

Experiences of Living with ALS

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Abstract

This phenomenological study utilized the philosophy of Merleau-Ponty to explore the experience of living with an Amyotrophic Lateral Sclerosis (ALS) diagnosis. Four ALS patients from South Central Appalachia were interviewed and asked, “What is it like living with ALS?” The existential grounds (World, Time, Other People, and Body) were identified to contextualize participant experiences. Five themes were found from patient responses: (a) hard decisions, (b) friend and family support, (c) sense of purpose/mission, (d) loss, and (e) changed perspective. Their experiences involved grief and sadness, but also determination and joy. These findings help inform interdisciplinary healthcare providers about life with ALS and how they may better support and care for that patient population.

Experiences of Living with ALS

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disease that affects motor neurons. Once diagnosed, patients have a three to five-year life expectancy on average with no periods of remission (ALS Association, n.d. b). The disease presents with motor symptoms starting with weakness and spasticity of limbs that progress to paralysis. Eventually bulbar function is affected causing issues with chewing and speaking. Finally, impaired breathing occurs, causing patient death unless mechanical ventilation is introduced. ALS has no cure, making the diagnosis terminal. Because of the three to five-year prognosis, patients must reckon with what this diagnosis means to them.

ALS is estimated to affect a mean of 7.7 cases per 100,000 people in the United States in 2017 (Mehta, et al., 2022). This, compared to a report of 5.5 per 100,000 people in 2010-2011, shows a recent increase in prevalence. The disease, though more prevalent in a few demographics (whites, males, ages 60-69), does not discriminate between race or gender and can affect persons as young as 18 years old. Thus, this illness bears strong implications to a wide population. Understanding more about the disease and, more importantly, the experience of living with the diagnosis of ALS holds great importance in the future of multidisciplinary support of those with the disease. Care is often coordinated between occupational therapists, physical therapists, respiratory therapists, neurologists, nurses, dietitians, and other professions. (ALS Association, n.d. a) who all stand to benefit from understanding the phenomenon of what it is like to live with ALS.

In the present study, the lead researcher had very little personal experience with ALS. The only involvement included participating in the ALS Ice Bucket Challenge, and their elementary school librarian being diagnosed several years after graduating from elementary school. The

reintroduction to ALS came during their sophomore year of undergraduate nursing school when they began work in a biobehavioral lab as a research assistant studying neurodegenerative diseases. In addition to collecting quantitative data, there was also a qualitative arm exploring participants' experiences of living with ALS.

The purpose of this study was to investigate and characterize the experience of living with ALS.

Literature Review

ALS has been qualitatively studied within the last 10 years, but it still lacks an overall view of the experience of the patient. Qualitative research on the topic is present, but much of it is related to specific areas of the disease such as mechanical ventilation (Thorborg, et al., 2023) or is specific to caregivers and family members of those with ALS (Cipoletta & Amicucci, 2015; Warrier, et al., 2020). A few studies do investigate the patient perspective of having this diagnosis and highlight themes such as a sense of lost control, dependence on others, appreciation for support systems, the need to move forward after their diagnosis (Caputo, 2019; Cipoletta, et al., 2017; Foley, et al., 2017; Yuan, et al., 2021). Despite having some literature regarding the topic of the patient themselves, continued research is necessary to solidify universal themes. In addition, most studies published that focus on the patient take place abroad including Italy, Ireland, and China (Caputo, 2019; Cipoletta, et al., 2017; Foley, et al., 2017; Yuan, et al., 2021). Thus, conducting similar research within the United States and more specifically within the Southeast, may yield new insights specific to the area and culture.

The purpose of this study was to investigate the experience of people living with ALS. Learning this information will offer insight into how people cope as they face this specific diagnosis, and should be translated into improvements caring for, encouraging, and supporting

patients. The questions the study serves to answer are what is the lived experience of having an ALS diagnosis, and how has life changed from the time of diagnosis to current day.

Conceptual Framework of Phenomenology

Phenomenology focuses on uncovering and understanding the lived experience of individuals that share a phenomenon (Creswell, 2013)—in this case, living with ALS. This is achieved by obtaining recounts of emotions, narratives, and perspectives that emphasize what is figural (significant) to their experience. Beginning in the 1800s, Edmund Husserl brought light to phenomenological philosophy primarily utilizing transcendentalism to obtain the essence of experiences. He was a major proponent and the founder of the idea of transcendental epoché and suspending the natural attitude towards the phenomenon (or bracketing) (Beck, 2020). His, and his student's theories on phenomenology uncover an abstract view of the human experience (Thomas, 2005).

In contrast, Merleau-Ponty's philosophy is closely rooted in existentialism. His philosophy emphasizes perception which allows for a direct, non-abstract understanding of the lived experience. Perception within context gives the experience meaning. He posits that complete reduction and epoché is not possible, and phenomenology must be looked at with a consciousness of the world (Merleau-Ponty, 1956). Similarly, within this consciousness, is the delineation between figure and ground. As mentioned prior, figural items (figure) are those that are significant to the lived experience of the participant. Ground serves as the context/background to this experience in four major existential categories: Body, Time, Others, and World (Cited in Thomas, 2005). Figure cannot be understood without ground.

This philosophy of phenomenology provides an opportunity for better understanding the human perspective. Similar ideas behind his framework place value on intentionality (what we

find meaning in and the connections between people and things), relationships with others, embodiment, time, and morality. All of which are exceedingly relevant to the chosen phenomenon—living with ALS. As such, this study used Merleau-Ponty’s approach to phenomenology and methods developed at the University of Tennessee (Thomas & Pollio, 2002).

Methods

Research Design Overview

This was a cross-sectional phenomenological study with a focus on the experience of the participants. The target population included patients with a diagnosis of ALS who can speak for themselves or have a spokesperson who can. The accessible population included participants who attend ALS clinics in East Tennessee. The sample for the study was recruited from ALS Clinics in South Central Appalachia and from the ALS Society in that region. The study was approved by the UT Health Science Center IRB as well as ETSU’s IRB under reference number 5081 approved on 3/25/2024.

Study Recruitment

Recruitment took place during ALS clinic days during April 2024 at two locations in different cities. Participants who did not have an appointment during recruitment days were contacted separately via phone and email based on recommendation from the clinic providers. Additionally, recruitment flyers were distributed through the ALS Society, and those who demonstrated interest were contacted via email. Informed consent was obtained at the clinics on paper when they were recruited and or verbally at the start of each interview. A copy of informed consent was emailed or mailed to participants, and it was emphasized that the interview was

voluntary and that they could choose not to answer questions or to stop the interview at any time. A member of the research team was present during the consent process to answer questions.

Data Collection

Interviews were conducted by the lead researcher who underwent a bracketing interview before starting the study. Bracketing interviews serve to reduce the influence of any preconceived notions about the chosen phenomenon—ALS—during the interviews and focus solely on the experience of participants and prevent projection from the interviewer (Thomas & Sohn, 2023). The lead researcher also performed two pilot interviews to practice interviewing skills. Interviews were conducted over the phone or through HIPAA-protected Zoom (teleconference) meetings at the participant's choosing. The interview included one pre-determined open-ended question regarding the overall experience of living with an ALS diagnosis, "What is your experience of living with ALS?" Probe questions were used based on interview responses and figural statements made by participants. Participants were encouraged to stop or take breaks as needed throughout the process. With participant consent, responses were recorded and transcribed, then videos were destroyed to protect the identity of participants. Recruitment and interviewing continued until recurrent themes were identified, and saturation of codes and themes was met. Following the interviews, demographic data was collected about participants.

Analysis

Transcripts were anonymized and brought before the University of Tennessee, Knoxville's Transdisciplinary Phenomenology Research Group (TRPG) to be read aloud and analyzed as a whole. Transcripts were read and reread throughout the analysis process. The lead researcher completed line by line coding and identified meaning units using NVivo software. In

addition to the TRPG group and the lead researcher's analysis, transcripts were further reviewed by two qualitative research colleagues to validate findings. The two inter-raters coded digitally on Microsoft Word by highlighting and making comments in the margins. Their coding and that of the lead researcher were done independently then reviewed side-by-side to identify concurrences. The researchers identified five themes that were supported by meaning units (codes). Existential grounds were identified as well (World, Time, Other People, Body).

Results

Study Population

Four participants in total were recruited and interviewed (see Table 1). All four were of the same ethnicity (white) and resided in South Central Appalachia. Their ages were between 50-70 years old, and the mean length of time since diagnosis was 21.5 months. Similar to incidence reports of ALS reporting higher rates in men (Mehta, et al., 2022), only one of the four participants was female. Interviews lasted between 50 and 90 minutes, depending on the length of participants' responses.

Table 1

Participant Demographics

Participant ID	Age	Gender	Race/Ethnicity	Marital Status	Occupation	Months since ALS diagnosis
P1 "Dave"	56	Male	White	Married	Appraiser	24
P2 "Kevin"	60	Male	White	Single	Civil Engineer	37
P3 "Fiona"	67	Female	White	Married	Retired	16
P4 "Max"	68	Male	White	Married	Retired	9

Contextual Grounds of the Lived Experience with ALS

To understand the themes discovered during analysis, they must be interpreted within the context of the four contextual grounds of experience: World, Time, Other People, and Body.

The first ground is World. The significance of World was primarily highlighted through adjustments to daily living following diagnosis, such as job changes, clinic visits and medical intervention, and assistive devices:

I'll be honest, when I started falling, because I'm in a small community, our superintendent of school let me teach from home...But the cool thing was, we made it work, you know. My aid got me live on the Promethean Board [a digital computer-like teaching tool], so we did like reverse Google Classrooms with the kids. And they thought it was great! (Fiona)

...talking with my GP, he helped me understand better also what the clinic approach was where you see a social worker, physical therapist, occupational therapist, speech pathologist, etc. Not just a neurologist. And that was good. I liked the idea of having all these specialty providers right there that I could talk with. (Max)

These adjustments and the involvement of things like clinics and other institutions (work) help characterize the environment that people with ALS experience. Participants approached this ground with acceptance of how World has changed from before developing ALS, and mostly discussed positive aspects of receiving multidisciplinary care and aid from work and using supportive devices to maintain function.

The second contextual ground is Time. Each participant specifically remembered the general time in which they noticed changes in their movement and the exact day they received their diagnosis. From that point on there are frequent mentions of time and the lack of it, but also maximizing the time left, and the uncertainty of amount of time left. Disease progression becomes focal as a general indicator of how much time has passed and how much may be left:

How long in the future? I don't know, that like everything with this disease. You can't see down that highway. (Max)

...if I look back over the last 6 months, I haven't digressed any. It's been about the same, if not a very slight change, maybe in my walking or steadiness. And if going off [the medication] means that stops, and I start to go faster, then I'd rather not take that chance. (Fiona)

The third contextual ground is Other People, involving the presence and influence of relationships within each participant's life. ALS affects relationships through empathy and emotional support but also vicarious stress and worry. While most participants felt content within themselves about their future and have accepted their prognosis, they expressed worry for what will happen to their loved ones after they die:

...thinking, "Okay, do I have everything in order? What's gonna happen?" And, you know, we always just assumed, because I'm the younger one that my husband would go first... So, it was kind of like having this, having to do all that and lying awake at night, "Oh wait! I've got to get my final arrangements. Oh wait! I've got to make sure he's on this account. Oh wait!" (Fiona)

She's a beautiful, beautiful child and so creative, and such a joy...But all I want is just make sure that I set things up for her, you know, as well as I possibly can in the time that I have left and just do what she deserves. You know, it just breaks my heart. It just breaks my heart that essentially, she's going to be without her dad, you know, at some point.

That is the hardest part of this whole condition and process and experience....clearly the hardest part since I've got this diagnosis is thinking of my daughter and what impact that's gonna have. (Kevin)

I told him, I think this is harder: grieving this side. Because I feel like I'm hurting all those people that I love. As I told you, I can read eyes; I can read people. And that is difficult because I know they're struggling more than what they are showing... I feel more of a burden to prepare them for that timeframe. So, I think, this side's harder... I know I'm leaving them behind with the hurt of not having me. (Dave)

The fourth contextual ground is Body. ALS is a motor neuron disease; thus, body holds weight for each of the participants. There is frequent mention of a sort of mind-body disconnect and the progressive loss of physical ability. Many described a short period of confusion prior to diagnosis about inability to complete certain movements and overall frustration with physical symptomology:

Probably the most extreme is the falls, you know, when initially stuff took me by surprise—wasn't expecting to drop foot, just trips you up, and you're not ready for it, right? But as the progression goes along, you know, physically you're deteriorating. So, things took me by surprise for a very long time, just the simple things that you don't ever think about until something goes wrong. But standing at one point like at the kitchen counter doing something and then making a turn to the right to walk down the counter or grab something else. You know, done it 10 million times in my life, but that simple little shift right there becomes more and more difficult. (Kevin)

At the library one day I was walking across the floor, a broad floor from the front door to my workspace, and I tripped a couple times. And I thought, “Oh my gosh, this floor is so uneven.” Well, it wasn’t the floor at all, it was me, and I didn’t realize it. So as this thing progressed and I as I knew something was going on, I started paying more attention to my gait, looking around. (Max)

On several of the falls I’ve had—and I’ve had maybe 4 or 5 since last December—I don’t know what happened. I don’t know how I got on the ground. I don’t know what I did wrong. (Max)

And it has started in my arms--it actually started in my shoulders and worked down to my hands. My neurologist and I discussed “Which would you rather lose first, your legs or your arms?” Fortunately, it's not in my bulbar mouth swallowing side yet, but it is frustrating. (Dave)

Thematic Structure

Following analysis of transcripts and codes, five themes with accompanying subthemes were identified:

Table 2

Themes and Subthemes

Themes	Subthemes
Making Hard Decisions	• Choice of positive attitude • Giving things up
Friend and Family Support	• Emotional • Physical • “It’s awkward”
Sense of Purpose/Mission	• Leave a legacy • Philosophy/belief system
Loss	• Loss of the future • Loss of independence • Loss of identity
Changed Perspective	• “Different lens” • “Everybody has some struggles”

Making Hard Decisions

This initial theme encompasses decisions and changes that had to be made as participants go through life with ALS. Some of these decisions pertained to introspection and approaching life following their diagnosis. Others involved making continual adjustments to their life as they continued to progress. “Making Hard Decisions” is supported by two subthemes: Choice of Positive Attitude and Giving Things Up.

Choice of Positive Attitude. Participants living with ALS described, explicitly or implied, a time in which they were faced with a “fork in the road” (Kevin):

Like either, you know, move forward, ‘what could I do from this point out?’ or you just fall off a cliff, you know. I feel like it would be easy. I certainly wouldn’t blame people going through this if they do fall off a cliff and just collapse because it’s pretty much with you every minute of every day of every week.

Kevin even acknowledges how easy it would be to pick the other option because of how much the illness permeates into his life. Regardless of ease, he continues to push forward and adjust to continue to function positively and constructively. Other participants expressed this decision as

well, often positioning it as almost an obvious choice, mentioning the negative option but deeply focusing on the positive one. In all four participants, a determination to persevere when faced with this choice was expressed:

When adversity hits you, you either become *bitter* or you become *better*, and there's one letter difference between the two words, and it's your choice which one you want to be. I feel I want to choose better. (Dave)

I was seeing so much negative. People were just giving up. People were just complaining about the “f-ing disease”—in their words—and it's like, okay but look at all the time you're wasting. And then I realized, you know, well I was kinda doing the same thing by saying I'm not gonna have my garden. ‘I'm just not gonna do it.’ Well, okay, who did that hurt? That didn't hurt your vegetables, didn't hurt anything. So, it's kind of like I realized, okay, you can...I can choose which sites I want to go on, so I need to also choose what I do here. And so that's, I'm gonna go and do the things. (Fiona)

And I don't think, if I may say this about myself, it's not because I'm, “oh poor poor pitiful me.” I don't feel that way about it. It's a physical burden to have to live with it... But I don't think about... ending my life or anything like that. And I don't feel sorry for myself. (Max)

Giving Things Up. Depending on each person and how far along they are some have symptoms affecting their upper body, lower body, or both. As such, ALS affects/determines their ability to do activities, tasks, and certain movements, many of which have declined in this ability

since their diagnosis. Tasks that are integral to adulthood and considered second nature are now incredibly difficult, impossible, or even unsafe to carry out themselves. One of these, mentioned by both Fiona and Dave is driving. Dave, who had to experience taking the keys away from his late wife and father, decided to “basically give it up on [his] own,” and felt he “would have been a hypocrite if [he] would have tried to drive and fight that.” Fiona came to the decision a different way:

I had a date that I was driving to school, and it’s about a 45-minute drive because it’s very rural, up in the mountains. And I had a leg spasm, and luckily my foot straightened out, and it hit the brake and not the gas. I kind of skid on the gravel, and everything was fine, but I pulled over and realized, this is not good. I’m doing this because I don’t want to give this up, but it’s not what I should be doing. And so I went into school that day and said, ‘I’m gonna have to stop,’ you know.

Fiona also expressed loving hiking with her husband, but an inability to do so now: “I like getting out, and I just can’t do that anymore. We’re on uneven trails.”

Many of the participants focused on other items they can’t do. Maintaining safety appeared to be the biggest motivation behind giving these things up. Max didn’t mention driving but stated, “I used to enjoy beer and wine, but I quit that because I don’t want to risk the fall.”

While Dave and Max stop things before they happen, similar to Fiona’s driving incident not all adjust as easily with such big changes. The varied degrees of acceptance are demonstrated in the contrast of Kevin’s determination to maintain a level of independence:

There’s a bunch of those moments that the reality sinks in and admittedly again, I’ve been incredibly stubborn to my own detriment. Those moments have happened, and I’ve still tried to do stuff that I really shouldn’t have been doing.

Giving up parts of life that you cherish is difficult, but all have recognized that at some point certain tasks are no longer compatible with the disease. Still, other interests are able to be preserved and are turned to. Max, for example, chooses not to dwell on what he's lost, and instead focuses his energy on other things: "But I still enjoy reading. It's a way to escape. Music, movies, books largely have been a wonderful way for me to escape this illness." Despite losing so much, focusing on what he is still capable of doing has had a positive impact on his outlook and helps maintain normalcy and self-actualization.

Friend and Family Support

One of the most recurrent themes across all transcripts was the involvement and support of the people participants have relationships with, blood-related and not.

Emotional. Much of the support was evident immediately in participant experiences, with descriptions of support being there on the day of diagnosis: "My husband was with me, and so he just squeezed my hand." (Fiona), "I had my adult son and my niece, who was in her 30s at the time, with me. So, you know, I had a team...they were there the whole time." (Kevin), "Had a friend show up shortly after [my diagnosis]. I shared it with him. He's like a brother, he and his wife and me and my wife, we're close." (Dave).

Physical. This backing continues in emotional support, however, after describing the initial diagnosis many of the support transitions to a focus on physical things like tasks around the house. Kevin talks about the aid of his neighbors in taking him grocery shopping then bringing them into the house. Max discusses his wife "[assuming] the responsibilities that [he] had previously" such as mowing and cooking.

The impact of these people (their friendship and assistance) “helps to rise above that frustration” (Kevin) of ALS and is integral to being able to live with this illness: “I can’t imagine not having the support. That’s what I’m so grateful for cause if I didn’t have the support, you know, I don’t know if I’d be here to be honest, to be perfectly honest.”

“It’s awkward.” One outlier found for this theme was Fiona. While she experienced lots of support from family, some friendships have lacked:

The biggest change, I have to be honest, it [has] been more friends because they, I love dearly, but I know it’s awkward for them. There’s some that I don’t hear from, really, but I think they’re afraid of what to say, or maybe the change, or worried that I’m to have taken a turn for the worse. I have a couple that I still, you know, talk to. We go out to lunch or something with, but I don’t see them as often. I have two or three that I talk to loosely, but the rest kind of slid off. It’s almost like a family has a death, and they’re kind of like separating themselves just because it’s easier. And I get that. It’s awkward. It’s awkward when somebody has a slow dying kind of thing, you know, not knowing what to say. But they just haven’t realized you don’t have to say anything, you know.

This is contrasting to others like Max who felt that “the few friendships I have [have] become stronger because of this.”

Sense of Purpose/Life Mission

While this illness takes away so many things from people’s lives, it seems to also give back in a unique way. Along with losing/giving up many of the things that people love (hobbies, driving, etc.), for some, ALS creates a renewed sense of purpose or a mission for the remainder of their life. Two ways that this was seen created subthemes: Leave a Legacy and Philosophy/Belief System.

Leave a Legacy. With the knowledge the four participants have received—that their time is now limited—some have viewed this as a time to accomplish something. In many cases this “something” would not have been possible or necessary without their diagnosis. For one, Dave took it upon himself to write a book for the purpose of sharing about his life including his ALS diagnosis. Additionally, by accepting their invitation to be a part of this study, every participant had a desire to contribute to research and therefore leave a mark in the world. Fiona consciously recognized that “there might not be a cure for [her], but if some little part of something that [she] could be in or help with leads to that or leads to an understanding or makes life easier for someone else, then it’s worth it.” The long-term impact of contributing to qualitative research and quantitative research--through her participation in pharmaceutical trials--was not lost on her.

For others their legacy is related closely to the wisdom and life experiences they will leave their loved ones. Kevin highlighted his desire to use his remaining time to “show [his daughter], you know, some of the things that I’ve had the privilege to see and things that are meaningful to me. [He’d] like to show those to her just because the joy and the strength they have given [him his] whole life. ...[He] just [wants] to try to set her up for a lifetime of being able to get through difficult times in [her] life.” Dave does a similar thing by writing notes and recording videos for his loved ones for after he dies.

Philosophy/Belief System. Three of the four participants mentioned the involvement of a religion or philosophical belief in their journey with ALS. While these belief systems offered reported comfort for some, it offered purpose for all three. Dave and Fiona both share a faith based in Christianity. While Max reported growing up with a Christian background, he based his philosophy on Asian teachings, namely Taoism.

Dave speaks frequently of feeling “called” by God and references ALS as a form of “ministry to reach people.” He has already discovered some form of purpose through the influence of religion by sharing his story and his faith with others. For Fiona, she seems less certain what God’s plan is for her but is confident He has one: “He’s gonna put me at the right place. He’s gonna let me have some kind of impact.”

Lastly, the influence of Taoism on Max’s experience with ALS is rooted in the idea of “action through inactivity” or Wuwei (Stefon, 2013). This does not mean literally doing nothing but placing more emphasis on efficiency and forgoing less important tasks to focus energy on ones that really matter. Like Fiona, Max did not name a specific purpose, but found motivation and a push to focus on the important things in his life such as handwriting letters to friends despite beginning to lose function in that area. His mission is to focus on what is important to him and the people he loves and accept that his diagnosis may mean needing to slow down or shift focus, but it doesn’t mean to stop completely and give up.

Taoism also presents a take on death that is shared between Fiona and Dave of not fearing it. In Taoism life and death are like yin and yang, two sides of the same coin, so there is an emphasis on not worrying about it. Max even states he likes to imagine himself “wandering around the cosmos [central spiritual plane in Taoism]” when he reads books. Fiona and Dave both discuss not fearing death itself because they believe in the promise of Heaven: “Once I’m dead, you know, I know where I’m going, and I’m going to be truly healed” (Dave). The participant’s religious and philosophical beliefs not only give a purpose or mission, but also offer comfort throughout having ALS.

Loss

Loss has been briefly touched on when discussing aspects of life participants have given up, however, it permeates much farther and in many more modalities. These are illustrated in subthemes Loss of the Future, Loss of Independence, and Loss of Identity.

Loss of the Future. Participants involved in this study were all within 50-80 years of age and were looking forward to the future. This was a figural object for many people, knowing that they “had a clear vision of what [their] next 30 years or more [were] gonna look like” (Kevin): traveling and empty nesting for Dave, furniture restoration and biking for Max, raising his young daughter for Kevin, and enjoying retirement with her husband for Fiona. Now with an expected prognosis of three to five years with progressive motor deficits, many of these plans become interrupted. Dave spoke on the difficulty of “not being able to enjoy the golden years with [his wife],” which is typically all one can hope for in life—to reach the golden years and fill them with what you love. To then have that taken away when you were so close to achieving it is a shared experience among those diagnosed with ALS.

Loss of Independence. The idea of asking for help is not something foreign but is increasingly more common for participants as the disease progresses. Tasks that were once considered personal and solitary now need to be opened to someone else. Dave hints at this, mentioning, “It's the little things in life all the way down to going to bathroom. And when you're in public, you know, if there's not a family restroom, you have to get very creative.” Max describes a similar personal hygiene experience with his showering: “We, I use the shower very slowly. My wife assists me. She helps me dress.” During the interview with Dave, he had a very candid moment in which something got in his eye, and he wasn't able to lift his arms to get it out.

Needing help becomes a necessity of functioning with the disease. What comes with this, however, is a sense of dependence. For many who described themselves as “hyper-independent,” (Kevin), “have never been in a position of needing help,” or a “go-getter” (Fiona), this shift into dependence poses new challenges and a sense of loss. Even further than that, it is situation that is “humbling and frustrating and embarrassing” (Kevin) for some. Kevin brings these feelings up when describing his neighbors getting his mail. Something arguably less personal than going to the restroom or bathing yet represents this same change in self-reliance and emphasizes how even a mundane task like getting the mail becomes so much more significant when you can’t do it yourself.

Loss of Identity. Hobbies and interests have a large effect on who we are as people and who we identify as. While ALS comes with lots of changes to physical abilities, most participants identified one focal attribute that they have lost and how it has taken away from who they see themselves as. In describing their life pre-ALS phrases such as, “I was ...always a physical guy,” (Max) “I’m the mechanical guy” “I’ve always been a go-getter, a type A, doing things,” (Fiona) “very active on walks, hikes, all the physical stuff.... I always spent so much time outdoors” (Kevin). They each describe themselves in reference to these things they’ve always been. With their diagnosis and symptoms, many can no longer do what makes them who they identify as. Fiona talks about this disconnect in reference to dance:

I took ballet for 12 years, you know, dance has always been an important, had always been an important part of my life and grace, being able to move around. And suddenly, you know, just walking across the floor I can fall...

Hobbies and interests aren't the only aspect of identity affected. Roles within the household and interpersonal relationships were also mentioned. Max references the new change from "fixing things in the house. And now, if the plumbing goes bad, [they] have to call someone." Within his marriage, he was the one that mowed, cooked, and fixed things around the house. He can no longer do any of those. He also touches on change within his relationship saying, "I gave up all those things that I love about my life. Physicality? Lovemaking? Bye!" Most humans are sexual beings in nature and that physicality is important in romantic relationships. As a husband, losing the ability to fulfill this changes what the role may look like and mean to him thus altering that part of his identity. Similarly, Dave mentions his desire to keep his legs functioning until his daughter's wedding to "walk her down the aisle and have the daddy daughter dance." He wants to fulfill his role of "Dad" in what may be considered the conventional way—on his feet. His determination to maintain leg function may indicate a fear of not being able to be "Dad" at his daughter's wedding in the way that he has previously envisioned. The disease is possibly threatening this role and therefore part of his identity.

Changed Perspective

In this theme, the quotations speak for themselves. Each person learned something about themselves and the way they look at life.

"Different Lens." "Once you are given a diagnosis of a terminal illness, you look at life through a different lens. And that's the truth. You look at life differently." (Dave). Participants explain that this experience has given them a world view that never would have been possible before. Their perspective has gained attributes like "gratefulness."

... it has given me a perspective and degree of gratefulness that I honestly didn't have before. I don't think I could have had this level of appreciation before this diagnosis,

because it really, honestly, it does change your whole perspective on life in general.

(Kevin)

“Everybody has some struggles.” Largely too, this perspective change involved the people around participants and recognizing that everyone is going through something. It isn’t a sense of “I’m the worst off, woe is me” but an opportunity to recognize that people everywhere are enduring life altering things:

Where I feel most clearly I’ve gained a perspective is trying to be accommodating, trying to be helpful to other people...everybody has some struggles that they’re going through. So, I’m not there yet, but I feel like maybe I’m looking more for where other people might be struggling. (Kevin)

But it was an education for me as well to realize that, you know, just when you think you’ve got it rough, there’s others out there that have it so much worse, and you know, life is kind of what you make it. (Fiona)

Discussion

Through this phenomenological study, a descriptive picture is painted about the experience of living with ALS. Some overlap of themes between previous studies conducted by others was visible in receiving support from friends and continuing to move forward following diagnosis. Themes of changed perspective, and sense of purpose were brought to light and were unique to this study. Patients across the board described their lives before diagnosis, on the day of diagnosis, and on days after. Although every day is different, each participant has undergone major life changes due to symptomology and disease processes. They explored giving up hobbies, driving, and activities they love. They described the various forms of loss they’ve

endured since receiving a terminal diagnosis of ALS. Participants also discussed more constructive changes like that of their perspective and finding a sense of purpose in their remaining time. All of these were found to be figural to the lived experience of having ALS.

Narratives were contextualized with the existential grounds: World, Time, Other People, and Body. Primarily explored aspects of these included assistive devices, clinic visits, and work; disease progression and amount of time left; worry for family and friends and preparing them for the nature of ALS; disease symptoms and loss of function. These grounds helped to form a framework to understand themes and further characterized the lived experience of ALS.

Like Caputo (2019), participants in this study touched on the loss of abilities that form identities, new dependence on others, and using social support as an important aspect of coping with the illness. What isn't named in previous studies is the desire to leave a legacy or comfort from a belief system—subthemes of Sense of Purpose/Mission. The one time that belief system is mentioned, the participant described their diagnosis as a sort of punishment from God (Cipoletta et al., 2017). Every individual who referenced God that partook in the present study saw their diagnosis as an opportunity instead—a calling--or they saw their faith as a source of strength, support, joy, and fortune. This could possibly be attributed to the cultural difference between the Southeast US and Northern Italy.

Understanding the experience of living with ALS is vital for providing care and support throughout the disease process. Because of its progressive nature, patients never enter a remission and must live with the disease every day. Every healthcare worker involved in the increasingly common multidisciplinary team stands to benefit from hearing the narrative of their patients. Additionally, this work is important directly for those with ALS. Phenomenological methodology is frequently thought of as therapeutic and reflective—offering benefits to

participants by expressing thoughts and emotions otherwise held in. Being able to see the shared experience may benefit them as well as a reminder that they are not alone and possibly restore a sense of normalcy within the context of the disease.

Limitations of this study include those posed by time. Because of the nature of this project, there was a deadline to finish, so four interviews were completed where more could have been possible. Saturation was still met, but the data could have been strengthened by more participants. Additionally, common to the phenomenological method developed at UTK is the practice of sending participants copies of findings to cross-check for accuracy. Once again, due to time constraints this was not done but will be in the future as the present study is part of an ongoing project. Lastly, unrelated to time, due to the method of recruitment, a convenience recruiting bias may exist. Because most recruitment occurred at the clinic, those who had appointments were easiest to reach. Also having the health care providers suggest people who may be interested may have contributed to the selection of participants who would be more willing to participate in an interview, or who had strong support systems from family and friends.

This study solely focused on one area—South Central Appalachia—which may not be representative of other areas in the US. Future research should be conducted to focus on other areas of the United States or to recruit from multiple areas to form a broader understanding of living with ALS.

During the present study, many participants described interdisciplinary care they received at ALS clinics as being impactful. As Centers for Excellence (ALS Association, n.d. a) become more standard, a new research question should be asked, “What is the experience and impact of attending an ALS clinic?”

As stated previously, this study involved participants that described religion and philosophical beliefs as having positive influence on their outlook. This was a unique finding and creates another opportunity for studying experiences of ALS with a focus on the influence of religion.

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