

Original Article

“What Gives your Life Meaning?” A Thematic Analysis to Provide Context for Advance Care Planning

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Abstract

Background: Reluctance to talk about death creates barriers during the stages of advance care planning. In order to explore end of life conversations, novel approaches to understanding the complexity of humans and what each person identifies as quality of life are needed.

Objective This study explores themes found amongst notes posted in a clinical setting when enquired, “What Gives Your Life Meaning?” to inform end of life conversations.

Subjects/Methods: Thematic content analysis of images and text expressions. Analysis of a pre-existing dataset from participants who chose to respond when asked what gave their life meaning; 2455 entries were collected representing 3592 basic meaning units.

Results: 29 themes reflecting main patterns of relating. 88 connections found within the patterns of relating. Connections within themes of family (n= 916), people (n= 546), spirituality (n=472) and love (n=201) formed over 80% of the responses.

Conclusions: Responses provided context on how to approach advance care planning. Equipped with this new knowledge, the clinician can guide the person to reflect on topics such as friends, family, spirituality, and love when encouraging introspection needed for advance care planning. Further suggestions for research include how to quantify the impact of these discussions on improved advance care planning.

Key words: advance care planning, end of life, values, qualitative

Background

Advance Care Planning (ACP) results in various benefits for the patient including less aggressive care at the end of life (EOL) (Mack et al., 2012), decreased use of life-sustaining therapies (Brinkman-Stoppelenburg, Rietjens, Heide, 2014), greater concordance with preferred and prescribed care (You et al., 2014), end of life wishes being

more likely to be known and followed and improved overall EOL care (Detering et al., 2010). These advantages also affect the surrogate decision maker with reports of less anxiety, depression, post-traumatic distress and stress (Song et al., 2015; Tamayo-Velázquez et al., 2010). Sound ACP implementation has economic implications as well. Avoiding unwanted acute care services through

ACP creates cost efficiencies in care (*Dying in America*: Institute of Medicine, 2015).

There exist clinical tools (VitalTalk, 2016), online resources (Litzelman et al. 2017), stimulating games, protocols for more serious conversations such as breaking bad news (MD Anderson Cancer Center, 2016) and research devoted to life review, reminiscence therapy and biographical work which demonstrate ample benefits (Aarons, Hurlburt, Horwitz, 2011; Zuiderveen et al., 2010; Tamura-Lis, 2017). Despite these efforts and tools, major gaps in executing ACP remain. Clinicians need to become more proficient initiating ACP conversations. This study provides novel context to the exploration phase (Aarons, Hurlburt, Horwitz, 2011) of ACP, investigating the philosophical construct of “what gives your life meaning” and specifically explores people’s values and priorities.

A thorough literature review to gauge different approaches aimed at providing context to ACP conversations revealed a dearth of literature. The data used for this research came from a project aimed to help the organization’s employees look at ACP and end of life conversations in a positive light, modeled after the California State University, San Marcos’ What Gives Your Life Meaning Campaign (Hamil et al., 2019)

With the Institute of Healthcare Improvement’s White Paper in mind (McCutcheon Adams et al., 2015) the hope was that these conversations would lead to more staff completing their own advance directives (Madani et al, 2018) with a subsequent ripple effect into the organization and community. During that process, over 3,000 entries were posted on public boards by families, patients, and staff about what gives their own life meaning and collected at the completion of the campaign. We used this pre-existing data to explore which themes would be identified that could provide knowledge and context to ACP.

Theoretical framework

A central purpose of ACP is to provide patient-centered care. To do so, it is important to know what people value most regarding end-of-life care and quality of life (The Regency Foundation/ National Journal, 2011). Focusing on quality of life is congruent with the primary goal of nursing in Rosemary Parse’s Human Becoming Theory.

According to Parse, the human is an open, freely choosing co-participant in the universe (Parse, 1992). The co-creating relationship between the human and the universe contributes to an evolving individual whose values give meaning to life. Using the nomenclature of Parse’s model, the diversity of *themes* which were identified represented “patterns of relating” within which *subthemes* noted as “connections” were identified.

Methodology

Study design: This study employed thematic analysis of texts and images written in answer to the question “What Gives Your Life Meaning”™. Thematic analysis is “a method for identifying, analyzing, and reporting patterns (themes) within data” (Braun and Clarke, 2008, para.8). We deployed the phases of familiarizing with data, generating initial features, searching for themes, defining and naming themes, and producing the report as described by Braun and Clarke (2008). Initially, the researchers became familiar with the data by becoming immersed in it and speaking about it aloud. Subsequent analysis developed subthemes (which came to be known as connections). Later sessions allowed for selection of compelling examples.

Sample description and inclusion criteria: This is an analysis of a pre-existing dataset from a quality improvement project from February to April of 2017 where volunteers posted a note to one of the seven posters in a health system with the following query, “What Gives Your Life Meaning?” There was not an inclusion or exclusion criteria. Anyone passing the poster boards who chose to respond could do so. These authors then confirmed with the institution’s Institutional Review Board that the project was research that did not require human subject’s oversight.

Sample size and Location of Study: 2455 post-it notes were collected from poster boards placed at two of the hospital’s cafeterias and each of their seven clinics. After dividing entries into individual themes, and completing the final grouping session, the number grew to 3592 responses. There was no contact between any subjects and researchers. Beginning in October 2018, an average of 3 research assistants met with the PI and mentors for each round of data coding to *be with* the data, identify patterns, discuss what the data was presenting, count and cut samples, and take notes.

During a six-month period consisting of eight 3-hour review sessions in which there was concurrent checking between team members to assure that the data being coded correlated with the identified theme. The process of sorting the subthemes, or connections, served as quality control because each categorized basic meaning unit on a post-it note was reviewed by another researcher, and discrepancies were discussed as a team and corrected. In each round of analysis and coding, the team obtained a sense of the data as a whole by reading the responses several times. After each session, the PI added to his personal research diary. During later sessions, responses viewed as noteworthy, those having a special characteristic or would epitomize a pattern of relating or connection were separated and photographed or written about in the field log for reporting.

Results

Through time spent with the data, deep parallels surfaced between what participants chose to scribe as giving meaning to their lives and Parse's perspectives on the human. Using Parse's theory as a framework in reviewing the data, parallels were

drawn between the open and co-creating nature of humans. The interconnectedness of these samples echoed in Parse's emphasis that human beings "live their health incarnating personal values which are each individual's connectedness with the universe."²⁰

Major themes called patterns of relating were identified within which subcategories called connections were named. Eighty-eight connections were found within the 29 main patterns of relating. The most significant pattern of relating was *family* (n=916) followed by *names* (n=546) and *spirituality/religion* (n=472). *Names* includes specific names of people such as Margaret whereas *people* included nonspecific persons such as 'me,' 'you' or 'doctors.' Of the 10 most significant patterns, the need for human- *human connection* made up the 1st, 2nd, 4th and 6th highest counts. There were a number of patterns of relating which analysts often split (common responses on same post-it note) such as *spirituality /religion* and *family, love* and *family, spirituality/religion* and *love, names* and *love*.

Figure 1: Patterns of Relating, Connections, and their occurrences.

Patterns of Relating	Connections	Samples
Food		113
Sex		26
Material Possessions		38
	Money	9
	Autos / Motorcycles	10
	Books	4
	Phone	4
	House	2
Health/Life		130
	Life	34
	Health or Healthy Living	39
Work		50
	Healthcare Work	9
	UCSD Work	9
	Success	7
	(Other Work)	7

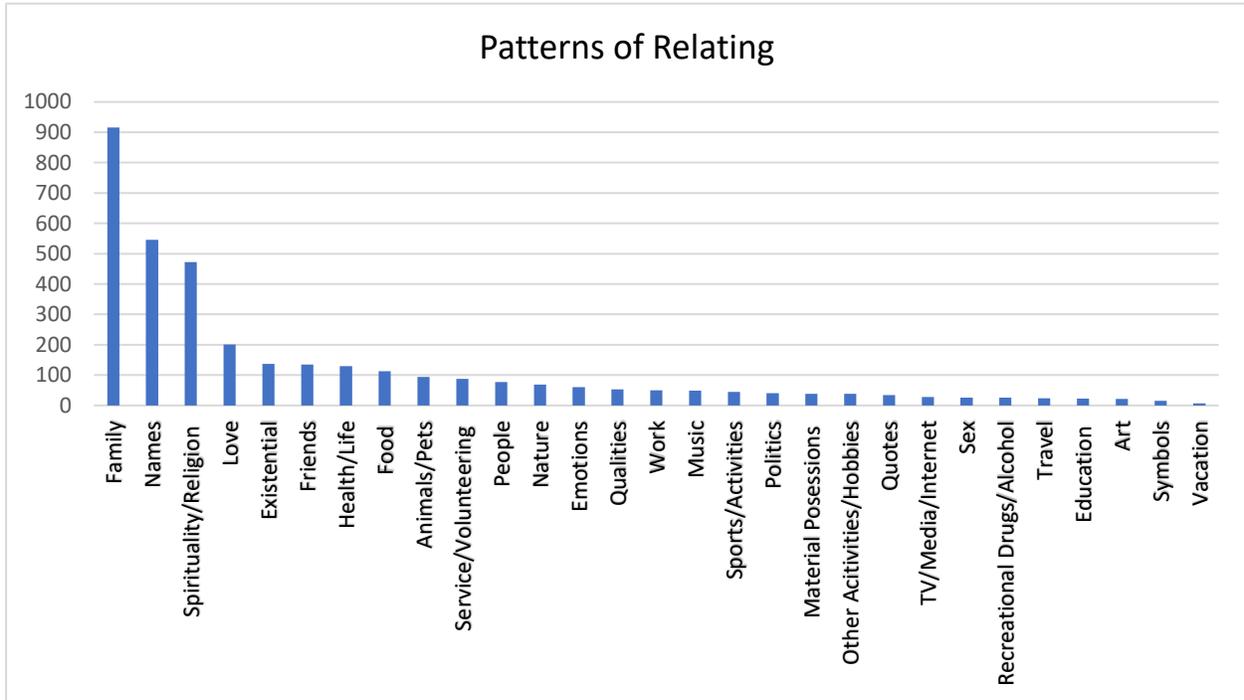
	Work	4
	My Job	4
	My Work	4
	Goals	4
	Retire	2
Family		916
	"Family"/ "My Family"	504
	Children/Kids	172
	Husband/Wife	87
	Parents	84
	Grandchildren	40
	(Others)	13
	Brother/Sister	9
	Grandparents	7
Names		546
Friends		135
	"Friends" 101	104
	Adjective preceding "Friend"	14
	Relationships	5
	Specific Friends Named	4
	Friendship	4
	Fellowship	3
	Friendship Quotes	2
	Neighborhood/ Community	1
	Best Friend	1
People		77
	Me	18
	You	17
	"Doctors"	9
	Boyfriend/Girlfriend	3
Love		201
	Generic Love	106
Animals/Pets		94
	Dogs	58
	Cats	14
Nature		69
	"Nature"	20
	Sun (sets, rise, days)	19
	Ocean/beach	7

	Earth	4
	The Environment	3
Emotions		60
	Laughter/Smiling	25
	Happy	14
	Joy	10
	Negative	3
Sports/Activities		45
	Sports	21
	Sports Teams	6
	Dance	7
Education		23
	Disciplines	13
	(includes 6 science)	6
	Teaching	5
	Learning	4
	School Names	4
	Knowledge	1
Existential		137
	Hope	36
TV/Media/Internet		28
Service/Volunteering		88
	Helping	36
	Service	13
	Making a Difference	12
	Caring	7
	Volunteering	9
	Making Others Happy /Smile	4
	(Others)	4
	Encouraging /Inspiring 2	2
Music		49
	"Music"	27
	Types of Music	9
	Names of Musicians	11
Other Activities/Hobbies		38
Quotes		34
Travel		24
Vacation		7

Art		22
	"Art"	13
Spirituality/Religion		472
	God	201
	Jesus	108
	Faith	45
	Religious Sayings	39
	Multiple Religious Concepts	17
	Pslam	12
	(Other)	12
	Jehovah	9
	Prayer	7
	Spiritual	6
	Allah	5
	Church	4
	Father in Heaven	3
Politics		41
	Trump/President	14
	Political Issues	10
	Freedom	7
	My Country	4
	Respect for People/Diversity of ideas	4
Qualities		53
	Kindness	12
	Compassion	6
	(Others including grateful, courage, empathy)	35
Recreational Drugs/Alcohol		26
Symbols		15

“What gives your life meaning?” A thematic analysis to provide context for advance care planning: Figure 2

Figure 2: Patterns of Relating Histogram



“What gives your life meaning?” A thematic analysis to provide context for advance care planning: Figure 3

Figure 3: Patterns of Relating and Connections Treemap

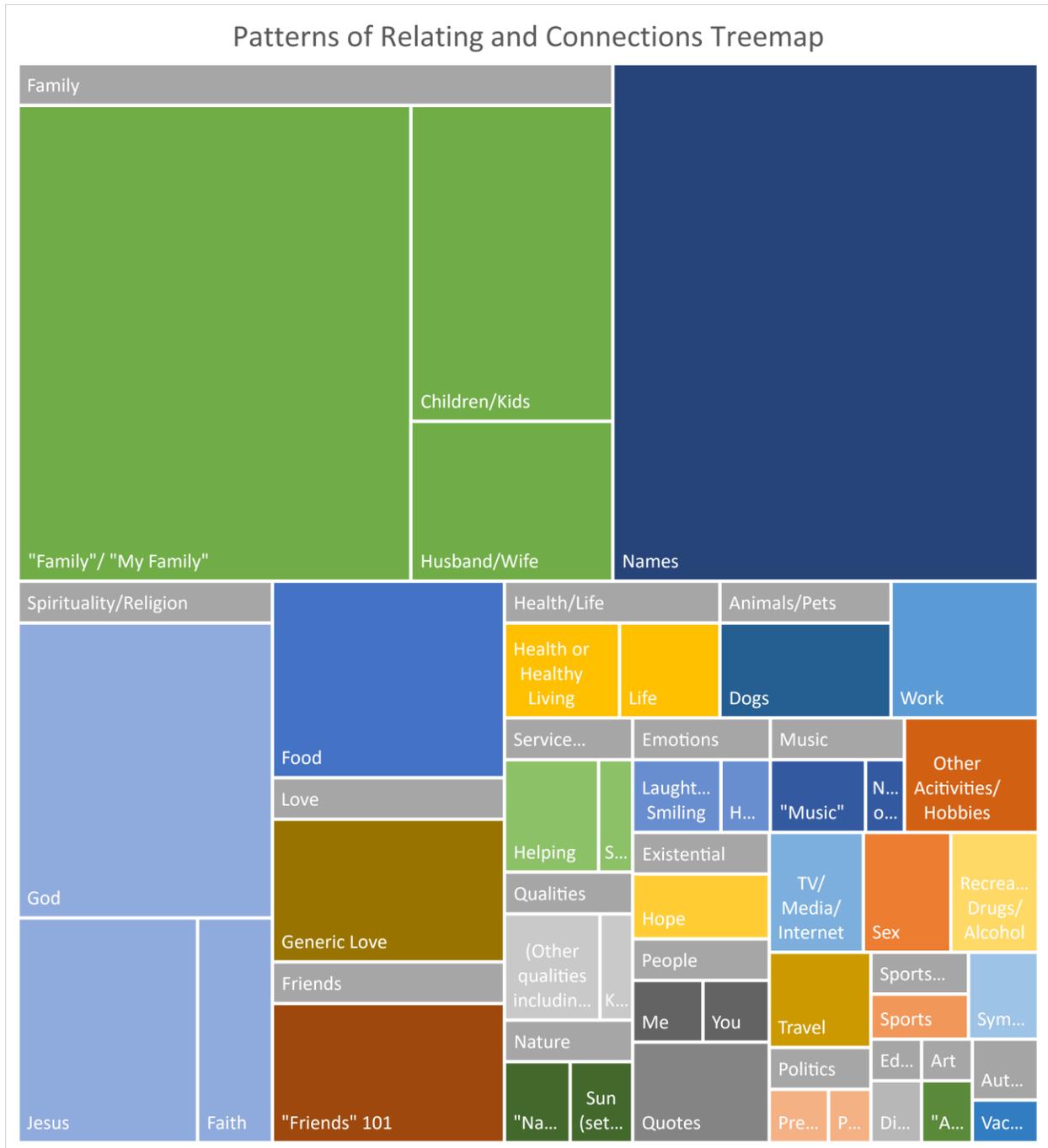


Figure Legends:

- Patterns of Relating Legend:**
- Food
 - Sex
 - Material Possessions
 - Health/Life
 - Work
 - Family
 - Names
 - Friends
 - People
 - Love
 - Animals/Pets
 - Nature
 - Emotions
 - Sports/Activities
 - Education
 - Existential
 - TV/Media/Internet
 - Service/Volunteering
 - Music
 - Other Activities/Hobbies
 - Quotes
 - Art
 - Qualities
 - Travel
 - Spirituality/Religion
 - Recreational Drugs/Alcohol
 - Vacation
 - Politics
 - Symbols

- Connections Legend:**
- Autos/Motorcycles
 - Me
 - Happy
 - Life
 - You
 - Sports
 - Health or Healthy Living
 - Generic Love
 - Disciplines
 - “Family”/ “My Family”
 - Dogs
 - Hope
 - Children/Kids
 - “Nature”
 - Helping
 - Husband/Wife
 - Sun (sets, rise, days)
 - “Music”
 - “Friends”
 - Laughter/Smiling
 - Names of Musicians
 - “Art”
 - God
 - Jesus
 - Faith
 - President
 - Political Issues
 - Kindness
 - (Other qualities including grateful, courage, empathy)

**“What gives your life meaning?” A thematic analysis to provide context for advance care planning:
Image 1**

Image 1: Review Session



“What gives your life meaning?” A thematic analysis to provide context for advance care planning: Image 3

Image 3: Symbols/ Images Post-It Notes Board



Discussion

Clinicians often do not feel prepared or empowered to discuss ACP directly (VitalTalk, 2016). This information provides context to initiate ACP conversations. Understanding the patterns of relating revealed in this study, clinicians can ask questions to better grasp a person's values, personhood, dreams, goals, fears, worries, and aspirations.

Framing goals of care conversations with these revealed patterns of relating may enable clinicians to overcome barriers of discomfort with discussions surrounding the topic of death (Martin and Koesel, 2010).

The patient's answer to the simple question, “what gives your life meaning” may provide clinicians with important information to frame ACP conversations in a personalized and non-intimidating manner. Initiating the introspection needed is the beginning of the exploratory phase of

advance care planning (Aarons, Hurlburt, Horwitz, 2011). Given what we have found, clinicians will need to be open to exploring comments such as “Harley Davidson,” understanding this might be a life goal to take one last motorcycle trip. After guiding the introspection that produces personalized answers, next steps can inspire actions. If sunshine and nature are valued most, the healthcare priority becomes orchestrating time outside.

This research also provides knowledge for clinicians in navigating goals of care conversations. Similar to life reviews that can lead to finding meaning and improved quality of life (Wren, 2016) speaking in terms of patterns of relating and connections may help reveal a person’s values and priorities. Helping a person consider the possibility of *not* being able to do what brings their life meaning can help reveal what a person can’t live without. Introspection of this nature near death may bring the sense of completion needed to accept the reality of dying.

Strengths and weaknesses/ limitations of the study

Having a diverse group of researchers from different ages, education levels, and ethnic backgrounds made it easier to decode responses. Answering a personal question with anonymity may have helped decrease response bias. It is unknown exactly how many people posted the responses because it is possible that one person posted more than one post-it. In retrospect, an additional piece of data would have been obtainable if we counted how many times the research team split individual responses.

What This Study Adds

The suitability of Parse’s label of ‘patterns of relating’ instead of ‘themes’ is demonstrated by the fact that the three largest counts (*family, names, and spirituality/religion*) demonstrate the human *need for connection*. This affinity of human nature was again noticed with the patterns of relating of *love, friends, animals/pets, service/volunteering, people, nature, work, sports/activities, qualities* and *sex* which signified the 4th, 6th, 9th, 10th, 11th, 12th, 14th and 15th, highest counts respectively. These findings correlate with studies that show most Americans want to die at home (Song et al., 2015) where it can

be presumed, they are surrounded by a connection to the familiar.

The human need for connection validates the human science foundation of Parse’s theory which focuses on the human being’s participative experience in the world (Parse, 1992). Our inability to separate ourselves from our existence and nature with the universe are demonstrated in the proximity in counts between the cognitive *existential* (137) and creature comforts-*food* (113). Such a data point is relevant when clinicians bridge persons’ knowledge gaps regarding death and the decisions they will need to make regarding artificial hydration or nutrition. Yet humans still choose the intangibles that make us the complex creatures we are, valuing *emotions* (60) over *material possessions* (38). Unlike our results, end of life studies cite being pain free a top priority for most (Meier et al., 2016). Given our findings it is possible that the choice to be lucid to feel emotions and interact with those who bring life meaning may instead be what some prefer. Clarifying these trade-offs during ACP conversations is important.

The dynamic inseparable view of humans living in multidimensional realms where we ascribe meaning to situations (Parse, 1992) resonates in the more surprising patterns of relating. These include *qualities* (53), *politics* (41), *television/social media/internet* (28), *recreational drugs/alcohol* (26), and *symbols* (15). In order to deliver care that is patient-centered,²⁴ time and space need to be created in order to learn these values which provide insight into the person being cared for or coached through advance care planning.

Reviewing the patterns of relating can provide insights into which items may constitute quality of life. Assessing the most frequent patterns of relating; *family, names, spirituality, and love*, one can signal these areas of foci for reflection and how they may relate to a person’s quality of life. The ability to be connected with family and specific people is not surprising, given what is known surrounding phenomena such as the widowhood effect takotsubo cardiomyopathy, aka ‘broken-heart syndrome’ (Shepard, 2015).

For many people, spirituality and religion bring purpose to life and are practiced through prayer, fasting, rituals, ceremonies, blessings, worship, baptism, congregation attendance, anointing,

dancing, singing, celebrations, chanting, and sacrifices (Swihart and Martin, 2019). People who avoid hospitalizations, who are not worried, who pray or meditate, who are visited by a pastor, and who feel a therapeutic alliance with their physicians have the highest quality of life at EOL (Zhang et al., 2012). With this information we can engage our patients to ponder what *dying well* looks like. Incorporating the family, specific people that bring life meaning (*names*), spirituality and opportunities to express and feel love in their final days is a unique and personalized approach.

The complexity of human nature cannot be underestimated as it relates to the *existential* pattern of relating. Responses such as “finding my purpose,” “living in sweet moments,” “the pursuit of truth like all truth,” “hope which is my worst enemy,” and simply “to dream” convey that as similar as we are, we are multifaceted creatures. The *existential* category revealed many philosophical views. The fact that the existential pattern of relating accounted for the 5th largest pattern of relating may connote that ACP should be done in advance, without the trauma of illness burdening the mind. Moreover, the philosophical presence noted in the responses could inspire clinicians to understand that these conversations are deep and can sometimes surface uncomfortable feelings. These findings support efforts to provide EOL communication training to clinicians (Tamayo-Velázquez et al., 2010; VitalTalk, 2016; Litzelman et al. 2017; (MD Anderson Cancer Center, 2016).

Some connections were not surprising due to contextual features. The connection to *nature* could be expected given the region’s proximity to the beach, mountains and desert. Sunny days and the ocean were commented on often; “being outside,” “sunsets” “warm weather,” and “Earth.” Given that the post-its were collected in a medical center was noticeable with many responses surrounding health and healthcare; “A good INR number”, “My husband’s lungs. Thank You UCSD for giving my husband a new lease on life,” “The nurses who help us,” “When I see my sick brother happy after a hyperbaric oxygen treatment,” and “Doctors who listen more than merely hear.” The term ‘doctors’ occurred 9 times and another 6 were named.

It should be noted that this project occurred shortly after the 2016 presidential election which was observable in the responses. Within the pattern of relating, *politics* were the connections of: *political issues* (10), *freedom* (7), *my country* (6), *respect for diversity* and *political views* (3). Issues of the day were reflected such as human rights, funding for education, support of military, the president, and a national healthcare plan, signaling that political issues impact the wellbeing, social psyche and value system of individuals deeply.

In earlier sessions analysts wrestled with whether hope should be classified as an emotion but as the theme *existentialism* was identified, the decision was made that it fit with other responses in that pattern of relating. The connection of *qualities* was identified as a theme out of *existentialism*. Almost all emotions were positive. There was a wide range of emotions, examples ranging from silliness to serenity to passion. *Emotions* were often interpersonal in nature, giving or sharing laughter, giving or receiving joy. The emotion was generated by activities with more than one person. Having laughter.

Items noted to represent health or its absence were both placed in health; “salud, salud, salud, salud” (health, health, health health), “being sober” and “please don’t kill me” (a lack of health). Medicine was also placed in the health pattern of relating.; “massage chair and motrin keep the body going” and “antineoplastics.”

Since human’s systems of ‘knowing’, ‘values’ and ‘meaning’ are in a fluid state relative to their experiences, the need for ACP is an ongoing process. This was demonstrated in differences in stages of life from my wife and new daughter born here 3/23/17” to “my ex wife I’m free now to do as I please”. As well as displayed in all ages; from a child’s scribbles: “helping my mom get through cancer” to the grandfather who wrote, “My Grandson ...he’s a jerk but I don’t know how I would keep going without him.” The range of human experience was also expressed from “helping humanity” to “nothing” followed by a sad face. A vast array of diversity from responses such as “Faith in Allah” to a post-it with a lipstick kiss imprint.

About the process: Researchers found this work to be a beautiful experience. Being with the data was

uplifting work as the vast majority of responses conveyed a universal positivity. The thread of humanity could be seen throughout the post-it quilt; “Coaching science to kids,” “Giving voice to the voiceless” “helping my mom get through her cancer (heart)” and “The journey of mother-parent. Watching my children grow, learn, love, thrive in friendships and relationships. They are such wonderful adults. Thanks be to God.” The researchers found this process to emulate Parse’s third principle, “Co-transcending with the possible is powering unique ways of originating in the process of transforming” (Parse, 1992, para.14). There was constant sharing aloud with many laughs and reactions to the vivid, raw emotions that were captured. The analysis and engagement between researchers led to moments where different perspectives were shared, ideas were challenged, and dialogue energized the birth of new concepts.

Implications: Much like the identified patterns of relating which began on one post-it note but needed to be split, a clinician understands that each human’s way of living is like that of others and still quite different. The fact that 29 patterns of relating were identified reveal the connectedness of life, yet the vast diversity in responses within each pattern illustrates that each individual’s values are as unique as their fingerprint. This commonality demonstrates Parse’s belief that clinicians must practice true presence by “being with” in a way that the clinician bears witness to the person’s own living of priorities. To achieve this connection the clinician needs to aid the person in going deep within themselves (Parse, 1992). In practicing this skill we can inspire the introspection that is needed before prioritization, reflection, and meaningful conversations needed for ACP. It is recommended that clinicians are given appropriate cultural awareness and ACP education and training, and appropriate staffing to make these moments possible. Patterns of relating and connections were identified in the themes and subthemes. However, we posit that data saturation would likely be impossible due to the dynamic, evolving nature of humans. It would be possible that expanding the study to others would reveal additional ways in which people find meaning in life.

Conclusions: In order to guide humans through ACP, deep introspection and respect for individuality as well as relationships is necessary.

Future research is needed to understand best practices in providing holistic care that takes into account human individuality.

Recommendations for further research: The uniqueness of every response coupled with the fact that *family* and *names* account for the highest number of responses warrants further exploration and discussion surrounding the importance of ACP in relation to neurocognitive and neurodegenerative diseases. If an individual can no longer recognize his or her family or the people who bring their life meaning, perhaps such conditions deserve earlier attention in the course of care. Research is needed to translate these findings into interventions tested to identify best practices.

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