependent (on physical support or medical devices) can send negative messages about living with a disability. One mother from the caregiver group offered clinicians two pieces of advice when speaking to young adults with disabilities. She advised clinicians to use age-appropriate language and to communicate information in “ways that are honest, but not horrifying.”

Members from both groups cautioned clinicians not to confuse a patient’s health status in a hospital setting with their typical baseline. One mother shared her frustration at having clinicians ask, “So is this her baseline?” while her daughter was in the ICU. She responded, “No. She’s in an intensive care unit. We don’t live in an intensive care unit.” She pointed out that inquiring about a patient’s baseline wasn’t problematic, rather it was the way the question was asked. Instead of saying, “Is this your/their baseline?”, she recommended asking, “What is your/their baseline?” Another parent encouraged clinicians to ask questions or find other ways of determining how a patient functions in the outside world. As an example, she described a physical therapist who watched a recorded interview of her daughter in order to gain an understanding of her typical speech patterns.

Patients with disabilities have the same need for privacy and respect for their personal boundaries as non-disabled patients. The existence of a disability is not automatic permission to act without a person's full consent. One mother relayed a story of her young daughter hitting an impatient doctor after they had pulled down her pants without her consent in order to perform an examination. Asking for consent and carefully explaining what to expect during a procedure will go a long way in the formation of a trusting patient-provider relationship.

4. Goals of Care

From Advocate Group:

> "They gave me too many drugs. I was puking a lot because I was so doped up. I was so depressed!"

From Caregiver Group:

> "The discharge nurse said, "Well she doesn't really need rehab anyway, she can't walk."
>
> "The expectation that a family and an individual can do the amount of PT and OT daily in a home program and have a life [is false]. I mean they're just unrealistic about what they think kids and families can do."

Clinicians may offer too much or not enough treatment based on preconceived notions regarding patients with disabilities. This has the potential to greatly affect health outcomes, and possibly the recovery process. Even patients with similar conditions may have vastly different histories, health goals, and levels of tolerance. No two people or disabilities are exactly alike. As one disabled advocate in the group described, "There is no textbook disability case."

It can be difficult to find a balance between treating symptoms of a serious, health condition and managing the effects of a disability. Finding the right balance requires having an honest conversation with patients and their families about their goals of care and how they operated in the world before the onset of their current condition.

If the patient is expected to either recover from or live with this new condition, they will need a way to function in their everyday environment. Part of their ability to function may depend on the amount and type of treatment they receive. For example, if they previously lived alone, they may need to consider new living arrangements. This could involve living with family members, friends and/or the involvement of either private or publicly-funded, in-home, attendant care. Living arrangements might also entail consideration of physical structures such as stairs, doorway widths, and other architectural features, especially if new mobility devices are required. If a patient was previously engaged in work or school outside of their homes, it is beneficial to discuss whether this is still feasible and if so, what adjustments might be required to return to an active lifestyle. Clinicians should discuss these factors with patients neutrally by assessing the patient's goals and then discussing options to achieving them. It is also important to determine the realistic amount of therapy given the priorities and lifestyle of a patient, and their support system.

5. Cultural Humility / Respecting Patient Experiences

From Advocate Group:

> "[I appreciate] when the doctor recognizes and believes you and wants to do something to help you."
>
> "Believe me. I may not have medical training, but I know a lot about my disability. Don't give up on me. Get training."

From Caregiver Group:

> "That's really important – when they see us as experts, and not as meddlers."
>
> "I think the most successful communication I've had is when the medical staff have been open to building relationships with me and trusting what I have to say about him."
>
> "Don't assume, don't judge. Listen and appreciate that either the patient themselves or their family members know more about their condition than you do."

Disabled people and their caregivers ask that medical professionals recognize them as the experts in their care and abilities. Some people with disabilities have had a lifetime of learning about their specific conditions. Along with their caregivers, they can provide clinicians with information that may be crucial when deciding among various treatment options. Disabled people have not always had their voices heard and respected within the medical community. Creating a safe, nonjudgmental environment will help empower these individuals and their caregivers, and goes a long way towards developing a sense of trust in each patient-provider relationship.

Several group members requested that clinicians trust the information and history they provide over the information contained in the medical chart. While electronic medical records (EMR's) are useful, effective, tools for continuity of care, they cannot replace patient input. One mother described an interaction with a clinician who was caring for her daughter. She said, "The chart ruled. It didn't matter what I said."

Unconscious bias can impact the care that a patient receives. Assumptions written into a chart one time, can forever predispose subsequent clinicians to a potentially false narrative about that patient's character or capacity. This is sometimes referred to as "chartomas" in the disability community, in joking reference to a persistent error or problematic characterization in one's chart. Capturing context is critical. For example, a patient who is in extreme pain or who has a history of neglect or abuse may present as anxious or agitated. This patient may be described in the medical record as "resistant" or "aggressive". These descriptors may influence how the patient is approached by clinicians in the future and create a negative feedback loop. This can be avoided by ensuring that charting is done with appropriate context, describing observations without using value-laden or judgmental terms, as well as correcting misinformation when it is encountered.

6. Adapting to Change in Function

From Advocate Group:

> "About 10 years ago, I became spinal cord injured. It's common with [cerebral palsy], but no one spoke to me about it. . . I had to relearn things. It was heavy."
>
> "A lot of CP [research and medical care] is focused on pediatrics and healing. I joined a Facebook group and found out the differences in my body, movement, and [response to] temperature will deteriorate faster. I am learning from others. No one had previously told me this information, so I didn't know what to expect."

From Caregiver Group:

> "This physician didn't know him, didn't know us, didn't trust our situation instead of listening to us as a family and trusting that we know what we can handle at home."

Acknowledge the human capacity to adapt to change and evolving circumstances. People with existing disabilities and their families can be quite used to adapting to new environments and health-related circumstances. Participants from both groups spoke of knowing exactly what they could handle outside of the hospital setting. Yet, they frequently had to convince clinicians of this internal knowledge.

Many members of the advocate group spoke of how aging with a significant developmental disability can be full of unknowns. The medical community does not traditionally view developmental disabilities, like cerebral palsy, as progressive, degenerative disorders. People with these conditions can attest to definite changes in their bodies and functional abilities. Participants in the advocate group made several comments about not knowing what to expect as they aged. They shared experiences and insights with one another during the group session. Peer mentors and support groups offer a wealth of knowledge, empathy, and resources. Clinicians and other allies can educate themselves on this aging process and be partners with patients and their supporters on this journey.

7. Identifying Services and Supports

From Advocate Group:

> "Two years ago, I injured my neck. My doctor asked, 'How would you feel about a feeding tube?' I thought it was a wonderful question. The surgeon wanted to know what I wanted. It was positive. I think it's always good to know how much intervention you want."
>
> "'Physicians sometimes make assumptions about my wheelchair needs. They don't consider my lifestyle or my activity level. Durable medical equipment does not have the same connotation for medical professionals as it does for those of us in the disability community."
>
> "With durable medical equipment, the doctor let me see the options. We reviewed them together. That had never happened before. It was nice to be let behind that curtain."

From Caregiver Group:

> “This is not like a wheelchair that anyone can use. This is her chair. It’s part of her.”

When someone acquires a new condition or loses functional abilities, the rate of acceptance and adaptation will take time, and can be a frustrating experience. However, significant disabilities should not be viewed as automatic death sentences. Clinicians can learn what their patients’ value, what is important in their lives, and how they can have the maximum amount of function for as long as possible. By offering a full range of medical interventions, supports, and social services, clinicians can help patients and their caregivers have a better life.

Some of these tailored supports and services might include: access to medication, technology for mobility and communication, therapy, support at home, architectural modifications, transportation, palliative medicine, social connections, psychological support, and quality, home-based, hospice care. People with disabilities can also benefit from the experience and support of mentors with similar conditions. When clinicians pass on the message that people with neuromotor or anatomical problems that impact breathing and eating can use medical devices, such as portable ventilators and feeding tubes, to lead meaningful lives, negative messages from the medical community will begin to disappear. Allow disabled patients and their care partners to take an active role in choosing the medical and mobility devices which will best meet their current needs and lifestyles. They may require different devices as these needs change.

8. Accommodations

From Advocate Group:

> “When I was in the cancer ward, they didn’t have enough nurses to do my care (like helping me into bed, turning me, etc.)”

From Caregiver Group

> “There’s not really an accommodation for that or a way to even provide pediatric supplies [in an adult setting]. And they weren’t safe. If I didn’t bring my pediatric g-tube, if I didn’t bring my own g-tube extension tube, there wouldn’t be one.”
>
> “Family centered-care does not mean that the family does all the care.”
>
> “It’s like they [parents] get used to being stressed all the time. It’s battle fatigue sometimes. Many parents do have Post Traumatic Stress Disorder. And part of that is always the unexpected coming around.”
>
> “Unless he really needs to see her [his primary care doctor], she’d rather just talk to me on the phone or MyChart with me. The neurologist now offers telemedicine, especially when he’s first gone home [after a long hospitalization]. You know, not having to bring him all the way in and all of that. And so, that’s great.”

People with disabilities use a multitude of healthcare services. In some instances, specific disability-related conditions require constant monitoring and intervention. Other times, people receive treatment for the same life-threatening illnesses, such as cancer and heart disease, as the nondisabled population. Regardless of the reason for a stay in the hospital, intensive care unit, or visit to the emergency department, disabled patients should receive accommodations in order for their medical care to be as safe, comfortable, and effective as possible. Admittedly, these accommodations may take a bit of extra time and creative thinking.

The discussion group participants recounted a number of situations where they did not receive adequate accommodations either for themselves or for their loved one. A participant in the advocate group mentioned repeatedly how the nursing staff could not meet her care needs. This led to additional health issues and drastically extended her hospital stay.

During a hospital stay, one mom said that her daughter, “Just kind of got lost, you know, fell through the cracks...” Besides issues with staffing, the cracks came in the form of medical supplies and equipment which failed to work with her unique body. This mom went on to say that the hospital system had made some improvements since her daughter was younger, but in this high-stakes situation, they were not equipped to meet all of her needs.

Family members were often expected to provide total assistance with all activities of daily living and managing certain medical care tasks. In these cases, providers did not recognize the parents as integral parts of a family unit with responsibilities to other children and financial obligations. They failed to factor in the psychological stress of caregivers when discussing goals of care. The parents in the discussion group wanted clinicians to recognize their need for support throughout the hospitalizations of their young, adult children.

Not surprisingly, members from both groups appreciated when clinicians offered creative and flexible care. One advocate encouraged providers to “Try multiple solutions – not just one.” Other participants valued home-based, medical care alternatives such as telemedicine, especially following hospitalizations or trips to the emergency department.

9. Coordinating Care

From Advocate Group:

> “It would have been good for my oncologist to work with my primary care doctor who knows about disability. If they knew about disability, then [my care] would have been more holistic.”

From Caregiver Group:

> (Referring to her daughter’s skin turning purple, something that developed while she was in the hospital.) “Did a doctor see this?” and the nurse said to me, “Oh, do you want a doctor to come?” So I said, “Yeah!” And an hour later the resident on call came in and looked at it and he didn’t even touch her. He was like, “Oh! Oh! We better get the wound care, the skin care people in.” Another hour went by, the skin care specialist came, and she said, “Oh, we better get OB/Gyn to look at this.” By then I was yelling and screaming, saying “Get them now! Get them now!”

Since a host of different specialists, therapists, and other vital members of a care team have an array of roles to play in facilitating treatment for a single patient, the coordination of this care is crucial. Higher levels of communication and coordination are usually required when conditions related to a disability have the potential to complicate treatment plans. A parent and an advocate both described situations where a lack of coordination had dangerous, unintended consequences. Thoughtful care coordination can lead to more up-front services which, as one parent pointed out, would lead to the decreased need for later services.

Another parent recommended the development of a concierge-type service. In his ideal scenario, a care coordinator with intimate knowledge of a patient's medical history and needs could help with scheduling appointments, and assist with in-person and remote communication between providers, the patient, and caregivers. For example, depending on the patient's needs, the concierge might request extra time for an appointment or would know to request an appointment at a time of day when wait time would be reduced. This service could streamline medical care, especially for patients who have a difficult time with traditional appointments or crowded waiting rooms.

10. Visits to the Emergency Department

From Advocate Group:

> "I pretty much stopped going to the ER because either they don't take me seriously or don't want to treat me because I have complicated health issues and they're afraid of messing things up."
>
> "People I see more than once are almost always okay. The problem is the emergency room or people who work in the hospital. They don't know who we are. They only see us for our problems and that's a real problem. They don't have a picture of our everyday lives."

From Caregiver Group:

> "The onus is on the patient and the family to do this download of information. For someone [like my son] who is here all the time, this information should be readily available."

Few people enjoy paying a visit to the emergency department (ED). Long waits in new environments can be difficult to handle when you are not feeling well. Many people with disabilities find these visits especially challenging. Those with sensory disabilities may struggle in an emergency department environment that is typically characterized by bright, sometimes flashing lights and loud noises. This sensory overload could impair their capacity to communicate with clinicians. Many people encounter new physicians and medical personnel who may be unfamiliar with their disability, medical history, baseline, or communication style. Clinicians working with disabled patients for the first time generally have little context to understand how the patients function in the world outside of the emergency department. This lack of familiarity and context can be even more frustrating during a major health crisis.

Some disabled people are survivors of medical trauma that can be easily triggered in an emergency department or any hospital setting. They may have experienced long periods of isolation, lack of communication, physical restraints or other extreme situations while in the context of a medical crisis. Thus, a patient may exhibit extreme anxiety, irritability, restlessness, hypervigilance or other Post Traumatic Stress Disorder symptoms, even when these symptoms are unrelated to their presenting problem or their main disability. Clinicians should be aware of this possibility, ask patients if there are any accommodations they need to be supported while receiving care, and be sure to communicate their plans to patients. This is critical to the health of disabled patients. Some discussion group members reported that negative past visits and experiences prevented them from seeking emergency care in the future.

Participants had several concrete suggestions to improve emergency room visits, including decreasing wait times and streamlining care. One mom whose son makes frequent visits to the emergency room wondered why his emergency department protocol was not flagged and highlighted in his electronic medical chart. She suggested that a higher level of coordination between departments, especially departments familiar with his needs, would benefit both her son as well as his providers. Another parent suggested making medication easier to pick up from the emergency department instead of transporting a sick, disabled person to an after-hours pharmacy across town. Pharmacies that offer after-hours deliveries may also help improve access to care.

11. Advanced Care Planning

From Advocate Group:

> "When I was diagnosed with cancer, at first things were fine. We got together and I decided my mom would be my decision-maker when I couldn't make decisions for myself."
>
> "Afterward, they kept talking about it, when I was doing well. A social worker came to my house and her first question was, "Do you want a Do Not Resuscitate?" This is when I was doing fine. All I wanted to do was move away from that conversation."

From Caregiver Group:

> "My [sixteen-year-old] daughter was sitting right there and he said, "Well you didn't expect her to live forever, did you?" And I was dumbfounded. And I said, "No, I don't expect her to live forever, but I do expect her to have every chance while she's here."
>
> "You know, Do Not Resuscitate conversations came up all the time, all the time, all the time!
>
> "After her spinal fusion experience, when she went back for surgery two years later, she downloaded and completed an advanced directive."

Advanced care planning involves a series of highly personal, complex decisions made by people with disabilities, their families, and their supporters. A deep degree of trust should be established before clinicians become involved in this process. Patients and caregivers want to know that their options are based on medical advice and not on assumptions about their perceived quality of life. Patients want to know that their lives are valued.

Some people with developmental disabilities may not have had much exposure to death or other end of life experiences. Their supporters may have tried to emotionally protect them from experiencing the death of a friend or loved one. Others are more familiar with death. They may have experienced the deaths of beloved pets, friends with disabilities, or family members.

Regardless of their past connections and experiences with this topic, disabled people need opportunities to make decisions about what happens to them during a medical emergency and at the end of their lives. Like all patients, disabled patients should be encouraged to identify trusted supporters. These supporters can either help them evaluate important end of life decisions or act on their behalf when they are unable to make decisions for themselves. Those identified to be surrogate decision-makers may not always be someone's closest relative or loved one, but should be someone who is able to prioritize what the patient wants, even if it conflicts with what the surrogate decision-maker believes is in their best interest.

Patients with disabilities may want assistance recording their preferences concerning life sustaining treatment, palliative care, hospice options, funeral arrangements, and how they would like their belongings distributed. The Coalition for Compassionate Care of California has created a plain language resource guide titled, "Thinking Ahead" (https://coalitionccc.org/what-we-do/eol-people-with-developmental-disabilities/) to assist people with developmental disabilities in planning for the end of life. Videos helping explain the resource are also available.

12. End of Life

From Caregiver Group:

> "It was very, very professional and very well handled. And the two people who were not professional were not doctors or nurses. But the PICU (Pediatric Intensive Care Unit) team was really amazing."
>
> "Well you can take your time and we'll do this second part later." And I sort of understood that it would be up to them to tell me when the next stage, which was going to be it, would happen. And I didn't realize until later that they were leaving it up to me"
>
> "At six weeks you get this card, and at 12 weeks you get this card. That was creepy to me. Because it wasn't personal and because it was like, "Well, now they must need this and now they must need this. "Oh, slot A, and in two weeks, they get card B." And it's signed by everyone in Palliative Care who I didn't know."

Death is a fact of life for everyone. At the end of life, all of us would like to feel that our lives have value and are respected. This holds true for people with disabilities and their caregivers. They want to be treated as whole individuals with intersecting identities. Along with a potentially strong identity as a disabled person, other specific ethnic, religious, and cultural identities may play factors in the type and amount of medical intervention these patients may want during a life-threatening event. These identities can also come into play when making decisions regarding hospice and palliative care. When at all possible, the wishes of the actual patient should be honored and followed.

Two mothers from the caregiver group had direct experience with end of life care in a hospital setting. Their disabled daughters had passed away unexpectedly within the last five years. They each spoke of how they sincerely appreciated the sensitivity and professionalism shown by the care team. One mother said, "I really appreciated how hard they tried to save her. They gave value to her life." Families in this extremely difficult and painful situation will have different needs. One mother said she appreciated the physician using a direct approach when presenting her family with information. She commented, "I appreciated that she made that hard line. [It seemed] so harsh and so direct, but I was so glad because I wanted to be sure that my husband was on the same page, and I didn't want to be the one to bring him there." Other families may need more time to process information, and if possible, may benefit from having some control over the timing of events.

Regardless of a loved one’s disabilities, their death is an emotionally difficult event. Grief is universal. While most people will grieve this loss, no two people will grieve in the exact same way. At the conclusion of the caregiver group, one mother said she had received a series of standard bereavement cards from the hospital. She was uncomfortable with how the cards appeared to dictate the timing of her family’s grieving process. This mother later said that a personal card from her daughter’s care team would have been a better way to honor her life and recognize their loss.

Conclusion

Quality, end of life medical care for people with developmental disabilities is an extension of a lifetime of good, patient-centered, healthcare practices. Since all successful patient-clinician relationships are built on a foundation of trust, listening to patients without making assumptions or judgments about their perceived quality of life will lead to a greater level of open and honest communication. Each disabled patient is a sum of all their intersecting identities. By understanding all these different identities, clinicians will form a more accurate picture of their patients’ lives.

Patients and their caregivers want to be heard. Disabled patients ask that clinicians acknowledge and respect their autonomy. They want to play an active role in the decision-making process. Honor patient wishes to the greatest extent possible, even when extra support is needed in making crucial medical decisions.

Recognize disabled patients and the people in their support systems as the experts in how their bodies function. They may not have specialized medical knowledge, but they do have an intimate awareness of their baseline health status and their ability to adapt to evolving circumstances. Access to durable medical equipment, medication, social services and coordinated healthcare will help patients remain in their chosen environment and have the best life possible.