2019 Kinsman Bioethics Conference

Raising Voices:
The Ethics of Dialogue and Communication in Health Care

PLENARY SESSION

<table>
<thead>
<tr>
<th>Title</th>
<th>So Tired of Life: What Does Respect Require?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speaker</td>
<td>Lynn A. Jansen, Ph.D., R.N.</td>
</tr>
<tr>
<td>Date</td>
<td>Friday, April 12, 2019</td>
</tr>
<tr>
<td>Time</td>
<td>1:00 – 1:55 PM</td>
</tr>
<tr>
<td>Location</td>
<td>Playwrights Hall</td>
</tr>
</tbody>
</table>

PLENARY SESSION OBJECTIVES

- Discuss characteristics of tired of life patients.
- Review trends in the treatment of tired of life patients.
- This Review ethical considerations bearing on the healthcare professional’s role in caring for patients who are tired of life.

PLENARY SESSION SPEAKER

Lynn A. Jansen, Ph.D., R.N.

Dr. Jansen is the inaugural holder of the Madeline Brill Nelson Chair in Ethics Education in the Center for Ethics in Health Care at OHSU. After receiving her nursing degree and working as a registered nurse, she pursued academic studies at Columbia University, earning a doctorate in political science with a focus on political theory, and at the University of Chicago, MacLean Center as a postdoctoral fellow in medical ethics. Her work has appeared in the leading journals in the field including The Hastings Center Report, The Kennedy Institute of Ethics Journal, Bioethics and The Journal of Medicine and Philosophy. Dr. Jansen is the Principal Investigator on a five year RO1 Grant funded by the National Cancer Institute designed to study the impact of the optimistic bias on risk/benefit assessments by patient-subjects who enroll in early phase cancer trials. She was recently awarded a grant from the Greenwall Foundation to study the normative significance of the optimistic bias to informed consent. Her work on the optimistic bias has received national media attention and has been discussed in leading medical journals.
“So Tired of Life”: What Does Respect Require?

Lynn A. Jansen PhD
Madeline Brill Nelson Chair in Ethics Education
Oregon Health & Science University

Lynn A. Jansen, Steven Wall, Franklin Miller. Drawing the line on physician-assisted death. Journal of Medical Ethics Mar 2019, 45 (3) 190-197;
Conditional Question

- Suppose that PAD for patients who are terminally ill has been established as a legal practice in a given jurisdiction, what reasons (if any) are there to resist extending it to further classes of patients who are not terminally ill?

A Doctor’s Dilemma: Sarah

- “Dear Doctor, I hope you can help me. I am so tired. So very, very tired. I have lived a wonderful and full life, and now I am just no good. No good to myself and no good to anybody else. I have become a burden to everyone, and I have nothing left to live for. I hope you will help me. I just want to die”


Narrative Foreclosure (NF)

- The premature conviction that, even though one’s life continues, in one’s mind, one’s life story has already ended.

Characteristics of Tired of Life/NF

- A sense of aching loneliness
- The experience of not mattering
- The perceived inability to express oneself
- Multidimensional feelings of tiredness
- A sense of aversion toward feared dependence and a concern about becoming a burden to others


A sense of aching loneliness

- “Deep inside you are very much alone. Totally, totally alone.”

- “Deep heartfelt lonely feelings, regardless of whether there were others around.”

The experience of not mattering

- A sense of being dispensable, redundant and not important to people or society.

- “At the moment, I strongly feel: my life is of no consequence anymore”


Inability to express oneself

- “If only I could express myself! I could give lectures, I could do lots of this, but I just sit here. Being unnecessary. Well, then it is easy to develop a desire for death.”

Multidimensional feelings of tiredness

- “A complex and overwhelming fatigue often accompanied by a gloomy and despondent mood.”


Policy and group centered paternalism

- Group centered paternalism seeks to devise policies that attend to the interests of all affected groups.

- Paternalism can be unjustified for an individual case, while being justified at the group level.

Two types of mistakes

- Mistake 1: when a patient who satisfies the autonomy and beneficence condition is denied the option of PAD

- Mistake 2: A patient is given the option of PAD when either or both the autonomy conditions is **not** satisfied


Justified group centered paternalism

- A concern with avoiding one type of mistake (that which occurs when patients are given an option that is not in their best interests or one that they cannot autonomously choose) justifies accepting or tolerating another kind of mistake (that which occurs when a patient is denied an option that she autonomously wants and is in her best interest)

Beyond autonomy and beneficence

- WHAT DOES RESPECT REQUIRE?

Responding to suffering

- Agent-narrative suffering
- Neuro-cognitive suffering
Conclusions...

- It is not enough to listen. One must also recognize the preconceptions that one brings to the listening. When we listen, we interpret; and when we interpret we make assumptions that help us understand the meaning of what is being said.

- It is important to listen to the voices of those who are tired of life not only to better understand their plight, but also to understand, and critically reflect on, one’s own preconceptions about the aged and their value to the society in which they live.