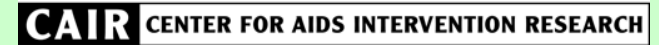




# End-of-Life Care Discussions: Are They Relevant Anymore?

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## Death and end-of-life care

- At diagnosis, patients commonly asked questions related to death:
  - “Am I going to die?”
  - “How soon will I die?”
  - “What’s the average lifespan for someone with HIV?”
- Providers defined end-of-life care in medical (treatment decision-making, advance directives/living will, health care proxy), practical (will, power of attorney, child custody arrangements), and relational (e.g., mending relationships, saying goodbye) terms
- Medical decision-making centered around:
  - Setting for care (e.g., hospital, hospice facility, home)
  - Aggressiveness and/or invasiveness of measures (to increase duration of life)
  - Comfort/palliative care (i.e., “how they want to die”)

## Context in which discussions occur

- Timing of discussion has changed since beginning of epidemic
- Providers differ in orientation toward timing of discussion
  - Never have conversation
  - At beginning of treatment
  - When patients becoming ill, but death not imminent
    - AIDS diagnosis or falling t-cell count
    - Unable to take medications and/or become resistant to virus
  - When all medical options have been exhausted and death is imminent:

“...You’ll come to a fork in the road with a patient’s care, and you can either keep pursuing things or you can stop. And...that’s when it comes up...when you think that nothing’s gonna help.”

➤ Periodically, and especially when patients choose not to take medications:

“The ones that I had trouble with, well not trouble with, the ones that are more difficult are the patients... who won’t take meds. Whose T-cell counts are now 20, who won’t take anything, and you are explaining to them, ‘Do you understand what will happen with this?’ And (it’s) just a little different than an end of life discussion, but I’ve talked to them about, ‘You need to have a will, you need to have a power of attorney, you need to have someone to take care of your son because if you won’t take these medicines, you have the potential of things happening, you need to make sure someone is going to take care of your son, or you need someone to take care of this.’ So these are a little different from end-of-life talks, because they are reality talks. I really don’t call them end-of-life, because it’s not that it’s imminent, but it’s a reality.”

## Discussion topics

- Empowering patients to make decisions about treatment
- Educating patients about palliative care: Reassuring patients and family that palliative care “doesn’t mean (that) we stop taking care of people”
- Describing consequences of continuing treatment when it is failing:
 

“We also talk about death because the options might be, ‘We can keep doing this and let’s just say you might need this surgery, but you could go into the OR...and you could die in there or you could never wake up again. Or, if you want, (you) can have this time (and) you can spend it with your family...and we can make it really comfortable.’”

“Let’s say if we treat the infection, then we’re gonna have to draw blood and (take) X-rays...You can’t just kind of give someone a medicine and not see what effects it’s having...You can’t...half-treat someone. I mean, so if you accurately describe what’s wrong and what the consequences of doing everything are to the patient, that’s the best you can do.”

## Ideal scenarios

- Patient is realistic
- Patient trusts provider and does not feel abandoned by him or her
- Patient does not have any unresolved personal issues
- Patient is not ambivalent
- Family in agreement with wishes

## Methods in Brief

- 2005-2006: 11 HIV specialists participated in one hour-long semi-structured qualitative interviews pertaining to end-of-life care discussions with their patients
- Interviews were audio-recorded and transcribed; data analyzed for themes using NVIVO7 qualitative coding software
- Most providers were physicians (64%) or nurse practitioners or nurses (36%);
- Infectious disease experience ranged from 2-21 years; 73% of providers had more than 10 years of medical practice experience
- None of the providers reported being HIV positive

### The Interview

Tell me what end-of-life care means to you.

What aspects of end-of-life care do you discuss with patients?

- When does that topic come up?
- How do you discuss death?
- When does the topic of death come up?
- Think of a time when an end-of-life care discussion went well. What made it work well?
- What is an example of a situation that did not work so well? What do you wish you would have done differently?

Are significant or supportive others ever present for discussions?

- What effect has their presence had on the discussion?
- What effect has their presence had on the patient?

## Worst-case scenarios

- Patient distrusts provider or medical system
- Patient is newly diagnosed and very ill; he or she still may be experiencing denial of or anger related to the initial diagnosis and unable to consider palliative care options
- Patient has unrealistic expectations: “You fixed me once— you can fix me again.”
- Patient or family deny possibility of death:
 

“I...have (family) saying, ‘Oh, we don’t have to worry about that. We’re gonna get you some medicine, we’re gonna get you fixed up, and you don’t even have to worry about that. That’s not even going to be an option.’ We don’t...discuss end-of-life because...they can’t hang on to it.”
- Family members disagree about best course of action
- Discussion happens in the context of non-adherence
- Discussion happens at end of life, especially with family members when the patient is unconscious

## Questioning relevance of end-of-life care discussions due to changing nature of HIV

- HIV-positive individuals are expected to live longer:
 

“I don’t have a big discussion about it with people (who) are doing well”
- HIV not unlike other chronic diseases (e.g., diabetes, hypertension):
 

“Other providers don’t talk about end-of-life care.”

## Ambivalence about having discussion

- General belief that those who become ill are non-adherent (vs. drug resistant), so death seems like a failure:
 

“It’s a pathetic loss if someone dies of HIV anymore.”
- Importance of maintaining a positive attitude:
  - To counter patients’ beliefs that they will die: “I share with them... (they) won’t die from it.”
  - Concern that discussing death precludes optimistic orientation:
 

“I will admit the first time I see the person, I don’t usually talk about end-of-life issues the way I used to. And when I first started doing this in the early ‘90s, that would actually be a standard part of my first meeting...and I stopped doing it and the reason I have—although I feel a little guilty about it—it’s because I just spent a whole lot of time telling the AIDS thing, that AIDS isn’t a death sentence anymore and they need to think positively about the future....And then to start talking about, ‘What would you want to do when it comes time for you to die?’ just seems counterproductive, so I usually wait until I know the person a little longer...”
  - Meaning of discourse:
 

“I don’t think we tend to do that because I don’t know—maybe (if we) focus more on (end-of-life care), the patient would think it was more negative. It’s not really negative—it’s just everybody should do this (have end-of-life care discussions).”

## Regrets related to discussion

- Should be more proactive about discussing end-of-life care
- Should initiate conversation much earlier in treatment: “(it comes up) too late and too close to (the) end of life”
- The discussion does not occur as often, as frequently, or with every patient as it should:
 

“We talk about complications (of HIV and) we really don’t go after it again.”

## Conclusions

- Providers framed end-of-life care holistically and in relation to significant or supportive others.
- Providers differed with regard to the timing of end-of-life care conversations; often, discussions occurred in the context of non-adherence.
- For some providers, discussing death and end-of-life care was incongruous with available treatments or implied treatment failure.
- Despite a belief that HIV has become a treatable, chronic condition, providers expressed regret at the infrequency in which end-of-life care was discussed.

## Recommendations

- Despite advances in HIV care, providers, patients, and their family members may benefit from considering end-of-life care options.
- Consider making discussions routine:
 

“This is something I talk about with all my patients...I don’t anticipate any problems like this happening, but it’s always good to know what—what people’s wishes would be before something happens.”
- Providers can emphasize benefits of planning:
  - Focus: “How you want to live?” vs. “Do you want to stop treatment?”
  - Frame discussion as an opportunity to ensure that relationship issues, financial arrangements, and treatment preferences are addressed
  - Educate patients and families that palliative care does not mean “giving up and not taking care of them.”