DOCUMENTATION BOOK
STUDIO C

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SCENE SUMMARY: THE MOMENT OF TRANSITION

At what moment does someone decide “enough is enough” when it comes to the aggressive medical treatment of a terminal disease? When does the doctor determine that the patient has “six months or less” to live, making them eligible for hospice? When/how does the doctor tell the patient that? Where do the facts get muddled by each stakeholder’s individual desires (to prolong life, to remain optimistic, to help...)? How is this choice influenced by the apparent hierarchies of services, where social recognition and value is given to rescue effort, and hospice or palliative could be perceived by patients and their families as abandonment? What structures are in place to support the patient and their families in the evaluation of the situation, and the existential and emotional needs of those facing a situation where “battling the disease” seems more and more like a lost war?

After three chemotherapy treatments, 34 year old Sara sits in an office with her doctor, her husband and her parents. A friend looks after their newly born child at home. The first two treatments of chemotherapy already failed. Sara’s CT scan shows that the last one has been unsuccessful as well. The tumor depots have grown substantially. The doctor and the family sit together to discuss what to do. There is another drug they could try, though only a small percentage of people had experienced extended life upon taking it, and that extension was only an average of two months.

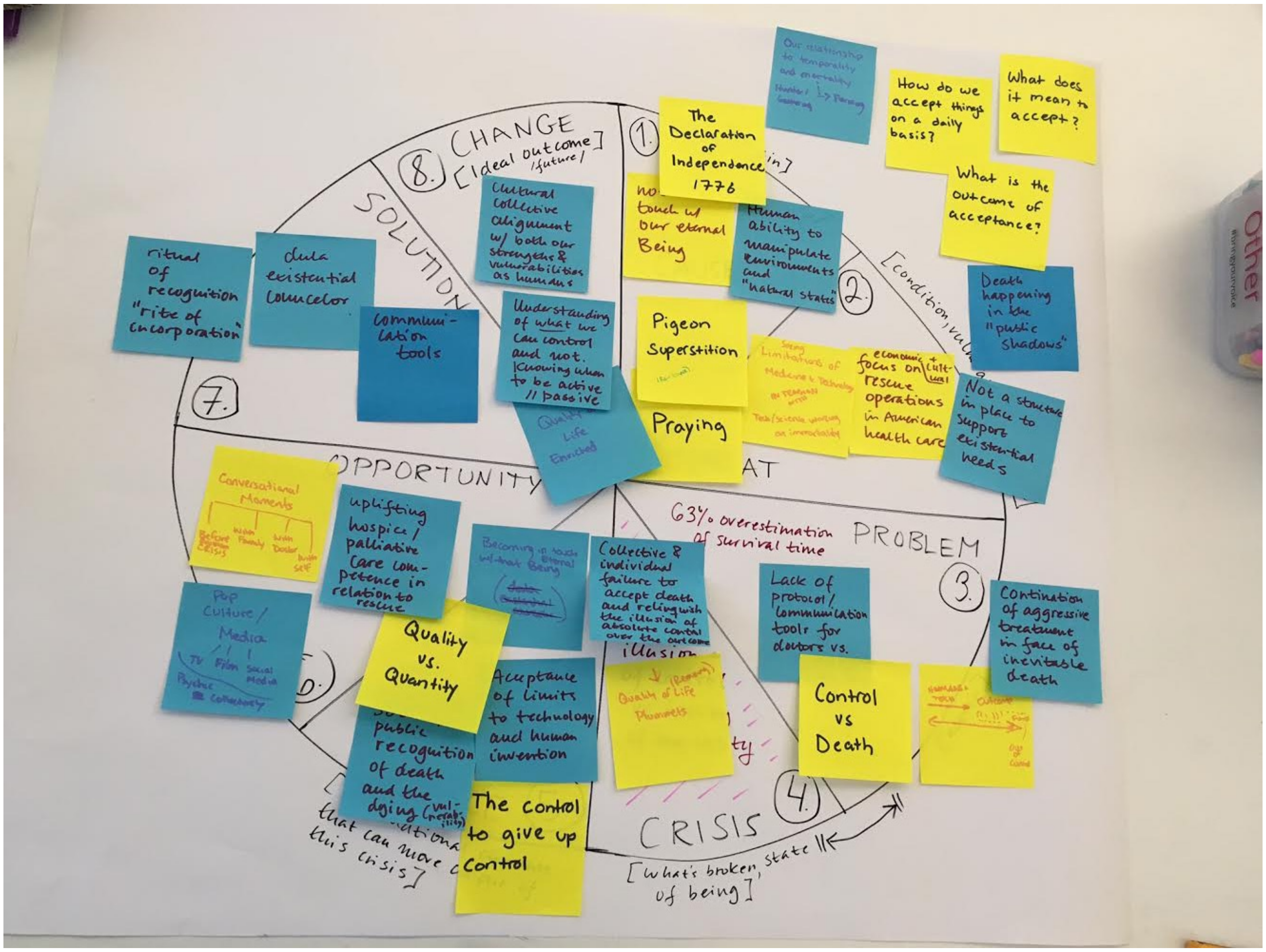
This scene explores the complications, multiple hierarchies, miscommunication, emotions, desires and conflicts that arise in the conversation about how to move forward. Family input, doctor discomfort and influence, the newly born child, Sara’s personal connection/investment to each stakeholder--and to her own desire to live--all emerge as interwoven, weighted factors as they collectively work towards a decision and an approach to a situation that provides little hope for much time left.

General themes and topics to explore through the scene

Life-saving = strength
Death = giving up
Dying = vulnerability = weakness
Overestimation of survival time 63%, doctors more comfortable with discussing a fantasy

Need to belong to a larger societal community
Disposal/lack of worth of unproductive members of society
The mindset of the patient and their family towards death and dying
Tools of communication
When there is nothing left to do - the transition (how are they meeting the needs?)
Hierarchy of power rescue operations vs “soft care”
Existential needs and care
Hope vs time
Attention = good care?

WHEEL OF REASONING



Cause ***(deeper origin)***:

- Human ability to manipulate our environments
- Settling into agrarian societies
- Pigeon Superstition: Rain Dance / Praying
- The declaration of independence
- Not in touch with Eternal Being
- Ego's attachment to personal identity

Threat ***(conditions or vulnerabilities that set the stage for the problem to arise):***

- Seeing limitations of Medicine +Technology IN TENSION WITH Tech/ Science working on immortality
- Economic and cultural focus on rescue operations in American health care

- No structure in place to support existential needs
- Death happening in the “public shadows”

Problem ***(moments of failure, problematic mindsets, what results in crisis)***:

- “63% overestimation of survival time”
- Lack of protocol / communication tools for doctors vs. patients
- Control vs Death
- The illusion of control vs. the reality of mortality
- Continuation of aggressive treatment in face of inevitable death
- Collective and individual failure to accept death and relinquish the illusion of absolute control over the outcome.

Crisis ***(the result of the problem, what is broken, the consequence)***:

- Quality of remaining life plummets
- Not getting the chance to die in peace: Sara dies in the hospital after a chaotic ambulance trip
- Family suffers from more intense depression and anxiety after Sara’s death this way
- Moral weight and uncertainty in doctor - patient communication / difficulty connecting as two humans as opposed to patient / doctor

Source ***(foundational elements that can move us out of the crisis)***:

- Quality vs. Quantity
- Temporality: does “accepting death” / giving up give you chances of actually living longer?
- The control to give up control
- Social / public recognition of death and the dying (vulnerability)
- Becoming in touch with the Eternal Being
- Letting go of ego attachment
- Acceptance of limits of technology and human intervention

Opportunity ***(conditions that could set the stage for a solution, places for solutions to occur)***:

- Conversational moments
- Before problem/ crisis
- With family

- With doctor
- With self
- Uplifting hospice/ palliative care, relocation of economic resources
- Media
- TV
- Film
- Social Media
- Advertising
- Culture
- Arts
- Hospital culture: Rites of incorporation (acting as witness, moments of honoring / respecting the dying and death itself)
- Transformative Education / Programming
- Personal Creative Work (arising out of the terminal illness)

Solution ***(change intervention)***:
- Ritual of recognition (“rite of incorporation”)
- Existential counselor
- Communication tools
- Specific programming (*open to further thought*)

Change ***(ideal outcome, preferred state)***:
- Understanding of what we can control--knowing when to be active and passive
- Cultural / collective alignment with our strength and vulnerabilities as humans
- Quality of life improved for Sara and family: Sara gets to spend more time with loved ones and less in operations, has less physical pain, more moments for joy and peace, sense of personal and collective acceptance
- Peaceful death
- Closure for family
- Moral clarity for doctors, allowing for the possibility of more genuine and human relationships (even with some laughter and lightness)

END OF LIFE RESEARCH

Statistics and studies

A National Study of Chaplaincy Services and End-of-Life Outcomes

- The analyses found significantly lower rates of hospital deaths ($\beta = .04$, $p < .05$) and higher rates of hospice enrollment ($\beta = .06$, $p < .001$) for patients cared for in hospitals that provided chaplaincy services compared to hospitals that did not.
- The findings suggest that chaplaincy services may play a role in increasing hospice enrollment. This may be attributable to chaplains' assistance to patients and families in making decisions about care at the end-of-life, perhaps by aligning their values and wishes with actual treatment plans. Additional research is warranted.

https://bmcpalliatcare.biomedcentral.com/articles/10.1186/1472-684X-11-10

Why So Many People Die At Hospitals Instead of At Home

- "She was going to fight it every inch of the way," says her husband Ron Faber. By August 2013 after much fighting, Paula Faber died at age 72. Ron Faber now regrets the intervening 11 months of chemotherapy, radiation, painkillers and side effects that reduced his wife to 67 pounds of frayed nerves. Instead, the pain could have been managed so she could focus on the quality of life. "I would have rather have had a really okay four-and-a half months than this endless set of treatments," the stage actor said.
- A year after his wife Paula died, he still believes her oncologist at Beth Israel Hospital was strangely optimistic about her prospects. Faber acknowledges it was Paula's decision to fight the cancer "every inch of the way," but he thinks she might not have, if her doctors had told her more about the upsides of palliative care and the downsides of aggressive treatment. "I think they sold her on it," he says. "She was so afraid of death that she was ready to buy, and they knew it. And I think it happens a lot." Hospice had come up before as an option, but the Fabers thought of that only as a place to go and die, and no one had told them otherwise.

http://www.pbs.org/newshour/rundown/many-people-die-hospitals-instead-home/

Where Do Americans Die?

- Studies have shown that approximately 80% of Americans would prefer to die at home, if possible.
- Despite this, 60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home.
- A minority of dying patients use hospice care and even those patients are often referred to hospice only in the last 3-4 weeks of life.
- However, not every patient will want to die at home. Dying at home is not favored in certain cultures (due to cultural taboos) and some patients may wish not to die at home, out of concern that they might be a burden on the family.

https://palliative.stanford.edu/home-hospice-home-care-of-the-dying-patient/where-do-americans-die/

- ⅓ of patients with advanced cancer spend their final days in the ICU receiving life-prolonging measures.
- Less than 50% of these patients receive hospice, and if they do, it's only for the last few days.

http://www.medscape.com/viewarticle/828499

Advanced Directives: PDFs State by State

Vermont and Utah have similar ones, and higher hospice rates, New York's is awful :(and the state has higher hospital rates

http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289

The High Cost of Dying

A report by the Institute of Medicine shows how lack of an end-of-life plan often leads to "prolonged hospitalization, soaring medical bills and unnecessary pain and suffering for everyone"

http://www.usnews.com/news/articles/2014/09/23/study-end-of-life-plans-are-rare-driving-up-costs-and-suffering
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2690284/

- "For a patient with a fatal version of the disease, though, the cost curve is U-shaped, rising again toward the end—to an average of sixty-three thousand dollars during the last six months of life with an incurable breast cancer."
- 2008 study by Coping with Cancer: Terminally ill cancer patients who receive life-prolonging treatment have a substantially worse quality of life in their last week than those who received no interventions.
- Six months after their death, their caregivers were 3X more likely to suffer major depression

How Can We Reduce End-of-Life Health Care Costs
http://www.wsj.com/articles/SB10001424052702304709904579411083208419794

Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life (2015)
https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near

Movies

"Dying"
https://www.academicvideostore.com/my-videos
(user: mrjohnbruce pass: jb331909)
Summary: Film depicting the dying process of three patients and their families.

"Dying at Grace"
part 1 http://www.veoh.com/watch/v362747183afaCMPm
part 2 http://www.veoh.com/watch/v36274717Rc6hf2nF
Summary: Film depicting the life at Grace Hospice in Canada.

"How to die in Oregon"

https://www.amazon.com/How-Die-Oregon-Cody-Curtis/dp/B007Y35YTS
Summary: Film about the law of "dying in diginity"/"assisted suicide" in the state of Oregon

"Being Mortal"
http://www.pbs.org/wgbh/frontline/film/being-mortal/
Summary: Atul Gawande´s account of doctor dilemmas and fight mentality in American healthcare.

"What really matters at the end of life"
https://www.youtube.com/watch?v=apbSslLLh28

On hope and hopelessness

Pema Chodron on hope and fear:
https://onedharmanashville.wordpress.com/2011/01/09/pema-chodron-on-the-benefits-of-hopelessness/, http://steamboatbuddhistcenter.org/_/Great_Videos_files/Fearless%20Non-theism%20.pdf

Summary: Pema Chodron on "the benefits of hopelessness". "Hope and fear come from feeling that we lack something; they come from a sense of poverty. We can't simply relax with ourselves. We hold on to hope, and hope robs us of the present moment. We feel that someone else knows what is going on, but that there is something missing in us, and therefore something is lacking in our world."

"We're all addicted to hope, hope that the doubt and mystery will go away. This addiction has a painful effect on society: a society based on lots of people addicted to getting ground under their feet is not a very compassionate place"

"Hope and fear is a feeling with two sides. As long as there is one, there is always the other."

"In the world of hope and fear, we always have to change the channel, change the temperature, change the music, because something is getting uneasy, something is getting restless, something is beginning to hurt, and we keep looking for alternatives."

“We can explore the nature of that piece of shit. We can know the nature of dislike, shame,and embarrassment and not believe there Is something wrong with that. We can drop the fundamental hope that there is a better "me" who one day will emerge. We can't just jump over ourselves as if we were not there. It's better to take a straight look at all our hopes and fears. Then some kind of confidence in our basic sanity arises.”

“The real thing that we renounce is the tenacious hope that we could be saved from being who we are. Renunciation is teaching to inspire us to investigate what's happening every time we grab something because we can't stand to face what's coming.”

“All anxiety, all dissatisfaction, all the reasons for hoping that our experience could be different are rooted in our fear of death. Fear of death is always in the background.”

“Relaxing with the present moment, relaxing with hopelessness, relaxing with death, not resisting the fact that things end, that things pass, that things have no lasting substance, that everything is changing all the time, that is the basic message.”

Social science study on usefulness in focus on hope

https://www.theguardian.com/lifeandstyle/2014/apr/12/change-your-life-case-against-hope
http://onlinelibrary.wiley.com/doi/10.1111/ecoj.12046/abstract

Summary: “Using German panel data, we show that unemployed people are, on average, less satisfied with their life than employed people, but they report a substantial increase in their life satisfaction upon retirement. We interpret this finding using identity theory. Retirement raises the identity utility of the unemployed because it changes the social norms they are supposed to adhere to. The social norm for people of working age prescribes that able-bodied people should be employed, whereas the social norm for the retired does not contain such expectations. Findings for various subgroups are consistent with that interpretation”. “The degree to which one conforms to or deviates from the norms of the social group one belongs to strongly affects the identity value and thus subjective well-being.”

Noticings: Referred to in an article about HOPE, as proof that "giving up hope" to fulfill a certain social expectation that you fail to fulfill, makes you happier.

Abandon Hope

https://www.lifepositive.com/abandon-hope/
Summary: "Hopelessness from a spiritual point of view can also be termed choicelessness,ie. having no other choice than to honour the present moment completely and gracefully."
"As Eckhart Tolle describes in The Power of Now, "Waiting is a state of mind which makes you want the future, not the present. You don't want what you have got, and what you have is what you don't want. With every kind of waiting you create conflict between your here and now, where you don't want to be and the projected future where you want to be. This greatly reduces the quality of your life making you lose the present."
"So when we embrace hopelessness we cease to look for exit routes, and instead honor, acknowledge and accept the now as it is."

Video game

A video game to tell the story of a family who lost their infant to cancer.

The article: https://www.wired.com/2016/01/that-dragon-cancer/
The Radio Lab: http://www.radiolab.org/story/cathedral/
The film made about the game and the family: http://www.thankyouforplayingfilm.com
The game: http://www.thatdragoncancer.com/#home

Articles/Videos

"12 Things a Cancer Doctor Should Never Say"
Summary: Fascinating article by a cancer survivor-now-strategist . . . and the comments by other survivors are also really interesting.
Noticings: The article valorizes hope, yet also pushes holistic care and alternative forms of medicine that respect the whole human. Some of the honest statements that we've noticed missing from patient-doctor interactions are criticized here as being overly blunt and hope-killing (which the article indicates is also life-ending).

"Cancer conversations: How to manage the tough talk for doctors, patients"
Summary: An article about the difficulty of having caring conversations between doctors and patients. There's a case study of a woman that sounds similar to Sarah: she's 38, pregnant with her third child, and a creative director of a NY children's magazine. She ended up creating "The Cancer Conversation"--40 cards that cover practical and emotional issues for patients that their doctors may not cover.
Noticings: "More than 68 percent of patients thought they had a far better chance of two-year survival than their doctors did. Of those, nearly 90 percent did not realize that their expectations differed from their doctors' predictions." This article also focuses on hope--it ends with a quote from woman who created the cards: "Part of going forward is always having hope." I wonder how the definition of "hope" might change according to context and over time?

"A conversation with a cancer patient about palliative care"
Summary: A conversation between two doctors, one of whom is battling advanced-stage lung cancer, diagnosed at the age of 36. They're doing the conversation as part of a series by the Stanford Center for Biomedical Ethics, in order to model what nurturing, care-giving cancer discussions can look like.
Noticings: "What surprised him most about his life after being diagnosed with lung cancer was just how hard it was dealing with existential types of questions, about what he valued most in life." Later in the article, it mentions that "As a patient, he found solace in poetry, in his writing, in his family and friends." These two doctors seem to pinpoint some of the main issues we're talking about: quality of conversation, existential needs, coping mechanism, focusing on patients and their stories, the need to be seen and heard.

"How Long Have I Got Left"
Summary: The NYT article by the doctor in source above that speaks both about his approach to giving end-of-life diagnoses, and experiencing one himself.
Noticings: "Be honest about the prognosis but always leave some room for hope. Be vague but accurate." --- It hadn't occurred to me before that doctors may use vague language not out of discomfort, but because they can't know for certain what the outcomes will really be. Or, that statistics can make people feel that certain procedures are more or less dire / necessary than they are. Then, when the doctor is himself diagnosed with cancer, he says "But now that I had traversed the line from doctor to

patient, I had the same yearning for the numbers all patients ask for." "I began to realize that coming face to face with my own mortality, in a sense, had changed both nothing and everything. Before my cancer was diagnosed, I knew that someday I would die, but I didn't know when. After the diagnosis, I knew that someday I would die, but I didn't know when. But now I knew it acutely. The problem wasn't really a scientific one. The fact of death is unsettling. Yet there is no other way to live."

"VA cancer patient secretly records doctor visit"
Summary: The first problem is getting an appointment (records nurses that agree). Then he records a doctor talking about how he's overwhelmed from the number of patients he has, and he "can only do what [he] can do". Nurses and doctors agree that the VA system is not the best. More issues arise as the video goes on, all dealing with systemic issues.
Noticings: The patient's advocate talks about training professionals to educate patients about The Choice Act, which gives patients the option to receive care from outside providers.

"Improving How Doctors and Patients Have Difficult Conversations"
Summary: An article about maintaining dignity in the end-of-life process. Links dignity with quality of life, symptom control, and even survival. Speaks to the distinction between "intention to cure" versus "intention to halt disease for some time."
Noticings: Interesting to see "dignity" instead of "hope" as a focal point.

Tools / Organizations

The Cancer Conversation (Cancer Conversation Cards)
Summary: Cards designed by a breast cancer patient and her friend to help other cancer patients with emotional and practical worries.
Noticings: This seems like an example of a possible design intervention.

VITALtalk (Nonprofit Organization)
Summary: "We specialize in developing and facilitating advanced communication skills courses and faculty training courses focused on balancing honesty with empathy when discussing serious illness and end of life care."
Noticings: Another example of a type of design intervention.

Patient-Doctor Conversation Guide
Summary: Online guide for patients to use to help them navigate the lung cancer conversation with their doctors.
Noticings: These guides seem to be speaking to a reality of OVERWHELM that a patient and family members may feel when trying to navigate the process of moving forward.

The Help - Hurt Tool
Summary: A tool for therapeutic decision making to help facilitate conversation. Ideally used when patients with advancing illnesses have to decide about treatment for relapse or refractory disease.
Noticings: "The challenges for effective specialist-patient communication are multiple: the known inaccuracy of physician estimated survival[6], the default role of life prolonging therapies in western medicine[7], patient anxiety, denial, or desire to protect loved ones, and clinician factors: lack of training, comfort, and time[8]."---Many of the reasons for creating this tool are similar to the ones we've come across. It's interesting these tools are mostly being designed by doctors. (This was made by palliative care physicians and oncologists at Montefiore.)

Hospice Help Guide
http://www.helpguide.org/harvard/dealing-with-a-loved-ones-serious-illness.htm
http://www.helpguide.org/articles/caregiving/hospice-and-palliative-care.htm

Conflicts in Goals of Care at the End of Life
http://www.medscape.com/viewarticle/828499

Approach to End of Life Care
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3399266/

DEVELOPING PRINCIPLES

Assignment: Develop three principles that will inform how we address a wicked problem.

What is our wicked problem (crisis)? ***(redefined from Wheel of Reasoning)***

Collective and individual failure to communicate openly about human limitations, fears and doubts in regards to death and social roles/cultural expectations.

Human limitations include absolute control over the time of death and the process of dying. Fears and doubts are related to death as well as our perceived inability to fulfill our social roles in regards to our profession or family.

Perceived expectations of social roles and relationship to death are much influenced by a cultural hegemony of emphasis of strength over vulnerability, life over death, rescue over "giving up", hope over fear.

Perception: As a doctor, as a mother, as a partner, as a sick person, I need to stay strong, positive, optimistic to fulfill the social expectations from my partner/my family/my patient etc. As a doctor, as a mother, as a partner, as a sick person, I need to stay strong, positive, optimistic to avoid death and bring about desired state of prolonged life (admitting possibility of death as self-fulfilling prophecy).

Result: Plummeting quality of life caused by persistent continuation of treatment (and a perpetuating silence-mentality) in the face of inevitable death. Internal battles connected to maintaining and transgressing social expectations and life over death.

What are the needs and challenges of the stakeholders?

Patient (Sarah):

1. Cognitive: What does doctor lingo mean? Existentially grasping death.
2. Emotionally: Space for processing emotions.
3. Physical: Pain management, touch.
4. Social: Need for belonging also as a potential dying patient. Not feeling like a burden. (ADD TO SCRIPT?)

5. Over-time: Need for family and doctor to adapt their support to respond to patient´s physical progression, need for closure.

Family (Zach, Liz, Tim, Rosy):
1. Cognitive: What does doctor lingo mean?
2. Emotionally: How to deal with possibility of partner´s death? External support.
3. Physical: Rest, sleep, maintaining general health.
4. Social: Define role in relation to Sarah and baby (what does she need from him and what does he need from her?) External support.
5. Over-time: Planning for the future (practical and identity), closure.

Doctor (Susan):
1. Cognitive: What are the actual odds of survival and possibilities of continued treatment? How can I best interpret and utilize my medical information?
2. Emotionally: Navigating difficult conversations and fear of failure as a doctor.
3. Physical:
4. Social: Linguistically navigating difficult conversations.
5. Social/Over-time: Define role in relationship to patient and family as physical progression is changing. (Is my role to be positive/optimistic/give hope? Or something else? When does it change and how do I adjust?)

Who are we designing on behalf of?
The hospital.

For whom on what levels?
Patient, family and doctor, on primarily emotional/social levels over time (secondary cognitive levels).

PRINCIPLES – What values do we want to bring?

One-liner: Provide opportunities for all stakeholders to visualize and express multiple modes of response to the situation.
Explanation: Creating a space for all stakeholders to discuss needs, vulnerabilities, doubts, hopes and fears.

Supports: Increased quality of interpersonal communication, and increased comfort with talking about death and possible scenarios of treatment. Belonging in the state of dying.
(Tactics)

One-liner: Accommodate changing emotional, practical, physical and cognitive needs of patient and family.
Explanation: Possibilities for the expansion of each stakeholder´s role to include more flexible modes of reaction and support related to the situation at hand.
Supports: Minimizes tension, increases authenticity.
(Tactics)

One-liner: Provide opportunities to discuss and address perceived expectations from the other stakeholders.
Explanation: Clarifying one´s own needs from expectations from others.
Supports: Minimizes stress caused by trying to live up to the perceived expectations connected to social or professional role.
(Tactics)

Result: Quality of life at end of death. Opportunities for closure and feeling of acceptance and belonging for all stake holders.

IDEATION

Guiding “philosophy” & insights

Pema Chodron: As long as there is hope there is fear, they´re two sides to the same coin. How do you move beyond these states into an acceptance of our existential groundlessness?

Pema Chodron: “We can know the nature of dislike, shame, and embarrassment and not believe there Is something wrong with that. We can't just jump over ourselves as if we were not there. It's better to take a straight look at all our hopes and fears. Then some kind of confidence in our basic sanity arises.”

“The degree to which one conforms to or deviates from the norms of the social group one belongs to strongly affects the identity value and thus subjective well-being.” = making explicit perceived expectations of social roles and making room for their elasticity brings heightened quality of life.

Guidelines

How might we provide opportunities for all stakeholders to visualize and express multiple modes of response to the situation?

Freedom/clarity in seeing conflicting states of being/opportunities/emotions “outside of self”, can help alleviate zone of crisis and discomfort where fight-mentality (short-term panic mode) and even more rigorous alignment with perceived social expectations and identities easily kick in.

What´s a healthy balance between “optimism” (Hope! Rescue! Fight!) and “negativism” (Help! This is not working out! I´m scared!)? How create a “healthy” dynamic to this? Create a space for hope, for fear, for doubt, for strength and for weakness in the process.

How might we accommodate changing emotional, practical, physical and cognitive needs of patient and family?

Time-perspective: What are the questions we need to ask at different points and what could possible answers be? Where is our intervention/s? At what point? Involving who?

How might we provide opportunities to discuss and address perceived expectations from the other stakeholders?

How can you redefine roles, based on the actual needs of the others, not the need you perceive?

Which multi channels can we use to address the needs and challenges of the situation?

1. People

- Collaborative teams for difficult conversations (doctor/nurse etc)
- Facilitator that guides family conversation
- “Non-support” support group
- Nurse to follow your journey (across hospital and hospice?)
- Spiritual guide/identity counselor
- Professional doubter

2. Communications

- Creating visualization of “death” or “cancer” as a tool to talk about or relationship to this? How is it perceived “spacially”, “bodily”?
- Creative expression to express your state in embodied or visual way
- Reflective listening/Reverse storytelling
- Use emojis
- Create mask or avatar
- Role playing
- Questionaire prompting discussion
- Letter to your dying self/to you family/to the sick person etc
- Review sheet with questions about your role

3. Environments

- Baking
- Make a literal space
- Exit/Escape sanctuary/cozy room for processing
- Darkness/closed eyes

4. Processes

- Doctor training
- Follow-up on conversations over time

5. Digital experience

- Video journal
- Virtual reality role play
- TV show about roles

6. Objects and artifacts

- Object/card you raise, “I don´t get it” etc
- Conversation cards
- Props/costumes to help you express different things
- “Playing field”/game with different stations to facilitate better communication
- Checklist for docs and patients
- Book/journal for processing
- Physical mechanism to facilitate conversation
- Confessional booth

Criteria for success

Increase authenticity
Increase stamina and responsiveness to other stakeholders through the ability to “step out of” one´s particular (dysfunctional) social role
See the situation from a systemic viewpoint
Better communication skills
Reframing what end of life could mean
Expand possible modes of response to death
Destigmatizing death
Ease in better decision making

IDEATION RESEARCH: METHODS

Theatre of the oppressed

Rainbow of Desire / Cops in the Head: investigating and fighting internalized oppression, also called introspective techniques

Aesthetics of the Oppressed: creating sculptures, 2D art, or poetry to represent a problem (it can be abstract). Short performances--can be silent or with words (getting at cops in the head)

Newspaper Theater: starting from articles in the news to develop plays

Concentric Circles: Systems of Oppression / Institutional Oppression / Interpersonal Oppression / Internalized Oppression (examples below

- Systems: Racism, Sexistm, Classism, Capitalism , Agism . . .
- Institutional: Government, NYPD, Schools, Prisons, Courts, Businesses, Restaurants, Shops . . .
- Interpersonal: Parents, police officers, teachers, students, therapists, politicians, principals
- Internalized: Fear, anger, depression, mistrust, hate, malice, disrespect, hopelessness
- This could be used as a format with which to explore the internalized nature of the hospital experience. E.g. the circles could still be Systems / Interpersonal / Internalization, but the things listed under them would be related to the end-of-life experience to help people process. Ex:

A. System: Taboo of death and dying, "no-code", cultural discomfort with sickness
B. Institutional: Insurance company, hospital, ER room, place of employment
C. Interpersonal: spouses, children, parents, doctors, nurses, social workers
D. Internalized: confusion, frustration, isolation, embarrassment

Interior Monologues: People pick their characters, explain the scenario, then spread out and start reciting interior monologues. Audience has an opportunity to walk around and listen to different perspectives.

Jam Tools

Check Ins: a process to allow people to feel seen and heard before going into more difficult conversation. Helps people "arrive" and be in a place to hear one another.

Story Exchange: partners tell a story about a time ______ (facilitator picks this). Each partner tells their story while the other listens. Then they switch stories, and narrate the other's tale back (so if my partner is Bob, I then pretend I'm Bob and re-tell his story as though I were him)

- Could be used between doctors/nurses and families/patients
- Could be used between family members

Zone Circles and Panic Zone Reactions: Comfort, Stretch, and Panic Zone

- Communication tool for all stakeholders that could help them navigate various stages in conversation
- Not Listening Exercise: theatrical process to show what listening and not-listening looks like. Can make a big difference in communication.

Tree / River of Life: a visualization tool that helps participants / stakeholders understand how their life story (or illness journey) has unfolded--what happened in the past, where they are now, what elements are feeding their current state, and what they're reaching or heading toward

Community Care Tools: massage techniques, breathing, sound circles

Visualization Process: a meditative, partner activity where you think about the present and future and sketch it out (first in image, then in words)--your partner then becomes your accountability buddy

Playback Theater

- All of it! Could either have stakeholders act, or have a troupe come and visualize/ perform a patient or family member's internal state
- Playback in the hospital? What would that look like? Maybe this could be a version of a "non support" support group?

InterPlay

- Gentle opening/story sharing techniques: Babbling, DT3, I Could Talk About…
- Body Check in Techniques

Systemic constellation work

Benefits/learnings: Possibilities for abstraction of concepts like cancer, death, intangible family dynamics etc. Visual clues about what is going on a systemic level. Facilitates "seeing" of contradictory constellations and acceptance of what is. Also allows for a "reconfiguration" of elements in a system (and experience of this reconfiguration) whether tangible or intangible.

- A group (workshop) is led by a facilitator. In turn, members of the group can explore an urgent personal issue. Generally, several members will be given an opportunity to set up a Constellation in each session.
- After a brief interview, the facilitator suggests who will be represented in the Constellation. These are usually a representative for the seeker, one or more family members, and sometimes abstract concepts such as "depression" or a country.
- The person presenting the issue (seeker or client) asks people from the group to stand in the Constellation as representatives. He or she arranges the representatives according to what feels right in the moment. The seeker then sits down and observes.
- Several minutes elapse with the representatives standing still and silent in their places. Initially, unlike psychodrama, the representatives do not act, pose, dialogue or role play.
- Emphasis is placed on perceptive intuition in placing the representatives and in subsequent steps of the procedure. The aim is supposedly to tune into what the psychiatrist Albrecht Mahr describes as the Knowing Field[9] and former biologist Rupert Sheldrake has suggested is morphic resonance.[10] The Knowing Field is claimed to guide participants to perceive and articulate feelings and sensation that mirror those of the real family members they represent; however, representative perception (morphic resonance) is not a concept with any scientific basis. The representatives have little or no factual knowledge about those they represent.

Nevertheless, the representatives usually experience feelings or physical sensations that are thought to inform the process.

- The facilitator may ask each representative to briefly report how they feel being placed in relation to the others. The facilitator, seeker, and group members may believe they perceive an underlying dynamic in the spatial arrangement and feelings held by the representatives that influence the presenting personal issue. Often, configuring multiple generations in a family is thought to reveal that severe traumas continue to unconsciously affect the living long after the original victims or perpetrators have died.
- A healing resolution for the issue generally is supposedly achieved after re-positioning the representatives and adding key members of the system who have been forgotten or written out of the family history. When every representative feels right in his or her place and the other representatives agree, the facilitator may suggest one or two sentences to be spoken aloud. If the representatives do not feel at peace with their new position or sentences, they can move again or try a different sentence. This is claimed, in an abstract way, to represent a possible resolution of the issues faced by the seeker. Sometimes the process concludes without a full resolution being achieved.
- When the facilitator feels that the healing resolution has taken hold among the representatives, the seeker is invited to "replace his/her representative in the Constellation". This supposedly allows the seeker to perceive how it feels to be part of a reconfigured system. When everyone feels comfortable in their place, the Constellation concludes.

Psychosynthesis

Spiritual goals of "self-realization" and the “inter individual psychosynthesis" - of 'social integration...the harmonious integration of the individual into ever larger groups up to the "one humanity"'[2] - were central to Assagioli's theory.

Wished also to support the blossoming of human potential into what Abraham Maslow [12] later termed self-actualization, and further still, into the spiritual or transpersonal dimensions of human experience as well.

For Assagioli, 'the lower unconscious, which contains one's personal psychological past in the form of repressed complexes, long-forgotten memories and dreams and imaginations',[15] stood at the base of the diagram of the mind.

The lower unconscious is that realm of the person to which is relegated the experiences of shame, fear, pain, despair, and rage associated with primal wounding suffered in life. One way to think of the lower unconscious is that it is a particular bandwidth of one’s experiential range that has been broken away from consciousness. It comprises that range of experience related to the threat of personal annihilation, of destruction of self, of nonbeing, and more generally, of the painful side of the human condition. As long as this range of experience remains unconscious, the person will have a limited ability to be empathic with self or others in the more painful aspects of human life.
At the same time, 'the lower unconscious merely represents the most primitive part of ourselves...It is not bad, it is just earlier '.[16] Indeed, 'the "lower" side has many attractions and great vitality', and - as with Freud's id, or Jung's shadow - *the conscious goal must be to 'achieve a creative tension'[17] with the lower unconscious.*

Subpersonalities based in the personal unconscious form a central strand in psychosynthesis thinking. 'One of the first people to have started really making use of subpersonalities for therapy and personal growth was Roberto Assagioli', psychosynthesis reckoning that 'subpersonalities exist at various levels of organization, complexity, and refinement'[25] throughout the mind. A five-fold process of recognition, acceptance, co-ordination, integration, and synthesis 'leads to the discovery of the Transpersonal Self, and the realization that that is the final truth of the person, not the subpersonalities'.[26]

'Dialogue, Gestalt techniques, dream work, guided imagery, affirmations, and meditation are all powerful tools for integration', but 'the attitude and presence of the guide are of far greater importance than the particular methods used'.[37] Sand tray, art therapy, journaling, drama therapy, and body work; cognitive-behavioral techniques; object relations, self psychology, and family systems approaches, may all be used in different contexts, from individual and group psychotherapy, to meditation and self-help groups. Psychosynthesis offers an overall view which can help orient oneself within the vast array of different modalities available today, and be applied either for therapy or for self-actualization.

Psychosynthesis allows practitioners the recognition and validation of an extensive range of human experience: the vicissitudes of developmental difficulties and early trauma; the struggle with compulsions, addictions, and the trance of daily life; the confrontation with existential identity, choice, and responsibility; levels of creativity, peak performance, and spiritual experience; and the search for meaning and direction in life. None of these important spheres of human existence need be reduced to the other, and each can find its right place in the whole. This means that no matter what type of experience is engaged, and no matter what phase of growth is negotiated, the complexity and uniqueness of the person may be respected—a fundamental principle in any application of psychosynthesis.

Zen buddhism

“Who is feeling these emotions?” “What is perceiving the perceiver?” “Who is thinking these thoughts?” Points to a place beyond identification with thoughts and emotions, where they are still there, but with a less strong hold on our being. Also a way of dis-identifying with social roles and projections on others.

SEEKING CLARITY IN FOUR PARTS

An Adaptation of Kegan & Lahey's Four Column Process

Introduction, if needed:

Deciding what treatment plan to pursue when facing terminal illness is far from an easy, clear, or straightforward task. Almost everything is uncertain. Questions stalk patients and their families like dark clouds: How much longer do I have left? How much pain will I be in? Is it worth pushing forward?

Because of this grave uncertainty, patients and their family can undergo extreme stress when trying to make decisions about moving forward. That stress can sometimes lead to losing sight of deeper values and priorities, causing patients and families to choose options that ultimately do not support what they really want.

Start process here:

This exercise is not intended to lead you and your family to a specific decision or push you any one way. Rather, it is a chance to regather as a group. We want to understand--without judgement--where everyone is at this stage of your _______ (insert illness here). This is simply a moment to pause, reflect and, if it makes sense, redirect.

In order to prevent influencing one another's answers, we'll do this exercise individually, then share at the end. I'd also like to note that each of you will answer the following questions as they relate to you. You are not answering on behalf of ______(patient name). The entire process will take us about 30 minutes. Questions?

I invite you to take a deep breath, let it out with a sigh and shake off some of the tension. Allow yourself to go inside as we work through these questions.

Intro

Think of some things that are causing you frustration. What's driving you crazy? Is there something missing in your life that would better support you?

Allow these questions to generate a list of complaints in your mind.

Now just take a moment and feel the emotional impact of those complaints.

Choose one complaint to work with through this cycle of the Clarity Process. Write your complaint down on the sheet provided.

Part 1: "Commitment"

Grounding Commitments

Most times, we try to get rid of, solve, or bury our complaints. After all, it can get heavy carrying them around all the time--they weigh us down.

However, there can be great value in not immediately resolving our complaints: they can teach us a lot about what matters most to us.

Complaints often reveal our underlying commitments and values: "we would not complain about anything if we did not care about something."

Complaints tell us all the things we can't stand. Commitments, on the other hand, say the things we stand for.

Look at the complaint you've just written down. Within that complaint, there lie a number of values and commitments. For instance, if my complaint is that "I don't have enough time to exercise and meditate", I might write: "I am committed to my health and spirituality" and "I value free time, work life balance, etc..."

Explore what commitments and values are within your complaint. Complete the sentences: "I am committed to……" and "I value….." You can list as many things as you'd like.

If you get stuck, it may help to think about why your complaint causes you frustration? THIS THING is preventing me from THESE COMMITMENTS and VALUES.

How did you feel as you answered the question above? Make a note of that feeling underneath your statement.

Part 2: Personal Responsibility
Actions and Behaviors

Here we focus on what you are doing (or not doing) to fulfill your commitments and values. Remember, the goal is not to come up with solutions to a problem. In fact, it is important to not try and change anything. Rather, I invite you to reflect on your behaviors--without judgement--and let them take you into a deeper understanding.

Continuing with my example: I said I was committed to my health and spirituality, and that I value free time, work-life balance, and more. What's preventing me from achieving those things? Well, I stay up late doing work, which makes it hard to wake up early and meditate, let alone get to the gym. I'm also working two jobs while trying to develop my creative career. Etc…

Remember: this is not about judgement or even analysis. I'm not saying: "I'm screwing myself over because I took on more than I can handle." This is just about noticing your behavior.

Your turn: record your answer to this question: "What actions are you taking, or not taking, that prevent you from living up to your commitments and values?"

How did you feel as you answered the question above? Make a note of that feeling underneath your statement.

Part 3: Competing Commitments
Underlying Commitments

Now that you've identified what your behaviors are, consider doing things differently.

How does it feel? Do you notice any fear or discomfort?

Typically, when you consider changing what you are doing that keeps you from fulfilling your commitments, fear and discomfort bubble up. Why? Because you are also committed to keeping away something you are afraid of from happening.

But do not stop there, by simply recognizing your fears or discomfort.This is not about just saying “I have these fears” and letting it rest. Rather, behind your fears and your discomfort are other commitments and values.

Part One represents values we are proud to stand up for. They represent the heaven we want. Part Three--this section, represents avoiding some kind of hell. This is usually a form of self-protection. This “hell”--your other commitments--is not something you’d jump on stage to tell people about; it can feel embarrassing, shameful, painful, or vulnerable. But it is not bad to be self-protective. The problem is that self-protective commitments are often invisible. And if they are invisible to you, they are likely to control you. A lot of energy is used to maintain this competing commitment.

Moving forward with my example, I’m now going to think of other commitments and values I have that are causing me to behave the way I just listed. Why am I staying up late? Why am I working so many jobs?

Well, I am also committed to fulfilling my roles and living up to expectations. I also value career security.

Your turn: What are the other commitments and values causing you to take the actions you just listed in Part Two? Explore them by completing the sentence: “I may also be committed to…..” and “I may also value . . . .”

Do your responses here contradict the values and commitments you wrote down in Part One? This is often the case. They are both true and you hold them simultaneously.

This is not something deficient in you; it merely reveals the complexity of your true nature. It also reveals a tension that holds you in a dynamic equilibrium that prevents change. If you look at the three sections together, they will reveal a pattern of resistance to change.

Your Part Two actions are not “mistakes” or “problems” in you. Rather, they are consistent, effective, even brilliant expressions of your Part Three commitments.

Again, it is important to not try to resolve this tension, but to hold it in your awareness and allow it to guide you.

Part 4: Big Assumptions

Big assumptions are those assumptions that you take as TRUE. Your Big Assumptions create the structure of how you make meaning; the foundation for the story you create of “who I am.”

As long as your Big Assumptions are assumed to be true, without reflection, they have you; they rule you. And they might be right or they might be wrong. When you are caught in your Big Assumptions you don’t look any further. Why? Because you already have the truth (their truth).

What you hope to achieve in the last part of this exercise is the beginning of a process of examining at least one Big Assumption to see if you still want to hold it as true, discard it, or alter it slightly.

Look at your Part Three response. We are going to try and locate the assumptions behind it. We’ll take the statements you wrote and turn them into if/then sentences.

For example, I said “I am also committed to fulfilling my roles and living up to expectations” So now I would change it to: If I did not fulfill my roles and live up to expectations, then . . .”

In other words, if you did something other than your commitment in Part Three you assume that ________ would happen.

Revisit your commitment sentences in Part Three. For each one, complete the sentence “I assume that if ________________, then ________________.”

Now, quickly and honestly complete the sentence: "What would I feel then is_____________."

Take a look at what you have written. Does your big assumption have dire consequences, like you would die, or it would be the end of the world, or incredibly painful? Then you are on the right track. Recall that this is an assumption and for now your task is to simply hold it, watch it, and see how it impacts your daily life.

Record any thoughts, feelings, comments or reflections you'd like to share from looking at your big assumptions.