Qualitative research: does it have a role in nephrology?

W. Van Biesen
Ghent University Hospital
Qualitative vs Quantitative
Qualitative vs Quantitative

- **What** is going on ⇔ **Why** it is going on
  - > in numbers (%, absolute)
  - > in ideas, concepts, feelings, emotions, motivations
Qualitative vs Quantitative

- **What** is going on ⇔ **Why** it is going on
  - > in numbers (%, absolute)
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**How Smoking Hurts Your Lungs**

- Smoking will damage your lung's natural ability to clean and repair themselves.
- This means cancer causing chemicals will be trapped in the tissues of your lungs.
- This is because the cilia and mucus lining are damaged and cannot remove the chemicals.
Qualitative vs Quantitative

- **What** is going on ⇔ **Why** it is going on
  - > in numbers (%, absolute)
  - > in ideas, concepts, feelings, emotions, motivations

How Smoking Hurts Your

- Smoking will damage your lung's natural ability to clean and repair themselves.

Emotional Understanding

damaged and cannot remove the chemicals

Can you see a difference?
Qualitative vs Quantitative

• **Why** it is going on $\Leftrightarrow$ **What** is going on
  – $>$ in numbers (%, absolute)
  – $>$ in ideas, concepts, feelings, emotions, motivations

• Focussed on **understanding** (vs **explanation**)
  – Processes
  – Interactions
  – Meaning
  – Patterns
Qualitative vs Quantitative

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• Focussed on **understanding** (vs **explanation**)
  – Processes
  – Interactions
  – meaning
  – Patterns

• Intended to **come up with a general theory** starting from the available data

\[\Leftrightarrow\]

do the **data fit** the (starting) theory
Examples

Kubler-Ross:
Model of bereavement process
Denial - Anger-Fight/Agitation - Depression - Acceptance
Examples

**Kubler-Ross:**
Model of grieving process
Denial - Anger-Fight/Agitation - Depression - Acceptance

- Based on 4 interviews with dying patients (!)
- Can be generalized to other situations where “loss” is at play
  - Getting sacked
  - Bad diagnosis
  - Failing transplant, start dialysis.....
  - Changing labour conditions
How?

• Starting from a **theoretical phramework**
  – Ethnography
  – Phenomenology
  – Grounded Theory

• **Technique:**
  – Interviews
    • Open
    • Semi-structured
    • Structured
  – Focus groups
  – documents (diaries, nursing notes...).
  – Observation
  – Purposive sampling
  – Saturation

• **Audiotaping/Verbatim transcription**

• Analysis based on a given **methodology/framework**
Dissect out what has been stated (implicit or explicit)

• **Codes**: Identifying anchors that allow the key points of the data to be gathered

=>

• **Concepts**: Collections of **codes** of similar content that allows the data to be grouped

=>

• **Categories**: Broad groups of similar **concepts** that are used to generate a **theory**

=>

• **Theory**: A collection of categories that detail the subject of the research
Quality criteria for the phramework

- **Fit**: how well the theory describes events
- **Relevance**: deals with concerns of patients
- **Workability**: explains how a problem can be solved
- **Modifiability**: theory is flexible to allow change when new data arrive, improving the fit, relevance and workability
Why qualitative research is of importance in healthcare/nephrology

• Social constructs of disease
Socioeconomic deprivation and barriers to live-donor kidney transplantation: a qualitative study of deceased-donor kidney transplant recipients

Phillippa K Bailey,¹ Yōaq Ben-Shlomo,¹ Charles R V Tomson,² Amanda Owen-Smith¹
Socioeconomic deprivation and barriers to live-donor kidney transplantation: a qualitative study of deceased-donor kidney transplant recipients

Phillippa K Bailey,1 Yoav Ben-Shlomo,1 Charles R V Tomson,2 Amanda Owen-Smith1

ABSTRACT

Objectives: Socioeconomically deprived individuals with renal disease are less likely to receive a live-donor kidney transplant than less-deprived individuals. This qualitative study aimed to identify reasons for the observed socioeconomic disparity in live-donor kidney transplantation.

Design: A qualitative study using face-to-face in-depth semistructured interviews.

Setting: A UK tertiary renal referral hospital and transplant centre.
• Barriers different for low and high SED
Socioeconomic deprivation and barriers to live-donor kidney transplantation: a qualitative study of deceased-donor kidney transplant recipients

Phillippa K Bailey,¹ Yoav Ben-Shlomo,¹ Charles R V Tomson,² Amanda Owen-Smith¹

• Barriers different for low and high SED
• Low SED (so richer)
  • Financial concerns
  • Location of the donor
Socioeconomic deprivation and barriers to live-donor kidney transplantation: a qualitative study of deceased-donor kidney transplant recipients

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- Barriers different for low and high SED
  - Low SED (so richer)
    - Financial concerns
    - Location of the donor
  - High SED (so poorer)
    - Passivity

I went into it a bit blind and I just went with the flow, what people were telling me to do. I didn’t look it up anything, I didn’t take charge of my—I didn’t take charge of anything really. I let people do it for me because I was scared and I didn’t really want to know any details. (Interviewee 16)
Barriers different for low and high SED

Low SED (so richer)
  - Financial concerns
  - Location of the donor

High SED (so poorer)
  - Passivity
  - Disempowerment

It was just something I didn’t want to have to ask anyone ‘Can I have one of your kidneys please?’ How do you even start to approach that subject? (Interviewee 17)

I never, ever knew that I had to ask for a test or anything or that I could be tested. (Interviewee 9)

We never discussed having a living donor...I don’t think there was ever a discuss—there was never a discussion of having a live donation. (Interviewee 14)
• Barriers different for low and high SED
  • Low SED (so richer)
    • Financial concerns
    • Location of the donor

• High SED (so poorer)
  • Passivity
  • Disempowerment
  • Lack of social support

I mean I haven’t got a massive circle of friends anyway and I know the ones that I have got, a few of them have got their own health issues anyway so... (Interviewee 23)
Barriers different for low and high SED

• Low SED (so richer)
  • Financial concerns
  • Location of the donor

• High SED (so poorer)
  • Passivity
  • Disempowerment
  • Lack of social support
  • Short term focus

I knew you could have trans, like obviously talking to other patients, but once again I wasn’t really thinking about - I just thought of what was going to go on now... I’m the sort of person that doesn’t think five years ahead. I don’t even try and think a year ahead. I think within the next couple of months, whatever. That’s how I’ve really had to have been through dialysis now...my whole life has been basically not thinking too far ahead. (Interviewee 11)

I always knew inevitably I would need a transplant but I kind of thought it would never happen. You don’t - they’re probably just telling me that but inevitably it did happen. I didn’t really think about it. I don’t think about anything until it’s right just about to happen...I just switch off, honestly...Until the day comes I sort of deal with it then. (Interviewee 22)
Barriers different for low and high SED

- Low SED (so richer)
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  - Disempowerment
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CONCLUSION: Just providing financial support to high SED will not solve the problem
Why qualitative research is of importance in healthcare

- Social constructs of disease
- Prevention and risk management
Why qualitative research is of importance in healthcare

• Social constructs of disease
• Prevention and risk management

“Nudging” vs “Shoving” vs “Boosting”
Impact of qualitative analysis

- Setting: randomised controlled trial on prostate cancer screening through PSA; watchful waiting vs surgery vs radiotherapy
- Recruitment very problematic...
- Qualitative analysis of recruitment consultations
Impact of qualitative analysis

Patients: Fear of taking (too much) risk by “doing nothing”
• Lay public notice that “cancer should be removed”
• Reference to friends/relatives who died with prostate cancer
• Media information biased towards screening “to cure before it is too late”
• Confused by “trial”: interpreted as “trying something trial and error wise” (as compared to “study”)
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Urologists:
• not genuinely convinced of equipoise of treatments:
# Impact of qualitative analysis

## Patients:
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## Urologists:
- Not genuinely convinced of equipoise of treatments

---

**Clinician 1:** “We believe that you are suitable for any of these three treatments ... The first is radical prostatectomy. Probably the simplest answer is to remove the prostate gland completely—that gives you the opportunity of removing the whole of the cancer in its entirety. The problem is that radical prostatectomy is a major operation and there are risks ... [26 lines follow]

“The second method is radiotherapy—you are trying to destroy the cancer cells by means of x rays without removing the gland ... [30 lines follow]

“The final treatment is what we call watchful waiting. The basis of this is that we don’t know whether your tumour is going to progress or not, and we can simply just watch it carefully ... [10 lines follow]
Impact of qualitative analysis

**Patients: Fear of taking (too much) risk by “doing nothing”**

- Lay public notice that "cancer should be removed"
- Reference to friends/relatives who died with prostate cancer
- Media information biased towards screening “to cure before it is too late"

**Clinician 2:** "Watching it and treating—it’s not treatment immediately, it’s a different form of management: you’re managing the disease rather than treating immediately, you’re monitoring it and treating it if [it] shows signs of progression … if it does start to progress and cause problems you deal with them usually with hormone treatment”

**Patient:** “Well I suppose it’s better for me to say now that I feel I would rather have something done about it at this stage”

**Clinician 3:** “Monitoring—obviously older people often choose that because they feel, you know, if they may not be around in 10 years time and it may be a good bet to take”

**Patient:** “Hmm”
Impact of qualitative analysis

- Setting: randomised controlled trial on prostate cancer screening through PSA; watchful waiting vs surgery vs radiotherapy
- Recruitment very problematic...
- Qualitative analysis of recruitment consultations

⇒ Instructions to recruiters:
  - Stress equipoise
  - Avoid hidden persuaders suggesting RISK difference
  - Don’t use “trial” but “study”
  - Elicit (and evt counter) underlying reasons for refusal to participate
Impact of qualitative analysis

- Setting: randomised controlled trial on prostate cancer screening through PSA; watchful waiting vs surgery vs radiotherapy

- Recruitment very problematic...

- Qualitative analysis of recruitment consultations

![Bar chart showing Nr Recruited and % consenting to randomisation for Categories 1 and 2]
Why qualitative research is of importance in healthcare

• Social constructs of disease
• Prevention and risk management
• Context and motivation: why do you?...
Taking hospital treatments home: a mixed methods case study looking at the barriers and success factors for home dialysis treatment and the influence of a target on uptake rates
Gill Combes et al, Implementation Science, 2015

Quantitative data: WHAT happened?
Qualitative data: WHY did it (not) happen
Taking hospital treatments home: a mixed methods case study looking at the barriers and success factors for home dialysis treatment and the influence of a target on uptake rates
Gill Combes et al, Implementation Science, 2015

mixed methods

Quantitative data: WHAT happened?
Qualitative data: WHY did it (not) happen

Fig. 1 Percentage of dialysis patients on home dialysis
Table 7: Summary of actions taken by hospitals to increase the uptake of home dialysis

<table>
<thead>
<tr>
<th>Actions taken</th>
<th>Hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Resources</strong></td>
<td></td>
</tr>
<tr>
<td>Significant additional resources secured from the hospital for staff and home dialysis machines</td>
<td>✔ ✔ ✔ ✔</td>
</tr>
<tr>
<td>Forward-looking resource and capacity plan developed for achieving the 2015 target for home haemodialysis</td>
<td>✔</td>
</tr>
<tr>
<td><strong>Widening access</strong></td>
<td></td>
</tr>
<tr>
<td>Assisted PD introduced to widen access to more frail patients or those living alone</td>
<td>✔ ✔ ✔ ✔</td>
</tr>
<tr>
<td>Rapid/direct access to PD for acute patients to prevent acute patients automatically going onto in-centre haemodialysis</td>
<td>✔ ✔ ✔ ✔</td>
</tr>
<tr>
<td>Rapid PD catheter insertion</td>
<td>✔</td>
</tr>
<tr>
<td>Solo home haemodialysis introduced, so patients do not need to have a carer involved</td>
<td>✔</td>
</tr>
<tr>
<td>Portable home haemodialysis machine introduced</td>
<td>✔</td>
</tr>
<tr>
<td>Self-care/minimal care routinely available in in-centre haemodialysis units as a possible stepping stone to home haemodialysis</td>
<td>✔</td>
</tr>
<tr>
<td>One-off reviews of in-centre haemodialysis patients’ treatment options</td>
<td>✔ ✔ ✔ ✔</td>
</tr>
<tr>
<td>In-centre haemodialysis patients successfully switched to home dialysis</td>
<td>✔</td>
</tr>
<tr>
<td><strong>Peer support</strong></td>
<td></td>
</tr>
<tr>
<td>Peer support scheme for patients interested in home haemodialysis</td>
<td>✔</td>
</tr>
<tr>
<td>Informal peer support available for patients interested in home dialysis</td>
<td>✔</td>
</tr>
<tr>
<td><strong>Staffing, training and induction</strong></td>
<td></td>
</tr>
<tr>
<td>Home dialysis included in the induction of all new staff</td>
<td>✔ ✔</td>
</tr>
<tr>
<td>Staff rotation used to increase staff knowledge of home dialysis</td>
<td>✔ ✔</td>
</tr>
<tr>
<td><strong>Hospital support</strong></td>
<td></td>
</tr>
<tr>
<td>Visible support secured from hospital senior management</td>
<td>✔ ✔</td>
</tr>
<tr>
<td>Home dialysis targets deliberately aligned with the hospital’s strategic plan</td>
<td>✔ ✔ ✔ ✔</td>
</tr>
<tr>
<td><strong>Approach to the target</strong></td>
<td></td>
</tr>
<tr>
<td>Focus on increasing both home haemodialysis and PD uptake</td>
<td>✔ ✔ ✔ ✔</td>
</tr>
<tr>
<td>Focus solely on increasing home haemodialysis</td>
<td>✔</td>
</tr>
</tbody>
</table>
Table 8 Main facilitators in all hospitals

Commissioner’s target and financial penalty scheme

“You know and it’s always a cost issue isn’t it? No matter what, patient care is cost, that’s what it is isn’t it? And that, I think that’s wrong.” Nurse, hospital 3, February 2012

“I’m slightly wary of targets, that to achieve a target we could be pushing it to people who aren’t happy with it.” Consultant, hospital 1, November 2011

Funding for additional specialist staff and dialysis machines

“But also the commissioners, by having a bit of a stick as well as a carrot for us to achieve higher home therapy rates, [it] has been very helpful in our negotiations with our Trust [hospital] to say “look, we’ll lose this amount of money if we don’t invest to achieve it”.” Clinical lead, hospital 4, March 2012

Clinical leadership and wider staff support

“I think we’re fortunate to have staff who want to do this … it’s been driven by enthusiastic staff wanting to provide, you know, better care for their patients.” Centre clinical lead, medicine, hospital 4, April 2012

“I’m liking the way now it’s [home dialysis] coming back in to the fore again. Because I think it is so much better for the patients than having to get on transport, taken all round the area before they come here and then waiting for transport again.” Haemodialysis unit nurse manager, hospital 2, October 2011

Training and support systems for home dialysis patients

“….they’ll say some patients need 3 days [training], some patients need 7, some people need 2 weeks. So we go as quick as what you need to go. So its quite good really.” PD Patient, (9) hospital 1, November 2011
Table 9 Barriers

Lack of training for non-specialist staff

“None [time spent on training about home therapies]. I very rarely get involved with PD peritonitis but that’s about it, nothing else and nothing on home haemodialysis.” Specialist Registrar, hospital 3, January 2012

“…it was actually one of the health care assistants, I was asking her about something to do with the [haemodialysis]machine and she said “Oh I don’t know what you’re bothered about asking for, you’re not going home…” and I was completely if you like shot down in flames over it. And I’m like I’m asking questions because I’m interested…..I mean for some people they’d just go “OK I won’t bother asking then”.” Home haemodialysis Patient, (24) hospital 4, March 2012

Pre-dialysis education

“Speaking directly to someone who has had it [dialysis], so you’re getting all the unfiltered information…it was useful to be able to speak to a person who had gone through that to give us, you know, warts and all what’s going to happen…” PD Patient, (15) hospital 4, March 2012
Why qualitative research is of importance in healthcare

• Social constructs of disease
• Prevention and risk management
• Context and motivation: why do you?...
• How the disease is experienced
A Thematic Synthesis of the Experiences of Adults Living with Hemodialysis

Figure 2. Framework of the experiences of adults living with in-center hemodialysis.
“A new dialysis–dependent self” (identity)
described the effect of HD on the identity of the patient and their family roles and relationships as well as changes in their social world and future.

“A restricted life” (lifestyle)
entailed the constraints of HD on time and dietary intake and the loss of choice and freedom.

“Regaining control”
the acceptance of being dialysis dependent, adjusting to and accommodating dialysis, and gaining expertise in doing dialysis.

“Relationships with health professionals”
involved information sharing, building relationships, balancing power, and seeking expertise.
Figure 1  Evidence-based decision-making for clinical contexts.
<table>
<thead>
<tr>
<th>Outcome</th>
<th>Mean scores</th>
<th>Median scores</th>
<th>Proportion 7-9 score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients/caregivers</td>
<td>Health professionals</td>
<td>Patients/caregivers</td>
</tr>
<tr>
<td>Graft loss</td>
<td>8.3</td>
<td>8.4</td>
<td>9</td>
</tr>
<tr>
<td>Graft function</td>
<td>8.1</td>
<td>7.9</td>
<td>9</td>
</tr>
<tr>
<td>Chronic graft rejection</td>
<td>7.9</td>
<td>7.8</td>
<td>9</td>
</tr>
<tr>
<td>Acute graft rejection</td>
<td>7.9</td>
<td>7.4</td>
<td>9</td>
</tr>
<tr>
<td>Death</td>
<td>7.6</td>
<td>8.3</td>
<td>8</td>
</tr>
<tr>
<td>Infection</td>
<td>7.6</td>
<td>7.4</td>
<td>8</td>
</tr>
<tr>
<td>Cancer (non skin)</td>
<td>7.5</td>
<td>7.1</td>
<td>8</td>
</tr>
<tr>
<td>Cardiovascular diseases</td>
<td>7.4</td>
<td>7.4</td>
<td>8</td>
</tr>
<tr>
<td>Cancer (skin)</td>
<td>7.3</td>
<td>6.4</td>
<td>8</td>
</tr>
<tr>
<td>Diabetes</td>
<td>7.2</td>
<td>6.8</td>
<td>7</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>7.2</td>
<td>6.5</td>
<td>7</td>
</tr>
<tr>
<td>Surgical complication</td>
<td>7.1</td>
<td>6.5</td>
<td>7</td>
</tr>
<tr>
<td>Cognition</td>
<td>6.9</td>
<td>6.3</td>
<td>7</td>
</tr>
<tr>
<td>Ability to work</td>
<td>6.8</td>
<td>6.6</td>
<td>7</td>
</tr>
<tr>
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<td>6.8</td>
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<td>7</td>
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<tr>
<td></td>
<td>Patients’</td>
<td>Healthcare</td>
<td>Patients’</td>
</tr>
<tr>
<td>Inevitability of death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The doctors are more interested in death, and you really can’t stop death because we’re all eventually going to die at some point, whereas a healthy graft will prevent that day from coming for a very long time, so I don’t really know that death should even be in there because we’re all going to die eventually. – P1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For my partner his attitude is even if his first transplant only lasted a year, he would have had a year without dialysis, and he would have lived that long and he will say nobody expected me to live this long. He’s gained something, he sort of cheated death, so if death comes a little bit later it’s a different thing. – C1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would just like to point out that death is not a core issue. As long as I have the organ, I can live quite well, but if my graft is not functioning well, I have to go back to my previous life that is dialysis, but I won’t die. I won’t die because of the loss of my organ. So I would not be afraid of death, but I would be afraid of the loss of my graft and I would have to come back to dialysis. So this is a matter of quality of life. – P1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Everyone has to face death, what I would like to have is a good quality of life rather than to face death. – P1</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Depression

|          | 6.8 | 6.3 | 7 | 6 | 58.1 | 48.1 |
Preventing premature death

As a doctor we have a kind of inherent problem with death. We try to fight death. We are trained to put back life. – H1

Ensuring safety and quality

Death is also a safety issue for us when we look at new drugs. – H1

Regulators tend to be very very cognisant of safety issues but the patients and the physicians are telling us that the most important things are retaining a graft, so if there’s a drug that’s being reviewed for approval, and it has some safety issues, that needs to be balanced against the potential for that drug to prolong graft function versus some risk of death. – ATC Plenary

We have to include death as our quality parameters anyways so that’s where the tension is what should be implemented as endpoints, in our clinical practice, and for trials. – H8

I was a little stunned to be honest that death wasn’t at the top. As transplanters from our point of view, death is a very important complication, actually any death within a year at my institution requires a formal debriefing and conversation as to what happened. H11

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<td>7</td>
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Quality Health Care

- Institute of Medicine

1. Effective
2. **Patient centered** => Based on patient preference, patient values
3. Safe
4. Timely
5. Efficient
6. Equitable
Can it work?

Does it work?

Does it work in real life?

Is it worth it?

Can we afford it

Do we really want this rather than something else

Evaluation

Intervention

Basic science

Evidence Based Medicine

RCT

Observational data

Core outcome sets

Advanced statistics

Epidemiology

Big data

Patient reported experience

Health economy

Public management

Qualitative research

Value Based Health Care

Patient Participation

Health organisation management

Implementation

Ethics

Cultural/philosophical

Advanced statistics

Epidemiology

Intervention

Basic science

Evidence Based Medicine

RCT

Observational data

Core outcome sets

Advanced statistics

Epidemiology

Big data

Patient reported experience

Health economy

Public management

Qualitative research

Value Based Health Care

Patient Participation

Health organisation management

Implementation

Ethics

Cultural/philosophical
Patient experiences of training and transition to home haemodialysis: a mixed-methods study

1. persevering despite trepidations
   - diminishing intimidation of machinery
   - acquiescing to fatal risks
   - reconciling fears of cannulation
   - dispelling concerns of neglect
   - tolerating necessary concessions
Patient experiences of training and transition to home haemodialysis: a mixed-methods study

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2. optimising the learning pathway
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   - learning from mistakes
   - grasping technical complexity
   - minimising cognitive overload
   - progressing at own pace
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   - practising problem solving
   - learning from mistakes
   - grasping technical complexity
   - minimising cognitive overload
   - progressing at own pace

3. developing confidence
   - believing in own abilities
   - adapting to independence
   - depending on caregiver partnership
   - faith in crisis support
Patient experiences of training and transition to home haemodialysis: a mixed-methods study

4. interrupted transition momentum
   - lacking individual attention
   - language barriers
   - installation delays
   - interfering illness and complications
   - acclimatising to new conditions

5. noticing immediate gains
   - reclaiming lifestyle normality
   - satisfying self-sufficiency
   - personalising treatment regime
   - thriving in a positive environment

6. depleting resources and energy
   - exhaustion with gruelling routine
   - confronting medicalization of the home
   - draining financial reserves
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   • acquiescing to fatal risks
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