

Supplementary File 3. Qualitative Analysis with Themes, Subthemes, & Exemplary Quotes

Barriers to Quality End-of-Life Care in Dementia with Lewy Bodies

Table 1. Overall factors

Theme	Quotes (Interview #)
<p>Misdiagnosis affects end of life</p> <p>[Interviews centered around end of life but many participants brought up misdiagnosis]</p>	<p>Misdiagnosis</p> <p>He had been diagnosed with mild cognitive impairment, major depression, Alzheimer's, you know, until the—November. We hooked up with the right neurologist and the right psychiatrist. (4)</p> <p>And he was not really diagnosed 'til, um, November, and he, you know—with the proper diagnosis. So his—he, uh, was getting all kinds of medicine and stuff, you know, and he wasn't—you know, I—it was probably making him worse. (4)</p> <p>I don't know how long for him to-to be diagnosed—- maybe five years. And he was not really diagnosed 'til, um, November, and he, you know—with the proper diagnosis . (4)</p> <p>'cause even early on, the doctors really—oh, there's something wrong with him. (4)</p> <p>First issue was he was misdiagnosed— and when he finally got d-diag-diagnosed, his, eh, um, his—he died about five years after being diagnosed. (5)</p> <p>Well, I-I don't think Lewy body dementia is that rare. Um, um, I think we were misguided by our neurologist, and, um, I-I'm puzzled why he was misdiagnosed. (5)</p> <p>They misdiagnosed him. Um, his pri—his primary doctor, um, I don't think that they-they even knew what to tell me. (5)</p> <p>Had we known earlier exactly what was going on or- or close to what was going on, had some idea, um, rather than, "Oh well, let's throw this at him and see if it works. Or maybe it's this and we'll throw"—cuz he was, you know, he- they said, "Well, he has orthostatic hypo- hypotension." And- and he did (9)</p> <p>I mean, he would stand up, he got dizzy, and, you know, that kind of stuff. And Dad had always had low blood pressure. Um, and, um, so they were treating it as that and not a dementia-for a long time. (9)</p> <p>when my brother first moved in—he first moved in with us, and the doctors thought he had Parkinson's. And then, after a year, I took him back to his neurologist, and his neurologist said, "Nope, he—it didn't advance in Parkinson's." He says, "I need you to go to {City} and—and talk to a doctor there." (11)</p>

	<p>So we moved in and, um, really saw her for about nine and half, ten years through the early to the late stages of, um, of the dementia. And for a long time she was misdiagnosed. (13)</p> <p>..my mom was misdiagnosed for a long time. Like many patients with lewy body dementia are. (13)</p> <p>.. I was the one that really pushed, um, you know, towards that diagnosis and finally I guess after about five or six years, um, that's what it was definitively diagnosed and it was more of, um, you know, exclusion. (13)</p> <p>in my practice right now as a PT, um, I have two patients that it took months, um, finally have been diagnosed with lewy body dementia and it's pulling teeth. Because doctors do not understand it. And I in fact have a, um, a sister-in-law who's a physician. She's the medical director of an insurance company for the longest time she, you know, lewy body dementia is a made-up disorder. And she didn't believe it. (13)</p> <p>I think in the course of my mom's whole illness it was the frustration from the health care community— of getting a diagnosis and then affectively treating it. (13)</p> <p>I've lived this and....it just it doesn't seem like, um, it, it just, it, it's taking way too long for people to get properly diagnosed. It's frustrating care givers and families and, um, it's still a diagnosis of exclusion versus, you know, let's treat this the right way. (13)</p> <p>For the next few years, we thought we were dealing with migraine headaches. He would literally sleep for days. He would sleep for 23 hours. He'd eat something and go back to sleep, and he would just sleep and sleep and sleep. Then that started with, um—they talk about, uh—the—the doctor would say, "Well, he has mild cognitive impairment along with these migraines." And that's kind of what we were dealing with all along— and taking testing.... (18)</p> <p>I would definitely say that if I could've had, um—of course, possibly now, if I could've had, um, a diagnosis of Lewy body dementia nine years ago—I think that things would've been very different in how we dealt with our—with life. Um, for me, the—the parts of it, the beginning, was how to deal with somebody that slept for 23-1/2 hours a day, and in that mode of "Oh, my god. What am I gonna do when he has a headache, and what do I give him and not give him and—" Um, just how all of that did.(18) <i>Speaking of what would've been done differently</i></p> <p>I think that the, um—the diagnosis needs to be done early. And, again, I'm very young. I did a lot of things. I can't imagine what happens to other people. Now, maybe his is a very, um, different experience than other people have. I don't know, um, but those are the things that I think would've helped us tremendously (18)</p> <p>...when I first took my husband to the emergency room they would put him in the category of Alzheimer's.</p>
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And I said he doesn't have Alzheimer. He could hear you. He could understand you at this point, so talk to him. And, uh, especially the nursing, um, the, uh, I was just in the hospital two weeks ago and the nurse had never heard of Lewy body. (21)

he was diagnosed with Parkinsonianism - in 2002. And he died in March—uh, the end of March, 2016. So, this was a journey for 14 years. ... he also showed signs of dementia from the beginning. There were very, very soft signs.... he could answer direct questions s-sometimes. Um, but he-he could not engage in conversation. Um, and, um, during, um—a-and-and there was a lot of confusion. He didn't have—one of the reasons he wasn't diagnosed is that he did not have outward hallucinations. (26)

So I had this in the back of my mind, and we went to our primary care doctor, and he knew something was definitely wrong, and he referred us to a psychiatrist. The psychiatrist saw {Name} for about two visits, and he said, "This is not a psychiatry situation—psychiatric situation." Uh, "You need to see a neurologist." And so the—we got the name of a good neurologist who um immediately tested him in the office, and suspected—I'm sure he suspected the Lewy body because that's what I was suspecting. But we—neither one said anything, but he put him through a very, very sophisticated scan, and we had to go to another town for it, and this was the only area in California besides {region of} California that had this particular machine that scanned for um Parkinson's and uh dementia, and that's how they determined that he had Lewy body dementia. And later, he was determined to have uh Parkinson's onset. (27)

Delays in diagnosis

I'm still as I say as a therapist jumping through hoops, you know, with some of your leading hospitals, University of {State} and things like that with neurologist, um, that, you know, this is classic Lewy body dementia. And they, they can't see it. Well yes it's something neurological, but it's—you know, and it, they, they just—I don't know. They don't listen.... it's taking way too long for people to get properly diagnosed. (13)

Earlier diagnosis would have helped

I attended a family and patient education session at the {Clinic}, Minnesota in June of this year. And so, I-I understand from presentations there that quite a bit of new work is going on on, um, diagnosing LBD. I think it might've been helpful to us to understand sooner than we did [laughs] what-what {Mother in Law} was suffering from. (20)

Conflicting diagnoses

	<p>She would go back to Michigan, where the neurologist there told her, "Oh, no. You don't have Lewy body." "You don't have anything to worry about. You don't need to listen to those people. They don't know what they're talking about." (3)</p> <p>Diagnosis only shortly before death</p> <p>w- we didn't get a really firm diagnosis, um, actually until really months before he went into his final last stages. And, um, his last stages were very quick. (9)</p> <p>My dad died in 2013, but we didn't get a partial diagnosis of Lewy Body Dementia until 2012. (9)</p> <p>She was diagnosed with—was given a probable diagnosis of, um, dementia with Lewy bodies about—just over a year and a half before her death. (20)</p>
Need for education at all levels of the health system	<p>Well, she's got, you know, Lewy body dementia." And it was just like, "What? Well, I've never heard of that," you know. So just—there needs to be some more education out there for people just to understand that there is this other kind of dementia. Everything is not Alzheimer's (3)</p> <p>the way you treat somebody with Lewy bodies is very, very different than how you treat somebody with Alzheimer's. It's-it's just a different beast, and they need to understand how different it is, and what they can do differently, or, you know, how they need to understand it differently. (3)</p> <p>The information needs to get out there. (8)</p> <p>...the more people can find out about this, because it seems like—it was something I had never heard of until my dad had it. (9)</p> <p>I think, um, it, it, it just comes back to education I think of— neurologists and PCPs and, um, making it so that, um, it's easier, um, for families to take care of their loved ones. Um, even nursing home staff and, um, you know, just online. I just read about, um, you know, some of the issues that people face in nursing homes and, um, you know, my heart goes out to them. (13)</p>
No system to help prepare families for memory care needs	<p>they really didn't know—they didn't—they don't have a system for, um, helping families amicably come to terms with, um, the inevitable need to move to the memory care, as they call it, um, and whatnot (2)</p>
Lack of religion	<p>I had a heck of a time finding-findi—well, I always ask the questions, uh, uh, question, are, you know, do-do you serve atheists? And they always serve all faiths. Well, that does not mean— no faith. Cuz we had</p>

<p>No good options for counseling for individuals without religious beliefs</p>	<p>no faith. We had no faith, and we fought it all the time. Um, e-even when I chose non-religious places, um, we confronted that. And h-he was a jerk about it. Even when he didn't know—have his mind. (5)</p> <p>I sought help and was, um, really disappointed, um, with his primary care person, with the neurologist. I was referred to, for like caregivin-caregiving counseling. And, um, one o—one of my griefs was just religious affiliations and-and, um, I-I mean, I felt like I was getting my hand patted and sent away. Um, so, there—I mean, there's plenty of spiritual guidance, but when you're not spiritual, it's not guidance, you know? (5)</p> <p>He wouldn't say that he was an atheist, but he was agnostic, and he—disliked, um, um, being prayed over, and he thought that was hokey. Um, and I-I made an effort to protect him for that—from that. And, for insta—for instance, when he—when he first became ill, he picked up the phone and he called the local hospice to come out. And he didn't—I don't think he perceived that he was calling the Catholic hospital for that. (5)</p> <p>they sent a nun out, you know, to speak to him. And, um, I knew that would make him angry, you know? So, then they sent another person out. I'm like, "Well, another person isn't good," you know, just because it's, um, um, when you have the—when you have those feelings, those, uh, end-of-life, um, death-with-dignity feelings, you don't pick up the phone and call a Catholic hospital. (5)</p> <p>well, I always ask the questions, uh, uh, question, are, you know, do-do you serve atheists? And they always serve all faiths. Well, that does not mean— no faith. Cuz we had no faith. We had no faith, and we fought it all the time. Um, e-even when I chose non-religious places, um, we confronted that. And h-he was a jerk about it. Even when he didn't know—have his mind (5)</p> <p>The hospice people were not warm and fuzzy, but they were very—um, you know, they did the right things. There was a chaplain who kept coming in and sort of standing over me, creeping me out, and so I told—no, really, it was-it-it made me feel very uncomfortable. First of all we-we're not religious, but it made me feel that the private time just to be with him, even though he wasn't that aware—but he was aware. It's like—um, so I did speak with one of the other hospice people and say I need the chaplain not to come in here. He didn't. (22)</p>
<p>Needing more caregiver support</p> <p>[See also "not knowing what to do"]</p>	<p>I can't emphasize enough the stress on the caregivers and there's just not enough support, um, for caregivers. (13)</p> <p>And the, the stress and the burnout the care givers experiences there's just not enough support there. And it's not just at end of life. It's, it's more those middle stages that are, that are hell when, you know, they're a little bit more mobile and they're, um, uh, that sort of thing. (13)</p>

	<p>I had support, but I think I would have enjoyed more support. (15)</p> <p>I think if somebody could have recognized that I was probably, as the caregiver—needed, uh, more support. Maybe I wouldn't have been open to it. May—I—you know, as I—as I think back, I-I recognize that I had a lot, uh—a lot on me, and I probably wasn't handling it as well as I should have. (17)</p> <p>You know, I coulda used that little extra support. Um, again, it didn't happen. (23)</p> <p>I was there—as you said, I was there for him. Um, you know, so many people would say, you'd hear people say, "Oh, you have to take care of yourself," and—and it's true. But I would—I would get angry because I'd say, "Now, just how the hell am I supposed to do that?" [Laughter] You know? It's like, "You wanna come over to my house?" "Yeah, come over to my house. I'll go out and go for a walk." [Laughter] You know, so, um, but that's—that's just a comment. There's nothing really that you can change about that. It's just that when I'm talking to other people, I try to get the point across without making it sound so cavalier. You know, "Oh, you have to take care of yourself." [Laughter] You know, cuz you do, you know. (25)</p>
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Table 2. Health system factors

Theme	Quotes (Interview #)
Need a team approach	<p>I just can't say enough about the importance of Hospice though and palliative care and a team approach to this. And it just, it can't be, you know, so many physicians. You know, it's a, a, a turf battle and there's not enough of a team with social work, with PT, and OT, and, um, there absolute has to be a team approach to dealing with patients with lewy body dementia. (13)</p> <p>Once he went into the nursing home, it was a full-time job to get them—anything—they have their own way of doing things. You wanna see a neurologist? No, we want you to see the psychiatrist. Well, the psychiatrist doesn't wanna talk to the neurologist. (22)</p>
Lack of coordinated care	Coordination of care, um, across the experience of the diagnosis to the inevitable stages of it. (2)

	<p>Just the—the whole idea of, uh—what do you call it?—the coordination of care . Um, there were a couple of different errors that happened, you know, well-meaning people. (2)</p> <p>across the team, you know, so it's so many people. The hospice people take over for the doctor, and then the hospice people are communicating with the in-house people, but the in-house people are in so many different shifts, and— Yeah, I mean it's just—it's so many people. (2)</p> <p>“once they figured out what to do, they couldn't execute it across the team, you know, so it's so many people. The hospice people take over for the doctor, and then the hospice people are communicating with the in-house people, but the in-house people are in so many different shifts, and— I'd call hospice. Hospice—says, "No. Your doctor has to write a order “(2)</p>
<p>Lack of coverage for care</p> <p>[see also facility costs below]</p>	<p>And I know it's a business to them and they gotta make money, too, but, you know, who can afford 24, 26, \$28.00 an hour? Are you kidding me? Nobody can afford that. You know, stupid insurance that, you know, they—you know, it-it's just ridiculous, the elder care in this country. (7)</p> <p>Um, and, of course, then our healthcare system. That, um—that I have—you know, I—it's darn expensive to put somebody in memory care. It's darn expensive to have somebody come to your house, and our healthcare system doesn't—doesn't allow for any help with that. I think it's terrible. I think it's terrible, terrible, terrible. (18)</p> <p>I would like to have my voice heard by the ombudsman in California for seniors, because there just really aren't enough facilities for seniors who are ill or um, you know, need some assistance. Um, even assisted living is almost beyond the-the pale for most middle-class people. Um, it's um the—it's a real deficit, and of course, the population is aging rapidly. (27)</p>

Table 3a. Organizational factors - facilities

Theme	Quotes (Interview #)
Facility lack of education, knowledge, experience	<p>how do we build, um, just a much more informed working population that knows how to treat everyone in that facility with the—the right... I feel like the care providers in the nursing home don't know the difference between Alzheimer's and Lewy body. (2)</p>

	<p>the way you treat somebody with Lewy bodies is very, very different than how you treat somebody with Alzheimer's. It's-it's just a different beast, and they need to understand how different it is, and what they can do differently, or, you know, how they need to understand it differently. (3)</p> <p>Yeah, they're not educated. And then you—then you get into the problem of, like I said, you know, they're more concerned about the-the physical plant and, you know, the draperies and the coordi—you know, calling in a decorator and, uh, the grand pianos in the lobby. And it's like, are you kidding me? You know? This is not what's important. You need to—you need to pay your staff. You need to educate your staff. You need to advocate for these patients. [Sniffs] You know? But, anyway, it's about corporations and them dollars. But, [sniffs] um, so, other than that, um, I think, uh, [sniffs] I think it's really the lack of education— (7)</p> <p>you mean other than having long-term care facilities that understand these disease processes? (7)</p> <p><i>Speaking of Are there other things that went badly or that someone could have done to make this time of life better?</i></p> <p>What complicated it was the nursing home that he was in had only been open for about six months and, um, was a beautiful facility, but, um, their- their staff was just not up to speed unfortunately. And they were not the most experienced people. (9)</p> <p>And so I'm not sure that the people that were working there were that well versed in their jobs at that point. And so there wasn't a lot of help for us. Um, I think maybe it helped them more (9) <i>Speaking of conference meetings with facility.</i></p> <p>The nursing home had not heard of it, so I actually pulled up the literature from the LBDA.org organization to try to share with them. They didn't really actually have a whole lot of interest. I think they just have their hands full, and a lot of it just keeps coming back (10)</p> <p>what I personally would do is, um—is to have like the CNAs and the nurses that work in these, uh, facilities— They should learn more about Lewy body... (11)</p> <p>I think, um, it, it, it just comes back to education I think of— neurologists and PCPs and, um, making it so that, um, it's easier, um, for families to take care of their loved ones. Um, even nursing home staff and, um, you know, just online. I just read about, um, you know, some of the issues that people face in nursing homes and, um, you know, my heart goes out to them. (13)</p>
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	<p>I think in general, uh, people who are, um, doing the most direct and personal care are not well-acquainted with Lewy body—and what distinguishes it from other forms of dementia. And a lotta the time that probably doesn't matter, but toward the end of life, I think it-itwould be helpful if people were—if everybody who is involved in care, um, has a sense of what's normal and what's not what's part of the disease and what's not. (20)</p>
Staff/providers unfamiliar with dementia or LBD	<p>Hospice, I think would've been a little more in tune with the dementia side than a visiting nurse, not that they don't have experience, but that's not their focus. Hospice would have much more, um, insight into where he was and how he was changing. Um, if I would've understood—I mean, I was thinking that he was going to slowly lose his ability to walk, and then he would be bedridden for a while. And, you know, I've got this whole long-term progression in my head, and it wasn't that at all. (28)</p> <p>I mean, he was still walking, albeit not nearly as well, and he needed a lot more help, but he was still ambulatory, um, until the infection set in from the pneumonia. Um, that-that really made things more difficult to me to understand what was going on. And once he got the pneumonia, um, [clears throat] she had said, um, about getting food in him, getting something. And I said, well, you know, he—we knew that the thin liquids were a problem. And I said, you know, we've been doin' these shakes that're, you know, definitely thicker. She said, "Oh, yeah, that would probably be really helpful." But then when I gave 'em to him, I did not know that he was aspirating it. Nobody was there to say, "Ooh, stop. He's aspirating." (28)</p>
Homecare providing rehabilitative services	<p>the primary care doctor did finally write an order for, um, an-an in-home care. And all they wanted to do was rehab her. I was like, "She's not—she's not gonna get better. She's not gonna walk. She's not gonna be strong." It is like they just didn't want to face what the reality was....they-they weren't addressing it at all, at all. (3)</p> <p>She didn't—she hated physical therapy. So but the doctors weren't quite getting it that, you know—y-you-you guys are the medical community. You know she's not gonna get better. You know? What-what is wrong with you people? (3)</p>
Delays making process harder	<p>So, Thursday, we were all ready to go, and I packed everything up, and, um, the doctor had been in earlier in the morning, and they had come in and-and done blood work, of course, in the middle of the night, like they always do. And, um, it came back that morning saying that ... somethin' was off, and I said, "Does that mean his kidneys are shutting down?" And the nurse said, "Well, you know, I can't say that for sure, but that's often a sign." And I just thought, "Okay, this is gonna be a long process, you know," and, um, so, a couple of hours later, the hospice people came in and said, "We've called the ambulance for transport, and it'll still be another hour and a half," or somethin' like that, whatever it was. And I looked at the clock,</p>

	<p>and it was 1:40, and I thought, “[Sighs] I wanted to be home by now,” and, [laughter] you know, so I just kinda sat down and-and was waiting and talking to a friend who was there with us. And she noticed that his stomach was no longer going up and down. (28)</p>
Trouble finding the right facility	<p>like kind of a—nice, but not—not super-nice, and like kind of nasty food and—- lots of like kind of semi-depressed workers (2)</p> <p>you know, our first thing was, you know, how do we make our house accessible? And then, something happened that, you know, that cued me that we can’t possibly make our house accessible in time, um, to have him here. And, um, then locating somewhere that they could physically care for him. Um, so, placement was a big thing. (5)</p> <p>I would call them, and they’re like, they’re, “Oh, you’re high-skilled.” Well, I need high-skilled. They-they—I-I don’t—you—and I asked one of the social workers at the hospital, “Have you ever driven out and visited any of these?” and she said, “No.” So, um, I-I get the impression that-that they were marketed to as the best places to go, but when you drive out to see them, they may or may not be, um, capable of taking your loved one. (5)</p> <p>You know, it wasn’t until I went to this facility and-and pleaded with the facility to take him that they finally, you know, we finally found a place that would take him. He was turned down from a couple of others. And, again, not DLB-related. It’s more systemic of our healthcare system. (10)</p> <p>. You know, he was on a facility that’s—a psychiatric ward at this hospital that was only supposed to keep him for 10 days, 14 days. He ended up being there six weeks because nobody would take him. (10)</p> <p>we couldn’t really find a place, uhm, that would like specialize in that type of stuff. So we did find one place, but I really wasn’t comfortable with their-their staffing to patient ratio— uhm, because I didn’t feel like they could pay close enough attention to the patients (19)</p> <p>He was there for three weeks. They were really wanting us to move him somewhere. We could not really find a place for my—he couldn’t go home. They said he—they didn’t want my dad to go home because my mom wouldn’t be able to care for him. (19) <i>Speaking of geriopsych</i></p> <p>I-I must have called every facility in this entire area and county, and they were full, um or they didn’t take uh that kind of dementia patient because they needed more care. (27)</p> <p>the hassle with finding a place [laughter] for your loved one is really awful. (27) <i>When asked that could have made that time of life easier or better?</i></p>

<p>Realizing a higher level of care needed</p>	<p>And it-it took me a while to come to the realization that this-this wasn't just skilled care; this was high-skilled care that we needed. (5)</p> <p>I think I was just one of the lucky ones cuz he was in the, uh, assisted living for quite some time, for eight years, before I put him in memory care. And, um, I knew it was time for him to go somewhere else because they couldn't keep—keep up with him. (11)</p> <p>I don't feel like my dad should have went to that initial rehab center. Uhm, they were supposed to specialize in like memory care but I don't think he should of been like, uh, in a rehab center. I feel like he should have—or-or like a re—I mean cuz people there were like getting up and going down to the dining room and—- uhm, like at that point, there were days where my dad needed help because, uhm, he couldn't eat properly- when just a couple of days before that, he was eating on his own. (19)</p>
<p>Lack of education about rehab stays at long term care facilities</p>	<p>what we didn't know—uh we didn't know about long-term ca—short-term stays at these places. Uh, nobody had explained that particular uh difference to us, or that it might be—you know, uh they-they just didn't talk to us about it. And uh, so they transferred him over there, and that's—he went there August—I think it was August 28th was when he went to the care center. And um, eh they informed us uh just before the 20 days that Medicare would not cover us. It was over uh after uh—I'm sorry—before the re—the uh Medicare would cover us for 20 days, and just before that was over, they informed us that they couldn't keep him because they didn't have a bed for long care—term care. So it was a real hassle for uh—For a while, it was pretty um—pretty stressful for me, and we finally uh—only because somebody passed away that was a long-term care patient, they were able to keep him. (27)</p>
<p>Facility costs</p>	<p>And I-I-I alert anyone that has to go into a memory-care facility, the cost is as-astronomical. Um, it-it averaged \$7,000.00 a month. And nothing ta—nothing pays for it, unless you have long-term care, but that's expensive... We didn't have it, and so it was \$7,000.00 a month. And as a caretaker, you then get into a little soul—a lot of soul-searching, like, where is this money gonna come from? Because if you look at it, 7,000 times 12 is \$84,000.00 a year,— and you have no idea how long it's gonna last. (6)</p> <p>And we had looked at independent living years ago, um, few years ago, but when she saw the price of it, she absolutely dug her heels in and she wasn't gonna do that. (7)</p> <p>We want you home with us. Um, you are paying a lotta money here for nothing. We can—for the amount of money you're paying here, we can hire in-home care.” And, uh, so I know, in her heart, because she never wanted to put anybody out, I know—- she was happy. (7)</p>

	<p>I-I see how that is, you know, people trying to not spend the entire life savings on, you know, this last couple months. (10)</p> <p>they, um, started charging me more because they said he was starting to become incontinent, although he still used the toilet (18)</p> <p>...my mom was struggling with the fact that we couldn't bring him home, but, uhm, there's not really an option unless you pay for that long term, uh, or in-home care— uhm, on your own, which most people can't do, you know. (19)</p> <p>...it's weird because California is-is a pretty wealthy state. Um, we pay a lotta taxes here, and - there should be more facilities, and there should be more financial aid for families, because honestly, you can go bankrupt with this sort of thing... the stay for {Name} uh was—w-well, it's now \$10,000.00, but over 10,000 a month, but if you want a-a facility that really specializes and is secure, that people won't wander away- uh and they specialize in this type of dementia, um they're around \$16-17-18,000.00 a month, and, you know, I don't know—I don't know many millionaires, so— I know I'm not one, and it-it was really extremely difficult uh finding— some financial help. And uh, and we had to get an attorney. Well, we-we had a will and a trust put together before, and uh by an attorney who specializes in this sort of thing, but we had to w-put out a lot of money to—in order to save our house and— and that sort of thing. So that, you know, would be helpful. - who are ill or um, you know, need some assistance. Um, even assisted living is almost beyond the-the pale for most middle-class people. I would like to have my voice heard by the ombudsman in California for seniors, because there just really aren't enough facilities for seniors who are ill or um, you know, need some assistance. Um, even assisted living is almost beyond the-the pale for most middle-class people. Um, it's um the—it's a real deficit, and of course, the population is aging rapidly. (27)</p>
<p>Nursing home wanting to change established care</p> <p>[sounds like there was poor communication – could be part of broader theme of communication]</p>	<p>They're [the nursing home] worried about the way that they're going to be, um, rated by state agencies and by Medicare. {Doctor} had him—his medications were-were cared for, you know, were-were monitored and in a very careful way. They kept saying that we're lying, actually. They're coming and saying, "Well, {Name's'} behavior indicates that we should cut, um, the dose of Clozaril, um, and we wanna cut it. And the-the pharmacy consultant says he shouldn't be on Namenda," which {Neurologist} believed people should be on because it could—it-it helps with some people. Um, "He shouldn't be on that." Uh, so they tried to make these, um, interventions into what was a solid and long-lasting medical relationship. That was painful. (22)</p>

<p>Poor communication</p>	<p>Um, but I do feel then as though the—it was almost as if the—it said, “Right, that’s it. She can’t swallow anymore, and we’re not even gonna try.” And I actually went to a nurse and said, mmm, “Well, what happens now?” And she said, “Well, nothing ‘cuz, you know, she can’t swallow. She can’t swallow.” And that—that just seems to be almost the end of it. they didn’t sit me down and say, “Right, you know, this is—you know, thi—we would expect that to happen. And because it’s happened once, you know, we’re not gonna try again because of X, Y and Z.” (16)</p> <p>And-um, and I know you can give it oral care, can’t you, where you’re supposed to try and keep the mouth moist and comfortable. Um, well, again, the-there was no discussing about, “Right, this is—we now need to-we now need to start performing oral care because”—“she can’t drink.” So, the care nurse says, “Right, we can-we can swab her mouth, and that might help keep things com-comfortable,” but there was no discussion about, I mean, “We should be doing this every X number of hours.” (16)</p> <p>So, she didn’t seem to be in any pain or distress. They were comin’ in periodically and tryin’ to reposition her slightly, and every time they did that, she seemed to be in pain when they did that— and she seemed to be a bit unsettled after they’d done that. And it got to the point where I was thinking, “Right, actually, stop doing that because I just don’t think it’s helping.” Um, and it’s almost like if you have to do that because bedsores or whatever, again, you need to communicate that to us— ‘cuz I don’t know. But I think if-if we had—did need to keep movin’ her for whatever reason, then I think we should’ve had the debate that says, “Well, maybe we just give her a bit of pain relief half an hour before we move her”— “because clearly when we’re touchin’ her, it’s hurting her.” Um, but then when she’d settle down, to be fair, she didn’t then seem to be in pain or distress. (16)</p> <p>The other things, um, I would’ve liked to see in these are, in the grand scheme of things, quite minor. But the-um, the communication between the facility and the families of people in memory care about such things as staffing changes was - suboptimal. And, uh, I think in memory care, the families are still involved with the staff and need to know that their loved one in care is having—um, need to know who’s caring for their loved one. (20)</p>
<p>Desire for better communication with staff</p>	<p>In retrospect what we should’ve done is sat down with a nurse and—you know, when it was—once she’d stopped eatin’ and said, “Right, this is what you’re now going to expect.” Um, you know, “The-the-there’s oral care we can do. There’s this sort of pain relief that we can give if she seems as though she’s distressed or sedatives or whatever.” But, again, the nurses were relyin’ on us to go to them to say, “We think she’s upset,” or, “We think she’s distressed”— whereas, to me, now, when reflectin’, they should’ve been comin’ in every hour and saying, “In our opinion, she’s comfortable”—um, ‘cuz, I mean, I don’t know what constitutes pain or distress, necessarily. Um, so, I-I think we should’ve had that discussion to say, “This is</p>

	<p>what's available." We'll co-come in every hour and check." Um, and-and then we can have debates, etcetera. Um, so the oral care I think should've been even better. I think we should've been made a bit more aware of what was available and what we could do. So, she didn't seem to be in any pain or distress. They were comin' in periodically and tryin' to reposition her slightly, and every time they did that, she seemed to be in pain when they did that—and she seemed to be a bit unsettled after they'd done that. And it got to the point where I was thinking, "Right, actually, stop doing that because I just don't think it's helping." (16)</p>
Conflict between families and facility staff	<p>so there were just lots of conflicts, um, with the nursing home people and my sisters, uh, and I with each other, around various issues that just 100 percent didn't need to happen (2)</p> <p>Conflicting expectations those places, you know, they think they're doing you a favor by givin' somebody a shower twice a week. And I said, "Nope. She-she showers every day, and that's what I want her to have." And, um, at one point in time, they even raised the price cuz I had 'em showerin' every day. I go, "Whatever. Just, we're taking a shower every day." (7)</p> <p>Disagreement with assessment I brought her to the nursing home—was um the psyche-psyche eval. Wow. I-I kind of—I don't even understand why that is a thing as soon as someone co—is brand-new to an environment. Obviously, people with dementia and—are gonna not be really happy that they're in - environment, and obviously, if you ask them if they'd rather not be here at all, the answer's gonna be yes. really think that means that you need to put down, "She's suicidal, and— we need to medicate her." Dude, no, I don't think so. I really laid into this one guy. I said, "Oh, my gosh, I—you're not even thinking here. This is—this is not—this is—of course this is the way she's thinking right this second. She's in a brand-new place, and she just—you know, and she's ill," and all this other stuff. So that, the whole psyche eval, I don't—eh the timing of that just seemed really, really odd. I didn't think that made a lot of sense. someone who has dementia.. Brand-new environment, has no— idea what's going on. Of course she'd rather not be there. (14)</p>
Challenge between standards and quality of life at nursing home	<p>He was in the second nursing home, and there it was always a struggle to—it was a struggle between their wish for safety and what the rules were and my wish to, um, give him better quality of life. (22)</p>

Nursing home stopping offering services due to condition	the facility almost seemed to give up that she was in a-a state where she wouldn't be able to do much or respond. (12) <i>Speaking of using music therapy and physical therapy when facility thought patient would not benefit</i>
Changes in providers	<p>Changes in physicians And that memory care facility was associated with another health care service. And so, actually she had a new physician through that service assigned at that time. The hospice was provided through that company, and-and— she saw a doctor. The doctor did change during that time, um, because the doctor she had started with took on some different responsibilities. Um, and we actually, my husband and I, never met the new doctor. He saw her once but didn't—we weren't notified that he was going to be there, so we—he didn't show up. (20)</p> <p>By this point, the—well, we'd had two different doctors. Um, one doctor—the first doctor we saw and we really liked, it was her last day. So, then we got pushed on to, uh, another doctor, and she was also wonderful. But, um, the-the antibiotic situation, what I believed I had understood, was that that would help him breathe better. Um, and the second doctor on the second day said, "Well, actually, no. He's probably gotten all he's gonna get outta the antibiotic at this point, even though it says it's a ten-day course." (28)</p>
Insufficient staff	<p>Turnover we had had weekly conference call- conference meetings when Dad was in the rehab facility in {City Name}. Those were not as helpful because I think it's just that the people that were working there- I- I think they'd had- in the first six months that they'd worked there, we found this out later, they'd had a great deal of turnover. (9)</p> <p>she was in—uh, the facility she was in was new, so it had a fair bit of staff turnover. But, uh, she received extremely compassionate care. (20)</p> <p>Recognition of problems maintaining staff I mean it—quite frankly, you're dealing with, you know a staff that's— it's-it's—some of it's even a minimum wage job. (10)</p> <p>Insufficient staff in system</p>

so I didn't know about the crisis in healthcare around, um, assisted living and whatnot in terms of the pipeline issues of just not having enough workers, not having enough trained workers. (2)

Insufficient staff at specific facilities

while I say, you know, they were pretty attentive to him, they're-they're also dealing—they had 22 people in this wing, and so they couldn't necessarily check everything, and there was a rotating nursing staff. So, not everybody saw him, you know, every day...days in a row... so, some of that gets lost in the shuttle, so—shuffle (10)

where the nursing home staff felt that she was wheelchair-bound or bedridden. Physical therapist really didn't believe that, and, uh, at some point, uh, we would have her walk the hallway of the facility. And then at one point we got to a point where she could even get outside and walk around the block. It was just, uh, quarter to half a mile. I'd follow with the wheelchair in case she needed it, but she never did. And the, uh, staff at the facility was just amazed that the physical therapist could get that kinda response because their level of caregiver—uh, they just didn't have a sufficient, uh, number of caregivers to pay that much specific attention. (12)

the facility...just didn't have a sufficient, uh, number of caregivers to pay that much specific attention. But that's why I took it outta my pocket to help the-uh, now, the quality of life, uh, over those, uh, three and a half years. (12)

So we did find one place, but I really wasn't comfortable with their-their staffing to patient ratio—uhm, because I didn't feel like they could pay close enough attention to the patients mean they don't sleep, like the dementia patients, they don't sleep. He couldn't stay there anymore, so we found a place that we were hoping, you know, do well him and my dad was there for ten hours and he fell and broke his hi... I don't know exactly what I can do. I told my sister, "We have to do something," because, uhm, when we researched it, they said that the state regulations are like, uhm, nine to one, uhm, nine patients for one caregiver, but it—with those types of patients, it just doesn't seem adequate. I mean I-I-I don't know. It just—I mean I just don't see how somebody could be responsible for nine patients, uhm, with-with that type of illness. (19)

the previous nursing home—I had moved-I had moved him from that nursing home because they changed the staffing pattern. I felt there wasn't enough coverage. (22)

<p>Facility care not to the level desired/expected</p>	<p>..I remember tellin' one director, "I'm not impressed by your grand piano in the lobby. All I care about is what goes on behind the doors where these people live." (7)</p> <p>You know how much care that piano would buy for somebody? But anyway, so, I, um—well, I found a place that I thought, "Okay, this is—this is nice. It looks nice." Uh, the director talked a good story, and I—it wasn't real far from where I lived, so I knew I would be there frequently. Well, little did I know, we got her there, and I literally slept on her couch the first five nights that she was there because I knew that they were not doing the rounds like they should And, uh, and they weren't. (7)</p> <p>It was a brand-new memory care unit. It was beautiful. It was gonna be better staffed, yada, yada. And, uh, so, I talked to her and I said, "Aunt {Name}, I'm-I'm gonna have you go back to this other wing because, uh, they're gonna have more staff," and, um, it—and it was beautiful. It was a beautiful layout. It was. It was. And so, we tried it, but, um, they were supposed to have alarms, motion detectors in the rooms, but, you know, all the state-of-the-art stuff. And, um, and so, one night, I was there and I said, "You know, I don't understand. If this is a motion detector and there are laser lights. Like, sh—how is that working?" "Oh, well, you know, it works by sound," or, I don't—it was always a story. Anyway, come to find out, the system had never been operational. (7)</p> <p>Well, little did I know, we got her there, and I literally slept on her couch the first five nights that she was there because I knew that they were not doing the rounds like they should. (7)</p> <p>That was one of the selling [laughter] points for people. "Oh, yeah. your loved one gets up and wanders." No, they had no idea. But, anyway, my aunt didn't wander, but I wanted it for safety, to know if she got out of bed. You know, I didn't want her walking to the bathroom by herself and fall. (7)</p>
<p>Negative experiences with nursing staff, care</p>	<p>believe she fell five times in five days. And, you know, it was like those systems just don't work. (2)</p> <p>then nurses that would forget or people that would eat in front of him, or bring him a treat. (5) Speaking of nurses and family feeding patient when food is being withheld</p> <p>Um, there were a couple times, you know—and I think this is probably true of every-everything that—you know, I don't think that she was treated as great as she could have been, you know. recall coming in to-to see her, and she was rocking in her wheelchair, and she doesn't rock. And I'm wo—and she was—her face was hot, and I'm like, "Why is she rocking in the wheelchair, and why is she hot?" This is in front of everyone. And then I looked underneath, and her foot was twisted underneath the pedal of the wheelchair. And I'm wondering how long that had been there, and she's obviously not able to verbal and</p>

	<p>share that, and it was just kind of like a non-awareness, I think, - the staff, but I think that probably happens everywhere. Yeah, I think that happens everywhere. (14)</p> <p>Um, so, I-I'd gone to get a nurse to say, "Look, I'm gonna try and get some—her to eat some yogurt." And, um, she tried, and she seemed to be shovelin' it in a bit quicker than I perhaps would've done. But, um, you could—you could hear a definite gurgling sound, and she said, "Right, I think that—I don't think she's—she—I think that's gone on to her lung. I think we should stop." (16)</p> <p>I think the only thing—I think the only thing that went well is the fact that the family were there. Um, but I think in a way, that-that [laughs] slightly hindered the process because, as I say, it was almost like. I mean, the care—the care home, they're under pressure. They're busy and everything, and it's almost like, oh, the family's there, and it perhaps took the pressure—took the pressure off them a bit— um, whereas to my mind, it shouldn't have done. They should have been doing more—they-they would've been doing whether we were there or not. (16)</p> <p>Um, so, that as well—I mean—and again, I-I-I feel as though, you know, when—whe—when the breathin' had got so shallow— that she started to turn blue, I mean, it's like, come on. I think then, on reflection, we should've just given her some morphine or something to just de—help— you know, keep-keep the— just—by that point, she was distressed 'cuz she couldn't breathe. Um, so, you know, I-I don't know what the answer is in the breathin' and because I had said that we weren't gonna start givin' her oxygen. But, you know, for ha—to have an hour where you're stoppin' breathin' and then gasping for breath to me is just not acceptable. And I don't know whether that's—that is, um, normal or not. But we were told that that's quite normal. (16)</p> <p>And we didn't give me mum much, and it—uh, you know, in hindsight, I think we should've just been givin' her regular pain relief- whether she wa—you know, and assume she was in pain, (16)</p> <p>he would have episodes where he would get aggressive with them, and they would put him on stuff. And at one point, he was basically comatose for five days before I realized that they had changed his medication. So, again, I'm like—I had to be on it all the time even though I think he's in a safe place and there's people that know what's going on— (18)</p> <p>when he went to that facility, I said to them, "Watch what—you know, we need to be careful." They wouldn't—they didn't—as, obviously, didn't call. Um, a couple of months ago, we had an incident where they—that medication was still in his chart, and one of the caregivers actually didn't pay attention and go further into it. And he was agitated, and she gave that to him. And I, of course, came in—and they have—</p>
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	<p>they have to call you an—with any—it's by law they call the—call me to say, "Well, we gave him the wrong medication." (18)</p> <p>it's very difficult. Sometimes you get angry because it's very difficult watching an aid being rough with your loved one especially at that time of—and so, um, you know, I, you know, I, I'm pretty, I was very protective of my husband. And I think most people who's a caregiver and a spouse is that way. think they should be, the aids and the nurses should be responsible, you know, aware of that (21)</p> <p>Administration</p> <p>I wrangled with the admini—the uh person who was the admitter uh at—uh person who did the admitting to uh—to the care center. Uh, she um—she came on pretty hard and fast to me, um kinda rough, about the fact that they couldn't keep him any longer, you know, so you better be having a Plan B. And um—and then when we had a meeting, you know, a care meeting, where they - where you're talking about this sort of thing, she said—she told a lie about me. She said, "Well, you said you would take him back home." [Chuckles] I said absolutely no such thing. There was no way that I was going to be able to do that. And um I'm usually a very diplomatic person. I worked in Human R—uh Human Resources [laughter]. You had to be diplomatic. And - I'm usually a very diplomatic individual, but that just—you know, she—and she also said that it looked like I was dumping him off and just leaving him there. And ah—excuse me? Oh, my goodness. And uh, I-I had to—I had to face her down... and I was hoping, and [chuckles], you know—if I ever have to go back there someday, I don't know if they'll ever take me if she's still there. But we had to work it out. We did work it out. I mean, there were—it was uh pretty tense after that situation, butuh, I had to, you know, put her in her place because she was lying about me, and I wasn't gonna— stand for it, and I was not dumping my husband off. I didn't want him anyplace but home, but I—it was just, you know—I was physically u-unable, and getting to be mentally unable also - to handle it. (27)</p>
Nursing homes expecting families to provide care	<p>I think the only thing-I think the only thing that went well is the fact that the family were there. Um, but I think in a way, that-that [laughs] slightly hindered the process because, as I say, it was almost like. I mean, the care-the care home, they're under pressure. They're busy and everything, and it's almost like, oh, the family's there, and it perhaps took the pressure-took the pressure off them a bit— um, whereas to my mind, it shouldn't have done. They should have been doing more—they-they would've been doing whether we were there or not. (16)</p> <p>And then the day—and-and-and it was gettin' more and more difficult to get her to-to take stuff on. And then I was-I was—a-and-and—but, again, they were almost expecting me to do it. And by that point, she started to make this, uh, kind of gurgling sound. And I was really uncomfortable feeding her by that point</p>

	<p>because I-I didn't know—I-I didn't really know what-what was choking and what wasn't. I-I didn't feel as though I was able to determine whether it was going down properly or not. (16)</p> <p>You know, so when—if she got a urinary infection, if she's particularly bad, you know, I'd go over and stay for a couple of days. Um, and the care home were quite happy for me to do that because it was almost—if-uh, if I was there, that almost relieved the pressure on them having to— spend more time with her. That's how it felt to me, anyway. (16)</p>
Facility unable to handle person with DLB	<p>... a lot of the nursing staff didn't seem to be very. I don't wanna say comfortable, but in tune with dealing with somebody with that type of progressive disease process (1)</p> <p>he was a transport issue. He needed a special lift. They bought a special lift for him. And as I went around trying to find care for him, you know, um, um, the nursing services are m—are marketing towards me because they want a client. And they would take him— and then call me three days later, or we'd have a-an emergency. Um, and I-I can't even remember how many times I moved him . One, two, three, four, five, six, seven. I moved him eight times within five years. (5)</p> <p>throughout his illness, we had to relocate him several times. Um, and I blame—I kinda blame marketing or-or, um, you know, nursing services that claimed that they could handle-handle him, and-and they couldn't handle him Cuz we— had a double issue that he was, um, uh, he was ahead—he was already paralyzed. (5)</p> <p>“You cannot take her home. You have to put her into a strong memory-care facility.” .. And I found one that I thought was perfect, and at the memory-care facility, they then send a nurse—sent a nurse to the hospital to check on my wife and see if she'd be a fit. And the shocking thing for me was they called me on a Friday afternoon and said, “We were there, and she is too much for us to handle. We cannot take her.” And it's literally like your whole world falls apart, like, now what do I do? (6)</p> <p>near the end she was extremely combative and— they said, “We have to take you and put you”—get her into a geriatric ward. And there's not many in many states. I think—Michigan there's only four, I think. (6)</p> <p>we got a call that said Dad had become combative and that we had to get him out of the unit immediately. Um, and so they had called everywhere in the area and said, "You have to find another place for him to go— but someone has to come out here and stay with him." (9)</p> <p>well one facility that he'd come out of that was supposed to [inaudible 00:12:05] I think, by law, held him a spot. Came back to us. And he was a challenge for them there. Came back and said, “I'm sorry, we filled</p>

	<p>all our spots. We just can't take him." Which I struggle to believe. The other facility basically said he was too low-function um, compared to their other residents. And so, again, it all comes down to cost. You know, here's one patient that's gonna take, you know, twice the staff, time as another patient. (10)</p> <p>I think the-the primary reason we heard was that his—you know, he was-he was too um, too low a function. And that was when he was coming out of that whole Haldol reaction piece - that they were evaluating for. So, he was, you know, really not terribly coherent. You know, he got much better, but he did have his episodes-episodes of uh, you know, where he was quite angry, and-and he would swear and - he never-never did before. (10)</p> <p>had some really unhelpful nurses here and there. The first nurse—we had put him in one nursing home and then pulled him out. Had to go to psychiatric ward until they cut his medication. And then finally got him into a vacility that was – that was very helpful (10)</p> <p>And their way of dealing with a-a incident of acting out was they'd send the person to the hospital. (22)</p> <p>Well, he um—he actually—he was pretty combative at the care center to begin with, so um um they—you know, they tried—they tried to help him, and he would hurt himself sometimes. He was in a wheelchair a lot, and sometimes he'd bang his arm and hur—just hurt himself on the— arm of the chair (27)</p>
Administration of antipsychotics	<p>Then, in a rehab facility, they administered Haldol... We had no idea this would've been a problem... when they administered the Haldol that he fell into sort of a—I wouldn't say comatose state, but he was uh, retreated quite substantially, and he never really fully recovered from that. And so, he-he-he did come back a little, and he was, you know, he was communicative again. But uh, you know, he sorta just went through, then, a steady decline. (10)</p>
Medication errors	<p>when he went to that facility, I said to them, "Watch what—you know, we need to be careful." They wouldn't—they didn't—as, obviously, didn't call. Um, a couple of months ago, we had an incident where they—that medication was still in his chart, and one of the caregivers actually didn't pay attention and go further into it. And he was agitated, and she gave that to him. And I, of course, came in—and they have—they have to call you an—with any—it's by law they call the—call me to say, "Well, we gave him the wrong medication." And, sure enough, he slept for 36 hours. (18)</p>

Table 3b. Organizational factors – home care

Theme	Quotes (Interview #)
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Difficulty finding good caregivers	...we were able to keep mother in her home. Um, we um, um, hired a team of uh, around-the-clock team of 24/7 uh, care givers. That was quite a process, because we had to weed out a lot of horrid folks. (24) we were just blessed almost every step of the way, except when we had um, care givers who uh, were not good people and who took advantage. (24)
Home care staff with different approaches	Well, um, the visiting nurse, um, the main one who was assigned to us, we really liked. Unfortunately, she was having a lot of health issues and ended up out for surgery twice during the— short time that she was with us. We got a substitute, who we also liked, but she didn't have the same outlook, didn't—um, um, she didn't seem to want to take charge as much as the other one did. And I understand she was a substitute for us, um, but the other one had a little more, "Well, I can-I can help you with this," kinda thing whereas the substitute was like, "Well, call so-and-so and find out such-and-such." I'm like, I'm already way beyond overwhelm, you know? Um, so, if we could've had our-our regular gal, if her health hadn't been an issue, I think it would've been easier. (28)

Table 3c. Organizational factors - hospice

Theme	Quotes (Interview #)
Waiting to meet hospice criteria	<p>when they finally called them, I-I mean, it was like, oh, my gosh. Finally. You know, that's a horrible thing to say, but finally, we get hospice... Um, but it seemed like a long time before he met those criteria of hospice. (5)</p> <p>So, finally they said—she said, "Have you thought about hospice?" And I said I thought it was too early. Well, she helped me, and the-the first hospice said, no, he's not—"We won't take him," essentially. They didn't think that he met the guidelines. And so, there was another hospice that said yes. So, he was in hospice for, I would say, about six months before he died. And the difference that that made was he had more freedom. I mean, the—he was able to—if we had more space, then it was less-less agitated. (21)</p> <p>they saw the writing on the wall, and I think they knew that he was destined for hospice, but because at that moment, which was M—early May, um h-he didn't meet all of the criteria at that time to be—admitted. It wasn't another two weeks until he finally got admitted, so mid-May. He was in hospice maybe two, three weeks, and he passed. (23)</p> <p>..the one thing that I would offer is, because of the rules that hospice has to follow, my father didn't fit in the box of their rules— until two weeks after they were first called. I mean, we called them in—well, the</p>

	<p>doctor called them in—um, oh, that’s the other thing. We—uh, the doctor called them in, and they—and h—the uh lovely woman, I think her name’s {Name} 24:35, came and she said, “Oh, yeah, yeah, yeah. It’s just a—it’s not today. It’s just a matter of time.” Well, I could have used you today. You know, I coulda used that little extra support. Um, again, it didn’t happen. It didn’t happen for a reason. Whatever that reason is, I don’t know. I think if-if hospice sees the writing on the wall, is two weeks really gonna matter? I mean, seriously, is two weeks really gonna matter um when you see folks kind of struggling? (23)</p> <p>So they came and did an evaluation, and that first time, he was—he was too functional. They said, “No, uh, I don’t think he really needs it,” so he didn’t. And then he had declined. Remember, I mentioned after a certain amount of time—he had really kinda dropped off. They came again, and at this point, I think I was feeding him. I don’t remember exactly, but he—he had just declined a lot in terms of what he could do for himself. (25) <i>Speaking of hospice eligibility</i></p>
Losing services once on hospice	<p>I knew about Hospice quite a while before I put my husband on Hospice. And I really, um—and this is another difficult decision is I really toyed with, you know, where is he at. Because once you’re going on Hospice, and this is the thing with Hospice is that it’s like end of life then and they don’t do anything regarding —- um, I know I was told that that’s just not part of Hospice. And so that’s why I had to, I didn’t put him on Hospice because I wanted him to have the most opportunity to keep his physical being going. Um, like walking, if, I knew if I stopped helping, trying to help him walk or get up and transferring on—not on his own, but at least helping us. That it would, it would end especially with the dementia.... And so I really fought not to put him on Hospice because I felt like he should have as much therapy and PT and—good experiences as possible and not just let him have end of life experience before he was ready. So. That’s the thing with Hospice is I think that with this disease, dementia, the person should be allowed to go on Hospice but have the therapy and the exercise to keep their brain going as much as they can. There will be a point when it’s not. It’s just, it’s, it’s, it’s not working, but I think the caregiver, kind of the spouse knows at that point then (21)</p>
Not getting treatment on hospice	<p>Um, then the next day was when-um, when she came by and said, you know, “The only way we can get this antibiotic in him is IV. We need to get him to the hospital.” Um, we called the ambulance for transport, and, um, the-the—one of the guys—there were three guys who came this time, and one of them was a jerk. He flat-out, in front of my husband and me, to the visiting—uh, the hospice nurse, said, “Why’re we taking them there? He’s DNR.” And then he fought with her over it. And she was so cool. She was wonderful. She said, “He has never had an illness. We don’t know that this is so severe at this point that he can’t recover from it.” And the guy was not—he-I mean, he argued and grumbled and fought it. And, um, you know, she had to get pretty firm with him and still remain—very professional. I was</p>

	impressed with how she handled him. But then we got to the hospital, and we got that same kinda treatment from the ER. (28)
Physicians didn't know about or recommend hospice	<p>I'd asked them about hospice, and none of them even recommended hospice. Um, there was really no discussion of what the end of life was gonna be like for her (3)</p> <p>I had called both of her doctors... And, um, talked to her family doctor, and, you know, none of them would make a recommendation for hospice. They said, "Oh, you have to contact hospice." Hospice says, "No. Your doctor has to write a order," un-until it got to the end. At one point, I said, "Get her into hospice. Let's just get her into the hospital, and we'll take it from there." But I had no idea it was gonna go the way that it went. So it wasn't—I mean, nobody can control it, but it wasn't the way I would have liked. (3)</p> <p>And I don't think enough physicians, um, just across the board and in general, you know, you think of Hospice for cancer patients and there is a definite need for Hospice and palliative care education for primary care physicians (13)</p> <p>the doctor said, "We'd like to have a meeting with you." And she had a group of about four people, including a social worker, and they started out by saying, "Have you considered what would happen if your husband could not go home from the hospital?" Ka boom. No. [Laughter] Uh, and so they gave me 24 hours to find him a place to stay. Nobody mentioned the word hospice. Nobody ever said it would be a good idea to look into that now too. Um, I didn't think of it. I should have, but, you know—and of course, we didn't know how end his near was. He was he was only two weeks in the home before he passed away (14)</p> <p>we did not get on hospice when we should have, and I didn't know any better. (15)</p> <p>Nobody mentioned the word hospice. Nobody ever said it would be a good idea to look into that now too. Um, I didn't think of it. I should have, but, you know—and of course, we didn't know how end his near was. He was he was only two weeks in the home before he passed away. (15)</p> <p>Nope. Nor did the woman nor did the woman who ran the the, uh—the adult care home say anything about that. It was 24 hours before he died that she said, "He's really not doing well." "He should be on morphine. You need to contact hospice." Now, we had had—I think we had a physical therapist come out and try to get him to stand up there and talked about using a Hoyer lift, and the woman, uh, who ran the the adult home said, "I don't think you're gonna get him to stand up. We've been trying and trying." (15)</p>

	<p>We did inquire about hospice. Uh, none of our doctors recommended it. In fact, I called the neurologist, and he thought it was too early. Uh, [chuckles] this was in 2016 when he was really r-just really goin' downhill, and I thought— wow, it doesn't seem too early to me. (27)</p> <p>And I wish we had done that m-much before. It would've been so much more helpful. But I didn't know. Nobody gave us full information. I knew hospice was not for just, you know, in their last days or weeks. I knew that they could do more than that. My mother had been on hospice her last six months or whatever. Um, but I didn't understand the scope of what they could do for us. (28)</p>
Needing more guidance about when to start hospice	<p>I I think I really needed {Health System}, to to step in more, to give me the advice of putting him on hospice. Again, now that I've done research for my book, I know that that these kinds of crises are are an indication that, uh, it would be a good idea—or palliative care. I would have taken either. They didn't do either. Um, and I I really felt like it was all dumped on me and that nobody was there to hold my hand. And, you know— you're used to that as a caregiver. You figure out how to do stuff, but, you know, he was in—he was in real crisis, and I was anxious. (15)</p> <p>we did not get on hospice when we should have, and I didn't know any better. (15)</p>
Staff inconsistency as a challenge	<p>One of the things that I thought that Hospice should have done is they kept giving me different nurses all the time. And I thought that, that it would have been nice to have the same nurse, the same— continuity. Um, the same with aids. And I, I feel like Hospice who, you know, there were several different organizations I could have gone with, but I felt that Hospice should focus on their best aids for the end of life. Because this is the, the person with the end of life this is their end of the ride. They deserve that. Um, and sometimes I didn't find that to be, like people didn't really understand that you had to move people very gently. Um, because it was another, another, a different person maybe coming in every day so you had to start the whole routine all over again with them. And as a caregiver you didn't have that energy. so I really think that Hospice should focus, you know, on making sure there's continuity with the nurse and with their aids that they bring in. (21)</p> <p>Um, so, I had 24-hour care. People came and went, and came and went. When they were very—the nurses, themselves, were very good.... And the nurse said to us at about 7:00, "Well, I have to leave at 8:00 and, um, and there's nobody here, nobody to come until, um, the, um—until 3:00.".... Um, she did not leave. She ended up staying, I think because she knew he was dying. (26)</p> <p>And I found that, uh, in a situation like that there were too many people that he came in contact with, uh, and the—everybody's way of doing things were different. And he had all his life been, um, a—oh, um, a-a</p>

	<p>fearful person.... He just didn't have the experiences I did. So, um, he would give them a very hard time (30)</p>
Different hospice providers give different care	<p>And I had called a couple of different hospice, uh, facilities, and I was surprised to find that n-not all hospice, uh, providers are the same. And there's a difference in what they'll provide- and what they'll do. Um, I went with y—who I thought was the best fit, and they-they did provide, uh, medication like morphine. (8)</p>
Insensitive staff	<p>I wasn't pleased with the intake person. It—I really didn't get any sense of, uh, compassion or sincerity. And, uh, just thanked her for the information she gave me, and-and I said, "Well, I'll just see how this goes." (7)</p> <p>when I talked with Hospice she just said to me, "You need to make that decision soon and it's up—you know, we can't help you with that. You have to make that decision." Um, and she didn't come out to talk with me. She did this over the phone and she said, "You let me know what your decision is and then I'll come out." (21)</p> <p>I didn't realize towards the very end that we had this odor and we kept him really clean. And my caregiver finally said, "{Wife's name}, you know, it's the bag. It's the cath bag. That needs to be changed." And I said, "I don't have anymore." So I went to the Hospice nurse and I said, "Could I get another one of those bags back because I'd like to change the bag because it's, you know, it's, because he's dying his kidneys are"—you know, it's not. She said, "What do you need that for he's dying?" So I said, "Well I want those back," and I said, "I will give whatever is extra back,"—I had bought them myself. I will give whatever extra is back to you, but my husband deserves—and it's not, you know, it, it smells. I mean you know— you, you don't want that. You know, I mean at the very end when you know your husband's dying or your wife you want the very best for them. (21)</p> <p>didn't tell you the worst part of—it just blanked out. They knew he was dying, and, um, when he passed, it was a quarter to 4:00 in the morning, and I'm there. I don't wanna leave him alone. You know, I just don't wanna— leave him alone. So I-I-I ring the call button, and nobody comes, and nobody comes, and nobody comes. So I go to the nurses' station. Nobody's there. I find an aide, and I say, "Can you please—where's the nurse?" "Oh, she's not on the floor." "I need the nurse to come." So she comes, and she says, "Now I have to get another nurse to-you know, to, um, kinda certify," whatever the word is, "to-to pronounce him dead" ""cuz I'm not"—he—so the other nurse comes. And then she says, "You-you know that-uh, we know that you're gonna do brain donation," and I had been told that what that means is that his body needs to be transported to the lab within-uh, within, uh, 6 to 12 hours or something of the time he passes.</p>

	<p>So the second nurse says to me, “Well, we have to wrap his head in-in-uh, in ice right now.” Um, and, um, I was sort of—I said, “Okay, but we need to come back.” “Well, now we need to do—you know, we need to take him outta there.” I said, “My son is on his way here. You’re not doing anything.” And the whole—it was terrible. I mean, it was really upsetting. (22)</p> <p>So, in the morning, when we got that-that, um, the nurse said, you know, “I’ve gotta leave at 8:00,” um, and, um, and so, she, um—I-I was sitting by his side, and she was across the room. And she said to me, “You can tell him he can go now.” And I was sitting there thinking of how—I mean, I was pretty emotional at that point, anyway. And thinking, “How did—how do I say that?” And I was tryin’ to think it out and word it out in my head. And then she called out, “You can go now,” to him. And it was so upsetting to me. And I also wonder, because of that incident, yes, he was on morphine. Did she up the morphine that morning? Did she hasten it? And, you know, it’s those things that you don’t know.(26)</p> <p><i>Insensitive EMR, ER staff for individuals on hospice</i></p> <p>Um, then the next day was when-um, when she came by and said, you know, “The only way we can get this antibiotic in him is IV. We need to get him to the hospital.” Um, we called the ambulance for transport, and, um, the-the—one of the guys—there were three guys who came this time, and one of them was a jerk. He flat-out, in front of my husband and me, to the visiting—uh, the hospice nurse, said, “Why’re we taking them there? He’s DNR.” And then he fought with her over it. And she was so cool. She was wonderful. She said, “He has never had an illness. We don’t know that this is so severe at this point that he can’t recover from it.” And the guy was not—he-I mean, he argued and grumbled and fought it. And, um, you know, she had to get pretty firm with him and still remain—very professional. I was impressed with how she handled him. But then we got to the hospital, and we got that same kinda treatment from the ER. (28)</p>
<p>Poor coordination, not responsive</p>	<p>..there was a mix-up at the doctor’s office. To make a long story short, uh, they (Hospice) didn’t come on Monday. On Tuesday afternoon, I called and said, you know, “I, um, kinda made this decision. It’s been very difficult, but where are we with it now?” You know, I—and so, um, you know, make a long story short, they didn’t know who to call, and it was just a mess. So, a-anyway, they ended up giving me a name of a difference hospice agency (7)</p> <p>Well, what it came down to was that was the way we could get him morphine. And I had to literally drive like the wind to get to the pharmacy as fast as I could to get him the morphine, but we couldn't do that until - until hospice was contacted and said, "Okay. Get him the morphine." So it was - it was a madhouse.</p>

	<p>I was calling, calling, calling, and trying to get somebody to okay this fast. So then we did have a hospice worker come to the home, but, um, you know, what was she able to do for us? You know, it was just a preliminary look, and so we never really got any help. (15)</p> <p>But uh, hospice uh, the negative on hospice is that I asked around in [City}, Texas, which-which—what are—who are the top three? I kept hearing that the top one was this particular company. They were a for-profit uh, hospice outfit. I signed up with them. They uh, the very first day just immediately fell apart, as far as not-not being there on time, not-not—or-or—it was something really dramatic that I just thought well, we’re not doing that. And uh, so I uh, ended that relationship before 24 hours were out, and then hired a uh, or secured a-a non-profit hospice. And I-I tend to think that there’s a difference in the quality of care between non-profit and for-profit. (24)</p> <p>There were many incidents like that where, um, he had a-a huge, huge, um, blister on his heel. It took me two days finally actually having a fit, crying and everything, on the phone, before they would—they sent somebody out to take a look at it. Um, and, oh, the reason they—no. Somebody had come out to-to look at it that night because I threatened to call the state... and he said he needed some kind of a—like a boot, or something, to protect that heel, cuz he was bedridden by this time. And, um, it took them—uh, i-i—that was on a-a Sunday night, I believe. And I couldn’t get them to respond. And finally, they sent out what they needed to send out. It was just—it was one incident like that after another. (26).</p> <p>the-the-the last incident was—the, uh, the last four days. So, he died on Thursday. So, Monday night, the director of the summer house, the nursing director, who was just a wonderful, uh, person—her name was {Name}. And {Name} finally called {Name of Palliative Care Company}. She’s the one who convinced me to take {Name of Palliative Care Company}. She finally called and she said, “You need to bring somebody in here. This is now the time to do the 24-hour.” And finally, they brought somebody in that-that, uh, Monday. Um, so, I had 24-hour care. People came and went, and came and went. When they were very—the nurses, themselves, were very good. (26)</p> <p>So, you know, the-the time I most needed somebody to be there with me, it didn’t happen(28)</p> <p>With one group, um, the first group we had, um, he start—my dad like failed like really quick where he wasn’t gonna eat or drink anything. He looked horrible. Just super stiff. And, uh, his face was all mask like and he was just kinda out of it. And, um, I told him, I said, you know, “Don’t feed him. Just, you know, let him go. I don’t want him havin’ any food or fluids or tube feeding or anything like that—,” you know? And,</p>
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	<p>um, he was dy—actively dying, and they were medicating him to keep him calms. Well, those idiots gave him a PRN pain medicine or whatever they were giving him to keep him sedated and clam. They ordered it PRN. So— it had been two days without food or water, and, usually, it's about three days, and-and they fall asleep and die. Well, I go in there, and, all of a sudden, my dad's sittin' up in the chair, and somebody's feeding him. I'm like, "Are you frickin' kidding me?" Oh, he's havin' a flight into health." I got, "No, he's not, and I look, and they didn't give him his pain meds cuz it was PRN." I'm like, "Are you frickin' kidding me?" Oh, he's havin' a flight into health." I got, "No, he's not, and I look, and they didn't give him his pain meds cuz it was PRN." And they thought he was fine, so they took him off the stuff that was dopin' up to help him pass peacefully. (29)</p> <p>Decreasing the care that was being received</p> <p>And supposedly, that-that was the group that would come in at the end, the last few, um, wh-when he was really in the dying stage, and be there 24 hours. And so, I chose that. It turns out that I was very, very unhappy with the kind of, um, response that they had. Uh, just a quick res—you know, kind of an—a-a-an example. Um, on Friday, um, he was in the nursing home. And we met and got this—th-the great sales pitch of, "We're so good, and we're so great because we're so big." Um, and, um, we signed the paperwork. The nur—the nurse and the doctor did not come to visit and do the initial eval until Monday night at 7:00, when he was really exhausted by that time. And at the end of that, um, that-that eval, they brought me back to their little office they were, uh, using. And they said they wanted him just left in his bed. Well, over the weekend, the-the caregivers had been, you know, putting him in the wheelchair and bringing him out and putting him in the—you know, bringing him to the dining room and putting him into the-the lounge chair where all the familiar and where people were all around him. And I started crying. I, uh, you know, I know that means. Let's just close the door and let him die. You know? (26)</p>
Not enough support/time	<p>And hospice-hospice came by every day starting that previous Friday, but hospice wasn't there longer than an hour max. Uh, I think um my a—my idea of hospice would have been for someone to be there more. Maybe they were too busy. Maybe they had too many other cases. I don't know, but—or maybe this is just their practice, but if the person i—the-the hospice patient is in their own home, the hospice nurses only come once a day. If the— hospice patient, obviously, is in a hospice facility, you're gonna get more service. Anyway, that's kind of an interesting thing, and-and understanding that, I think, would be a—a—something for people to know right off the bat. I don't— think people understand that. (23)</p> <p>And the nurse said to us at about 7:00, "Well, I have to leave at 8:00 and, um, and there's nobody here, nobody to come until, um, the, um—until 3:00." And I was like gasping. I wa—and-and she says, "Well, I'll</p>

	<p>show you how to suction him.” And so, that was, uh, it was just—it was unbelievable. He died at 9:16 that morning. Um, she did not leave. She ended up staying, I think because she knew he was dying. (26)</p>
Needing more education from hospice	<p>I think if I understood a little bit more about the medication and the hospice flow, yes, how-how that goes,— right? Is it—is it, “Initially we do morphine, and then for three days—and then this”? Like, do y—do you—is there some sort of protocol, or is it really fluid, or—I feel like, also, that I-I wanted to—and this is actually a point that I wanted to share with you—I wanted to have—I tried to get a hold of the head nurse for hospice—cuz I think there’s-there’s like two different people to make decisions, right? It’s like her or the nurse on the floor, but I think uh they kinda defer to hospice once you get—into hospice, and I-I think that I couldn’t get a hold of her when I had—I think it was the-the retching problem with—the morphine, initially. And I just was kind of not understanding what to do next. (12)</p> <p>I feel like we had a little lack of information as far as meds and how it goes. they are—you know, as the days progress, we’re assuming that her kidneys are shut down and they’re gonna hurt her, so we’re give her more morphine, or—yeah, how does that—how does that go dow—go down? I think that would be helpful. (14)</p> <p>The very end of life was like nothing I’ve ever experienced, obviously, and incredibly painful and confusing and exhausting. I think that it was, again, not-not really understanding um the morphine situation, like whe-when hospice can give morphine. (14)</p> <p>Um, no, not really, to be fair, but, I mean, we-we were visiting often—- so, I mean, it was evidence that—that, um— things weren’t going well. And it—and every time there was an incident like if she had a fall or what—you know, the swallow and stomach incident, they would ring us up and say, “Right” “this happened. You know, you might-you might want to come over.” Um, and they did work with us in terms of we-we got some special of, like, um, head pads to protect her for the—from the falls—- um, and stuff. But there was no real discussion about, you know, this is what likely to to happen over the next, you know, number of months. (16)</p> <p>I know it’s a difficult question for them to answer, but we were just kinda, like, trying to say, “Do we know, you know, how long she’s going to go on, for how long she’s likely to”—and they would just do—you know, I know-I know it’s a very difficult question to answer, but they were just all very vague, really, and said, “You know, she could-she could rally. We just don’t know.” So, it was difficult. (16)</p> <p>they didn’t sit me down and say, “Right, you know, this is—you know, thi—we would expect that to happen. And because it’s happened once, you know, we’re not gonna try again because of X, Y and Z. It was just, “That’s it,” you know. Um, so-so she—and that was probably maybe ten—the-the last time she</p>

	<p>took-to-took that last bit of yogurt, I think it was probably ten-ten-ten days to-to a week before she then died. ” (16)</p> <p>Well, I think-I think in retrospect what we should’ve done is sat down with a nurse and—you know, when it was—once she’d stopped eatin’ and said, “Right, this is what you’re now going to expect.” Um, you know, “The-the-there’s oral care we can do. There’s this sort of pain relief that we can give if she seems as though she’s distressed or sedatives or whatever.” But, again, the nurses were relyin’ on us to go to them to say, “We think she’s upset,” or, “We think she’s distressed”—whereas, to me, now, when reflectin’, they should’ve been comin’ in every hour and saying, “In our opinion, she’s comfortable”— (16)</p> <p>It was very surreal, actually. They—the, uhm, the, uh, hospice team was nice. It was a little shocking because we didn’t realize that my dad wasn’t gonna like be eating or drinking there. (19)</p> <p>Needing help making decisions</p> <p>...our experience was- was prior to his last weeks, it was just a horrible time because making decisions and trying to figure out what to do, we didn't have a lotta help with that. (9)</p> <p>my experience with Hospice is later on that was not good. Um, and they did not really help me with the decision. They said, “Well you have to figure out soon what you wanna do because if you’re gonna put—and I put the feeding tube back in him when it fell out. (21)</p> <p>Hospice incorrect regarding estimates</p> <p>And then when we—when-when we finally came to the decision with hospice to withdraw food—they told me it would be about 10 to 14 days, but it ended up being more like 3 months. It was awful. (5)</p>
Family not understanding hospice	<p>I think this is a—this is something kind of a key point, which you’re probably hearing a lot of; people don’t really know what hospice is. and they don’t know that it’s not necessarily—it doesn’t necessarily mean she’s gonna die in three weeks. (14)</p> <p>But it—having an explanation from them about exactly what hospice would do differently than what they were already doing, I think that was the biggest problem for me, looking back— is I didn’t understand the difference between the two. I thought they were gonna offer exactly the same thing - just with a different person because one is there because it’s a healing wound, and the other would be there because there wasn’t any expectation of healing. (28) <i>Speaking of difference between hospice and visiting nurse</i></p> <p>And, um, what I learned much too late was the incredible assistance they could’ve been. Like, you know, I was payin’ for all of the, um, pads for the bed, and— um, the-the Pedialyte and things like that, whereas</p>

	<p>they could've been supplying that all that time. And I was already so stressed about money - and nobody said, "But they can give those to you as part of the program," you know? [Laughs] That would've helped me so much on-on some of the fear about the financial side of it. (28)</p> <p>Family resisting hospice approach Dad had stopped eating and drinking, she was like, "Well, can't we put him on fluids? It just seems cruel." I said, "Does he look like he's suffering?" "Well, no." It's only to make yourself feel better and he had signed— years before what his request was. I said, "Please don't do this to him." I said, "He is not going to survive." (9)</p> <p>Patient afraid of hospice And so, she was terrified of hospice. So, I was trying to respect her wishes. Um, that was resolved easily by nobody said the word hospice at the end. She wou—they were just nurses and caregivers. So, um, in hindsight, I would have started hospice in July. I just was afraid to-to make my mom afraid. (8)</p>
<p>Difficulty with medications during hospice</p>	<p>Trouble swallowing medications for pain And the morphine, the liquid morphine, and all these liquids that they're administering through the mouth had no way—my mom ha-had no way of swallowing it (8)</p> <p>I think that it was, again, not-not really understanding um the morphine situation, like whe-when hospice can give morphine. So she stopped eating and drinking completely. Um, and then she just kind of—when—just was sleeping most of the time. Um, and-and then they wanted to reduce her pain because the body started breaking down, and they'd give her some morphine, but initially—I remember this. Initially, they gave her morphine, and she um uh uh—she had the ga—a gag reflex to it for a whi—quite a while, so it wasn't—it wasn't agreeing with her. So I was like, do we stop it, right? That was also a point of con—kind of confusion for me. Do we—do we stop the morphine— because she's gagging? It just doesn't seem like a-a pleasant end of a life right now. Um, so we did... (14)</p> <p>Multiple errors with medications one of the bad things that happened, um, repeatedly for my mom is that they kept messing up the morphine level, so Um, just the—the whole idea of, uh—what do you call it?—the coordination of care there were a couple of different errors that happened, you know, well-meaning people. (2) It was clearly not intentional, but—but nevertheless, it kept happening. So like one of the reasons it happened was this stupid thing where they switched pharmacies, and the f—the shape and the size of the</p>

pill changed, so they thought it was, you know, a different level than it was - cuz it matched the other—you know, like silly things like that... so that's why she kept being in so much pain, and that was, you know, excruciating, obviously, to watch. (2)

Use of antipsychotics

They, um, started him on initially, um, morphine IV every two hours as needed. And then that wasn't really keeping him comfortable, so about—I'd say about 12 hours after we made that decision, they started him on a morphine drip. And then, um, they, augmented that with, um, as needed Ativan IV Robinul, and I think he received a couple of doses of IV Haldol, but I think that was just two doses... once they started the drip, he became more comfortable. Prior to that, it was a little rough, but they addressed it quickly. (1)

I think he received a couple of doses of IV Haldol, but I think that was just two doses.... Not that I'm aware of. No. (1) *When asked if Haldol caused problems.*

He looked at the strings hanging down from the overhead lights and he thought they were a noose. I mean, it wasn't anything you know, anything I was worried about. I was just relating to [the nurse] how things had been going. And she suggested Haldol. And I didn't research it... About two, two and a half hours since he had his Haldol... He was suddenly sitting upright... Every muscle in his body was clenched. His mouth was clenched. It was opening and closing, opening and closing. His tongue was thrusting out. He almost bit his tongue off at one point and he was groaning and moaning, and he was in terrible pain... His temperature skyrocketed... From there, his kidneys shut down, and he was gone by Tuesday morning. (#17, wife)

he was bedbound, I think the first or the second was maybe a Thursday or Friday—by about Friday night I had to start giving him Haldol um from the hospice comfort pack. And that started once every six hour—once every eight hours. Then it went to six hours. Then it was almost once every four hours, um until about s—Monday, M-Mon—uh Sunday my mother had ordered a hospital bed because he kept moving around the bed, and even though, believe it or not, they were still in the same bed, um he was moving around so much and he would hit her. (23)

Haldol helping, stopping made patient worse?

Now originally when he went, um, to the nursing home, they put him on a very tiny dose of Haldol. And he did well for about the first five, six months. And then all of a sudden it was like he'd had a stroke. And I was sitting with him and, uh—and I watched him breathe, and I said, "Wait a minute." And I called my son

	<p>and he said, “Yeah, mom”—he said, that’s “CNS breathing.” He said, “That’s the Haldol.” So I found out that the medicine girl had stopped the Haldol three days before I noticed this. And so it wasn’t too long until he came out. But he wasn’t able to-to eat—it was just like he’d stroked out. (30)</p>
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Table 4. Provider-level factors

Theme	Quotes (Interview #)
Physicians/clinicians do not know about DLB; lack of education, awareness	<p>Physicians in general do not know about DLB</p> <p>I really believe that not enough people in the medical community—and not just—I mean, there are some doctors that truly understand it, but there are so many people in the medical community that do not understand this illness, what it does to somebody, what the effects are gonna be, what they respond to, what they don't respond to. (3)</p> <p>I think the doctors don't understand... I think the doctors even need more understanding of this crappy disease. (6) <i>Speaking of what could have made it easier or better</i></p> <p>I was kind of shocked at the lack of information, even in the medical community. (8)</p> <p>I think there's—you know, there's just a lack of information. When I would take her to the emergency room, uh, people—honestly, you know? Nurses did not know—oh— She has Lewy body dementia? What is that?" You know? And it—"Oh, it's Robin Williams', you know, uh, cause of death." "Oh, okay!" And—but that's—all that clarifies is that's the disease— Robin Williams died from, so... (8)</p> <p>And physicians do not understand it. And, um, you know, the let's try haldol, or let's try this and try that. Um, none of 'em understood the complexity of the behavioral issues. And that's what made the management of it from the mid to the late stages so difficult. (13)</p> <p>aside from the end of life issues not enough primary care physicians, and even neurologists, know about lewy body dementia. (13)</p> <p>And I don't think enough physicians, um, just across the board and in general, you know, you think of Hospice for cancer patients and there is a definite need for Hospice and palliative care education for primary care physicians. Um, that and I think, um, there needs to be, um, better education to physicians on the effects of medication on the elderly. (13)</p> <p>We were constantly going to the doctor w—just, you know, to be reassured that he doesn't have stomach cancer, but nobody every said that stomach pain, constipation, could very well be because you do have Lewy bodies, you know? (17)</p> <p>There was just things like that. Um, a sec—um, impotence. He-he-was, and that was one of the earlier signs. Do we—did anybody tell us that, the urologist tell us that? Hm-mmm. No. Had they told us that this is a sign, this is what—and-and we can help you with that, or we can't help you with that but it is because</p>

	<p>you have Lewy bodies. I think a lot of these symptoms that he was having, that, uh, we just didn't understand, had people put in perspective for us, we, I think, could have better prepared— and a better understanding of the process. (17)</p> <p>I think that we have to find—we have to diagnose early, and we have to make doctors aware that all these other symptoms that are around it—this is what it could be... And you can't give—there's a—a—you can't give Alzheimer's medication to Lewy body dementia people because we did have, um—he went—at one point, they put him on Namenda. He had a suicidal, um, episode... (18)</p> <p>It seemed like not, uhm, not e-even the doctors were super familiar with it. (19)</p> <p>One of the things about doctors is that a lot of doctors don't even understand this disease at all. And I think the, mm, mm, you know, when I first took my husband to the emergency room they would put him in the category of Alzheimer's. (21)</p> <p>Doctors don't know a l-whole lot about it, um unless you get a neurologist who has certainly come uh h-into—you know, had dealt with this before. And— luckily, ours d-had. (27)</p> <p>Even our neurologist's office was very, um, ignorant about that sort of thing. It-it surprised me, especially with the neurology office. You would think they would have wonderful resources to share, and they just didn't. Well, it's definitely something that needs more work, uh, because for many people with this, the neurologist really is the-you know, the-the point of contact and-and where a lot of the-the guidance is most likely to come from. Um, and so if they don't have it, uh, that's a real-a real lack and something that we can definitely work on. (28)</p> <p>You know, there's a lotta people that aren't getting good medical care, and the lack of awareness about Lewy Body dementia is a real problem. (29) <i>Physician caregiver</i></p> <p>Primary care providers do not know about DLB</p> <p>Um, his pri—his primary doctor, um, I don't think that they-they even knew what to tell me. (5)</p> <p>her primary physician and nurse practitioner were not unfamiliar with Lewy body. But I don't think they were deeply knowledgeable about it. So, I think education of both, um, the general population and the medical community would be helpful. (20)</p>
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Neurologist lack of knowledge

this neurologist recognized the poss—and he started talking about Lewy body dementia. And then we got to a point when he said, "I—I don't know what else to do with—I can't help him anymore because this is the limit of what I know about it." And, um, so then that's when we started about a facility because, of course, as I said before, he started, um—so, again, I think the education of—of, well, primary care first of all so that they can refer people - and then, you know, neurologists have to be able to at least—we have to find people that are specializing in these—well, memory care, of course, or memory issues but Lewy body specifically because it is such a aggressive, angry disease. (18)

I mean, we were going to neurologists, and they weren't diagnosing him with Lewy body. Um, I did notice by about, I would say, two thousand el—between 2011 and his death, that just going online, they were beginning to-to, you know, refine the definition. Or the ca—you know, the c—the categories o-of, and, um, the, um, uh, uh, the diagnosis. They were really refining it, until— finally, you know, there were neurologists who were saying, "Well, he doesn't have, you know, h-hallucinations." But that is not necessary (26)

Even our neurologist's office was very, um, ignorant about that sort of thing. It-it surprised me, especially with the neurology office. You would think they would have wonderful resources to share, and they just didn't. (28)

ER physicians/staff do not know about DLB

We were in emergency, and they had asked, you know, about her. And I says, "Well, she's got, you know, Lewy body dementia." And it was just like, "What? Well, I've never heard of that," you know. So just—there needs to be some more education out there for people just to understand that there is this other kind of dementia. Everything is not Alzheimer's and the way you treat somebody with Lewy bodies is very, very different than how you treat somebody with Alzheimer's. It's-it's just a different beast, and they need to understand how different it is, and what they can do differently, or you know, how they need to understand it differently. (3)

When I would take her to the emergency room, uh, people—honestly, you know? Nurses did not know—oh— She has Lewy body dementia? What is that?" You know? And it—"Oh, it's Robin Williams', you know, uh, cause of death." "Oh, okay!" And—but that's—all that clarifies is that's the disease— Robin Williams died from, so... you know, the—I was astounded. (8)

	<p>I- had a bunch of pamphlets on what is Lewy body, and I would literally carry them around with me, and I literally handed them out in the ER when Mom had been—had to be taken there a couple times—because they have no idea how to handle someone. Not only dementia or Alzheimer’s; they just don’t know Lewy body. And then there was that big, big concern about some of those drugs that would potentially—could be fatal if someone— with Lewy body takes certain drugs. So I was—I am sorry that I don’t remember exactly what it was at the—at this point, but I remember at that point, “Don’t give her this. Don’t give her this.” And that’s wh-always what they give people to calm them down. So um, just from day one, it was lack of awareness (14)</p> <p>One of the things about doctors is that a lot of doctors don’t even understand this disease at all... when I first took my husband to the emergency room they would put him in the category of Alzheimer’s. (21)</p> <p>Hospital providers don’t know about DLB Nobody at the hospital had ever heard of Lewy body dementia. (25)</p> <p>Hospice staff lack of knowledge When the nurse came to see him on Thanksgiving, I had mentioned something about, you know, he looked at the-the strings hanging down from the overhead lights, and he thought they were a noose. I mean, it wasn't anything, um, ex—you know, anything I was worried about. I was just relating to her how things had been going. And she suggested Haldol. I went and picked up the Haldol the next day, and that was Friday... And I would say within a half hour—and this is about two, two and a half hours since he had his Haldol—he had a neuroleptic malignant episode... And I truly believe that it was the Haldol that hastened his death., and my—the inexperience of the nurse who suggested it, the inexperience of the provider who okayed it—- the inexperience of the pharmacist who filled it. Why are we—you know, somebody with a LBD diagnosis, why are we giving Haldol? (17)</p>
<p>Having to see specialist outside local area</p>	<p>The neurologist, um, that we went to, I think there’s issues with the neurologist in {Illinois City}—in-in my location. I’ve heard this before. But the neurologist that he got referred to, um, a-and I don’t say this lightly, I think he was just a quack. He’s supposedly the expert on several things here in {Illinois City}, and every i-in-instance—I mean, I’ve hear—pe-people travel away from {Illinois City} to find a good neurologist (5)</p>

	<p>... After a year, I took him back to his neurologist, and his neurologist said, "Nope, he—it didn't advance in Parkinson's." He says, "I need you to go to {City} and—and talk to a doctor there." (11)</p>
<p>Lack of conversation/ discussion with physicians</p>	<p>No discussion of fact that dementia can be terminal probably at least addressing and saying that, you know, this is terminal, and these- are the types of things that we have to talk about or think about. And-and that never happened. ... That never happened. Um, yeah. And-and I think that if-if that had happened, maybe we would have been able to get hospice sooner. (3)</p> <p>where I—where I've figured out that she was gonna die-d-die is from reading all the material I could get. But the doctor, I don't think, ever said she is gonna die. And I-I think that's important for this person to know, and you know, you really don't know when they really got it.. the lifespan of the Lewy body patient is seven to eight years, I believe, and depending on when they're diagnosed, how long do you have to go? I think the doctor needs to be very specific with the caretaker. Now, the patient may not wanna hear it. That, I think, would be up to the caretaker. My wife would never wanna know she was gonna die. I know that. She felt—I-I-I'm certain she felt she was gonna die, you know, soon. (6) I think the doctor needs to be blunt with the caretaker that this patient's gonna die (6)</p> <p>No discussion of what to expect at end of life, lack of education regarding end of life none of the doctors even—I'd asked them about hospice, and none of them even recommended hospice. Um, there was really no discussion of what the end of life was gonna be like for her. (3) no conversations with any doctors about end of life, um, or what that was going to be like, or what to expect, or what to plan for. I mean, nothing, nothing (3) I'd asked them about hospice, and none of them even recommended hospice. Um, there was really no discussion of what the end of life was gonna be like for her (3) They listed it as just failure to thrive, which was— a term I had never heard of before. So—and just the-the whole thing was—I don't know. I just didn't feel like I was getting any guidance from anybody. (3) And, you know, both of us were like, "W-w-we don't know what to do," you know? (3)</p> <p>we-we did talk about it in generalities (4) <i>Speaking of end of life</i></p> <p>he had issues with choking and he-he choked at—choked on food a couple times and had trouble swallowing, and-and, um, they made me aware that that's where it was leading, and— Um, I-I didn't actually perceive that, um, not remembering to swallow would be an issue, Um, and I wa—I didn't really—</p>

	<p>when they explained to me how awful feeding tubes were, they didn't really explain to me how awful not eating was. And I clearly understood that we weren't gonna be able to teach him, retrain him (5).</p> <p>I-I don't think they prepared me as well as they could've (6)</p> <p>I believe that knowledge is really key for people to-to be able to process what's happening. And so, more information is better. And if, uh, if it's a tough thing, bluntla—bluntness with compassion is so much kinder than the platitudes and— (8)</p> <p>I'd spent tons of time sort of combing through the literature, you know, I worked for a drug company, so I sort of have access to a lot of the medical literature. You know, I could find no journal—I found a few journal articles that kinda spoke to sorta the average lifespan of a living patient being about three years- - after an initial diagnosis. But um, I don't know how accurate that was (10)</p> <p>I think if we would've had a little more information as to what to expect, I think that's probably how I spent the lion's share of my spare time, just trying to research things. Ironically, I worked in the Alzheimer's space, so I have a little bit of that knowledge, but uh, um, it-it was tough, you know, not-not really knowing what to expect and not having sort of well-document, you know, these are sort of their logical progressions. This is what's happening in the brain. You know, these are the faculties that we lose first, and these are the kinds of things that you see would—you know, would happen towards the end. (10)</p> <p>I think that the most important thing to-to avail people with would be resources about expectations for the end-of-life... But, you know, they're just—there's so little information... maybe it's just me being a scientist. I want to know exactly what I'm, you know, will be expected of me, in-in terms of, you know, what to expect when I see this happening in my dad, it translates to this much time left or these kind of things... So, that's kind of the scientist in me. Maybe other people don't want that information, but I think it would be helpful. (10)</p> <p>I just—there was such a uh, uh, dearth of information that uh, it was—it was really challenging for someone that—being a scientist and just wanting to know how long do we have? What's going to be the progression? I think there's a lot of information available for Alzheimer's disease, and just so little available for Lewy body dementia that it was uh, it was extremely frustrating, to me. (10)</p> <p>That was one of the main problems. So now that I've done my research, I realized that he was having failure to thrive, um, and, you know, he should have been on— (15)</p>
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	<p>Yes and no. Uh, the nurse who - who ran the home was telling me symptoms that she was seeing—that was still only the last week. Um, so some—again, I—I've done my research now, and I understand these symptoms better. So she was saying things like, you know, his cheek—the skin on the cheekbones was tightening, and he was—- breathing more, uh, ragged, and he was, you know, sleeping all the time. You know, all of those kinds of signs that—- the end was coming. He didn't want to eat at all, even pureed food, so— (15) <i>When asked if caregiver felt prepared for what to expect</i></p> <p>I think just possibly being a little bit more prepared and being a little bit more educated on like what-what your options are. Uhm, we-we just were not prepared. We had—we didn't know what to expect, like I said, and—but my dad was diagnosed with the-the disease and then he, uhm, he-he declined so rapidly— (19)</p> <p>Well, I was fortunate. I know you—you had some questions about hospice. Uh, the way it happened, uh, while we were still, uh, up north, um, I had a friend who was—who worked for hospice. She was a music—is, still is, with a different a hospice, but a music therapist. And so she said to me, she said, “You know, I think he might be eligible for palliative care.” And I never would've thought of it if she hadn't suggested it. (25)</p>
Lack of caregiver support	<p>I don't feel that from his PCP perspective, when [my mother] would take him in and explain things to the doctor, like that he was declining, that she was—my mother, that is—was offered, um, any type of additional care—- for perhaps like end-stage—the end-stage Lewy body dementia. Like hospice or palliative care support. (1) <i>Speaking of having to take over caregiving from Mom- who was previously primary caregiver</i></p> <p>I sought help and was, um, really disappointed, um, with his primary care person, with the neurologist. I was referred to, for like caregivin-caregiving counseling. And, um, one o—one of my griefs was just religious affiliations and-and, um, I-I mean, I felt like I was getting my hand patted and sent away. Um, so, there—I mean, there's plenty of spiritual guidance, but when you're not spiritual, it's not guidance, you know? (5)</p> <p>When I say platitudes, I mean, um, I called in and had a question about something that was happening to my mom, like two days before she died. And the lady that answered said, “Well, I'm sorry that her death isn't what you visioned it would be.”.. And it's like, well, that—uh, you know, this is not how—so, I think</p>

	<p>bluntness, even though it's blunt, uh, is much more palatable for people at that time. Because we're so tired. (8)</p> <p>It is so hard being a caregiver. And I think it's really unrecognized by people who aren't living through it. Um, and doctors don't do a good job of supporting it a lot of the time. (17)</p>
Receiving mixed-messages from different physicians	<p>But, um, the-the antibiotic situation, what I believed I had understood, was that that would help him breathe better. Um, and the second doctor on the second day said, "Well, actually, no. He's probably gotten all he's gonna get outta the antibiotic at this point, even though it says it's a ten-day course." And I had a friend come to my house and-and get clothing and all kinds of stuff. I thought I was movin' in there for ten days. And then this doctor the next day says, "No, that's really not gonna help his breathing. What will help his breathing is morphine. We cannot do that in the hospital, but hospice can do it at home." And I'm goin', this makes no sense. Yeah, it just—that's ridiculous. [Laughs] But we wanted to be home. So I was like, I am all for that. Uh, why did nobody tell us this earlier; would've been home earlier. (28)</p>
Physicians not knowing how to get things arranged	<p>Not knowing how to arrange lab</p> <p>And he says, "Well, do you have a nurse that comes in. They could do it." I was like, "No. I'd like to have a nurse that came in, but, no. What do I do?" He says, "Well, call around the labs. There'll be some lab that does it." None of 'em did. (3) I Speaking of failed referral for testing at home</p> <p>Not knowing how to arrange hospice</p> <p>..there was a mix-up at the doctor's office. To make a long story short, uh, they (Hospice) didn't come on Monday. On Tuesday afternoon, I called and said, you know, "I, um, kinda made this decision. It's been very difficult, but where are we with it now?" You know, I—and so, um, you know, make a long story short, they didn't know who to call, and it was just a mess. So, a-anyway, they ended up giving me a name of a difference hospice agency (7)</p>
DLB diagnosis not considered during medical care for unrelated concerns	<p>I was at most of the appointments leading up to that, and it was not addressed. (1) <i>Speaking of discussion about if surgery framed in the context of him having dementia with Lewy bodies.</i></p> <p>I mean, he had this major procedure, and they put him in the car, and he's yours now. And they—and they didn't even ackno—the staff, that he had, you know, anything mentally or, you know, wrong with him. (4)</p>

<p>Medical team with unrealistic expectations</p>	<p>they ended up keeping her in the hospital for, like, three or four days, so that then she could go to a skilled nursing center for rehab. She was there probably only about three or four days, and I finally said, "List-listen, this—she's not going to get better. She needs to be in hospice." (3)</p> <p>I was like, "She's not—she's not gonna get better. She's not gonna walk. She's not gonna be strong." It is like they just didn't want to face what the reality was.(3) Speaking of medical team</p> <p>You know, after all these horror stories I hear about— people having surgery, and when they come out, they're never like when they went in. Um, so I thought, "Whoa, this—this is really good." So he started healing up well, and, um, so then they sent him to rehab, and the rehab that they sent him to was one— cuz I had visions of getting him walking— bringing him home and back to, you know, pretty much the status quo, or what the status quo had been. So, um, he went to this rehab, and he was just getting weaker all the time. He was—he was deteriorating, not from the anesthesia, but I believe it was just the whole ordeal was too much for him to handle. (25)</p>
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