Qualitative Research in Chronic Illness for Practice and Policy
Living Well with Chronic Disease
Institute of Medicine
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4 things about qualitative research

• Highlights how people
  live with chronic illness, participate in health care, provide care

• Focuses on the things people do, say, know according to their ways of doing, saying, knowing

• Diverse methods
  ethnography, analysis of action, interview

• Complements and critiques other approaches to research
3 Studies of Patients’ Stories

• Describing patient-centered care, 1988
• Defining patient-perceived outcomes of treatment for early prostate cancer, 1995-2002
• Explaining completion of antiviral treatment for hepatitis C, 2009--
Primary Care Internal Medicine Training at Boston City Hospital

• Two videotaped interviews by 3rd year residents
• “good” and “poor” interviews, as judged by primary care faculty
• Clarify attributes of patient-centered interviewing
  – Attentiveness
  – Facilitation
  – Collaboration
Attending to patients’ stories: reframing clinical tasks

- Doctors’ Tasks: assess adherence with medication regimen by patient with recent seizure
- Patients’ Tasks: demonstrate adherence as practical accomplishment
- Focus on patients’ stories to reveal how physicians help or hinder patients collaborative efforts
- Collaborate in telling a story of the seizure
Opening a story of a seizure

R: “Okay, so you had a seizure...... yesterday?

P: Uh u yesterday yesterday about *........ About eleven o’clock yeah

R: Hmm *.. At work?

P: (h)um hum

R: Okay . uh

{ 

P: Well I’m not really worried itz same thing you told me not getting ya-know not upset and aggravated
Quality of life with early prostate cancer: Men's’ accounts

1. Symptoms of anatomic/physiologic changes
   – Urinary, bowel, and sexual dysfunction
   – Identified by expert panel of physicians
   – Patient-based scales

2. How life has changed since treatment
   – Findings from focus groups with men who had undergone treatment
   – Patient-based scales
Themes expressed in focus groups: how life has changed since diagnosis

• Urinary incontinence: changes in behavior
• Erectile dysfunction: manifold effects
  – Sexual performance
  – Everyday interactions with women
  – Sexual fantasies
  – Masculine self esteem
• Uncertainties about cancer and decisions
  – Misgivings and regrets
Outcomes of Diagnosis and Treatment for Early Prostate Cancer

<table>
<thead>
<tr>
<th>Background</th>
<th>Decision &amp; Treatment</th>
<th>Outcomes of Treatment</th>
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<tbody>
<tr>
<td>Personality</td>
<td>Decision Making Process</td>
<td>Response to Diagnosis</td>
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<td>Social Resources</td>
<td>Treatment Chosen</td>
<td>informed decision</td>
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<td>Social Ties</td>
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<td>cancer control</td>
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<td>Stress of Cancer</td>
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<td>regret</td>
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<td>Health Status</td>
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<td>Function-Related Well-Being</td>
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<tr>
<td>Bodily Function</td>
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<td>urinary control</td>
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<td>Cancer Diagnosis</td>
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<td>bowel control</td>
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<td>sexual intimacy</td>
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<td>Additional Treatment</td>
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<td>Cancer Control/PSA status</td>
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Patient pleads not guilty in wounding of urologist

A prostate-cancer patient, who became impotent after an operation for the condition, pleaded not guilty yesterday to charges of shooting his physician in the groin during an office visit last week.

Arcadio Arguizel, 62, was ordered held in jail under $500,000 bail on charges of torture, attempted aggravated mayhem and assault with a firearm. He is charged with shooting Dr. George V. Sofla, 45, a Kaiser Permanente urologist, during a visit Friday in an examination room at a Kaiser office complex on Van dever Avenue.

Arguizel fled to Mexico after the shooting but surrendered himself to police Sunday. Sofla was released from the hospital after a day.

Arguizel's lawyer, Daniel Horwick, told Municipal Court Judge Rafael Areola that Arguizel wasn't told that the prostate-cancer surgery would render him impotent. Horwick said the surgery was unsuccessful and that Arguizel now requires radiation treatment.

Deputy District Attorney Peter Cross said Arguizel carefully planned the shooting, noting that videotapes about the shooting were found at the patient's home. In the tapes, Arguizel named other people who had angered him, Cross said.

Sofla was released Saturday from Kaiser Medical Center in Grantville after surgery to remove the bullet from a buttock. He is recovering at his San Diego-area home.

Not-guilty plea: Arcadio Arguizel, accused of shooting his doctor, listens during his arraignment yesterday.
Poor completion of antiviral treatment for hepatitis C

- HCV is prevalent: 1.6% of US pop; 5 – 10% of VHA patient population
- Few patients undergo antiviral treatment, although that’s expected to change this year
- Current treatment: long and debilitating
- Less than half complete a full course
- Reasons for premature termination are unknown
### Hepatitis C Study Sample

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<thead>
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<th></th>
<th>Bedford</th>
<th>Boston</th>
<th>San Diego</th>
<th>St. Louis</th>
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<tbody>
<tr>
<td><strong>Retrospective</strong></td>
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<tr>
<td>Completed treatment</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Did not complete treatment</td>
<td>9</td>
<td>10</td>
<td>10</td>
<td>8</td>
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<tr>
<td><strong>Prospective</strong></td>
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<td>Pre-treatment baseline</td>
<td>10</td>
<td>12</td>
<td>15</td>
<td>11</td>
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<tr>
<td>4 weeks</td>
<td>10</td>
<td>8</td>
<td>11</td>
<td>11</td>
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<td>20 weeks</td>
<td>10</td>
<td>8</td>
<td>11</td>
<td>10</td>
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<td>40 weeks</td>
<td>3 (3)</td>
<td>0 (2)</td>
<td>5</td>
<td>2 (3)</td>
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<tr>
<td>Supportive others</td>
<td>4</td>
<td>1</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Clinicians</td>
<td>1</td>
<td>0</td>
<td>10</td>
<td>3</td>
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Numbers in parentheses are still completing treatment
Patients’ stories explain their actions

• Tell me what it’s been like for you... since it all started
• Events leading to treatment
  • Contracted HCV
  • Got a diagnosis
  • Decided to start
• Getting through treatment
  • Early indication that it’s working, or not
  • Side effects are tolerable, or not
  • Circumstances are conducive, or not
Codes: elements of stories

• Treatment regimen
  – Disease
  – Actions to restore health
    • monitoring hepatitis C
    • preparing for treatment
    • prescribed and improvisational treatment practices

• Embodied actor
  – Identity (including risky behavior, sobriety)
  – Decisions to start, stop treatment
  – Learning about hepatitis C
  – Bodily/mental experience of treatment (side effects)

• Circumstances
  – Relationships: clinical, personal
  – Places: HCV clinic, VA, residences, rehab programs, work
treatments [P. uh-hmm], and maybe, you know, the best way to begin is, tell me how Hepatitis, the whole experience began for you? Like when did you find out you had Hep C?

P: Uh, I believe it was, uh, '95 [P: Yeah?] and um... I was in a drug and alcohol program up in Maine that wasn’t um... it was a private program, and um, they used Togas and they had, they had tested me and uh, had told me and, at the time it was no big deal, you know I didn’t really... uh... know all that. I mean I knew what it was but basically didn’t know, um, you know what it did to your body as far as how long or, or, you know the damage it did, and, um. I’d go back a little ways, you know, I used to shoot dope and um... uh... um... a few of the people that, you know, I used to hang out with had gotten um... had gotten the HIV virus, you know, on top of the Hep and, you know for a couple of years I, you know, I thought that... I’d gotten it too and um, you know, thank God I didn’t. I mean I was happy just finding out I just had the Hep, you know? [P: Yeah] And uh, you know, I haven’t shot any drugs since uh, early 80’s. And uh... when I finally got tested again it was, you know, it was no big deal, and you know, they explained to me, basically what it was, not what I could do about it except not drink and, you know I don’t. I don’t believe there wasn’t any treatment at that time. And uh, I suffered from, I still suffer from major depression but, you know, thank God you know it’s in check right now. It’s the first time in years that, you know, I could actually say that I, you know, that I feel human. [P: Hmm] And uh... uh prior to, uh... I still, you know, I drank and I did you know, other drugs you know, over the years. I had, had gotten three and a half years clean until I, you know, blew one of my knees out again and they put me back on painkillers and you know, it just snowballs after that and uh... I had a, I had a very good doctor down in um, Pennsylvania that I was seeing but she wouldn’t, because of the depression she wouldn’t, and I, at the time I didn’t want to take it either because I had friends who’d taken you know, the interferon and uh, you know, they had told me, you know how horrible it was and it only worked, you know, like a third of the people that, that uh went through the treatment. And um, (long pause) so again I mean I put it off for years and, you know, um and I was okay with
4 reasons for pursuing treatment

• Pilot study: 21 patients
  17 completed; 4 ended prematurely

1. CURE: 7
   sought to cure the disease, according to a medical rationale

2. BUY TIME: 14
   highlighted inexorable progression; sought not “cure,” but to avoid coming to a "bad end"
   for 9 the end was coming soon
• MEET CHALLENGE: 15
  side effects as personal challenges to be overcome without complaint, with notable pride

• REDEMPTION: 9
  defined treatment as part of recovery from a once dissolute life with substance abuse, demonstrating new personal worth
How the findings will be used

• Survey of patients
  – structured assessment of motivation
  – develop a model of treatment completion

• Identify interventions to support completion
  – Provider strategies
  – Peer and other support practices

• Inform the redesign of care for hepatitis C
Qualitative research in chronic illness

- Render what people do, say, and know
  - Everybody knows – Coontz’s Law
  - Every person has stories to tell
- Stories display what they know and explain why they act as they do
- Inform design of patient-based measures of processes and outcomes of care
- Supports clinical practice and policy