APPRECIATIVE INQUIRY: CHRONIC PAIN

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What is appreciative inquiry?

• Process to elicit experiences where participants had a positive outcome; in this case overcoming (functioning with?) chronic pain
• Focus is on successes instead of doing problem-solving
• Facilitators asks “What works?”
• Attempting to “make the random the usual”
• People sharing stories in individual interviews or small groups
Process and Team

• Overall team – two groups: 2040 Partners for Health and High Plains Research Network with UCD investigators
• Various groups sought out participants who had CP; invited them for interviews
• Doreen, Jodi, Don, Mary completed interviews with participants
• Doreen, Jodi, Mary and Matt – “coded” the transcripts and created categories to capture the essence of the responses and created summary tables
• Doreen, Jodi, Mary; entire group – discussed the coded data and determined main themes from the stories
Data collection summary

- Means of eliciting AI: the successes
  - 22 individual interviews; two in one together
- Total of 24 stories
- Took place in coffee shops, libraries, conference rooms, people’s homes
- All eager to talk and share their experience
Stories Represented

• Ages spanned from young adult to senior (25-77)
• 4 males, 20 females
• Variety of underlying conditions/incidents: car accidents, overuse injury, migraine, arthritis, fibromyalgia, Crohns, general pain unspecified
• Variety of pain locations: back, head, neck, knee, arm
• Variety of treatments discussed
• Stories told from perspective of self
Our Caveats or Cautions

• This only represents the stories told to us
• Some storytellers are better than others at expressing their story and the elements of success
• As qualitative analysts we struggle with the right words to describe this intimate, emotional experience
• Transcripts are only the words; some of us could see the pain while in the presence of interviewees
Common elements of stories (although rarely universal)

- CP is ongoing and in most cases not totally resolved. It is ‘chronic.’
- Pain has waves where it gets worse and better
- Many reached a point where they made a mental switch to working with (agreeing to have?) treatments or digging in to making their life functional
Some findings: the early part of the pain experience

The role of anxiety or depression -
• Common in the throes of the most serious pain
• Feeling out of control
• Some crying, why me?
• Tension between resiliency “get on with it”/ “be in control” and despair in moments of pain
“I remember looking out into the darkness out the window thinking - is anybody else up in the world feeling what I’m feeling, and how do I…and sitting in the tub at 3 am. It was always 3 am… and like how do I just get out of this body? Where can I go? I’m trapped. It’s a very um [sighs] it’s just very hard.” P21
“Yeah it was kind of the depression. I mean I think you really have to come to terms with yourself and your life. I mean because being a mother I couldn’t live my life in bed, and that’s where I was at that point, and you know like you were saying though the stressors of life, how am I going to support my family? How am I going to do this? How am I going to do that? How do I function from here because your whole life has been changed.” P16
What is “success?”

• There ARE limitations on people’s lives due to pain, but seldom debilitating; several people quit work
ELEMENTS OF SUCCESS
Getting at AI: What works?

• Answers vary for everyone; instead of a single one

• Those with underlying condition that could be resolved — getting treatment still important

• Others with ongoing issues — combination of the following: prevention/expectations management, dealing with it (mental approach or perspective), ways to deal with acute episode (meds, exercise, compresses, etc.)
Finding options that work

- Adaptability and change instead of “trial and error”
- Process of seeking options – medical almost always, but also sometimes alternative or complementary treatments (or ‘right’ medical)
- Process of educating oneself
- Sense-making
- Seeking what works for the individual, what is less successful and what doesn’t - when
“No I think you know that’s…anything that works for anyone. You have to try. You have to try everything, and believe, and have an open mind because if you don’t have an open mind, it won’t work. You know and always believe that things work out. You know maybe not how you planned, but even in the most stressful, horrible situation things can work out you know.” P2
“I: It’s not like there was one magic bullet. It was kind of like this little bit helped, and this little bit helped, so that you’re kind of in a better place but it wasn’t like one major, does that seem right or no?” P: “Yeah things kind of just built on each other and progressed to where it is now. I can see it progressing even [laughing] more in the future.” P7
“Nobody knows your body better than you do. These doctors are always practicing medicine. Key word: practicing. They don’t know. They can’t feel what you’re going through. I felt like I had to push it. I knew something was wrong. I knew my body was telling me other things. I knew who I was before in comparison to what I was becoming and have become since.” P4
Remedies, treatments vary

• Kind of like having tools in the tool box
• Possible “buckets”
  • Dealing with acute pain episodes,
  • preventing future pain episodes and
  • dealing with the overall/underlying issue
• Responding to changes
“This has been a life-long thing. You know and the medications have done a lot of damage, so I just thank God I am where I’m at because now with all the other damage because of medication and illness I can’t imagine having to deal with myself now [laughter]. You know without all these tools you know. It’s like having a tool bag.” P2
“Exercising, hot baths, getting rid of red meat…taking the medication. I would recommend Turmeric or ginger tea.” P3

“I do still have headaches pretty much every day. I think it’s just being able to have like a label to it and know how to adjust my environment to accommodate my headaches and make them a little bit better. That helps. I mean I made it through school, and I do things that I want to do.” P7
An array of helpful choices

- Medical procedure (injections, surgeries, patches, etc.),
- Over the counter medications (i.e. ibuprofen),
- CP meds,
- Physical therapy and exercise (formal PT plus water therapy, exercise, yoga),
- Prayer/meditation/relaxation,
- Alternative (chiropractic, not as much - acupuncture, herbals, marijuana),
- Self-care (dietary, compresses, gels).
“…so far as my healing I think the aquatic pool has been the most effective for this kind of injury.” P19

“…the thing that helped the most was this specialized chiropractor, but I mean I have done lots of…or just going to like different exercise classes.” P20

“I was going through physical therapy and that was really helping, I was feeling much better.” P24

“I haven’t had any of the major pain type things like I did have when I was working, because I haven’t been working. Fortunately I haven’t fallen down, slipped on the ice or something.” P24
Averse to medications

- Tendency for outright opinion/reaction at the onset about pain meds
- Several actively avoided CP meds, did not want to be controlled by it or get addicted
- Some CP meds just didn’t work as folks wanted them to work - so they were not inclined to take them regularly
- Some had to use CP meds – pain so severe they have/had to take them
“I’m not a pill person. I really don’t like medication. I don’t like pills, but if it’s extreme where it’s been so bad sometimes I will take the Ibuprofen. That seems the only thing that kind of helps.” P5

“I want to be in full control…I can’t imagine being on something and trying to make decisions that might you know hinder things, driving, or watching my grandkids.” P5
“I don’t like a lot of chemical stuff in my body. I prefer natural remedies.” P8

“I might have taken a few pain pills, but I think they scared me a couple of years ago when they said you need to take a pain pill because some of those pain pills will prevent inflammation, and will let you know you are sick. Because if I cover up…and that’s my argument was if I take the pain pill then I don’t know something’s wrong with me [laughing].” P13
“Yeah after the surgery. Yeah and I mean I didn’t really like that either, mainly because that stuff stops you up. You know you get constipated.” P14

“It was because I was afraid. I didn’t want to put this stuff in my… I call it like shooting up [laughing]…this stuff in my body that…because there are side effects, and like there’s some lymphomas that could form later.” P21
Facilitating relationships

• Some stories feature others
• Good doctors who facilitate finding the cause of the problem and truly listen/believe the patient are golden gems (my terms)
• Family a source of inspiration for getting on with it; especially children and grandchildren
• Spouses or partners sometimes a significant source of support
• Support group important for some
“Yeah and then she also doesn’t...she goes to medications more as a last resort, and I think she does that because she knows that’s kind of my own values too, and she listens to me in that regard too, and she always asks me what I think or my own opinions on what she’s saying or whatever. I really like that a lot.”
“My PCP just was a marvelous human being, and we just had conversations when I’d see him. I trusted him, and he knew that I would tell him every detail, …I think it’s really important to be comfortable with the person who is helping you be in charge of your body, and thus your pain. You have to be comfortable with that person because you have to be honest, totally honest, in order to get their best professional opinion, because they can’t read your mind. They don’t know your pain. No one knows your pain like you know your pain, and you have to be in a situation where you feel comfortable expressing it, and just tell them the absolute whole truth.” P8
“Deal with it” – “Be You”

- Perhaps the word is resilience
  - Developed through experience or have it to start?
- Predominant mental approach about the pain; this was more evident in those who had occasional or controllable pain
- Define selves instead of or defined or controlled by pain
- Divert attention; focus on something else
- Pray, sleep, engage in other activities, etc.
- Have “attitude of gratitude”
“The mind is something that’s amazing. It can get you through almost anything if you use the power of your mind over matter, which the pain was the matter, and I had to concur that through my mind, took meditation, lots of reading.” P15
“Everybody’s pain is different. Everybody’s activities are different, so you know there’s really not a whole lot that you can…you know of course your support system. You know a higher power. Acceptance within yourself, and you have to be able to accept yourself because no one’s every going to understand what you’re going through. You know don’t stop living your life. You have to just keep pushing.” P16
“I guess I’d say really just try to ignore it. I mean, you really don’t ignore it, but just to put it as far back as I can and try to focus on something else. Maybe get involved in a bit of reading or something.” P24
“I think it’s important for us to hold onto our dreams. It’s important for us to never lose sight of who we were before we became the injured person we were, and know that’s there’s always a new beginning for you. There’s always hope. There’s always change. You can never give up.”

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Boot Camp Translation
MANAGING CHRONIC PAIN

Mapping out a successful journey
CaReNet PAC