Empowering Questions

Uncovering ways to empower patients at the end of life.
There's a lot things we lose in old age. Losing control over our own healthcare shouldn't be one of them.
So this should be simple*

*Except, of course, it isn’t
First insight: No demand for change.

- Rapid Research Review
- Key Informant Interviews
- In-Depth Individual Interviews (n=80)
  - Caregivers / family members ('good' v. 'bad' death)
  - Very seriously ill patients (likely to die soon)
  - Oncologists, gerontologists, cardiologists, palliative care specialists, and ICU nurses
  - Clergy members and social workers
- Added Qs to survey of 3,520 adults (PN’s HealthStyles)

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<thead>
<tr>
<th>ASSUMPTION</th>
<th>FINDING</th>
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<td>We could engage at the time of the terminal diagnosis</td>
<td>There is often no clear recognition of terminal until the very end.</td>
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<td>We can give people the power they want.</td>
<td>No one thinks they need more power to control their care.</td>
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- Lots of work here
- Decision here may not predict choice later
- Tough to make choices matter

Let’s focus here – this is where an important dynamic is being built. This where the real change will take place.

- Not a sole intervention point: We would need to load the patient's voice prior to this
What patients are seeking.

Values

- Being a loving mother / father / sister / etc.
- Being true to myself
- Living life to its fullest

Emotional Benefits

- Showing / receiving love
- Feeling secure
- Being heard
- Avoid regrets
- Autonomy
- Feeling good

Benefit & Burden Stage

- Make everything easy on family: I don’t want to be a burden.
- Getting along
- Do the things that matter
- Comfort: avoiding pain and suffering
- Extending my life
- Have everything in order (for planners)
- Good health (50+)

Steeping Stage

Can we help with this?
So we tried – we envisioned, we prototyped, we tested, and then we tested some more

- 29 dyads testing product concepts with seriously ill and caregivers (n=58)
- National survey of 1501 adults age 50+ that oversampled Boomers with Living Parents (613), Affluent Silents (352) and Seriously Ill Patients (359)
- 21 focus groups of Boomers with living parents and Silents with adult children (n=86), testing creative and product concepts
- Sprint & prototype testing
- Names/tags tested with 1,241,189 unique Facebook users

ASSUMPTION

We can make great EoL tools.

FINDING

People prefer ‘better life’ tools.
Doctors not seen as candid about negatives
Most respondents think there’s a similar drop in candor from their doctor as the conversation turns to the downsides of treatment. More importantly, they want much more candor than they think they receive.

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<th>What people want to happen</th>
<th>What people think happens</th>
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<tbody>
<tr>
<td>Negatives of Treatment</td>
<td>82%</td>
<td>35%</td>
</tr>
<tr>
<td>Positives of Treatment</td>
<td>86%</td>
<td>48%</td>
</tr>
<tr>
<td>General Health</td>
<td>88%</td>
<td>47%</td>
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Q32. How candid and thorough do you think doctors are generally when doctors talk to their patients about their health and the positives and negatives of possible treatments? / Q33. How candid and thorough do you want your doctors to be with you when they talk about your health and the positives and negatives of possible treatments?
Total (N=1501)
Oversimplified original approach

Market Forces

Medical-Industrial Complex

We want this.

I will give it you.
Oversimplified campaign approach

We see a problem.

I recognize we need to do things differently.

Market Forces

Medical-Industrial Complex

Campaign
Current approach (still oversimplified)

The disruptions are the questions we trigger.

This is a relationship. Not just a conversation.
What is a Trust Card™?

Your doctor may be the expert on your diagnosis, but you’re the expert on you.

The Trust Card™ helps your doctor understand you better.

The Trust Card™ is a new communication tool that helps patients with advanced illness who are visiting a new doctor convey their values and emphasize what matters most about their goals for care.

Customize the card to fit your needs.

Patients answer a few simple questions online and create a customized greeting card, building the foundation for honest conversations about treatment. They can print a free Trust Card™ at home or get one printed professionally for $10 to take to the new-doctor visit.
Why are you seeing the doctor now?

- To discuss a new problem
- To discuss my treatment options
- To follow up on tests or treatment

Diagnosis Decoder