

# Defining Personas of People Living with Chronic Pain: An Ethnographic Research Study

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**Introduction:** Pain is the leading reason for which people seek medical care in the United States, and chronic pain (CP) affects approximately 50 million people in the US. Pain perception is deeply personal, is highly correlated with behavioral and emotional disorders, and is greatly influenced by physiological and environmental factors. The patient-provider relationship can have profound implications for clinical outcomes within the context of treating CP. However, limited access to pain specialists, the complex nature of many CP-causing conditions, the absence of instruments for objective pain measurement, and the need to foster a trust-based patient-provider relationship throughout treatment pose unique challenges.

**Objective:** To support a more optimal CP care delivery system that leverages a healthy therapeutic patient-provider relationship, we systematically gathered deeper knowledge of the behaviors, interpersonal dynamics, home environment, values, and mindsets of people who experience CP.

**Methods:** We employed ethnographic research methods to collect and analyze data on views, habits, strategies, attitudes, and life circumstances of a range of participants living with CP. We aggregated, analyzed, and summarized participant data to identify trends and similarities.

**Results:** Our findings suggest that patients can be broadly categorized into five predominant pain typologies, or “personas”, which are characterized by respective symptom durations, care management preferences, values, communication styles, and behaviors.

**Conclusion:** Identifying CP personas may enhance the ability to personalize CP care and help foster more robust therapeutic relationships, which may lead to greater trust, improved patient satisfaction, and better clinical outcomes.

**Keywords:** chronic pain, personas, biopsychosocial, doctor–patient relationship

## Introduction

Chronic pain (CP) is a common, potentially debilitating condition highly correlated with behavioral and emotional disorders,<sup>1</sup> with diminished quality of life,<sup>2</sup> poor health,<sup>3</sup> and decreased life expectancy.<sup>4</sup> Pain perception is a multi-faceted, highly subjective experience influenced by genetics, biology, physiology, psychology, social determinants, and more.<sup>5,6</sup> Approximately 50 million Americans report experiencing chronic pain<sup>7</sup> that impacts their quality of life, including their ability to maintain close relationships and to fully engage with their respective responsibilities.<sup>8</sup> CP is also financially expensive, costing the US an annual estimated \$635 billion (in 2010 dollars).<sup>9</sup>

The biopsychosocial model of pain dominates the scientific community’s understanding of chronic pain.<sup>10</sup> The role of provider-patient relationship in chronic pain care is less well described.<sup>11</sup> A growing body of literature highlights the manner in which the patient-provider relationship can influence patient health outcomes.<sup>12</sup> Steward et al for example, demonstrated that a physician’s awareness of a person’s physical, psychological and social ailments is positively associated with patient recovery.<sup>13</sup> Kerse et al, determined that physician-patient concordance predicted medication compliance in a primary care setting.<sup>14</sup>

For a wide range of reasons, CP care presents several unique challenges to the patient-provider relationship.<sup>11</sup> Due to factors such as underdiagnosis, doctor-patient mismatches, treatment-resistant pain, restricted mobility, limited provider availability, drug management difficulties, challenges with symptoms and the social stigma of being viewed as a “chronic pain sufferer” or “drug seeker”, patients with CP often struggle to obtain sufficient care, establish supportive patient-provider relationships, and maintain long-term compliance with lifestyle changes and treatments.<sup>15</sup> A recent meta-analysis of ethnographic research studies on the experience of living with CP revealed commonalities in several distinct conceptual categories including: a) my life is impoverished and confined; b) struggling against my body to be me; c) the quest for the diagnostic “Holy Grail”; d) lost personal credibility; e) trying to keep up appearances; f) need to be treated with dignity; and g) deciding to end the quest for the Holy Grail is not easy.<sup>16</sup>

Providers face challenges as well in the form of pressure to rush through appointments, the time required to adequately explain many CP concepts to patients, and a lack of systematic resources for supporting patients’ behavioral and lifestyle changes. Providers may also struggle to continue to offer a positive, non-judgmental care stance and may, over time, fall prey to brownout or burnout.<sup>17,18</sup>

We posit that a granular understanding of people living with CP will enable similarly granular levels of care tailored to these patients’ particular needs, goals, mindsets, and behaviors. We further assume that demonstrating a deeper understanding of patient personas could improve clinical decision-making and inform the development of a strong therapeutic relationship. Herein we gathered deeper knowledge of the behaviors, interpersonal dynamics, home environment, values, and mindsets of people who experience CP to define patient personas that can be leveraged to support more optimal CP care delivery.

# Methods

## Study Design

For this discovery-oriented, exploratory work, we employed ethnographic research methods from the discipline of user design<sup>19</sup> to develop a deeper knowledge of the behaviors, context and mindsets, phenomenological experiences and interpersonal values of people who live with CP. Specifically, we used contextual inquiry,<sup>20</sup> including direct observation (audio/visual using zoom) of participants in their natural environment, as well as diary studies.<sup>21</sup> Each participant was invited to complete two virtual interview sessions. Each session was led by a research facilitator; sessions were also attended by primary and secondary note-takers. The research facilitator used guided interview scripts to support consistency and enable comparability. The questions were designed to broadly collect information regarding participants’ motivations, values, beliefs, pain experiences, pain care teams and current or prior pain treatments. Guided interview scripts are summarized in Table 1. During the interview sessions participants were asked to show the interviewers their homes, living spaces, medicine cabinets and to demonstrate any relevant treatment routines such as home exercise space,

**Table 1** Guided Interview Script for Patients

Session 1			Session 2		
All about you	Draw your pain world	Show us the good stuff (referencing pain diary)	Figuring out what is going on with your pain	Finding new ways to get relief	Exploring new concepts and ideas (new concept cards)
Tell us about yourself	Tell us about what you have drawn	Describe your last experience seeing a pain care provider.	When did you last research your pain?	What made you decide to look for something new?	How did you rank the concept cards?
Where do you live?	Who is involved in this system?	How does your pain care provider communicate?	Do you go back to the same resources?	What kind of information are you looking for?	What is the most valuable to you?

(Continued)

**Table 1** (Continued).

Session 1			Session 2		
Tell us about your family	How did drawing this make you feel?	How do you keep track of your pain and treatments?	What is the most valuable thing you have learned?	How do you know what is trustworthy and what is not?	What is totally useless?
What do you do for a living and why?	Where do you fit into this drawing?	How did you find your current treatment team?	How often do you research your pain?	Where did you purchase your last non-prescription treatment and why?	What is missing from these concept cards?
What is your community like?	What is missing from this drawing?	How has the team changed over time?	Does anyone support you in this research? Family? Friends?	When you are looking for new treatments, what type of information is useful?	What is your top choice?
Are you involved with any religious organizations?	If you were pain free what would be different?	Do you ever combine your medications with other things?	How important is it to understand the underlying cause of your pain?	What information on new treatments makes you feel skeptical?	Is your top choice perfect?
What makes you, you?	Are there any specialists involved in your pain world?	What do you love or hate about your current treatments?	What's the most surprising thing you have learned?	Can you know me something you recently purchased that is trustworthy?	What would you change about your top choice to make it perfect?

medication routines or medical devices they use. Strict adherence to the Helsinki Declaration guidelines was followed, including obtaining informed consent from all participants, ensuring the protection of their rights and welfare throughout the study. Due to the minimal risk nature of the survey research involving human subjects, formal oversight from the ethics committee and institutional review board was deemed unnecessary.

## Participant Selection

Individuals from across the United States were sampled using internal recruitment campaigns via customer relationship management marketing emails. Interested candidate participants were prescreened using an online survey. Then, participants were further screened for qualification and inclusion by a partner agency (SHRINKWRAP<sup>®</sup>), a qualitative research consultancy.

## Participant Prescreening

Prescreening questionnaires were emailed to 5000 prospective patients from a database of people who expressed interest in receiving CP care through the online pain management platform Clearing ([www.clearing.com](http://www.clearing.com)), a telemedicine company that provides non-opioid based and non-interventional chronic pain care to individuals across the US. 62 prospective patients completed a prescreening survey. Patients with pain < 3 months in duration or with pain severity 1–3/10 were screened out, producing a sample of patients with moderate or severe pain of 57 people. All qualifying prospective participants were contacted and provided with study details including expectations, time commitment and compensation. 16 patients agreed to participate, and 12 participants were selected from the remaining pool based on demographic data such as age, gender, symptom chronicity, symptoms severity, household income and location within the USA to ensure the sample was well distributed.

## Interview Domains

Sets of interview questions were drafted within the following four domains: 1) *Motivations, values, and personal beliefs*: specifically, who the participants are in terms of their characters and how they perceive themselves. 2) *About pain experiences*: what the participants know, and believe they know, about their pain and what their relationship with pain feels like to them. 3) *About pain experts*: how the participants work with their primary care providers, pain physicians, therapists, and other specialists. 4) *About pain treatments*: the treatments the participants use. A summary of specific questions assigned to each domain are available in [Table 2](#).

**Table 2** Specific Questions for Patients Assigned to Each Topic Domain

Topic Domains	About Motivations, Values and Beliefs	About Pain Experiences	About Pain Experts	About Pain Treatments
Resources	Where do you draw strength from when things get tough?	Do you ever spend time researching your pain? What do you look for?	Who have you worked with to get relief from your pain?	Where do you find out about new things to try?
	What do you do when you are really feeling bad?	What is the most helpful information source on pain you have come across? Which is the least helpful?	When you think about a great doctor, what comes to mind?	What are the attributes of a pain treatment that make you feel excited? Skeptical?
	Is there anyone in your life who really “gets it”?	Are there any blogs, podcasts, or people on social media that you go to for insights and information?	How do you manage and track your visits and care regimen?	What does it mean for a treatment to work well?
	Who makes you laugh when it comes to your pain?	What inspires you as it related to chronic pain?	How did you find your care specialist?	What are the qualities of effective pain relievers?
	Who do you really admire and why?	What about chronic pain brings you down?	When was the last time you visited your pain care specialist, why did you go, what was the process like?	How long do you try a product before you decide it's not working?
	What matters most to you? Achieving personal goals, relationships with friends and family, passion projects, am meaningful career?	What is the most important thing for you to understand about your pain?	If you could change one thing about your care provider, what would it be?	What is your current relief regimen?
	Where do you go when you need a good laugh? A good cry?	When you are feeling bad, how do you get through the day?	What is missing from your care team now?	Is there somewhere you keep track of what you have tried or are trying now?

## Session Preparation

Participants were provided with worksheets that prompted them to relate more information regarding their personal pain narrative according to specific themes (Overview of Pain, Gaining Insights, Recovery Process, Seeking Help, and Symptom Appearance); they also answered accompanying guiding questions (summarized in [Table 3](#) and [Figure 1](#): Sample *My Pain Story* worksheet). Participants provided researchers permission to follow their public profiles on social media platforms as a means of acquiring further insight. Each participant was additionally provided with a seven-day *Pain Diary* worksheet to complete prior to the interviews. Patients documented daily decisions made due to pain; they also captured insights that they gained about their pain and any information-seeking they conducted about pain-related topics and treatments. Finally, patients were asked to write a love letter or break-up letter to their favorite or least favorite pain-related doctor, therapist, friend, or treatment. What has this person, or treatment done to be so wonderful and what about this person or treatment was so great? ([Figure 2](#)).

## Session One (90 Mins)

The goal of this session was to check in with completed homework and establish the baseline details of participants' lives, enabling researchers to learn about participants' routines, environments, and experiences

**Table 3** Sample “Draw Your Pain World” Questions

Symptoms Appearance	Seeking Help	Recovery Process	Gaining Insights	Overview of My Pain
When did your pain start?	When did you first seek help?	What are you doing today to ease your pain?	Have you been able to understand what is happening to you?	Where in your body do you feel pain now?
Where did you first feel pain?	How many doctors did you see before you got a diagnosis?	What treatments have you tried in the past?	Did you find patterns or triggers that make your pain better?	On a scale from 0–10 how severe is your pain?
Did anything trigger the pain?	How long did it take to get a diagnosis?	What has worked?	Did you find patterns or triggers that make your pain worse?	Do you feel pain all the time?
How do you remember feeling about your initial pain, emotionally?	How would you describe your relationship with your doctor?	What have you noticed about different treatment?	How is your understanding of pain now vs when you first felt it?	Does your pain radiate to another part of the body?
Was there anything you had to stop doing or start doing because of your pain?	What therapies and medications are you using for your pain?	Do you keep track of your treatments?	Have your belief shifted at all since the beginning of your journey?	What does your pain feel like? (Burning, shooting, sharp, aching etc.)
With whom did you share you experience with?	Did you ever get a diagnosis?	Have you learned anything that has help you manage your pain?	Has this experience effected your interest or pleasure in doing things?	How has the pain impacted your mental health and relationships?

with CP management. *All About You* (10 mins): Participants introduced themselves and explained broad experiences with CP. *Draw Your Pain World* (30 mins): Each participant was encouraged to visually depict their individual pain ecosystem, including significant support figures, care providers, emotions, challenges, and anything else that they considered relevant to their experiences with pain (Figure 3a); participants were also provided with the option to depict an aspirational world free of pain (Figure 3b). Participants were then asked to explain their drawings by answering specific questions about what they had drawn and why they had done so. *Show Us the Good Stuff* (30 mins): Leveraging the Love Letter exercise as a starting point, we asked participants to describe what CP treatments were currently effective for them. They also addressed their relationships with their current care providers and provided details regarding their overall care plans and ongoing treatments. Finally, participants completed a live on-camera exercise in which they showed researchers their current pain management routines and methods. *Figuring out what's going on with your pain* (30 mins): Referencing their pain diary entries, participants were asked whether there was anything about their pain that they wished they better understood. *Finding new ways to get relief* (30 mins): Again, referencing their diaries, participants were asked if they had recently heard about any new treatments that they had researched or about which they would like to know more. If they had already investigated the topic, participants were asked whether they could describe or demonstrate how they had found the information. If not, participants were asked to describe the theoretical process that they would use to learn more about a novel treatment.

## Session Two (45 Mins)

This session assessed researchers' understanding of care experiences that patients would consider optimal. During the session, participants were presented with digital cards on a virtual white board listing potential pain management features or treatments and were asked to rank these in order of perceived appeal while explaining their choices to researchers.



## EXERCISE NO 1 : MY PAIN STORY

## 04 Gaining insights →

## Guiding questions

- Have you been able to understand what is happening to you?
- Did you find patterns that make your pain better or worse?
- How is your understanding of pain now vs when you first felt it?
- Have your beliefs shifted at all since the beginning of your journey?
- Has this experience effected your interest or pleasure in doing things?

Circle any emojis that relate — draw more if you want!



I have spent countless hours Googling trying to understand what might be happening, trying to piece together my medical notes across all the disparate specialists I have seen.

I do find patterns. The things I described on previous page make it better + worse. My pain usually is low in the Am after resting w/ Tizanidine (lying on my left side with a pregnancy pillow to avoid putting pressure on right). Then the more I move and try to massage the area, the more painful it gets. Really anything that puts pressure on my right side tends to make it worse.

I have learned a TON about my pain. I have read multiple books, blogs about pain. I've listened to podcasts. I've done Curable. I still don't know what is causing my specific pain. I would pay thousands of dollars if someone could help me figure this out.

I am still staying open minded to the pain reprocessing therapy, to the idea that my pain might be caused by neuroplasticity.

However I still believe there is some physical cause of my pain, it's just been confusing to know where exactly it's coming from. I currently believe it to be coming from either my hip or my spine. If it's my hip it's likely my cam deformity (femoro-acetabular impingement) causing weird compensations and overuse of my muscles. If it's my spine it's probably a trapped nerve from a disc or arthrosis. My MRI's show the cam deformity and disc bulges.

I can't enjoy free time nearly as much as I used to.

My emotions here are often feeling like a shell of my former self.

Figure 1 Sample My Pain Story worksheet.

## EXERCISE NO 2

## Love Letter / Breakup letter

Write a short love letter to the best treatment, doctor, specialist or friend who has helped you deal with your pain.

- What have they done to be so wonderful?
- What is it about working with them or using the treatment that's so great?

Or, if a love letter is too hard to relate to, try writing a breakup letter. Think of a treatment, a specialist, a person or an event in your life that you would like to say goodbye to.

TODAY'S DATE:

CURRENT TIME:

Use this space to write down your response. Once you're done make sure to collect all the worksheets and mail them back to us.

Dear PCP's,

As a chronic pain patient, I have decided to break up with you for all of my chronic pain issues. In my heart, I gave up on you a long time ago. You didn't know a damn thing about chronic pain, you always thought chronic patients are just annoying, opioid-seeking cowards. You never made me feel like my pain was real, or worth spending any time on me. You made me feel small. You were not there for me emotionally, intellectually, or in any expected way. You are simply not present for me in my chronic pain journey, when I desperately need a quarterback the most.

When I thought things can't get any worse - I happened to be interviewing PCP's for another business I'm working on in chronic migraine. The PCP's had no idea I was a chronic pain sufferer. Multiple PCP's told me 'chronic pain patients are so annoying,' 'I hate pain patients,' 'pain patients are just too complex.'

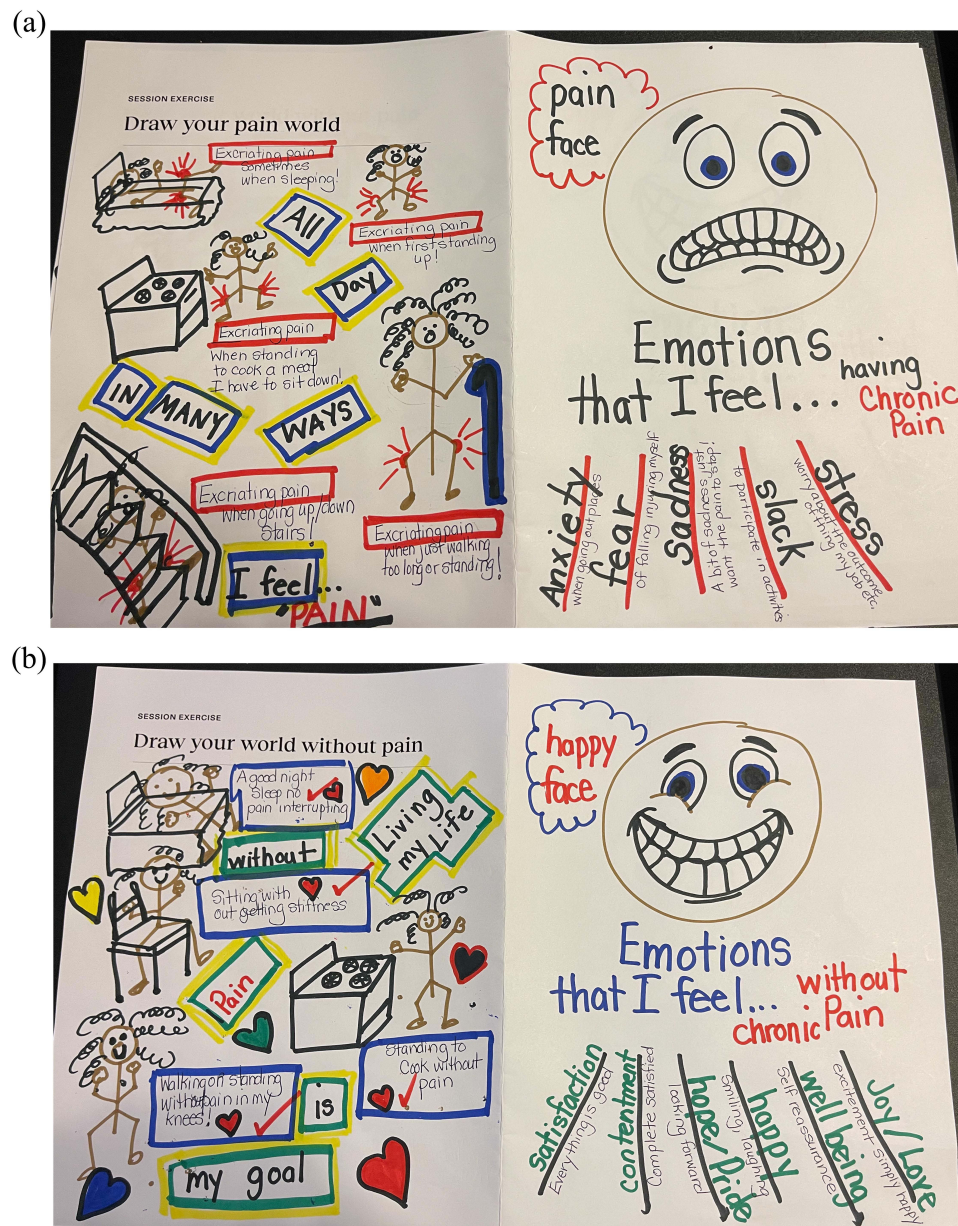
Hearing all this made me sick to my stomach. I am constantly shocked by how terrible our healthcare system is, but PCP's in chronic pain just don't get me started. My Sinai PCP just wants to run tests like a mindless robot. I tried to find someone better at One Medical. I tried to be very open-minded and saw a DO. This turned out to be even worse. I was pushed to do a chiropractic manipulation, during which the DO/PCP seemed to have no idea what she was doing. She was visibly uncomfortable and cross-checking anatomy with me, as if I the patient should know where my ASIS is. Then she started Googling it right in front of me, because she had no idea. I walked out with not a single difference made, and a \$300 surcharge on top of the bill to my insurance.

Of course I am used to going countless appointments with zero value add, and being billed \$100's of dollars for absolutely no help at all.

So I am breaking up with you. If I could put a sign up for chronic pain patients in front of your office, and/or site, I would say "chronic pain patients - WARNING. DO NOT GO HERE FOR YOUR ISSUES. COMPLETELY USELESS. YOU SUCK."

Sincerely,

Figure 2 Sample Love/Break Up Letter.



**Figure 3** Sample Draw Your Pain World exercise (a) with pain; (b) without pain.

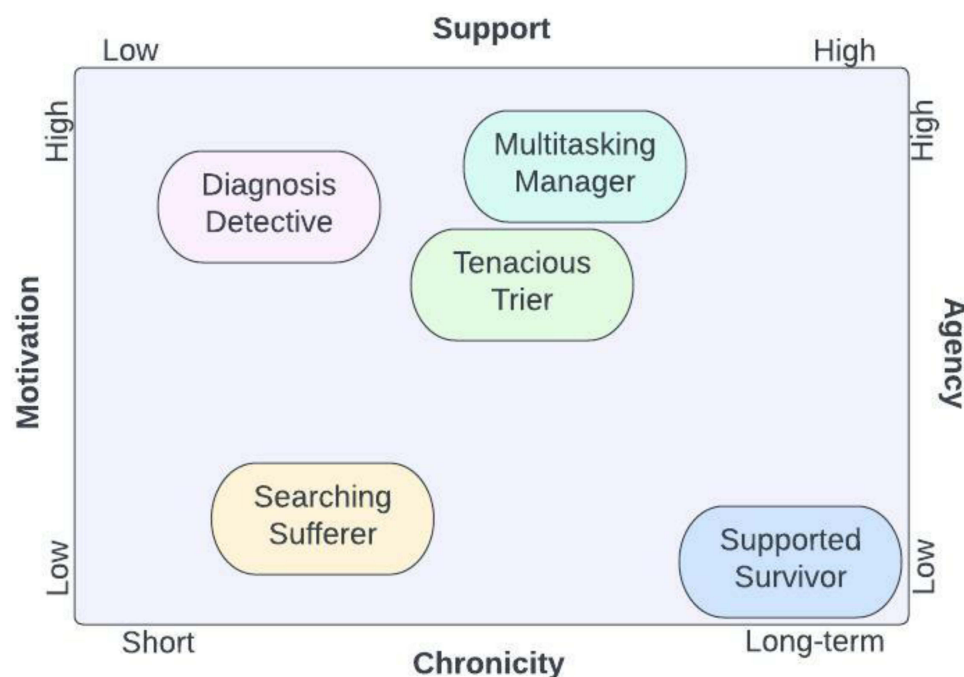
These included:

1. Online community: connect and compare notes with other CP sufferers
2. Pain prevention prompts: receive prompts on how to adjust one's routine to avoid a potential flare
3. Relief coach: an expert to answer patients' questions, work with them on treatments and listen or provide advice if they are having flare-ups
4. Relief on-the-go: pain relief therapies in which patients can engage anytime from their phones with a panic button for flare-ups
5. Mind-body connections: learn mindfulness techniques that decrease pain
6. Comprehensive treatment library: access an ever-evolving library of top pain treatments and therapies
7. Diagnosis match: enter one's symptoms and see possible diagnoses for what they may be experiencing

8. National specialist network: easily find and work with verified therapists who specialize in treating pain such as physical therapists, chiropractors, massage therapists and acupuncturists right where in one's geographic region
9. Pain history hub: everything about patients' pain in one easy to access and easy to share place
10. Access a trained pain doctor: connect with a physician who is specialty trained to treat chronic pain
11. Pain tracker: easily track everything about one's pain from triggers to treatments.

## Synthesis of Observations

Digital multimedia narrative arcs were developed utilizing *Miro Boards* (online whiteboard for visual collaboration; miro.com). Content from at pre interview homework exercises, clips and images from live interview session and images and posts from participants social media were used to portray and describe each individual participant's "pain journey", meaning their past and present experiences with pain, including patient means of seeking support, obtaining pain care, practicing long-term pain management, and developing beneficial relationships with care providers. Videos from interviews, call transcripts, and interview notes were shared, independently reviewed, and annotated by reviewers. Once all participant interview sessions were completed, reviewers met to discuss and summarize the key concepts and learnings from each individual participant's interview. Breakout sessions were conducted for smaller group discussions regarding findings for individual participants, followed by larger group discussions in which data and observations were summarized. Drivers and motivators, barriers and access to care, beliefs about physical symptoms and the healthcare system, and emotions for each participant were analyzed. Based on a synthesis of the interview sessions and materials, common themes and shared values amongst CP sufferers were extrapolated and summarized. Similarly, based on responses to questions regarding motivation and support systems, participants were individually rated by members of the research team based on motivation (low, moderate, or high), support (low, moderate, or high) and agency (low, moderate, or high). Motivation was defined as incentive and desire to heal and live pain free. Support was defined as having financial means, strong community ties, loving family members or friends and reliable healthcare systems and care professionals. Agency was defined as taking responsibility for one's life and desire to find a better outcome for oneself. High motivation,<sup>22</sup> support<sup>23</sup> and agency<sup>24</sup> are positive predictors of successful outcomes in chronic pain care. Emergent themes guided researchers in developing a series of five distinct patient personas. A visual graphical representation of the five personas based on the ratings of motivation, support and agency as a function of disease chronicity (short term and long term) was then plotted (Figure 4).



**Figure 4** Chronic pain persona's: chronicity, motivation, support, and agency.



## Results

### Recruitment

We received 62 completed prospective participant responses. Regarding pain duration, 37.1% of respondents reported having been in pain for >10 years, 30.6% for 5–10 years, 16.1% for 1–3 years, 12.9% for 3–12 months, and 3.2% for <3 months. For pain intensity rated on a 0–10 numerical rating scale (NRS), 11.3% of respondents rated their pain as 9–10/10 (“My pain is all I can think about and I can barely move or can’t move at all”), 21% as 7–8 (“I am in pain all the time and cannot do most activities. It’s difficult to listen and talk”), 62.9% as 4–6 (“I am constantly aware of my pain and I can’t do some or many activities because of it”), 4.8% as 1–3 (“I have low level pain, but I can ignore it most of the time”).

### Participant Demographics

Eleven out of twelve participants completed the exercises and interviews. The average participant age was 50.4 years (SD 12.9, range 32–72). Fifty-eight percent of the participants were female, with thirty-three percent experiencing chronic pain for 1–3 years, 33% for 5–10 years, and 33% for >10 years. The average household income was 55K (SD 32.2, range <25–150K). The average pain score was 5.63 (SD 1.48, range 4–9). Twenty-five percent did not complete high school, 25% completed high school only, 33% had a college education and 17% obtained a graduate-level education. Demographics summarized in Table 4.

### Emergent Themes

Six themes emerged as common shared values amongst the participants: 1) *Self-reliance*: having been left alone to fend for themselves, many CP sufferers have learned that they are their own best advocate for relief. 2) *Critical thinking*: the healthcare system can be overwhelming and often feels like a confusing, endless maze; patients need to learn to navigate the care system and make decisions based on medical advice they receive and their own research, even when the two are conflicting. 3) *Creativity*: CP sufferers can spend decades designing and testing their own relief regimens until they find what works for them. 4) *Determination and resilience*: Even after years of seeking treatments, and despite countless bleak medical experiences and ineffective regimens, CP sufferers often maintain hope that they can find something that will help. 5) *Generosity of spirit*: Patients have a special desire to aid other sufferers, hoping to help them avoid the mistakes and trials they have endured. 6) *Identity and authenticity*: People living with chronic pain want to feel like a person first and a CP sufferer second. They can take hard news and appreciate it when it’s delivered frankly and with authentic support.

**Table 4** Chronic Pain Persona Screening Sample

Participant Number	Age (Years)	Income	Pain Chronicity (Years)	Severity NRS (0–10)	Gender (M/F)	Location (State)
1	35	\$26–49k	5–10	7–8	M	Mississippi
2	40	\$50–99k	>10	4–6	M	Texas
3	59	\$26–49k	1–3	4–6	F	North Carolina
4	32	\$100–149k	1–3	4–6	F	New York
5	57	\$50–99k	5–10	4–6	F	Florida
6	47	\$26–49k	>10	4–6	M	California
7	59	<\$25k	>10	4–6	M	New York
8	72	\$50–99k	>10	9–10	F	California
9	59	<\$25K	1–3	4–6	F	Florida
10	58	<\$25k	5–10	N/A	F	Florida
11	37	\$50–99k	1–3	4–6	F	California

*Personas:* In conjunction with extracting emergent themes, we also developed patient personas, fictional character types that represent the goals and behaviors of participants within our sample, based on our observational and ethnographic data. Participant assessments for motivation, agency and support system were plotted as a function of average chronicity of symptoms (Short 1–3 years, Intermediate 5–10 years, Long-term >10 years; [Figure 4](#)). The following five personas or typologies of CP sufferers emerged.

## Diagnosis Detectives

These patients possess high motivation, high agency, low support, and short symptom duration. Diagnosis Detectives are determined to find and fix the source of their pain. Almost everyone is a Diagnosis Detective at some point in their journey with chronic pain. The diagnosis is held up as a turning point: “Once I get the right diagnosis, I can start getting the right treatment and get better”. Unfortunately, chronic pain-causing conditions can be difficult to diagnose and are often multifactorial (not necessarily causal), leading Diagnosis Detectives down dead-ends at best and to damaging treatments at worst. Diagnosis Detectives feel lost and left alone to understand and treat themselves. Diagnosis Detectives rank a pain history hub and pain tracking as the most interesting new concepts worth exploring. Of participants, 9.1% were categorized as Diagnosis Detectives.

## Searching Sufferers

These patients have low motivation, low agency, low support, and short/intermediate symptom duration. Searching Sufferers exist almost outside of the care system, lacking clear information or resources to achieve relief. Their educational backgrounds are often limited, which restricts their access to information, making it challenging to determine what is worth trying and what is not, so they often opt for naturopathic or over-the-counter treatments. Despite reporting the worst pain compared to the other groups, they are comparatively doing the least to get better. Searching Sufferers rank health coaching, access to pain physicians and online community as the most interesting new concepts worth exploring. 9.1% of participants were categorized as Searching Sufferers.

## Multitasking Managers

These patients exhibit high motivation, high agency, moderate/high support, and intermediate/long-term symptom duration. Multitasking Managers have typically spent years cobbling together an effective relief regimen on their own. They have given up on the healthcare industry providing them with support, and only visit physicians to get what they have already decided they need. Outside of a few good care providers who have helped them, they are deeply resentful of the “healthcare industrial complex”, which they feel has often caused them more harm than good. Multitasking Managers rank mind-body connections and a comprehensive treatment library as concepts most worth exploring. 18.2% of participants were categorized as Multitasking Managers.

## Tenacious Triers

Tenacious Triers have moderate/high motivation, moderate/high agency, moderate/high support, and intermediate symptom duration. They often possess more clarity regarding why they are experiencing pain compared to the other groups. Tenacious Triers have been living with CP long enough to have identified some treatments that work and some that do not, but still feel like they have yet to crack the code on relief. Emotionally, Tenacious Triers have moved past some of the denial of Diagnosis Detectives but have yet to reach the sense of acceptance of Multitasking Managers. Tenacious Triers can be among the pain patients most at risk for hopelessness, distress, and psychological challenges. They still question whether what they are doing is the best possible path forward, or are unhappy with some aspect of their care. Tenacious Triers rank mind-body strategies and health coaching as the most interesting concepts worth exploring. 27.3% of participants were categorized as Tenacious Triers.

## Supported Survivors

They possess low motivation, low agency, high support, and long-term symptom duration. Supported Survivors have access to good care and a sense of having assembled what they need to feel adequately supported. Supported Survivors

are confident in their belief of what is causing their pain and have accepted pain as part of their life. They are also working within a care system and with a care team that feels supportive to them. While they experience many of the same frustrations of the other personas, they are not as angry about their condition or as mistrustful of the healthcare system. Supported Survivors rank a pain history hub and national specialist network as the most interesting concepts worth exploring. 36.3% of participants were categorized as Supported Survivors.

## Discussion

Tools that support a beneficial patient-provider relationship can be extremely useful in clinical practice and burgeoning evidence in the literature highlights how this relationship can enhance resilience for people living with CP.<sup>25</sup> The use of patient personas in CP care could help providers demonstrate that they empathize with patients and endorse the crucial importance of listening to patients' CP-related experiences.<sup>26</sup> Using CP personas also promotes more granular, relevant treatments and fosters a more informed patient-provider relationship. In a qualitative study involving CP patients, participants highlighted three aspects of the patient-provider relationship that enabled them to maintain their well-being: a) facilitating patient empowerment, b) promoting health literacy, and c) providing psychological support.<sup>25</sup> Similarly, a qualitative survey of 2898 patients with CP showed that considerable improvements in pain intensity and quality of life were observed in patients who perceived their providers as highly empathic, reinforcing the idea that a positive patient-physician relationship characterized by empathy has a positive influence on CP outcomes.<sup>27</sup> Due to the stressful nature of CP and to the added burden of common comorbid conditions such as anxiety or depression,<sup>28,29</sup> patients may also struggle with their mood and motivation.

Countering these factors, CP sufferers who: a) resist catastrophizing and other negative cognitive patterns;<sup>30</sup> b) demonstrate psychological resilience;<sup>31</sup> c) possess adequate social support;<sup>23</sup> d) employ advantageous coping strategies;<sup>32</sup> e) follow lifestyle medicine recommendations;<sup>33</sup> f) manage stress levels;<sup>34</sup> g) have access to Cognitive Behavioral Therapy (CBT) or Acceptance and Commitment Therapy (ACT);<sup>35</sup> h) are willing to combine multiple pain-management tactics;<sup>36</sup> i) encounter supportive clinical spaces;<sup>11</sup> and j) locate providers who offer empathic listening and actively work to build trustworthy relationships with their patients are more likely to realize better overall outcomes.<sup>11</sup>

The personas we have identified could aid providers in connecting more efficiently and effectively with patients to promote these factors. For example, when encountering a Diagnosis Detective persona, the provider can suspect that front loading diagnosis-related information will best satisfy the patient while also helping the patient feel supported with self-identified needs. The provider can be assured that the Diagnosis Detective's high degrees of motivation and agency will aid in treatment compliance, particularly if the patient receives adequate holistic support.

Patients who fit the persona of a Searching Sufferer may feel they have already been failed by the health care system and/or by others in their lives who they hoped would provide more support. Expressions of empathy, hopefulness, understanding, and support are therefore crucial for foundational trust-building. Additional calls, check-ins, information, and referral to health coaching services, pain psychology, social work, or other means of support could help keep a Searching Sufferer focused on successful treatment and increase adherence.

To forge a helpful patient-provider bond with a Multitasking Manager, the provider may want to explicitly recognize these patients' drive to solve their own problems. Multitasking Managers desire to have their efforts acknowledged and be actively enlisted in care-related decisions. The provider, therefore, should be proactive about soliciting input from a Multitasking Manager while also remaining attentive to these patients' willingness to trust their own intuition.

Rapid support for treatments that have worked previously for Tenacious Triers is recommended, as well as consistent expectation-setting. This can be paired with explicit recognition of these patients' desire and drive to improve, along with referrals for additional mental support services, if needed. Tenacious Triers may appreciate physician-initiated discussions or information regarding new treatments for CP, along with check-ins about any current treatments, their effectiveness, and what could and should be replaced.

Given the typically long periods of time Supported Survivors have been dealing with CP, they are in some ways seasoned veterans, well versed in the navigation and management of their pain and the healthcare systems at large. They have also come to terms with a life of CP and are looking for ways to optimize their condition. Thus, a provider is well-served to continue the types of treatments that have already yielded success in the past while also demonstrating support

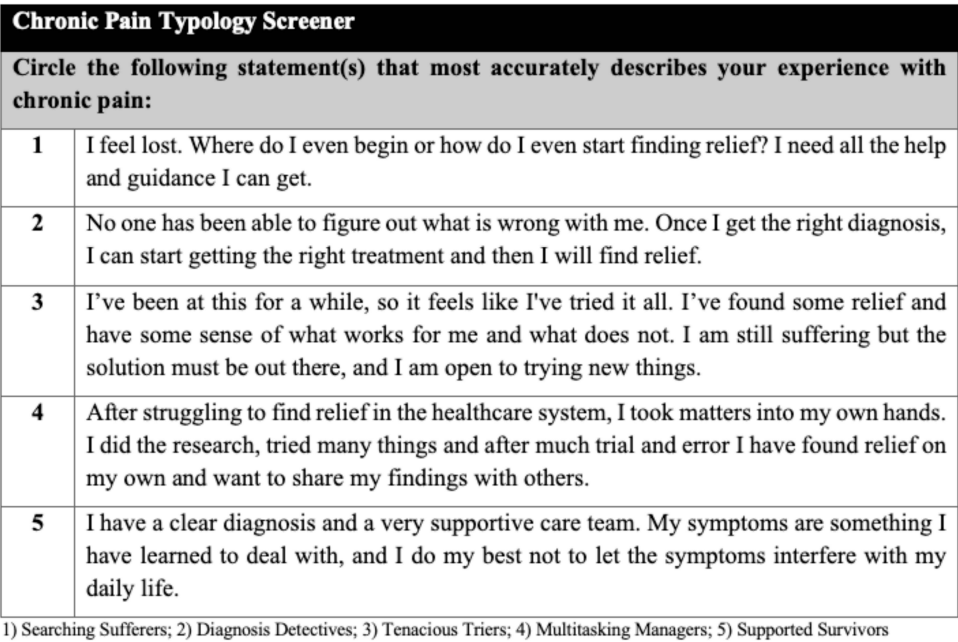


Figure 5 Chronic pain persona screening tool.

and trustworthiness when attempting new treatments. Treatments that improve quality of life (and are not focused solely on pain eradication) are likely to be welcomed by these patients.

Information regarding a patient’s pain persona may be established using a brief, unvalidated screening tool that we plan to validate in the future. We have preliminarily proposed the early form of this measure (Figure 5). By leveraging the insights permitted by CP patient persona development, clinicians can more efficiently address many of the barriers to sufficient CP care. By potentially expediting and facilitating treatment and trust-building, the use of a personas screener as a tool and/or using personas-based guidance for clinical conduct could result in healthcare cost savings while also enabling similar or perhaps even more effective health care overall and improved provider job satisfaction.

The observational, exploratory nature of this study involves several limitations. First, the sample size was relatively small, although this is typical of qualitative analyses. However, this type of research design will hopefully provide important information that will facilitate future quantitative analysis. Other limitations concern the study’s aims, as these observations were designed to aid understanding of general patient concerns and were exploratory and discovery-oriented rather than hypothesis-based. Furthermore, the guided interview questions were not validated, although we anticipate that this will be done in our future studies. Finally, our conclusions suggest further avenues of exploration and applicability more than they prescribe discrete courses of clinical action, which was our goal in initiating this seminal project.

Conclusion

Using a screening tool we developed (Figure 5), clinicians may demonstrate a deeper knowledge and respect for patient priorities and needs. This knowledge and respect, we propose, could result in improved patient-provider relationships and more optimal patient outcomes. The use of patient personas, in turn, could help providers demonstrate that they empathize with patients and endorse the crucial importance of listening to patients’ CP-related experiences. Using CP personas also promotes more granular, relevant treatments and fosters a more informed patient-provider relationship. This information is applicable in both in-person and virtual clinical settings, and could enhance the patient-provider relationship, thus enabling the quality of trust needed for effective long-term management and treatment of CP (particularly for treatment-resistant cases). The personas offer, at a minimum, a promising starting point upon which to ground initial patient-provider interactions. Further research is required to validate this screening tool and to determine whether these personas aid the development of



tailored CP care delivered in-person or within a telehealth setting. It will also be beneficial to conduct studies that examine how the use of patient personas impacts clinical outcomes, patient-provider trust, and patient satisfaction.

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