Care Planning and Decision Making in Dementia

Controversies and Solutions

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BrainXChange Integrated Webinar Series
April 20, 2016

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PALLIATIVE AND THERAPEUTIC HARMONIZATION

Objectives

- Dementia care is fraught with controversy
- My goal is to open the door to a second look at some of the cultural clinical assumptions we make in dementia care
    - Outline some challenges
    - Explore unique needs of patients/caregivers in frailty/dementia
    - Suggest an approach

Reflection 1:
Advance Care Planning: Everyone; Early

- If every physician was committed to having early and routine conversations with our patients to ensure that they have advance care plans, we could avoid suffering at the end of life.[1]
- "By planning in advance, you can be sure that your family, friends and/or health care providers know your wishes, and can ensure these wishes are followed"[2]

1. Howard et al. Can Fam Physic 2015;61:663-556
2. BC My Voice Advance Care planning Guide

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Case: Mrs. A

- 83 year old woman: CHF, CKD, COPD, DM
- Admitted to hospital with pneumonia
  - She lives alone and reports that she is independent with all activities of daily living
- While in hospital, develops chest pain
  - Consents to cardiac catheterization: 3 vessel disease
    - Develops GI bleed with anticoagulation
  - Consents to scope
- Develops delirium, team is considering CABG

Mrs. A

- Daughter is called (for the first time)
  - She sees her mom daily at home, provides assistance for all IADLs
  - Reports 5 year history of cognitive and functional decline including repetitive dressing
- Daughter brings in an advance directive completed 3 years ago with GP
  - Appoints her daughter as SDM
  - “Full code” and that she does not want to go to LTC

Mrs. A: Challenges

- While in hospital, Mrs. A has “consented” to multiple interventions
  - Presently CABG has been proposed
- Mrs. A has requested to be “Full Code” and avoid LTC
  - How do we reconcile the feasibility and appropriateness of this directive with the present situation?
- Did Mrs. A have capacity when she completed the AD?
- Has ACP maximized her autonomy?

What does the literature say?

- We routinely miss baseline cognitive impairment
  - – In the community
    - Primary care clinicians may not recognize cognitive impairment during routine history in as many as 76% of patients with dementia or probable dementia[1-5]
  - – In acute care[7,8]
    - 42% of hospital admissions had dementia, < half were diagnosed
    - And then there's delirium…
- We misidentify capacity 58% of the time[6]
  - – Identification of capacity is not a routine part of AD programming

1. Valcour VG Arch. Intern. Med. 2000 Oct 23;160(19):2964–8
2. Ganguli M. J Am Geriatr Soc. 2004;52:1668-75. [PMID: 15450043]
3. Holsinger T. JAMA. 2007;297:2391-404. [PMID: 17551132]
4. Chodosh J.. J Am Geriatr Soc. 2004;52:1051-9. [PMID: 15209641].
5. Querfurth HW.. N Engl J Med. 2010;362: 329-44. [PMID: 20107219]
6. Sessums LL. JAMA. 2011 Jul 27;306(4):420–7.
7. Moorhouse CCD Abstract Oct 2015.
8. Russ et al. Age Aging

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Understanding capacity impacts care

- When we understand cognition/capacity: decisions change!
- Data from the Palliative and Therapeutic Harmonization (PATH) program:
  - 57% of referrals had a diagnosis of dementia
  - A further 19% diagnosed as part of PATH
    - 89% of those changed their decision to decline proposed intervention after completing PATH process[1]
- Cognitive/capacity assessment must become a routine part of care where:
  - Procedures are being proposed
  - Advance directives are being created/updated
  - Discharge is being planned

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1. Moorhouse & Mallery JAGS 2012;60:2326-2332.

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Strategy: Getting the most out of ACP

- ACP is like any procedural skill
  - Not every physician is well-positioned in ACP
- ALWAYS involve a second decision maker in the process (regardless of cognition/capacity)
  - – Resistance is an opportunity for education
  - – A second set of ears to hear information, understand health as it changes
- Disclose the limitations of ACP
  - – Not all wishes are feasible to follow (circle of care)
  - – Written wishes are only as good as the updates that follow them– what is “right” today, may be harmful tomorrow
- Close the loop with navigation: Ensure whoever will be seeing the patient during the next health crisis is involved/aware

Reflection 2

- Patient-centred care means having the patient (or SDM)
  - Tell us how much information they want
  - Tell us which direction they choose
- There is no place for paternalism in modern medicine

Case: Mr. B

- 78M with dementia and severe COPD
  - (FEV1/FVC 25%)
- Lives with wife
- Dysphagia, recurrent aspiration pneumonia
  - – 4 admissions in 3 months despite modified diet
- Admitted with pneumonia: NPO, ABX, team considering G tube but concerned about operative risk/code status

– His wife (SDM) wants “everything done”

Mr. B

- When wife approached about goals of care, became angry:
  - *"I don't understand why you keep asking me this. I've already made my decision. I want everything done!"*
- *Are* we done here?

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What does the literature say?

- A diagnosis of dementia is not the fulcrum upon which capacity rests
- Even in MCI, patients have difficulty with some aspects of the consent process
  - Appreciation of how the risk/benefits apply to them[1]
  - Imagination of future self[2]
  - Impaired recall impacts understanding for future decisions
- We never assess the cognition/capacity of an SDM
  - "*She's* not our patient!"

1. Okonkwo et al., Neurology 2008;71:1474-1480.
2. Dening et al., Int Psychogeriatr 2011;23:1535-1551.

Cognition is not sufficient for capacity

- Health crisis is an intensely emotional time
- Emotionality is associated with poor executive function and inability to cognitively engage with decision making[1]
- Learned helplessness[2]:
  - Disengagement, avoidance, withdrawal

1. Mitchell and Phillips. Neuropsychologia 2007;45:617-629
2. Sullivan et al., Chest 2012;142:1440-1446.

Impact of emotionality on provider

- Clinicians are trained to heal
- Our response to feeling helpless[1]
  - – Anger, resignation, shame
  - – Anxiety: we have to *do* SOMETHING!
- We must reframe, and help our patients reframe
    - Clinician helplessness indicates engagement
    - Frank, honest information/recommendations don’t destroy hope, they reframe it[2]

1. Back et al., J Pall Med 2015;18:26-30.
2. Coulourides Kogan et al., J Pall Med 2015;18:1-7

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Is autonomy leading us astray?

- Has our emphasis on autonomy, under the auspice of "patient-centred care"
  - Insulated us from having to feel helpless?[1]
  - Clouded our ability to appreciate the benefits of a more nuanced approach to decision making?[2]

1. Back et al., J Pall Med 2015;18:26-30.
2. Hamel R. Second Opin 1995;20:75

The problem with the primacy of autonomy in medical ethics

- It unfairly absolves the clinician
  - I’m not responsible for the outcomes of patients’ choices
- It undermines the value of physician judgment and opinion (experience!)
  - What is no RCTs apply?
- It is predicated on capacity
  - But capacity is over-estimated and insufficient

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Strategy

- Be aware of the impact of emotionality and “helplessness”
  - Impact on patient capacity
  - Impact on provider micromanagement
- Take autonomy off its pedestal
  - Feminist ethics may be better suited to the nuances of complex decision making
  - Enlarge the circle of care
- Consider guided decision making

Mr. B

- Asked wife if there was someone else who could hear the information and help with decision making
- Discussion with daughter:

  "I know they're both terrified of death. My mom is worried that refusing resuscitation will mean the staff will give up on him. He doesn't want to suffer. He'd be devastated if he couldn't go home again"

  "I can't make the decision between life and death for him"

Mr. B

- Provision of information and recommendations
  - He is in the last chapter of life
  - A focus on his quality of life (symptoms) is appropriate
  - Extubation would be difficult
  - “Recovery” from each health crisis will deliver him to a state of worsened health
- Daughter decided: no code, no intubation, modified diet for comfort, antibiotics for now
- Discussion with daughter and wife
  - Wife deferred to daughter’s judgment/directive

The burden of decision making

- Being forced to make “life or death” decisions is a burden
- Patients and SDMs report:
  - Confusion: Incomplete information/experience (n = 1)
  - Uncertainty: “What if I make the wrong choice?”
  - Guilt: “If things get worse, it will be my fault: I have to consent to whatever they offer”
- The end result:
  - Less-informed decision making
  - Arguing the intervention instead of the disease as a means of insulating from guilt
  - Fracturing of therapeutic alliance: “we’re not *really* in this together”

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Strategy

- Reflect on the individualized risks and benefits of interventions *before* presenting options to patient
  - Is there *really* a decision to be made?
    - What’s medically possible? What’s appropriate?
    - What’s socially feasible?
  - “Often the truth is that there is no decision to be made and there is no burden to bear. The conversation needs to be reframed to clarify that the patient’s disease has already made the decision”[1]
  - Litigation is more common when clinicians pursue aggressive treatments, not when they limit options[2]

1. Roeland et al., J Pall Med 2014;17:415-420
2. Milani AAA. Wash Lee Law Rev 1997;54: 148-228

Shared decision making

- Shared decision-making continuum[1]
  - Patient-driven care vs provider-driven care
- The clinician is responsible for determining the appropriate level of patient autonomy when assessing treatment decisions
  - Patient values, culture, personality, limitations of medical science, the disease itself
  - Maladaptive coping necessitates more provider-driven care

1. Kon AA. JAMA 2010;304:903-904

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Maladaptive coping cues

- Emotional distress/reactivity:
  - “I don’t care what you say…”
  - “I don’t know!. You people tell me nothing!”
- Fixation on specific points:
  - “But my labs are fine!”
  - “We can’t let him die of pneumonia in this day and age!”
- Repetitive questions
  - “Why can’t you just take the cancer out?”
- Avoidance:
  - “Only god knows. Whatever will be will be”

Palliative Paternalism[1]

- Clinician directed approach to communication that
  - Uses limited open-ended questions
  - Uses well-informed discrete options during discussions
  - Is grounded in compassion and humility
- Goal is to minimize the burden of choice and avoid non-beneficial care
- When you experience maladaptive coping, it’s time to take a more directive approach
  - Direction does not close the door to discussion
  - Follow up with empathy and assurance

1. Roeland et al., J Pall Med 2014;17:415-420

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Strategy

- Identify incapacity beyond cognition
  - Embrace and shoulder the emotionality
  - Don’t wait for readiness or certainty
- Identify maladaptive coping
- Identify the drivers of unreasonable demands
- Candour and opinion are appropriate
  - What *is* certain
- Reframe hope
  - We are going to do everything we can to provide you and your husband with a comfortable and dignified death experience

Reflection 3

- We are comfortable with the idea of palliative care in dementia

Case: Mr. C

- 79 M with CLL, severe COPD, CHF, DM, stable angina, and severe stage vascular dementia
  - 3 months earlier: admission to GAU for agitation.
    - Precipitated further agitation (prior incarceration)
    - Wife brought home AMA
  - Now wandering at home, ran into traffic x 2
  - Adult Protection: if further episodes, he will be taken to ER by police for admission
  - Wife wants to keep him at home but she is not sleeping

Mr. C

- Home visit:
- Mildly agitated “trying to get home” with loose paranoid delusions “I’ve been kidnapped”
- Difficulty understanding instructions
- MMSE 11/30
- No evidence of delirium
- Seroquel 200 mg/d, 5mg olanzepine wafers prn not helpful

What does the literature say?

- BPSD are prevalent
- BPSD have adverse impacts on function and caregivers, living arrangements, and costs[1]
- Although there is modest data for their efficacy in BPSD (NNTT 5-11)[2], there is growing concern about the risks associated with antipyschotics (including atypical antipsychotics)

1. AGS Consensus Statement. JAGS 2003;51:1287-1298
2. Banerjee et al. Department of Health, 2009

Risks of antipyschotics

- Extrapyramidal side effects (EPSE)
- Anticholinergic side effects
- Alpha blocking: orthostasis
- Death: AR = 1% within 3 months
- Stroke: AR = 2%
- DVT: RR 32%, estimated AR = 0.1% over 1 year
- Resulting in Health Canada and FDA warnings and guidelines that discourage their use
  - With the caveat that they may be justified in some patients who are experiencing extreme distress

1. CATIE-AD trial. Schneider et al. NEJM 2006;355:1525-1538.
2. Banerjee S. Department of Health, 2009.
3. Schneider et al. JAMA 2005;294:1934-1943.
4. Gill et al. BMJ 2005;330:445.
5. Parker et al. BMJ 2010;431:4245

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Pain and suffering re-imagined

- Dame Cicely Saunders
- “Much of our total pain experience is composed of our mental reaction”[1]
- “Our goal should be to understand the experience of suffering in a rounded way”

1. Saunders, C. (1959) Care of the dying 3. Control of pain in terminal cancer. *Nursing Times* October 23, 1031-1032, p1032.

Consider

- BPSD are forms of distress in a terminal condition
- Sometimes there is no external antecedent that can be removed or mitigated
- We are willing to accept the risks associated with palliative chemotherapy in cancer
  - What can we learn from treating cancer pain?
  - Constant pain needs constant control: don’t wait for the pain!
- The current culture regarding these drugs is impeding our ability to effectively relieve suffering
  - The risk may be justified, even if life is shortened

Mr. C

- Discussion with wife
  - He has multiple end stage health issues
  - Intractable agitation
- Started nozinan 5mg PO TID
  - Goal: in bed, or chair. Able to walk with assistance
  - Reviewed typical risks but also decreased PO intake, AKI, DVT or pneumonia associated with sedation

2 days later

- Docile and sedate
- Difficulty understanding speech, speaking nonsense
- Caregiver exhaustion/abandonment prompted urgent inpatient admission
  - Nozinan given prn but whenever awake, violent with staff, persecutory delusions
    - Midazolam s/c used prn
  - Could not achieve consensus that nozinan should be given regularly

What is the real issue here?

- Our discomfort with antipsychotics is part of a bigger problem
- 2015 European Association of Palliative Care Delphi Panel:
  - Could not agree on the applicability of palliative care in the dementia trajectory

- *“Palliative care, with its goals of improving quality of life, maintaining function, and maximizing comfort, applies throughout the full disease trajectory in dementia”*
- Unfortunately:
  - Most of our patients with dementia have several other comorbidities that limit life
  - We’re terrible at knowing when the end is near

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Strategy

- Consider the internal suffering associated with BPSD (“total pain”)
- Contextualize treatment plan within life stage and suffering
- Embrace the risk in order to unburden the family, and ease total pain
- Acknowledge overuse, but also acknowledge a role for antipsychotics in palliation

Palliative and Therapeutic Harmonization

- The PATH model provides a framework for identifying frailty and responding to it in a way that improves patients' experience and value for healthcare dollars
- PATH includes:
  - Structured clinical models of care
    - Primary care, acute care, LTC, rehab
  - Change management/training for teams
  - Clinical Practice Guidelines for frailty
  - For more information: pathclinic.ca

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The Principles of PATH

1	Frailty must be at the forefront
2	Information changes medical decision making
3	Care planning should be collaborative, guided, and rigorous
4	Not all decisions can be made in advance; guidance during transitions in health is important

PATH Principles in Action

1	**Understand**	Standardized processes and tools to assemble the picture of frailty and health trajectory ***"What is this patient's story?"***
2	**Communicate**	Standardized approach to discussion of frailty and prognosis with the decision-maker (patient or proxy) **"Did you know?"**
3	**Plan/empower**	Build decision-maker's skills ***"What information do I need to make a decision?"***
4	**Respond**	Be available during the health crisis. ***"Who do I call and when?"***

Conclusions

- ***Advance*** care planning is not the answer
  - – Navigation during the health crisis is the answer
- Intact cognition is not sufficient for capacity
- Emotionality (ours and patients’) is an opportunity to take stock and reframe
  - – Unreasonable requests from patients
  - – Terrible decisions by doctors
- Because of these truths, we need to re-imagine our role as care providers in dementia

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- Be with the patient and family as 'the friend who can be silent with us in an hour of grief, who can tolerate not knowing, not curing, not healing, the friend who can face with us the reality of our powerlessness’ who can anticipate our dynamic needs, and guide us home

Adapted from Nouwen H. Reaching out: The three movements of the spiritual life. Garden City. NY: Doubleday 1975

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