

# On Understanding the Role of Shame and Guilt in End-of-Life (EOL) Decision Making

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OMS-III



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I have no conflicts and nothing to disclose



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## Objectives

- Delineate the differences between:
  - Nourishing shame and toxic shame
  - Healthy guilt and toxic guilt
- Discuss how shame and guilt present barriers to effective communication and decision-making in end-of-life (EOL) care
- Review current practices and research on establishing effective communication in EOL care



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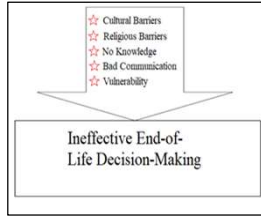
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## Barriers to Effective EOL Care <sup>1-4</sup>

- Lack of knowledge in:
  - Prognosis
  - Death and dying
- Cultural and religious barriers
- Ineffective communication
  - Discomfort with discussing EOL
  - Perceived or apparent lack of skill
  - Fear of conflict
- Vulnerability



Bates, Breggin, (2014). Diagram on Barriers Contributing to Ineffective EOL Decision-Making (Diagram)




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## Shame and Guilt in EOL Care <sup>5-8</sup>

- EOL care and the decisions made therein are stressful
- When a person feels as though there is disconnect between these two, guilt and shame can arise
  - *“Guilt and shame discourage rational thought about how we want to carry on with our lives. They are emotional warning lights to cease and desist. When they grow stronger ... they can become paralyzing” – Dr. Peter R. Breggin (2014)*




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## On Shame <sup>8</sup>

- Shame is a uniquely human power with both positive and negative qualities
- Shame takes two forms:
  - **Nourishing shame** has an inherent positive purpose in our lives
  - **Toxic shame** is an unpleasant internal experience




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## On Guilt <sup>8</sup>

- Guilt is an emotional response to one’s actions
  - Requires a sense of empath
  - Pushes individuals to assess their actions
- Guilt takes two forms:
  - **Healthy guilt** is a positive emotional feeling
  - **Toxic guilt** holds no positive connotation <sup>8</sup>

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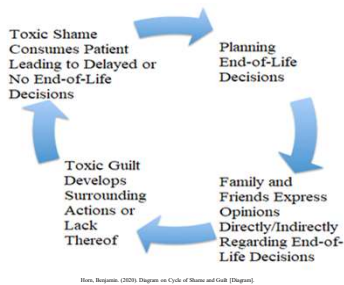
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## A Never Ending Cycle




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## Shame & Guilt in Action

- Guilt and shame activate different types of thoughts
  - What is best for me as the patient?
  - What is best for my family?
- Both impact the decisions that our patients make in EOL care decision-making and planning
  - *“Receiving help and support ... can facilitate a sense of having fulfilled [one’s] duties and responsibilities and therein reduce feelings of guilt and shame”* – Dr. Birgitta Andershed <sup>9</sup>(2014)

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## Moving Forward

- Continued training in advanced directives and handling EOL decision-making <sup>10</sup>
  - Open discussions = Establish Goals of Care
- Acknowledgement of experiences of shame and guilt in patients, family members, and medical professionals <sup>11-12</sup>
- Interdisciplinary collaboration
- Sickness narrative sharing <sup>13</sup>
- Continued research/empirical data




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