



# What are People That Seek Care for Rotator Cuff Tendinopathy Experiencing in Their Daily Life?

Journal of Patient Experience  
Volume 9: 1-10  
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DOI: 10.1177/23743735211069811  
journals.sagepub.com/home/jpx  


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## Abstract

This qualitative study sought to answer three questions: What is it like to live with rotator cuff tendinopathy? What are the barriers and facilitators of a healthy lifestyle with an aging shoulder? And, what are the outcomes that matter most to people seeking care for rotator cuff tendinopathy? Patients diagnosed with rotator cuff tendinopathy participated in group discussions using semi-structured guides that focus on diagnosis, daily experiences living with rotator cuff tendinopathy, goals, concerns, and clinical care experiences. A hybrid of initial inductive coding of themes and subsequent deductive consideration of these themes within the capability, comfort, and calm framework was utilized. Themes associated with rotator cuff tendinopathy were less restful sleep, difficulty with work and life transitions, loss of baseline abilities, and limitation in social roles in the capability realm; physical pain, despair, and loneliness in the comfort realm; and lack of direction or progress and feeling uncared for in the calm realm. Barriers identified included: the sense that rotator cuff tendinopathy is something correctable rather than age-associated and the sense that painful activities will make the tendinopathy worse (common misconceptions); tenuous relationships and limited trust with clinicians; loss of hope; and a sense that care is directionless. What matters most to a person seeking specialty care for shoulder pain are feeling that they are getting effective care and not being dismissed; maintaining meaningful activity and life roles; and replacing despair and frustration with hope and progress. Anticipating these needs may facilitate the design of more effective care models.

**Level of Evidence:** N/A.

## Keywords

patient experience, symptoms, limitations, rotator cuff tendinopathy, shoulder pain, qualitative research, patient outcomes, experience group methodology

## Introduction

This qualitative study focuses on the daily experience of living with rotator cuff tendinopathy (RCT). When patients with a similar condition share their experience with each other in small groups (a so-called “experience group”) (1) the discussions often unearth things patients do not tell their doctor. Musculoskeletal specialists stand to benefit from this information because understanding what matters most to a person seeking care is a key aspect of a therapeutic relationship and helps ensure that care strategies work toward patient goals. Knowledge derived from qualitative research can help clinicians identify and address common gaps in care for people with RCT, informing new approaches that achieve better outcomes and experience.

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Shoulder pain is common and increases in incidence as people age. RCT is, by far, the most common reason a person with upper limb pain seeks care (2). Two different theories exist regarding the pathophysiology of RCT: 1. Expected age- and gene-related thinning of the rotator cuff tendons; and 2. Impingement of the tendon between the humerus and scapula (acromion and coracoid) with overhead activity. Current evidence favors the former (3,4).

Although some people have acute defects after an injury, most defects occur over time, unrelated to injury or activity. Most thinning and defects cause few symptoms. By age 80 more than 60% of people have rotator cuff pathology on imaging (3,5,6).

Rotator cuff defects can get large enough to limit active motion. The largest defects are associated with rotator cuff arthropathy, a form of shoulder arthritis. To date, we do not know the factors associated with an increase in defect size (3). The ability of exercises (7), injections (8), and surgery (9–11) to alleviate symptoms or change the natural history of the pathology is still open to debate (3).

The current understanding of the experience of living with RCT is primarily derived from studies that use questionnaires (patient-reported outcome measures) to quantify the illness experience. From these studies, we know that an individual's experience of this disease often does not correspond with the pathophysiology (12). For instance, tendon defects tend to enlarge slowly over time, but symptoms often resolve (13,14). New pain can cause RCT to seem like a new problem when the asymptomatic shoulder has comparable degeneration (15,16), which is consistent with the known tendency for humans to misinterpret new symptoms as representing new pathology (17). Even if the pathology is not worsening, painful movement may feel harmful as embodied in the well-studied unhelpful thoughts of kinesiphobia and catastrophic thinking, creating or reinforcing a sense of vulnerability (18). Stress, distress, and misconceptions—more so than measures of pathophysiology—are often the factors most strongly associated with variation in symptoms intensity and activity intolerance (18). These aspects of human illness often go unaddressed in patient–clinician interactions.

To better understand the experience of people seeking care for RCT, we invited people with RCT to discuss their symptoms in groups to answer the following questions: What are patient perspectives on living with RCT? What are the barriers and facilitators of a healthy lifestyle (experiencing capability, comfortable, and calm) with an aging shoulder? What are the outcomes that matter most to people seeking care for RCT?

## Methods

This study was approved by our Institutional Review Board. Experience Group sessions are a qualitative research method designed to gather insight on the health outcomes that matter most to patients who share specific medical and life circumstances and the gaps or obstacles that may impede the

achievement of those outcomes. The group sessions are designed to collect information on 3 dimensions of health: capability (ability to function and do the things that are important to the patient), comfort (reduction of physical or mental suffering), and calm (reduction of stress, chaos, and inconvenience from the process of receiving medical treatment) (19).

Each 60- to 90-min session brings together <10 people who share similar medical circumstances to have a conversation about their daily experiences living with their health condition, as well as their goals, hopes, and concerns. During the session, 2 experienced and trained male PhD facilitators encouraged participants to discuss their experiences both inside and, in particular, outside the clinical setting. This focus on lived experience fosters insight into the successes and the challenges faced in situations that are less observable by clinicians. The interviewers are not known to the participants and have little knowledge of RCT.

Each experience group session uses a semi-structured interview guide organized around specific discussion topics, which are posed to the participants as open-ended questions. This established methodology seeks to encourage conversation among the participants, including previously unarticulated issues of concern. Facilitation focuses on enabling participants to self-select the issues, experiences, and moments of importance to them. Facilitators took notes during the sessions. Each group's conversation was audio-recorded and transcribed verbatim. Participants did not review the transcripts or provide feedback on the findings.

Purposive sampling was used to recruit patients diagnosed with RCT who visited our unit within the prior year. The protocol allowed us to use billing records to identify patients and contact them. All identifiable health information was on password-protected servers. Nineteen people were contacted by phone and agreed to participate in the research. Three sessions were conducted in person, in a conference room, in English (a 5-person, 4-person, and 7-person group). Additionally, 3 people whose primary language was Spanish participated (a 2-person group and a 1-on-1 interview). No one other than the facilitators and participants was present. The mean age of the 10 women and 9 men was 54 years with a range from 31 to 75 years. Six participants identified as Latino/Hispanic, 8 as white, and 2 as black or African American, and 3 did not offer a racial or ethnic identification. One patient had prior surgery for shoulder pain. All participants were compensated with a grocery store gift card. There were no repeat interviews. After 19 people participated the facilitators agreed that data saturation had been reached with no new themes arising.

## Analysis

Interview transcripts underwent thematic coding separately by 2 researchers using NVivo (QSR International; Melbourne, Australia), a qualitative data analysis software. Throughout the coding process, themes were cross-checked

and compared for differences and similarities. After the initial round of inductive thematic coding, the data went through the second round of analysis in which we organized outcomes and insights about unmet needs and obstacles using the previously mentioned framework of capability, comfort, and calm.

## Results

### Outcome Themes

The following themes were identified in the experience of living with RCT (see Tables 1-3 for representative patient comments).

**Capability (Table 1).** One theme that emerged was a desire to get back to regular sleep patterns. RCT is known for being more painful when people are recumbent. Participants related that the condition was particularly problematic when trying to sleep.

A second theme was finding suitable work. RCT is part of the age-related bodily changes that can make it difficult to earn a living in a labor occupation after age 50. Participants talk about fears and frustrations regarding how they would support themselves and their families.

The third theme was regaining identity, both at home and at work. Participants expressed the desire to be able to do the things they perceived as core to who they were prior to the shoulder pain. People who self-identified as “construction worker,” “athlete,” or “handy person” expressed a sense of despair in the loss of flexibility, agility, strength, and comfort that can come with age in general and RCT in particular.

The fourth theme in participant comments was difficulty engaging in meaningful activities with loved ones, such as playing with grandchildren, engaging in sports, and helping with home projects. Avoidance of these activities contributed to feeling disconnected, isolated, or alone.

**Comfort (Table 1).** Two themes were placed within the comfort domain. First, many participants reported that their shoulder problem made them feel down, fatigued, hopeless, and lost. They long to get their prior energy back and want to be able to look to the future with hope.

Second, people voiced frustration with the pain associated with treatment, particularly exercises often used in treating rotator cuff disorders to strengthen the muscles of the shoulder girdle. These exercises can be painful, which may feel unhealthy. Participants reported feeling less healthy as their days were filled with more painful activities as well as the achy aftermath of those exercises. For many, the pain seems to signal a lack of progress in treatment, adding to a sense of futility and suffering.

**Calm (Table 1).** Patients with RCT seek care that has clear health goals. Clinician explanation of changes as

“age-appropriate” sounds to many participants like they are being cast aside as they grow older. Participants also reported that having their pain explained as a normal aspect of aging seems to trivialize the problem. In addition, the focus on exercises as treatment makes many individuals feel that they are being blamed for not doing enough, especially given that exercise does not yield immediate alleviation of symptoms.

Many participants reported placing hope on imaging to identify a problem that could be fixed with injection or surgery. Some participants expressed feeling neglected or mistreated if clinicians do not order imaging.

### Barriers to Health

An analysis highlighted the challenges that keep people from achieving the health outcomes they seek (Table 2). A key theme is that RCT can seem related to an event rather than an ongoing change in the body, so participants can feel frustrated with a perceived lack of recovery. Participants expressed that painful daily activities and exercises meant to help can feel like they are adding to the damage. People often feel they are not getting the attention and care they need.

### Gaps in Care

Some people with RCT said the care they received did not provide adequate support for restful sleep, practical everyday activities, and occupational transitions (Table 3).

## Discussion

Effective care is founded on an understanding of patient experience and priorities. Gathering people to talk about an illness they share can elucidate what outcomes they most desire from their care and what needs remain unmet in achieving those outcomes, directing clinical teams to potential improvements that often include better coordination and collaboration. The themes identified may not be the typical topics of discussion in musculoskeletal specialty visits: worthiness, life roles, and hope.

The decrements in health associated with RCT took the form of less restful sleep, difficulty with work and life transitions, loss of baseline abilities, and limitation in social roles in the capability realm; physical pain, despair, and loneliness in the comfort realm; and lack of direction or progress and feeling uncared for in the calm realm. Attentive specialists tend to organize care formulaically: establish the diagnosis, institute a treatment, assess, and consider another treatment. Specialists may prioritize the next set of exercises, medicines, and surgeries that can palliate or alter the natural history of the disease. The results of this study suggest that the people they treat are thinking more narratively. They are living a story—in variable degrees of pain, isolation, and despair. This suggests new approaches for teams that care

**Table 1.** Representative Quotes.

Theme	Example quotes
<i>Capability</i>	
Restoring regular sleeping patterns	<p>“One of the things that I found is that it’s hard for me to sleep. I sleep on my side, and when I try to sleep on my right side, which is where I’m injured, the pressure points are just too much. I have to move around.”</p> <p>“I totally understand the tossing and turning. It interferes with sleep. Golly, you slept for just so long and you just like, 30 min later, I can’t stand it, I got to move over.”</p> <p>“I think that probably is the biggest thing, that being unable to get a good night’s sleep. And, not being able to get a good night’s sleep, more so for women than men, I have way too much time to spend on the internet now that I’ve retired.”</p> <p>“I can’t sleep on my back, but somehow I’ve been managing it, you know, just fall asleep, I don’t know. I just like, I’d be so tired or mentally drained with this, I just go to sleep. And I told my doctor, I need something for sleep, so he gave me something for sleep, but I know once I take it, I’m going to be on my back like this, because I’m not moving.”</p> <p>“Another thing I used to do to help me sleep and kind of ease the pain before I had the surgery I’d just sit in the chair, I’d sleep in the chair.”</p>
Finding suitable work	<p>“The line of work I was in, I couldn’t use my arm, so it’s just like, I got to figure out something, you know what I’m saying? I was trying to just see if I could go to therapy and get my arm back good so I could continue to do what I was doing, but it just got to the point to where I couldn’t do nothing.”</p> <p>“So I’ve been living with it, but I was a tattoo [artist] . . . I still do tattoo work, but just lifting the tattoo machine for a little while, it gets painful. They’ve offered to give me naproxen and other medicines, but I just choose not to deal with it, not to take it. That’s just what I’m going through. It sucks, but I got to deal with it.”</p> <p>“But if I was to see a doctor that would be able to do the repairs that I need, that would be an option and I would really be thankful for that, [so] that I could move my arm again the way I used to before. I’m an auto repairman and I do a lot of lifting: quarter panels, doors, fenders, things like that. I can’t even do that anymore so that took me out of what I was doing.”</p> <p>“Just last year, I was in a lot better shape. I’m like a bull, you know, I do maintenance work with all kinds of stuff as well, and I could lift, I was the guy to go to. Now, my neighbor, he got some maintenance guy but he saw I’d still help him out, covered my rent, but they still expect me to carry the heavy loads, the big ladders, and I have to tell them, “Hey, I need some help now.” It gets a little bit depressing because before, I was like, “I’m going to help you out. Come on, let’s get it! Let’s go! Let’s do this!” But now, I’m like, ‘Hey, can you all help me out over here?’”</p>
Regaining Identity (both at home and at work)	<p>“Well, the thing is for women, there’s finding out, it has serious metabolic effect, and that simply going without sleep can make someone of a normal, healthy size 6 weight, gain 3-4 pounds a month. The three of us all need to lose some weight. We’re in a situation where we’re in pain, we’re not sleeping well, so now we got a double fight. It’s like there’s more that we have to either maintain or take off just because of the pain. And that also, I think, feeds into self-identity and whether or not you’re at all depressed.”</p> <p>“I’m 58 and I just was really shocked when they told me that [I had rotator cuff tendinopathy] . . . I didn’t realize I was that old.”</p> <p>“I just felt like, uh oh, I’m heading toward old age here. You know, [it’s] the first time I’ve had something that I might not recover from it? I might not ever get back to where I was . . .”</p> <p>“I think the worst thing for me is . . . I used to be able to work on my own vehicle, change my own oil, my own brakes. I could change my own flat. I can’t do that no more. I don’t have the strength to take off the lug nuts. It’s so painful to, first of all, jack up the car, take off your oil filter. There’s just no way. So now I’ve got to depend on someone to do that, and that’s very irritating for me.”</p> <p>“I’m a stay at home wife, but you know, I still had to clean my house, I mean, I’m working still, and I hate to ask him to do anything when he done worked 10 h a day and I’m like, babe, can you come get this down from there, you know?”</p> <p>“I am able to get around with a cart and I’m also using a cane, but I also keep on trying to keep going and moving. I just don’t want to become a [couch potato]. I don’t want to give up. I try to keep on and try to help myself, and help others at the same time. I know that right now, my situation isn’t perfect, but I believe in myself and I ask God every morning to give me strength to make my day a little better.”</p>
Engaging in meaningful activity with loved ones	<p>“My son looked at me like you can’t throw the ball, you can’t do this, you can’t do that, and then if he hit me on it [my shoulder] or anything . . . oh lord, you know what I’m saying? So that’s what made me just go on into the doctor like man, look, I want to have the surgery.”</p> <p>“I was attempting to just like, man, you know . . . I’m just going to tolerate the pain, I’m going to deal with it, we ain’t going to have no surgery. I’m going to go home. But then it’s like I can’t do nothing</p>

(continued)

**Table 1.** (continued)

Theme	Example quotes
<i>Comfort</i>	<p>with my little boy, I can't do nothing with my grandkids, it's just like all right, what you going to do? You just going to sit around and have one arm and you can't do nothing, you know what I'm saying?"</p> <p>"Like you said, with your kids, I have 6 grandkids and the youngest ones are 5 and 6, maybe 7? I can't even pick them up, play with them, run after them, or do anything because of this. And they're like, "Come on, Grandma!" I just can't do it anymore. It's painful. It's hurtful, too."</p> <p>"They didn't give me no ball thing, but they did give me exercises to do and I've got a great grand baby, she's three, and I'm like come here, let me put you and let me try to get you, you know, trying to lift. And she'll be just like no, you can't pick me up."</p>
Restoring mental health (depression)	<p>"What I was basically told when I left was, 'If it doesn't get better in 12-16 weeks let us know.' But, I'm just saying that I'm at the point when I can feel myself getting really depressed. That's happened to me twice in my life, which is kind of typical for a lot of people. But I know that spiral."</p> <p>"I dread getting up in the mornings. I have to take my shower, get dressed, this and that, and I'm like, "Oh no." I actually cry. I actually cry. And then I go about my business, I go to work and try to do as much work as possible. When I get home, I just go and sit down on that sofa, on my right side because my left side just ... And I stay with my uniform on until I get ready to go to bed because it's so frustrating having to like, ahhh. I live alone, I don't have anybody to help me with everything."</p> <p>"When you're feeling heavy and sluggish, the beginning of depression, that's that vicious spiral that you don't reach out to people and you don't get into your activities and you don't keep trying to go through it. And then that, of course, just makes it worse. You become more isolated. Fortunately, I have a lot of commitments I have to follow through with. I've been very aware of that and I've deliberately broken through that because I didn't want to go down that path again."</p>
Reducing pain associated with treatment	<p>"I think what you need to find out is, when it's hurting, is that a muscle that's healing and it's part of the building the muscle. Or, are you actually aggravating it?"</p> <p>"But with me, with therapy, it's like I can't even pick it up, I can't even do anything with it. Like to cook, to clean, sometimes my house ... Sorry, my apartment is so dirty that I can't ... It makes me more depressed and I just ... Even to start to pick up my plates or skilletts or whatever, it hurts. At nighttime, it hurts, like I said, to bathe or whatever, it hurts. Therapy didn't help at all."</p>
<i>Calm</i>	<p>"Part of it is making me, in fact, if I went in for another visit and they agreed that there's this, that and the other, at some point you start thinking, 'Is this just all in my head? Should this have gotten better by now? Is there something wrong with me? I'm not doing the exercises right.' You kind of get into that spiral. And the benefit of having had a follow-up, even if it was a nurse calling once a week for a couple weeks, or even somebody calling you back 8 weeks later and saying, "Do you feel like it's getting better?"; would for one thing, motivate me."</p> <p>"Basically, the doctor, after he had explained, and yes, I saw the video, and I thought they were very, very thorough. When I left I felt as though I had a very good understanding of what was going on and what I needed to do. I mean, I spent two hours learning exercises and getting feedback. So, I felt like I was getting a lot of attention, and then never any contact again. And I think, at that point, if I had had some follow-up from the therapist assigned to the case, and I met with her for about an hour and then I was turned over to a therapy resident, I just would have felt that I was getting some reinforcement and I could have asked some questions."</p> <p>"I asked the doctors to give me something for sleep. For real, because sitting up in a chair or doing this, but what you're saying, find a good doctor. One that don't sugar coat it, and tell you well, okay, you're going to be well in six weeks. No."</p>

for people with RCT such as allowing people to tell their story (narrative medicine (1)), empathic noticing and legitimizing (relationship building), and guiding rather than directing people to healthier ways to think, feel, and behave with this illness (motivational interviewing techniques).

The identified barriers to health among people who seek care for RCT—including cognitive bias (e.g., "hurt equals harm") contributing to misdirected hope (i.e., "I need to get the problem fixed"); tenuous relationships and limited trust; and loss of hope and direction—suggest a need for more

effective communication and care strategies. During specialty care, planned and practiced communication strategies can help people understand and accommodate RCT. It may help to explain the problem in increments, separated by time, giving people adequate time to absorb and reflect on the information that is unexpected and counterintuitive. For instance, a first visit might describe the anatomy and age-associated changes. Patients might be given something to read or watch to build their understanding and gently correct common misconceptions. If they feel ready, they

**Table 2.** Representative Quotes: Barriers to Health.

Theme	Example Quote
Depression	<p>“[when you wake up] That’s when it’s ... I mean that’s kind of sad, you know, you wake up sad.”</p> <p>“They just kept with that therapy thing, kept on giving me painkillers and muscle relaxers, things like that. I was even taking Norco. Now, I take the naproxen, that’s how much difference it’s made on myself, trying to work at it myself. But other than that, it was really tough. It was really depressing, I felt like I didn’t want to be left out from doing activity, and I still try to do my best, and I think that that has helped me but it still hasn’t made me perfect.”</p> <p>“What’s so crazy and so sad and so bad is that there are times where I just look at myself in the mirror, and I look at my scissors, and I want to cut all my hair off ... because I can’t comb my hair.”</p> <p>“I don’t know, I just really can’t sleep for a long period of time. Yes, the depression part, I can’t do nothing. I’m just laid up.”</p>
Therapy itself sometimes exacerbates pain	<p>“You’re sent to physical therapy but it just doesn’t work and makes it worse.”</p> <p>“At nighttime, it hurts, like I said, to bathe or whatever, it hurts. Therapy didn’t help at all.”</p> <p>“My primary care doctor referred me to physical therapy but that was just making it worse.”</p> <p>“Yeah, therapy just made it worse.”</p> <p>“I would tell a new patient don’t be afraid to speak up if your physical therapy is hurting you, because it may very well make it worse, so tell your providers that and they’ll escalate the issue.”</p> <p>“You’re sent to physical therapy but it just doesn’t work and makes it worse.”</p> <p>“I went to the specialist and they’re like well we’re going to take an MRI. They took the MRI and he’s like you’ve got two options, you can go to therapy or surgery. I’m like I don’t want surgery, he’s like good. Because I don’t want you to have surgery, either. He said we’re going to try therapy. So that’s when I went to therapy. And it’s like I wasn’t getting no better, and it’s like, it’s just, it was getting worse, though.”</p>
Perception of condition as an injury rather than chronic disease	<p>“I just felt, I’ve never had an injury I couldn’t recover from ... So, as far as my first thought it was just like okay, when am I going to be back to my normal self?”</p> <p>“So my decision for me not to be in surgery, it was a fact that I’m thinking that I am still young enough to recover myself. I don’t want it to offend nobody, I just—it wasn’t my own challenge because I was thinking myself, what happen this happen to me when I’m 70 or 80? What happen? How many surgeons have to work through that age?”</p> <p>“I think my fear is not to know when am I going to recover, and if I’m going to stay like this the rest of my life. Hopefully not, it’s a battle that I have myself.”</p> <p>“This lady told me, she was in her 60s, that she went to see this specialist and she never recovered. And her internal somehow happened within transiting pain anything else, so even now after four, five years after, she can even reach nothing with her right arm. So my opinion, honestly, I’m not a specialist or nothing like that, I think this should be taken care of for an orthopedic doctor up there, and also for a physical therapist.”</p>
Lack of clarity in diagnosis led to uncertainty/confusion about the disease	<p>“[The doctor] said, even though I know when it happened, that in my case, and he did not give me an MRI. I wanted an MRI, he said they only do that if they’re going to do surgery, and he didn’t do surgery unless the physical therapy doesn’t work, which is fine, I don’t want surgery. But, like you said, I Googled it, and they say they need to do an MRI to kind of know. He says I can tell you a hundred percent it’s not a tear, that it’s—he says you’re not going to like me saying this, but it’s degeneration due to age.”</p> <p>“Every visit I go they call it a different diagnosis. “You have rotator cuff tendinopathy, frozen shoulder, et cetera, et cetera.” Now, they’re just basically advocating passive rest.”</p> <p>“I guess part of me still wonders, if he had done the MRI, would he have found this massive tear and would it have changed the way that physical therapy’s going? But on the other part, he’s like, you know, they found a tear, so let’s go right up into surgery. So, I don’t really know how to precisely say how I felt.”</p>
Strained patient–clinician relationship	<p>“We can probe him for the longest time, but just in here, in this hospital, they told me about it and I left the building and they gave me a piece of rubber like this and they said 5 times per day, just take it and keep arms close to the body and do that. Kind of like, you make some inner muscles stronger if you take hold and push your arms back, like</p>

(continued)

**Table 2.** (continued)

Theme	Example Quote
Patients sometimes “manipulate” MDs to get the care they need	<p>shoulders back. They actually asked me to do this and at first, she asked me, “Lift your hand.” I lifted and said it hurt. She said, “Make this,” a thumbs-up, and all the way back. Now, I lift it and it feels okay. But it was okay only for one or three times. After that ... She said, “That’s it.” She gave me that rubber. That’s how I left for home. With rubber. Nobody discussed. I don’t even need to ask her what’s going on. I’m not born in America, and our doctors [outside the US] are more involved with you. They will kid with you, they will smile with you. It’s different when you go there and here. Here, you’re just kind of like numbers. I don’t know, I mean, they just don’t have time to explain it, they don’t want to explain. They’re waiting for your arm to fall down on the floor.”</p> <p>“For me, just knowing that people can have all kinds of injuries in car accidents, stuff like that, they will cut their legs off then will put them back. Now, people losing arms and put them back. They put a liver in you, an artificial heart. And they know that this hurts, don’t tell me that you cannot fix it. It’s, for some reason, I don’t believe it. It’s like they don’t want to do it. I don’t know why. What is the problem doing it? Because, like I said, I mean ... come on.”</p> <p>“I wasn’t even 60—I turned 60 a week or so ago, and he’s saying degeneration, you know, sounds kind of like decomposition, you know? Like I’m 85 or something, you know? Plus, I really think he’s a good doctor, my physical therapist is fantastic, but the doctor, I just thought ... does he really believe me? Does he really believe, since I so precisely felt it when I was doing ....”</p> <p>“Sometimes you have to exaggerate yourself for them to take you seriously. That’s what I’ve found with doctors over the years.”</p> <p>“They have that scale of pain from 1 to 10, they ask you that, is that right? Everybody was asked about that. It’s the first thing, like, on a scale from 1 to 10, what is the pain? And maybe I was like 3, maybe that’s the problem. Maybe you need to go there and say 8? More, like, pushing or something? I don’t know. Maybe the 3 give you that rubber, and 5 they give you maybe pain medicine, so let’s go a little bit further?”</p>
Patients do not always trust that doctors are providing necessary care	<p>“Can I ask something, I don’t know, but me, I’m on MAPS [Medical Access Program] ... You know, I was thinking, if I had Bill Gates’ money, they’d do the surgery, you know.”</p> <p>“I was thinking if I did have the money, or the medical insurance, they would do it [surgery], but I mean ... I think maybe the low income ... [effects the kind of care I receive]”</p> <p>“Like I said, I have a feeling that for some reason, they don’t have real interest to help those people. With certain problem. And I believe it is not the only one, where they kind of avoid going to the problem and solving it. It’s not money-wise for business or something, I don’t know.”</p> <p>“Participant 1: It just takes certain people with good, good insurance to take them in a lot faster than people with low income or no income.</p> <p>Participant 2: It’s harder for them to collect the money at the end when somebody’s on MAP and stuff like that. It’s hard for the hospitals and doctors to collect that. I just, this is what I hear when I talk to people.”</p>
Pain medications impede on work and social life	<p>“That medicine makes me drunk all the time. I can’t remember people’s names or what people were talking about so people give me funny looks at work.”</p>
Financial burden of disease	<p>“Basically, once you have the surgery you can’t do nothing for a whole year. You’re basically just like ... you need to work, you’ve got to find a way to work to make you some money without having to use your arm. Or you’ve just got to use your one arm.”</p>

Abbreviation: MRI, magnetic resonance imaging.

could be taught a few simple exercises to do on their own. The care needs to be warm and feel continuous. Another check-in a few days later, by phone, video, or in person, could allow people to ask questions, express emotions about what they are learning about their body, and confirm that (painful) exercises are helpful rather than further damaging. At each point of contact, the ways that people manage RCT successfully could be reviewed as the patient shows

curiosity. Based on learnings from our participants, this type of gradual, relationship-building care has the potential to ease people’s sense of frustration connected to an overall limited understanding of the condition and limited expectations for the future.

Easier access to specialty expertise via asynchronous text, email, or medical record-based communication portals, and synchronous chat, audio, or video check-ins might also

**Table 3.** Representative Quotes: Gaps in Care.

Theme: Lack of ...	Example Quote
Care that enables sleep	"I wake up every morning and feel the pain. You wake up sad. And if you wake up in the night, you're not sleeping anymore."
Timely help managing depression	"I was diagnosed in December 2018. Three words? Interferes with sleep. And, we all know that leads to depression."
Help with occupational transitions	"I'm like a bull, you know, I do maintenance work with all kinds of stuff as well, and I could lift, I was the guy to go to. Now, my neighbor, he got some maintenance guy but he saw I'd still help him out, covered my rent, but they still expect me to carry the heavy loads, the big ladders, and I have to tell them, 'Hey, I need some help now.' It gets a little bit depressing because before, I was like, 'I'm going to help you out. Come on, let's get it! Let's go! Let's do this!' But now, I'm like, 'Hey, can you all help me out over here?'"
Solutions designed for practical, everyday activities	"I can't comb my hair. I can't wash it. I can't do anything."
Follow through to result	"... the benefit of having had a follow-up, even if it was a nurse calling once a week for a couple weeks, or even somebody calling you back 8 weeks later and saying, 'Do you feel like it's getting better?', would for one thing, motivate me."
Expectations	"He [the doctor] simply told me what I told you ... that he had seen the MRI and that only 'do these exercises at home. You have to learn to live with pain'. Okay ... I was like okay."
Relationship with a clinical team	"We could tell the doctor, 'The truth will set you free!' Let me know what's going on. I really think it could be a money problem or something, but it's best to, I think, be straight up and just come on out with it and let us know our options and what we can do. I think that would be the best because they give us therapy that doesn't work, so let us know what's going on."

Abbreviation: MRI, magnetic resonance imaging.

help. Increasing the number of ways to access specialty care and making communication more convenient for patients might help them to feel more cared for. An increased number of touchpoints with clinicians might help to improve the patient–clinician relationship, and trust in particular, which is often lacking based on the experiences documented herein. This points to the opportunity for interdisciplinary, team-based care. A shoulder team member, such as a physical therapist, health coach, or social worker could be introduced at the first visit and then keep in touch with the patient regularly to support progress.

Given the prevalence of RCT, it is likely that many people manage without specialty care. For people that are searching the internet about their sore shoulder, experts can make accurate, reassuring, and hopeful information easy to find. Expert information can be crafted to facilitate the process of adjusting to an aging shoulder. One key element is to explain RCT in a way that makes it easier to reorient common misconceptions about pain. Non-specialists may share some of these misconceptions, and specialists can be more deliberate about helping non-specialists gain a more healthful understanding of the aging shoulder. Clinicians will benefit from anticipating what matters to a person seeking specialty care for their injured shoulder.

The patient–clinician relationship deserves priority, given that validating despair and frustration, correcting common misconceptions, and guiding people away from tests and treatments that are unlikely to improve health are learned skills that most surgeons have not sought or practiced. Traditional management of RCT might reinforce existing

gaps in care if surgeons and care teams assume that alleviation of pain will address all the outcomes people seek, such as restful sleep, normal daily activities, and occupational transitions. People with pain from RCT are learning how to manage their aging body. They need support, guidance, and planning to age gracefully, evolving their identity to match their body. Specialists may not be trained to address these aspects of human health. Employing other team members—such as social workers, psychologists, and physical therapists trained in techniques for guiding people to healthier thoughts—could help people feel better and do more, while allowing clinicians to focus on the things that they are trained to do, enhancing the joy in their work. Plus, as long as the team has a sufficient volume of patients, the per-patient cost is lower when the specialist's time and expertise are leveraged through team members.

Limitations of this research include our use of a group of people with the time and motivation to participate. In particular, we had relatively few Spanish speakers, so additional experience group sessions might highlight further themes. Because this is qualitative data, we cannot determine the prevalence of these themes and sentiments or their relative influence among all patients seeking care for RCT. However, while our participants' life situations might not be representative of all patients seeking care for RCT, their sentiments and experiences seem to represent common themes, as they are consistent with experience from clinical practice and evidence from other sources (3,5,7,9).

A strong patient–clinician relationship also has potential to help patients make sense of pain. As noted above,



people seeking care for RCT often misperceive their condition. A new pain may feel like an injury; a gradual onset of pain might feel like accumulating damage. The realization that pain is due to a gradual onset condition that is age-appropriate can be counterintuitive. A strong therapeutic relationship—one that includes trust, common understanding, and engagement—can help patients develop healthy thoughts (e.g., “Even though this hurts, I can get through it”), an adaptive mindset, and a supportive environment—all of which can limit symptom intensity and activity intolerance as one ages (12,20,21).

The patient perspective brings to the fore the importance of mental and social health. Formulaic biomedical approaches such as the stepladder of pills, shots, exercises, and surgery may not adequately address the despair, loss of identity, loneliness, and aimlessness that also represent health opportunities. There is experimental evidence that biomedical interventions such as corticosteroid injection and subacromial decompression may not outperform simulated injection and surgery (placebos) (8,9,22). There are also questions about the potential for benefit from surgery to address tendon thinning or small tendon defects in the rotator cuff as well as large defects with associated muscle deficiency (3). On the other hand, there is growing evidence that genuine, trusting patient–clinician relationships; connectedness, meaning and purpose in daily life; and healthy thoughts and emotions help people accommodate age, disease, and injury while reducing symptoms and limitations (the so-called placebo or meaning effect (23–25)). Understanding patients’ perspectives can inform the design of services that improve care and better achieve these aims.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.


### Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

### Ethical Approval

This study was approved by our Institutional Review Board.

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### Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with our Institutional Review Board’s (2018-04-0132) approved protocols.

### Statement of Informed Consent

Verbal informed consent was obtained from the patients for their anonymized information to be published in this article.

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