

Supplemental Digital Content 1. In-vivo Quotes from the Narratives of People Living with Durable MCS

Category	Subcategory	In-vivo Quotes
Impediments to ACP	Aligning self with best care	I mean this is first class. You know, I mean look at this. This is, you can't get any better than this. I've been meeting all these people that have had heart transplants and all I'm telling you, that's the way to go da-da-da-da-da, you know, keep the faith. (P03)
		I said, "Honey, we've hit the lotto. We've come to "A" (hospital), we've hit the lotto." (P03)
		Before this, year, year and a half at the max with getting this done, "A" (hospital) is the number one facility in the nation. You're at the best place. We get it done. It's going to happen. (P13)
		I don't think like that, I just kind of wait for them (clinician) to say, "This could be an issue," or "You might want to think about that," from their own experiences with other patients that have gone through the same thing I have. I trust their judgment. (P01 ²)
		I don't know that I've had discussion with any of my doctors on advance healthcare specifically. I think where they maybe tie in would be in just the trust that I have with their guidance and care. (P08)
		And, like I said, I don't want to seem like I'm saying that they didn't give me all of the information that they should have, because I know they did. That is one of the best hospitals. Everyone there is very knowledgeable. I know I'm getting the best care I could possibly get. I know all of that. (P09)
		They do an excellent job. They do an excellent job. Because I understand they're walking that tightrope also, whereas they want you to have hope. They want to give you hope. They don't want to give you expectations that may not come out. (P13)
		I remember a time seeing a doctor say something and I was looking over the doctor's shoulder at one of the other clinicians that were in there and they were shaking their head no, like they didn't agree with the doctor. I'm feeling a little, hmm, this is interesting. But I think everybody was being honest. The doctor was probably trying to pick me up, keep me positive about going forward and not getting depressed about it. But some of the others might have a view of, don't get your hopes up too much. (P18)

		With me, vocalizing a lot, I show what I want, I can tell them what I want instead of just always agreeing with what they think is best. Sometimes you need to tell them what you think is best. (P05)
	Maintaining a positive outlook	Just stay positive, it's going to happen. I'm not that type of person like, it ain't never going to happen, I'm not that type of person. I'm going to try to stay positive always. (P04)
		I have a positive attitude of this one, a very positive attitude. So that has helped, I think. (P14 ¹)
		But things happen and if it has to be from one thing to another, well we've got to keep moving on until we get to the right part of life. (P07)
		It's like a pendulum. It kind of swings back and forth, it's not so bad or yeah, I really wish we got this over with. (P01 ²)
		It's very precarious. It's very precarious. The device could malfunction, I could have the cord ripped out of me in an accident. I get it's very much a tightrope of an existence. At any time I could fall. But I don't dwell on that. (P06)
		I have to remind myself, because I tell them, "I'm a tough kid, tough individual." I'll try to do things that may be pushing the limits or the boundaries. They have to remind me, "You're still a very sick individual." I've even been told this by the doctors. (P13)
		You start looking at these things when you do have a palpitation here or there, or when you do go up the stairs and you start getting winded, or you bend down you get dizzy, the approach I take is, "Well, that's just the street I live on." That's the new normal for me. (P13)
Uncertainties in MCS outcomes	Living in limbo (external)	After I got through that, I really feel like I am living a normal life until I'm waiting for the transplant. But I do feel like my life is in limbo while I'm waiting. (P01 ¹)
		It was a little discouraging (transition to DT), but I think it was way more discouraging to my wife. But just a little bit to me. I mean, I feel good that I don't know. This is fine with me. (P11)

	<p>Other than giving me an idea of how long this LVAD will last and what to expect if it goes into failure, would they (clinicians) be able to replace it (MCS device) or would I be too old for it? That part, I guess, they (clinicians) should talk to me about. (P11)</p> <p>"Well, it's a 10 hour or eight-hour surgery and open the chest and God knows how many things, lungs and all this, which I went through." Then I said, "No, no, it's (transplant)not for me." (P14¹)</p>
	<p>Well, I was a little disappointed at first (change to destination therapy), but I got over it and it is what it is. (P16)</p> <p>I do not believe that the medical team that I have right now ... I don't think their objective is to find me a heart, I think the objective had turned to where, "Okay. As long as we can keep Mr. "U" convinced that he'll have a heart sooner than later, but our main purpose is to keep him stabilized and sustained on the LVAD, because he's doing so well." (P03)</p>
	<p>The hardest thing is when you are thinking about a transplant, you're thinking about an offer and you will be consumed by just thinking on that, when it's going to happen, how long am I going to wait? How long do I have to wait? Will it happen tomorrow? Will it not happen? Will I provide until it happens? You can be consumed with that aspect to the point to where it interferes with your daily life routine. (P13)</p> <p>I asked the question what happen if I don't end up getting my heart, and they just said they just adjust the machine. They just keep adjusting the machine. But I asked the question has anybody... I also asked the question have anybody passed away with the machine by waiting. (P22)</p>
<p>Leaning on spirituality (internal)</p>	<p>You know, I talked to a lot of people, and "B's" (city) a very deeply religious community, and I found that people that are deeply religious, they do better in situations like this. They (people who are deeply religious) have a comfort and belief system that God will take care of them, and I don't have that belief system anymore, so I don't have an idea, I haven't made up my mind what death is. I don't believe in prayer. I mean, I believe in people sending me goof thoughts and things like that, but I don't believe in prayer, so I don't have</p>

		<p>much comfort zone, anything to hold me up on this since it's so unknown to me, where it used to be I had this firm idea what life after death is. (P06)</p>
		<p>The only big basic question that constantly came was why, (am I bleeding) again and again, this thing is happening to me. This is the third time (I was readmitted for bleeding), but then again, you have to accept it. You know, they say, what is it, that is the wish of whatever powers it be. So let us accept it (the complications of living with MCS). (P14²)</p>
		<p>But my wife asked me about six months in after the surgery, she says, "If they called you today and said we've had a change of heart, you are eligible and we have a heart available for you, would you have a transplant?" And I said, "No." I don't think my life expectancy would be significantly greater and the impact of my daily life would not be improved enough that I would go through the experience again. (P18)</p>
		<p>It probably doesn't in that I think because I'm not a believer of the literal pie in the sky heaven and all that, my spirituality more than my religion guide my decision in palliative care. I'm a big believer when the gig's up, it's up. Thanks for the memories and thanks that you had it. (P21)</p>
Promoters of ACP communication	Distrusting clinicians	<p>Even though, at this point, I can honestly say I really don't trust what they tell me at the clinic anymore. I just don't, you know, I just don't. I think that they've seen every situation you could think of and consequently as a result, I think they've got predetermined responses for just about everything because they've seen it all. (P03)</p>
		<p>Don't expect the doctor or nurse to give you all your answers, you know? Um do your own research and due diligence. You have to write down your questions, you have to ask your questions, you have to try to research your own stuff because it's not just going to all be handed to you, that's for sure. Don't think they just going to drop a load on you and they don't say, "Hey, this is what's going to go on." You have to do your own research. (P23)</p>
	Managing incongruent expectations	<p>You can call it a negative expectation in the sense that I did talk to my daughter and wife that you know, this machine, I don't know how long it will remain, how many years and what if stability stops, all those kinds of things. There is an apprehension, basically. (P14²)</p>

	<p>I try to keep everything positive. I like to talk to talk about positive things. Always something down, down, down, down. I'm like wow, can y'all talk about something positive or make it positive or something? I hate to make a person feel down. I won't try to be teared by, I don't like to be teared up. (P04)</p>
	<p>I'm scared of the unknown, and I'm really scared of other organs failing. I don't want to walk around with a piss bag for the rest of my life. I mean, those people smell, they go in for dialysis, whatever. I don't want that. I'd rather die than that. And I told my wife, if it comes to that, I really don't want to live that life. I don't want to be in a wheelchair with the piss bag. And even if I have, down my pants, I don't want it. There are always accidents. You always end up smelling, and anyway, ask me another question. (P10)</p> <p>It took about two, three weeks and I would be very honest, even just when I completed two years, I wrote a letter "Dear LVAD." And I put all my feelings and those that email, that letter I emailed to my son, daughter, my wife, explaining that ... Even though I had accepted it, but sometimes I'm angry why I wish that it was not there, but then I said, "I'm not angry at LVAD don't worry you are my friend and you'll be remaining with me until the end of my life. (P14¹)</p>
	<p>You have to think very hard about, I mean, it's easy to say I don't want to be kept alive by artificial means, but my body is full of equipment. I've got an ICD and I've got an LVAD, I wear an insulin pump. So, I've got all kinds of artificial means attached to me that are addressing both the quality and quantity of my life. So, say I don't want to be kept alive by artificial means, I already am. I would have died long ago without some of this equipment. So you have to dig a little deeper about what that means. (P18)</p> <p>Several times people, including one person that I interview, I talked with, that had an LVAD is that eventually you won't even know that you have... "It'll feel like you won't even notice it's there." Well, that's *@#! You will always. Every second I am aware of it, 24/7. I am never, ever not aware of that LVAD. (P21)</p>
Perceptions of supportive others' experiences	<p>Sometimes I feel like I might be a burden to my mom because she has to do so much for me. So that's one of the things that depresses me because I feel like I'm a liability. (P09)</p> <p>Is it really worth it all? Is it worth going through this? Worth continue to be doing this? If they put the finality on a hope for a transplant, do I want to stay like this forever, however many years I may have? Do I want to keep putting my family through this? (P13)</p>

Decision-making about ACP communication	<p>They come in and there's doctors and nurses and coordinators and people taking different information and different people asking you questions. My wife's fielding half the questions and I'm fielding the other half, it's all going on at the same time, which that is an interesting process in itself. (P18)</p>
	<p>And when I asked the MCS coordinator about the longevity of (the device). You know, what could I expect, and she said, "Well, we don't have any data on anybody that's had one more than ten years." (P19)</p>
	<p>I'm following what they say because they are trained, I'm not. Like I have a saying, "Stay in your own lane," and I believe in staying in my own lane, because I'm not a doctor. (P02)</p>
	<p>I don't want to be told things in a way that is not clear to me. Tell me what you mean or what you're saying. Let's not worry about bedside manner at this point. I want to really know what you (clinicians) think. I may not listen to what you (clinicians) think, but I want to know. Then I'll make my own judgment. That's how I felt at the time. It was a gut punch. My wife and I were sitting there with our mouths open thinking, we certainly didn't expect to hear this. Like I said, I've always recovered from things pretty well in the past, and I did recover from the pneumonia but it took a while. It was somewhat debilitating. But we didn't expect a doctor to say, "Hey, you're in a serious situation here, so you'll have to figure out if you really want to do this again." That was eye-opening. And maybe a good view into my own mortality that I needed to confront. (P18)</p>