Social Work and Advance Care Planning
What is our role in ensuring the respect of patient’s wishes for future health care?

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Introductions

• Who are you?

• Where do you work?

• How well do you know the substitute consent/advance care planning legislation in BC?

• How many episodes of the Simpsons have you watched in your lifetime?
Introduction

- Despite our best efforts, 100% of our patients will die
- We know this, our patients know this & their families know this
- Our patients deserve to be able to talk about this & express informed wishes that reflect their values, wishes & beliefs
- Yet we frequently avoid & mishandle the ACP/EOL conversation

*How can we change this culture?*
Our first obligation is to ensure our patients understand their rights

- Patients have a right to either consent to or refuse offered treatment
- Patients have a right to express their health care consent/refusal into the future by:
  - Expressing their wishes (in many forms)
  - Appointing someone to express their wishes for them
  - Expecting their SDM & HCPs will follow their wishes
  - Expressing consent instructions directly to the HCP in an advance directive

Patients must be informed about these rights to make informed decisions

- This means we must be able to talk about advance care planning
- We must find ways to be honest
- We must lose the paternalism
- We must communicate what we know about the benefits of treatment and that sometimes in health care we go too far & people suffer
- This is why we as HCPs tend to forgo futile treatment
What is the social workers role in all of this?

1. Start the culture change
2. Confront the reality of death
3. Develop competence & comfort with the conversation
4. Incorporate stories & experience
5. Be knowledgeable about the legislation and options

Marg Simpson has a new diagnosis
Defining ACP

- For capable adults for themselves
- About wishes, values, beliefs &/or instructions for health care at a time when you are not capable of making health care decisions
- A continuum, an ongoing conversation with your substitute decision maker (SDM) & health care provider (HCP)
- Possibly a written advance care plan, but not necessarily

Stages of ACP over a life-time

**First steps:** identifying a proxy & what you would want if a serious neurological event

**Middle steps:** with diagnosis of chronic disease, what would be quality of life & goals of treatment?

**Last steps:** establish a specific plan of care expressed in medical orders
4 options for ACP in BC

In BC Advance Care Planning is the process which may result in an Advance Care Plan

1. Informal communication of wishes to a TSDM
2. Representation Agreement (RA) (2 types)
3. Advance Directive (AD)
4. Representation Agreement/Advance Directive ‘combo’

The Hasting Centre Report

Limits of Advance Directives (AC Plans in BC)

- ACPs tend to be either too general or too specific to shed light on the issue to be decided.
- The best ACPs seem to be those that designate a health care proxy, but communication with the proxy is necessary
The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

309 legally competent inpatients > 80 yrs randomized into usual care vs usual care & facilitated ACP in Melbourne, Australia

- Pts EOL wishes much more likely to be known & respected (n=56 86% vs 30%, p<0.001)
- Less survivor stress (p<0.001)
- Less survivor anxiety (p<0.02)
- Less survivor depression (p<0.002)

Hope and advance care planning in patients with ESRD

Qualitative in-depth interviews with ESRD pts

- Pts rely on HCPs to initiate the ACP conversation
- The focus on clinical care without attention to future goals of care is a barrier to maintaining hope
- Unaddressed fears about the future and a lack of preparation for what lay ahead were constant threats to hope
- Pts need more and earlier information with a focus on how treatment options would affect their daily lives

Davison & Simpson, BMJ Online First, 21 September 06
VCH public forum on ACP

Community Engagement Advisory Network ACP Forum, March 27, 2010

• emphasis on benefits to person & family: “a gift to your family”
• be pure in our intentions
• ”normalize ACP“: death phobic society so present in a way that ACP does not result in lost hope

VCH public forum on ACP

Community Engagement Advisory Network ACP Forum, March 27, 2010 (cont’d)

• start ACP conversations before a crisis so that people are prepared; consider timing eg discharge from acute
• encourage conversations with friends, family & spiritual leaders as well as medical people
• access to information to learn about & understand health options (eg feeding tubes, ventilators)
An ACP with no RA or AD

Identification of the TSDM
Conversation/expression of wishes:
  - My Voice pp. 30-31
  - Informal
  - Verbal, on video, on looseleaf
  - The Catholic or other faith-based guide

Limits on refusal of life supporting care or consent to facilitate/group home placement
The TSDM list

- Spouse (marriage-like relationship, same sex)
- Child (any, equally ranked)
- Parent (equally ranked, includes adoptive)
- Brother or sister
- Grandparent (new)
- Grandchild (new)
- Anyone else related by birth or adoption
- A close friend of the adult (new)
- A person immediately related by marriage (new)

Representation Agreements

2 types of Representation Agreements:

Section 9 (enhanced) – bigger #, bigger powers
Section 7 (standard) – smaller #, lesser power
Advance Directives

- Written instructions made by a capable adult to give or refuse consent for health care directly to the adult’s health care provider
- Relevant to the decision required
- No TSDM is sought for the applicable decision in the AD
- If adult also has an RA, decisions by the representative are based on instructions in AD
- May not bind providers to give treatment that is medically inappropriate

Advance Directives

- For people with an enduring instruction

- For people with no one they trust to follow their wishes/act as a decision maker
The RA & the AD combo

- Someone who wants both to appoint a SDM and provide instructions to the HCP
- If want the AD instructions to be acted upon without the representative, must state so in the RA
Patients do not WANT CPR

They want the outcomes they think are likely to result from CPR

Decisions on CPR should be made around:

a. The patient’s pre-CPR quality of life
b. The patient’s likely post-CPR quality of life
c. The probability of CPR working

Serious Illness Communication Checklist*

1. What is your understanding of your illness?
2. How much information would you like about what is likely to be ahead?
3. What are your most important goals in whatever life you have remaining?
4. What are your biggest fears and worries about the present, the future?
5. What abilities are so critical you cannot imagine living without?
6. If you become sicker, how much are you willing to go through for the possibility of more time?
7. How much does your family know about what you want?

*Dr Susan Block, Dana-Farber Cancer Institute/Harvard Medical School
Additional Provincial Resources

▪ Health Care Providers Guide to Consent

▪ BCMA
> https://www.bcma.org/news/advance-directives

▪ Healthlink BC
> www.healthlinkbc.ca

▪ Seniors BC website link:
> http://www.seniorsbc.ca/legal/healthdecisions/

Contacting BC Health Authorities

▪ Fraser Health
> advancecareplanning@fraserhealth.ca
> 1-877-825-5034
> www.fraserhealth.ca/your_care/advance-care-planning

▪ Vancouver Coastal
> advancecareplanning@vch.ca
> http://www.vch.ca/your_health/health_topics/advance_care_planning/advance_care_planning
Contacting BC Health Authorities

- Providence
  > acp@providencehealth.bc.ca
  > Wallace Robinson wrobinson@providencehealth.bc.ca
- Vancouver Island
  > http://www.viha.ca/advance_care_planning/
  > Deanna Hutchings Deanna.Hutchings@viha.ca
- Northern Health
  > http://www.northernhealth.ca/YourHealth/AdvanceCarePlanning.aspx
- Interior Health
  > http://www.interiorhealth.ca/YourCare/EndOfLife/AdvanceCarePlanning/Pages/default.aspx
  > Judy Nicol Judy.Nicol@interiorhealth.ca

Videos

- Dr Doris Barwich “Health care consent laws have changed – what you need to know” http://www.youtube.com/watch?v=a-HFLkL5lRk
- Fraser Health Advance Care Planning
  http://www.youtube.com/watch?v=-M31-NiH3yU
- Speak Up! Advance Care Planning
  http://www.youtube.com/watch?v=2a0X9abJhio
- Atul Gawande How to Talk EOL with a Dying Pt
  http://www.youtube.com/watch?v=45b2QzxDd_o&NR=1
Additional Resources


Additional Resources

- Respecting Choices® – Gundersen Lutheran Medical Center: www.gundluth.org/eolprograms
- Australia: Respecting Patient Choices: www.respectingpatientchoices.org.au
- Calgary Health Region – Care at the End of Life Initiative-Advance Care Planning: www.albertahealthservices.ca/advancecareplanning.asp
Additional Articles

- The New Yorker Aug 2, 2010
  “Letting Go: What should medicine do when it cannot save your life” Atul Gawande

- LA Times July 26, 2009 “100 things, leading to a single choice” By Dr. Martin Welsh

Concluding comments & questions

http://www.youtube.com/watch?v=2aOXqabJhio&feature=player_embedded
Thank you!