Patients’ with Parkinson's Disease, Caregivers', & Clinicians’ Perspectives of Advance Care Planning for End-of-Life Care

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Acknowledgements

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Study Questions

1. *What approaches do patients living with PD, their caregivers, and clinicians identify as being most helpful and respectful of patients' values and wishes when engaging in ACP for EOL care?*

2. *How does the therapeutic relationship between patients and their healthcare providers, the (un)availability of a support network and EOL care resources shape patients with PD's approach to EOL care planning?*

“**Advance Care Planning** is a process of reflection and communication. It is a time for you to **reflect on your values and wishes**, and to let people know what kind of health and personal care you would want in the future if you were unable to speak for yourself.

It means **having discussions with family and friends, especially your Substitute Decision Maker(s)** – the person or people who will speak for you when you cannot. It **includes discussions with your healthcare providers** to ensure that you have accurate medical information on which to make decisions. It **can also include writing down your wishes**, and may even involve talking with financial and legal professionals.”

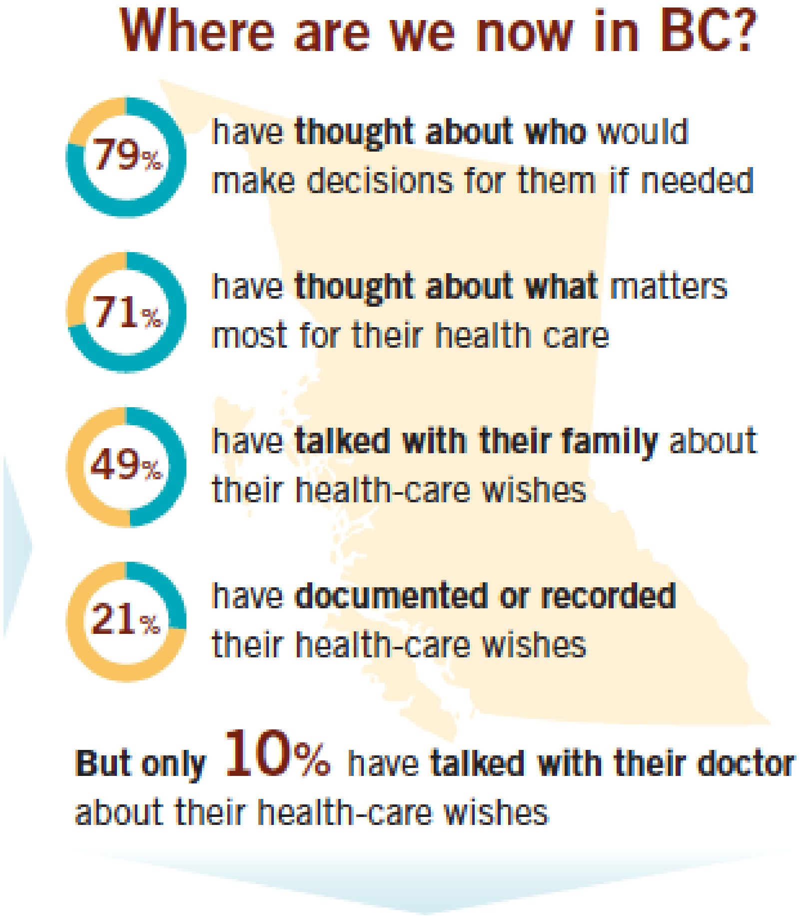
Speak Up www.advancecareplanning.ca

Background Literature

EOL care planning is highly favoured, yet patients wait for their HCPs to initiate discussion (Davison, 2006)

HCP's professional role and perceived responsibilities and degree of comfort with EOL conversations can affect their ability and willingness to support patients' and families' EOL decision-making

(Ho, Jameson, & Pavlish, 2016)



Where are we now in BC?

79% have **thought about who** would make decisions for them if needed

71% have **thought about what** matters most for their health care

49% have **talked with their family** about their health-care wishes

21% have **documented or recorded** their health-care wishes

But only 10% have **talked with their doctor** about their health-care wishes

(BC Palliative Care Centre, 2017)

Background Literature

30.3% of patients and 22.6% of family members had discussed EOL preferences with a family physician;

30.2% agreement between pts' expressed EOL preferences in an advance directive and what was documented in their medical records

(Heyland DK, Barwich D, Pichora D, et al. , 2013)

Quality of EOL communication and decision-making ranked low in 12 hospitals across Canada

(Heyland et al., 2017)

Background: Parkinson’s Disease (PD)

Calls for research on *who, how, and when* to raise advance planning for EOL care in context of Parkinsons Disease (PD) (Campbell et al., 2010; Tuck, Brod, Nutt, & Fromme, 2015; Walker, 2013; Walker et al., 2014)

Background: Parkinson’s Disease (PD)

- 100 000 Canadians with PD, incidence is predicted to triple in the next four decades (Parkinson's Society BC, 2015; Lai, 2001)

- Complexity due to:
  - Uncertainty with prognosis;
  - Variation in rate of progression and clinical presentation;
  - Cognitive impairment or dementia, in some cases (up to 70%);
  - Global functional decline leads to life-threatening complications

Study Design

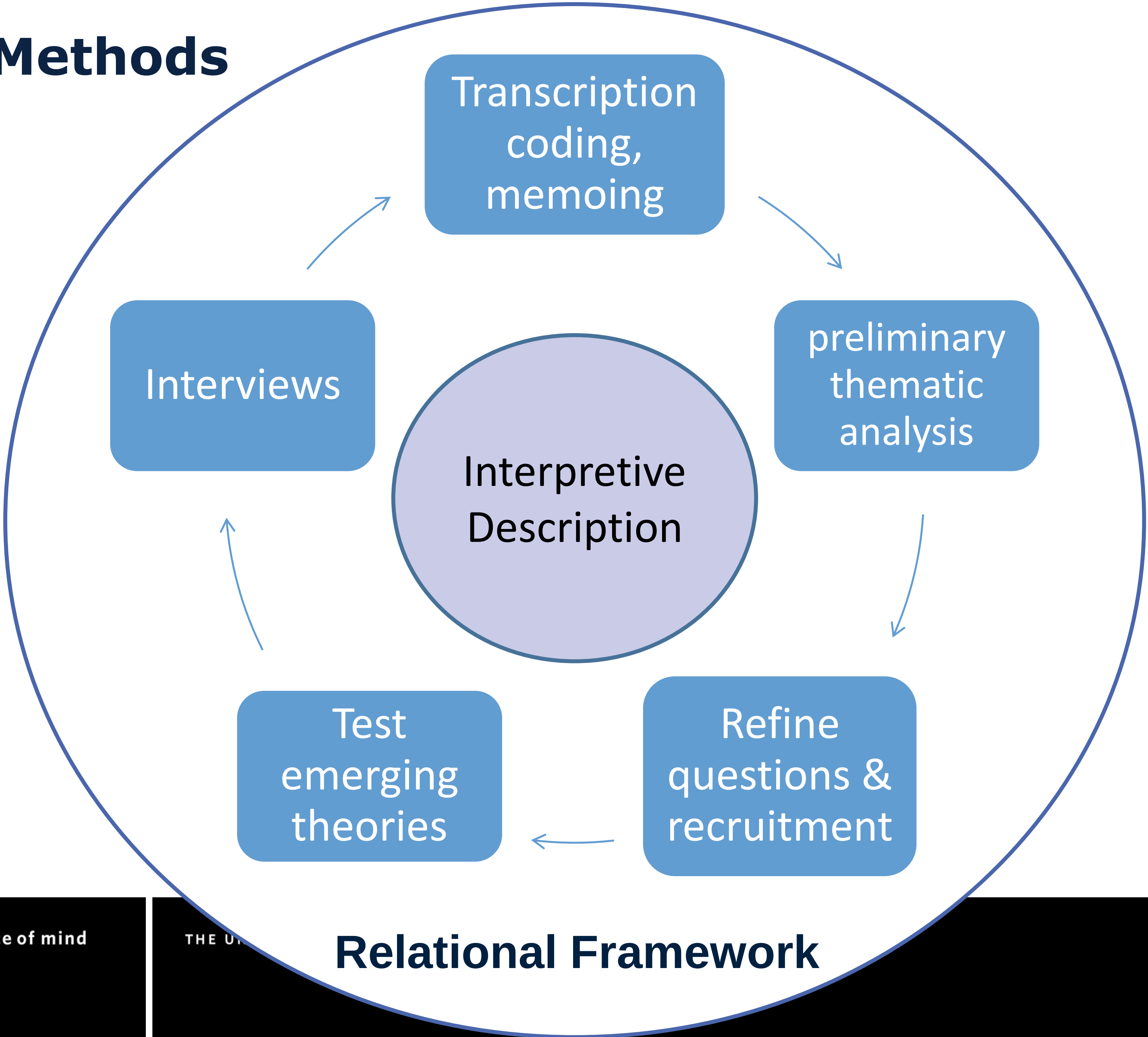
Phase 1

- Secondary analysis of interviews from "Supportive Decision-Making for Diverse Populations" study
- 8 patients with PD and 4 of their caregivers

Phase 2

- Triangulation of finding from in-depth interviews with:
- 15 patients with PD, 10-15 of their caregivers, and ~10 clinicians (Neurologist/GP/Nurse/Social Worker)

Study Methods



Transcription coding, memoing

preliminary thematic analysis

Refine questions & recruitment

Test emerging theories

Interviews

Interpretive Description

Relational Framework

Relational Autonomy Framework

"A capacity or skill that is developed (and constrained) by social circumstances. It is exercised within relationships and social structures that jointly help to shape the individual while also affecting others' responses to her efforts at autonomy"

(Sherwin, 1998, p. 36)

Preliminary Results

Demographics	Patients (16)	Caregivers (9)
Female	8	5
Age range		
46-55	-	2
56-65	3	1
66-75	8	4
76-85	3	2
86+	2	-
Ethnic origin		
White/ Caucasian	14	7
Asian	2	2

Demographics	Patients (16)
Years since diagnosis	
Range (average)	1-21 (11)
Unknown	2
Self-reported health status	
Excellent	3
Good	8
Good/Fair	1
Fair	3
Poor	2
ACP engagement *(out of 10)*	
Discussed with loved ones	7
Discussed with clinician	3
Made Advance Directive	6
Appointed Representative	7

Preliminary Findings:

Relational Facilitators:

1. *Caregiving experience*
2. *Being a burden*
3. *Supportive network*

Psychosocial & Relational Barriers:

1. *Reluctance*
2. *Reliance*
3. *Lack of clinician engagement*

Caregiver experience

*[My mother] just ended up being a vegetable there…. I kept thinking, **I don't want to be like that**. That's why I'm trying to make my own decisions now*

(PT Isla)

Being a Burden

I don’t want to be a burden on my kids*…. It's the not being me, the kids looking at me and me not knowing them. I think that would be really hard… I'm going to redo [my AD] once the [MAID] legislation comes out again*

(PT Jennifer)

It’s the dementia piece that would motivate a decision (on MAID) I think. And then ***that’s tricky because you wait too long and you’ve lost the right or the ability to choose and manage*** *and you do it. And you’re contemplating it probably while you still have fairly decent quality of life, you know.* ***It’s really a dilemma.***

(PT Renee)

Support network

"I'd say with Pamela's [wife] training, her education and work experiences have really led us to look ahead, having observed other friends and families. ***So I'm more of a follower here****."*

(PT Gregory)

Preliminary Key Findings:

Relational Facilitators:

1. *Caregiving experience*
2. *Being a burden*
3. *Supportive network*

Psychosocial & Relational Barriers:

1. *Reluctance*
2. *Reliance*
3. *Lack of clinician engagement*

Reluctance

*His dad had Parkinson's and he has seen the progress, **I don't think he wants to go there**…. and he has enough to deal with so I don’t push that.*

(SDM Bonnie)

Reliance

We pretty well run every decision by [my wife]. But, to be honest with you, ***I haven't had too much conversation with people about future care****.*

(PT Richard)

Lack of Clinician Engagement

I probably would have done it five years ago if somebody had raised it. *Somebody that I respect and trust, a neutral person. … because as you get further into the disease it's tougher to do…. The fatigue alone and with Parkinson's and you get a little confusion going on and you never know what else you're going to get.” (PT Brent)*

Key Lessons (to date…)

- Clear gaps in provider-patient conversations on EOL care
- Patient-centered care requires HCP to have understanding of the social, familial, structural, and historical factors (in addition to medical facts) that impact their patients' decisional context in order to address questions of *who/how/when* to engage in ACP for EOL care.
- Shared decision making approach;
- Individual-level (e.g. education) and system-level changes (e.g. space; interprofessional care) are needed to support patients' relational agency when engaging in ACP for EOL care

Next Steps

☐ Targeted recruitment of 5-10 patients living with advanced stages of PD and complex care needs

☐ ~10 clinicians (GP/Neurologists/Nurse/SW) of patient participants to compare & contrast perspectives.

☐ Develop guide for clinicians and patients with Parkinson’s disease on advance care planning for their end of life care decisions that promotes and respects the patient’s relational agency.

THANK YOU!

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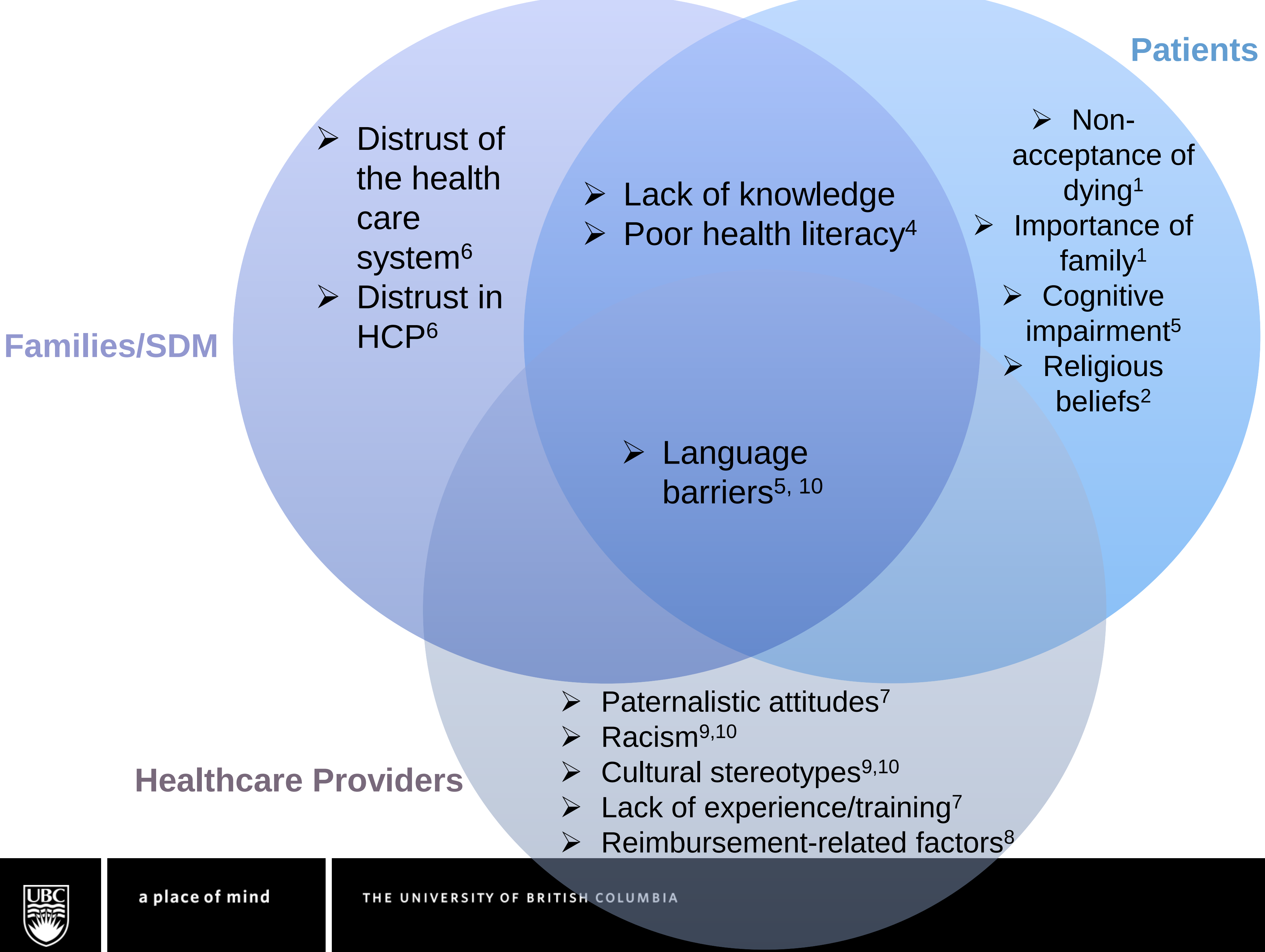
Research on ACP

- Widespread support for ACP across patient and healthcare provider groups

  (Blondeau, Valois, Keyserlingk, Hebert, & Lavoie, 1998; Hughes & Singer, 1992; Kelner, Bourgeault, Hebert, & Dunn, 1993)

- Research on outcome of ACP processes
  - Quality EOL for patients and their caregivers (Detering, Hancock, Reade, & Silvester, 2010)
  - Less aggressive healthcare interventions or palliative care approaches (Silveira, Kim, & Langa, 2010)
  - Reductions in healthcare costs due to fewer patient hospitalizations (Molloy et al., 2000)
- ACP approaches that lead to increased AD completion rates
  - Patient-centered; On-going process over several sessions; Introduced early (Bravo, Dubois, & Wagneur, 2008; Patel, Sinuff, & Cook, 2004)



Patients

- Non-acceptance of dying[1]
- Importance of family[1]
- Cognitive impairment[5]
- Religious beliefs[2]

Families/SDM

- Distrust of the health care system[6]
- Distrust in HCP[6]

- Lack of knowledge
- Poor health literacy[4]

- Language barriers[5, 10]

Healthcare Providers

- Paternalistic attitudes[7]
- Racism[9,10]
- Cultural stereotypes[9,10]
- Lack of experience/training[7]
- Reimbursement-related factors[8]