

Supplemental Table 1. Themes, Subthemes, and Additional Quotes	
Themes/subthemes	Quotes
EXPERIENCES WITH MEDICAL CARE	
Overall experiences	
Positive	<p>But I have to honestly say, I mean most people would get second opinions on things like this, but I had a lot of confidence in Dr. X. I thought I had the best doctor.</p> <p>I've had to call a couple times to talk to the nurses and they are all incredibly supportive and kind and helpful and that just makes all the difference in the world ... when they pay attention and they listen and they answer your questions.</p> <p>... and I liked it because no one was giving me any false information as far as making me believe something, but they're being real, as a woman to a woman explaining.</p>
Negative	<p>I understood my actual coverage for visits doesn't start until September. This ... doctor told me to go to the emergency room and I knew that was not right because I would only go to the emergency room I would imagine ... if something was oozing out or some extreme pain. If I go to the emergency room, they will tell me to find a doctor.</p> <p>I [said] "Is it absolutely necessary to do this [biopsy]?" And the nurse and the doctor looked at me like I had three heads.</p> <p>So, they sent me to see Dr. X and although he may be a very good surgeon, I'm not talking about his techniques or anything, but he had a scary way of attacking the LCIS. He had pretty bad bedside manner, and he basically came out and said — even though I didn't have cancer he wanted to remove like a golf-sized ball, or have you thought about double mastectomy? And that's how it came, right like that.</p> <p>We'll take it all out and it'll be done with and you'll move on and it will all be a distant memory.</p> <p>It felt like, "This is what we [physicians] do, and you do it. And trust us."</p>
Mixed messages	<p>At first, yeah, things were kind of wishy-washy. It was like, you know, you're going to have to have mammograms every 6 months now, but the surgeon disagreed. She said, "No, I don't know where that's coming from. Everything is good. Everything looks good. Your yearly mammograms will be fine."</p> <p>Yeah. It seemed like it, you know, first I'm getting communicated that it's not cancerous. Then I'm getting communicated that ... we need to do a ... incisional biopsy to remove, to really look at it because ... with what we have now, we're really not sure. We want to make sure. But then it became more than that. Then it became, you know, removing the whole piece.</p>
Recommendations for other women	<p>They [other women] need to have a good doctor ... just so that they're explained it clearly and understand and have a plan. And can be comfortable with that.</p> <p>Be comfortable with whoever is going to be handling ... your case and your decision and just have support.</p> <p>So, first feel comfortable with your providers.</p> <p>I would always say — get a second opinion so you have more things to work off of. I'm a true believer of the second opinion now seeing how different opinions can be.</p> <p>I would probably just ... tell her to do more research on it like I did ... weigh your options. Certainly, know that this is just the beginning. It doesn't mean that we have cancer. And just ... basically do more research.</p> <p>I'd tell her not to worry.</p> <p>And try to tell people not to worry because I lead a totally normal life. Nothing to worry about, there's no reason to worry now until something happens. Hopefully nothing happens, but ... if it's something really, really bad you might want to jump into a second opinion. I would tell her to do exactly what I did. Go get it done. Have it taken care of.</p> <p>Be proactive. Don't wait. Trust your instinct. And ... be a squeaky wheel to get what you need, because, you know, it doesn't always work in the medical system and you have to be proactive and just go after what you need.</p>
DECISION-MAKING	
Preferred role in decision-making	<p>I already walked in with my plan; that I would come into X to have another mammogram ... so I did my research and told them what I wanted.</p> <p>Even though I'm a professional nurse and everything, [I] still am in the culture. I'm always deferring to ... professionals and the medical [experts] because they know better than I do.</p> <p>If they [physicians] say "Take it out," you take it out.</p> <p>I understand that there's new information that the doctors have now that especially you know in the XXX Center, have a level of trust with their decisions because you know they do a lot of research so they're the, they know the, I'm assuming they have the top knowledge of what's necessary in my case. So, they, I had to put a lot of trust in their knowledge.</p> <p>I had confidence and faith in what she was saying — "This is the protocol for this."</p> <p>If the doctor tells me — this can help, I'm in ... because as you said — I trust them.</p> <p>I feel very confident in the doctors, I feel confident in the surgery.</p> <p>That's what my doctor said, so, that's what they did.</p> <p>I'd say, "Whatever they say or do is good with me."</p> <p>But I understand the business of things [because I am a nurse]. You know if it has to be done, it has to be done ... as it was, me knowing a little bit more, I deferred [to the doctor].</p>
Decisional inputs	<p>My girlfriend ... she's actually had breast cancer. Her mom died of it, her aunt died of it, both very young. My friend ... had a double mastectomy. I talked to her a lot because she's definitely lived through it and knew.</p> <p>I had a nodule in the same area that had been there for many years. And we were keeping an eye on that ... I was concerned ... cause my dad had cancer. I just figured "Well, it could be in my genes, it could become cancerous real quick if I don't do anything about it." Why mess with my health at this point?</p> <p>What kind of other second opinion could I get except ... should I have it [atypical cells] removed or not? And that one I think is a fuzzy one. And I think it's fuzzy in medicine period. I mean, medicine is an art ... it's not just science. You know the person that thinks it's just science is fooling themselves. It's an art.</p> <p>I'm surrounded by nurses, you know? My sister-in-law, my mom is a nurse, my cousin is a nurse ... I have a few cousins who are nurses. If I have any questions I go to them.</p> <p>My father happens to be a retired physician who worked in radiation oncology so I had him as a resource. So, I was able to say — okay, what do you think and with some family history and stuff. We just made some decisions that way. I had him as my sounding board as well, an inside track.</p> <p>I have an aunt that works at the X Clinic. So, I talked to her ... I talked to her and she explained a lot of things to me.</p> <p>Somebody I work with happened to be diagnosed with DCIS, probably about the same time I was or a year or two before, and she ended up going on tamoxifen for a year, but then she developed cancer in the other breast — just swap war stories. Okay, I'm pretty lucky. And I've had friends with breast cancer.</p> <p>The surgeon, and he actually discussed tamoxifen with me at that time. And at that time, I didn't want to [take it] ... he was telling me the pros and cons, and he said, "It's really up to you." But at that time my brother hadn't had the kidney [problem], so you know, there was more things involved ... when this came up about the family tree, I was like, "Yes, let me get on the tamoxifen," because of what had happened since.</p> <p>I got a little bugged out because my mother had breast cancer.</p> <p>... and I talked to my daughters. I have one going into nursing and one that is a nurse so I would talk to them and had stuff to bounce off of them because I know they could understand.</p>
Risk-reducing medication	<p>She gave me the rundown [on tamoxifen], and I'm not really one to — I'm not on any medication for anything ... my body has very weird reactions to medications. I'm very sensitive to a lot of weird things. And it's [tamoxifen] just not something I was willing to risk.</p> <p>I had one sister who had gone on tamoxifen and she had had a number of side effects, and she was always kind of regretful that she went on it. So, I was very hesitant to go on the tamoxifen.</p> <p>That [risk-reducing medication] wasn't even mentioned really, or maybe she mentioned it, but she said she wouldn't advise anything or wouldn't have recommended anything else.</p> <p>I think about it. I'm taking a pill every day for 5 years. I'm on tamoxifen so what they tell me about that was by taking this pill for the next 5 years you can reduce the risk by up to 75 percent, so it seemed foolish to not to take it and with minimal side effects.</p> <p>I have a coworker who took tamoxifen and she was at a different stage in life and she could not deal with the hot flashes, the night sweats and all of that. She was a little bit more into the later in life and was already experiencing them and it made them worse. She stopped. She chose not to continue taking it. I hadn't experienced it yet and within two days the hot flashes were there. I didn't speak with her — someone else, another friend, and they were told they were in high risk and it would help them considerably. So I heard from one person who said she didn't like it and stopped it, and the other person I spoke to was still taking it and didn't really have a problem.</p> <p>Whatever my body does, it's a body that could continue to make those [atypical cells] and having the pill ... takes away the risk of developing cancer. So, when they identify a person like myself — she says out of 100, 30 percent have recurrence and 70 percent does not. She said — if you take the pill they can knock off 50% of those odds — it would be 15%. So now I would be 1 out of 15.</p> <p>...and it was my choice of course. It was not any pressure ... from anyone at any point in time. Yes, I had a choice.</p> <p>I guess the tamoxifen kind of scared me just because you hear the horror stories ... I'm just one not to take a lot of medication. So, I was a little concerned about that and I knew enough ...and I had confidence and faith in what she [physician] was saying — this is the protocol for this and no you don't need to go on it. I certainly get that — that I could have chosen not to.</p>
Understanding risk and benefit	<p>I think for me, and I would assume most women, would want any medical professional to be up front and honest with all your options and saying "You don't have to do this if you don't want to." And they were with me, they told me "This is the benefit, this is what's going to happen."</p> <p>There's a good chance — well, a higher chance, they didn't really give numbers — that within the next 5 years it [cancer] would show up.</p> <p>I was just "Is there any way, is it absolutely necessary to do this?" And the nurse and the doctor looked at me like I had three heads. Oh no, there was no option to say no. I mean I tried to and ... the body language, talk about body language ... well the body language said, "Why are you even asking this question?" They were trying to be respectful, but I understand because I do that too. I try to hide my face but my face says everything.</p> <p>Yeah. And I wish ... I could have been a little bit more proactive for myself. It probably could have ended up being the same decision. But ... I then could have owned the decision a little bit more. Now for me, forever, this is gonna be ... a question in my mind: Was it absolutely necessary?</p> <p>Percentage-wise? I don't think that I had a real sense that there was any grave risk. It was just a potential.</p> <p>... I understand ... with breast cancer there's so much ... that we don't know. Like I don't know how often these lobular hyperplasia blah, blah, blah develop into cancer. I don't know the risk. I didn't get that number, maybe that would have helped. You know, the chances of this ... evolving into cancer is 10 percent, 20 percent, 30, 50, 60, 70, 80.</p> <p>Just that I was at a higher risk ... a higher risk of developing ... because of my grandmother and because of what I was just diagnosed with ... and I really don't even remember that much.</p> <p>I don't think I've ever been told there is an increased risk. I think I've read that, and I think they've told me just because they're watching me so carefully, that I really ... don't have much to worry about. And she threw around a lot of numbers that, again, I didn't understand how to interpret them.</p> <p>So, they explained, it was ADH. They explained that it was cells that could become cancerous in 15 to 20 years ... that those are cells that could become cancerous in the future and, so, right now, as it is right before I started taking the tamoxifen, because of my history, because of my age and all of that, I had a 1-in-4 chance of developing breast cancer. After 5 years of being on the tamoxifen, I will have a 1-in-8 chance, which is the same as the general population.</p> <p>[It felt] Empowering. I felt good about that. I think it was presented as: "Now you can make this decision, this is your choice." I think if I hadn't made the choice that I had, there would have been a recommendation or if I had said, "What do you think I should do?" or "If you were me, what would you do? What do you recommend?" I think I would have gotten the same results because I think they would have recommended that I go with what I was doing. But it was very much presented as my choice. And that was good.</p>
MAKING SENSE OF ATYPICAL HYPERPLASIA, LCIS	
Emotional responses	<p>(Pragmatism) Yeah, I think I was surprised at first only because there was nothing in the family. We said — okay, we'll just go ahead and have this done. You have to have it done. Things don't faze me like they faze other people. Most people don't like change. I embrace change. Most people just get stagnant and I kind of roll with things. I'm just wired differently than most people.</p> <p>(Concern inevitable) Just I think the concern of will I ever get it [cancer]? You know, that's a question that's in the air — is it "if" or "when?" But I then I say, if it is to be, it will be and I'll get through it.</p> <p>(Relief) So, he kept saying, "It's pre-pre-cancer and you're lucky you got it at this stage, it's very important to know that, you know, we're not saying you have cancer."</p> <p>(Body image) Of course she's divorced, she doesn't have a man in her life. But for me with my husband, even if he didn't mind, I minded. I think it was more emotional for me.</p> <p>(Sexuality) So I had a lot to think about. It's sexual. Even talking about it right now I feel like I want to cry.</p> <p>(Fear and weight of words) It gave me pause because of those words, "precursor to cancer." That's the word nobody really wants to hear. Again, it was just a kick in the teeth.</p> <p>(Fear and weight of words) When I was first given the diagnosis my thought went straight to a double mastectomy because that's just where I went. I just remember hearing the word carcinoma ... so, it went straight there. I was at work. I wanted to cry. It's still scary.</p> <p>(Fear and weight of words) Yeah, it makes it official because I think that when someone says lumpectomy or mastectomy [it] is related to cancer. You associate those terms with cancer.</p> <p>Yeah, and it could change at any moment, so ... I'm gonna take it a day at a time. I feel like I'm dodging a bullet every time I go. I'm just dodging that bullet that I probably will end up with something just because the way my family history is and the way my female parts have been my whole life.</p> <p>Is this going to lead to something else? Is that one event connected to something that's going to come in the future? And there's no way to know that.</p> <p>What I learned, too, even more so, is to never take anything for granted.</p> <p>All in all, it just makes you more aware how precious life is each and every day. And how you really, really need to go after what it is you want and to cherish everything that you have and everything that you're going after. So, it just makes it more real.</p> <p>I value what I put into my body and I'm careful about things and I exercise [now] ... it can be taken away like that. And that's what you learn when you go through something like that, how precious life is.</p> <p>He [son] told me how scared he was that day and I was just like, "Oh, I'm so sorry." And I was like, "Would you rather me not tell you?" And he was like, "No, I want to know these things." But, as a mom, you want to protect them from that.</p>
Impact on life	<p>I felt fiery ... I kind of motivated [before diagnosis]. I'm just not where I was — I feel like ... part of me just kind of dropped off somewhere. Yeah, I felt really motivated, very energetic [before diagnosis].</p> <p>It was unsettling but, you know, I'm a Christian, so I just go with the flow.</p>
Support-seeking	<p>My sisters, like I said, I'm the oldest so if something happens to me they fall apart.</p> <p>I'm not good at asking for help. I worried so much about everybody else and how they would deal with it, like my first thought was, "Oh, my god, how do I tell my sisters this?" Or, "How do I tell my father?" And then I wallowed in some self-pity for a while, which was good for me, I needed to do that.</p> <p>I am very religious. I may not go to church as often as I do need to, but I'm very religious so I talk to God about it.</p> <p>... and my church — just knowing that people were thinking of you and praying for you in case it turned out worse than it was.</p> <p>That was my decision. I didn't talk to anybody about it. I didn't talk to my family about it. This is my body, my decision. This is just something I'm pretty firm on.</p>
Living in a gray zone	<p>This could be just me, but I don't know how to consider myself. I'm not a cancer patient, I'm not a cancer survivor. I'm a ... might-have-cancer-in-the-future person. And that's a little hard to know what to do with ... and I had this surgery ... when I talk about it, like with my friends or school or people at work or whatever, I say, like I was telling them I was coming here to meet with you, I said because of my health stuff. And I don't know what to, you know, I don't have a label for that.</p> <p>When you hear the words "Your mammogram is irregular," immediately, you go to cancer. There's nothing else in between. You go right to cancer because, you know, I've never heard of atypical ductal hyperplasia. That's not out there. All you know about is breast cancer. So the reason you have a mammogram is it's a breast cancer screening ... I mean, you automatically go to the cancer place ... and that's really stressful ... I'm not in cancer but what am I?</p> <p>I read a lovely article in the Huffington Post last week, written by this woman who had prophylactic breast ... had mastectomies, and she said she never connected to the "pink" and she said we're not celebrating my ta-tas ... once again it goes back to I didn't have chemo, I didn't lose my hair. Like all that stuff didn't happen, but it's still hard for people to really truly conceptualize how my body went through a lot and my brain did.</p> <p>Yes, because people always ask me, "So, did you have chemo or radiation?" I'm like, no, I didn't have any of that. Cause I didn't have invasive breast cancer. And people don't understand it.</p> <p>Well, they [BBWC] have these open hours where you can go and talk to someone. I don't know what they call them, like a peer counselor or something like that ... where you can go and just talk about your diagnosis and your questions and your somethings, so I thought I would start there and then see ... that they probably have a support group of some kind that I could go to, but then, you know, the people who have been diagnosed with cancer, sitting in the support group and how do I fit into that? I don't.</p> <p>I think, in a doctor's mind, this is a good diagnosis because you have an irregular mammogram ... Everybody panics, freaks out, blah, blah, blah ... you get into the doctor's office right away and ... we're all thinking, oh my god, I have cancer and I'm going to die, and the doctor's telling you, "Oh, you only have ADH" ... which is good because you don't have cancer, but I still have this thing that's really icky ... and scary and unpleasant. And although it's not cancer, it's still a yucky diagnosis. And ... that feels big.</p>
ADH, atypical ductal hyperplasia; DCIS, ductal carcinoma in situ; LCIS, lobular carcinoma in situ.	