Advance Care Planning:

Whose Job is it Anyways?

BC Nephrology Days 2008
Sue Grant, Alex Kruthaup-Harper, Karen Mahoney

- Experiences of ACP from the Patient and Family Perspective
- Experiences of Starting an ACP Program at the Health Authority level
- One Program's efforts to Engage Staff in Introducing ACP to Patients and Families

Workshop Overview

Hemodialysis Families' Perspectives on Advance Care Planning

Discussion based on the study titled:
Advance Care Planning Conversations: The Family Perspective

Alex Kruthaup-Harper

- What does ACP offer Families?
- Notion of Timing
- Readiness
- Finding Meaning
- Family Identified Barriers
- Characteristics of an ACP Facilitator
- Participant Families’ Advice

Study Overview

Study Overview

Research Style

A Qualitative study using semi-structured interviews

Setting / Inclusion Criteria

- In-centre Hemodialysis unit in a large urban tertiary hospital in BC
- All participants had worked with an ACP facilitator and completed the specified ACP workbook

Recruitment

11-months from September 2006 until July 2007

Study Overview: Participant Characteristics

Families

- Members held different positions
  - 2 X (common law) husbands
  - 3 X (surrogate) daughters
- Varied in ages from 30 years old to mid 80s

Sample Size

A total of 11 participants
  - 5 families (1 family member & HD patient)
  - 1 ACP Facilitator

HD Patients

- Were all women
- Varied in ages from 60 years old to mid 80s
- **Were not actively palliative**
- Had been on HD from < 6 months up to 3yrs

ACP Facilitator

- 2 interviews

What does ACP offer Families?

- “Peace of mind”
  - Makes the witnessing of patients’ health decline less isolating

    “That’s why I think this is so important because I wouldn’t wish it on anyone to be just thrown into [a health crisis] that is much harder. That’s what I realized and after feeling as bad as I did how it alleviated all that pain and anxiety…”

- Creates a supportive environment
  - Encourages critical reflection and open dialogue

    “This way we don’t have to argue. We know our places and we know her wishes, so there’s no more arguments, which is very good”

What does ACP offer Families?

- Context for expressing unspoken fears

> ***“I mean subconsciously I’ve thought about it. Obviously, because my mum is on dialysis you know but to face it that was the worst that’s the hardest thing. But it’s the illness, what she has and the dialysis that makes it so horrific, because we know it’s going to happen eventually and that’s what’s so scary…and now…I’m much better. We all are, I think, in the family…”***

- Often brought families closer together

> ***“It’s to enjoy what we got now. We can waste our time. We can dwell on things and be sad…Let’s just enjoy what we got …”***

Notion of Timing

Time was needed to:

- Assess individual’s ‘readiness’ for a conversation
- Work through the process alone then together
- Have a meaningful experience

“For my mum it took a long time for her to be able to decide to talk about [her ACP wishes] but eventually she did. The [ACPF] and I, we had quite a few conversations…”

Notion of Timing

Families needed time to:

- Consider their individual role(s) in the process
- Reflect on how they might react to various health situations
- Plan ahead and revisit the topic when life or a family member's health changes

"If there's an argument. I think, thank goodness this wasn't the crisis. We're arguing now? Imagine if there was a crisis…how would it be then? Our emotions would be twice as high…Yeah we'll just have a practice run…Let's see how everybody gets along…and I think sometimes you don't need to give the answer now. Come back in a month. Come back in two months"

Readiness

HD patients had to be ready to explore the meaning of life, death and their place within it.

Family members had to be ready to explore their perspectives on their loved ones’ declining health and the challenges of living on HD.

Stages of Readiness

1. Being matter of fact about death
2. Talking out loud about death
3. Facing mortality
4. Anticipating fear in the other person’s response.

Being Matter of Fact & Talking Out Loud about Death

Readiness to acknowledge the potentiality of death.

"If death happens right away, it's much easier then when you see your mother in this condition"

"I never think so much over you know [death], I always choose to go away from [the subject] but then when [the ACPF] comes, so then we do all together…then you say a couple of times these words and it's easy"

Facing Mortality & Anticipating Fear in the Other Person's Response

"Facing your mortality that's all it is and that's what hits you"

"… It's part of something that we have to face every day [in the HD unit]"

The anticipation itself becomes a barrier.

> ***"I haven't had a chance to [speak with] my family member[s] because I haven't figured out a way to do it yet, the way to approach my sister and my brother on it. That's the hardest part"***

Finding Meaning

Patients: An opportunity for completing a life review/legacy work

> ***"So now after my dialysis, after the depression and so on, I said, 'why am I going to take it that way anymore … I want my kids to see that I'm a happy mum. That's why I changed"***

Families: Expressing fear of the unknown and the challenges of this experience.

> ***"That's when I found out about life, especially my mother that it [kidney disease] came so early in her life…"***

Family Identified Barriers

- “Knowledge is power”
- Families are not being asked how they are coping with ESRD and HD
- Relying on patients for updates on their HD care when their cognition is often compromised by uremia, anemia and other complications
- Lack of <u>staff</u> readiness to engage in ACP conversations

Characteristics of an ACP Facilitator

It is not only about who does the talking but how it is said!

- ✓ Approachable, non threatening
- ✓ Flexible, open-minded & non-judgemental
- ✓ Available to act on the moment when patient status or something else in the family changes

"This is how it is and [the ACPF] really made sure we got the point…[the ACPF] wanted to make sure we understood 100%"

Participant Families' Advice

- ✓ Do not assume what the other person's wishes are, or that everyone involved is of the same understanding
- ✓ Making critical decisions during a time of crisis is distressing, planning ahead reduces the distress
- ✓ Regardless of anyone's age and health status, ACP is a necessary process that every family should go through
- ✓ An ACP facilitator or healthcare provider should be present when reviewing all ACP related documents to ensure clarity & provide additional examples to support everyone's interpretations

Participant Families’ Advice

“Communicate. [The staff] have to do something. They just assume that my mum understands“

“[Staff] to be more approachable…to come to me and talk to me is there anything we can do for you…”

“…Because I suffered a lot, especially when [mum] was diagnosed…I was terrified you know… I think what could have helped if I would have a doctor or an experienced person that I could discuss this with, what’s my role now, what should I do, you know, how should I approach this. I didn’t know”

Take Home Messages

1. **Don’t Assume**

   Unless the questions are asked upfront nobody can predict how another person will react or what actions they will take and in whose best interest these decisions will be.

2. **Communicate**

   HCPs must facilitate ongoing consistent open communication with both HD patients and their families, assessing their needs and providing supportive resources.

Creating an ACP Program at the Health Authority Level

Sue Grant
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- When you hear the term “advance directive” what do you think of?
- What is Advance Care Planning (ACP)?
- How is ACP different from living wills?
- Who is responsible for ACP?

Table Talk Questions

- People who have expressed a desire for only comfort care do not need to be subjected to the harsh reality of acute medical interventions
- Disagreement amongst families, health care providers can prevent patients from receiving the care they would have chosen while capable
- It takes a significant stress away from families if the person has made the decision before—because in the stress of the moment the system pulls them along.
- It allows an organization to honour the dying process.

Why do we need a process?

- Plans to develop an advance directive tool for use in residential care settings (2003)
- Hired a Project Manager
- Looked at different models of advance directive tools in the U.S., Australia, and Canada
- Chose the Respecting Choices® model of Advance Care Planning (ACP) because of its focus on “the conversation”

The Fraser Health Experience

- 4 health care professionals (hcps) took the 4-day instructor certification course offered by Respecting Choices® in April 2004
- Renal pilot program (35 patients) using the newly developed “My Voice” document as a guide to the conversations
- Toll free number for ACP information
- “*My Voice*” adapted as a result of feedback from patients and families

First Steps

- Identified a need to have champions for ACP in key areas throughout the system

- Respecting Choices® faculty came to Fraser Health—60 hcps (social workers, nurses, physicians, spiritual care coordinators) took the facilitator training course, and of those, 16 also took the instructor certification course

Next Steps

More Next Steps

- On-going ACP conversations with patients and families in renal program and mini pilots in 4 residential care settings
- Produced “Let’s Talk” ~ an educational DVD promoting ACP conversations
- Used interpreters to broaden the accessibility of ACP
- Partnered with South Asian community to produce an educational video in Punjabi
- Many other tools and resources developed; White Rock/South Surrey project

Legal Issues

- Worked closely with a legal expert on ACP (Joan Rush, LL.M.) to ensure that the Fraser Health process met all the requirements of the law
- During the development of the Fraser Health ACP model, legislation was being introduced to support instructional advance directives as well as proxy advance directives

- System support (health records, documentation, time, etc.)
- Legal issues seeming to sidetrack best practice
- Fluctuating budget constraints
- Strain on the acute care system resulted in ACP getting less attention

Challenges

- Increased education in home health with case managers; more resources for home health to facilitate ACP conversations
- Increased education for the public
- On-going support for ACP champions across the continuum of care

What would we have done with more resources from the get-go?

2 Main Acts:

- Health Care (Consent) and Care Facility (Admission) Act [HCCA]

- Representation Agreement Act (Proxy only)

- New AD Legislation (Instructional Advance Directive & Proxy) has been passed and received Royal Assent. Not yet enacted and regulations not yet available.

BC Legislation

- Patient—capable adult
- Representative - Appointed in a written Representation Agreement
- Spouse
- Child
- Parent
- Brother or sister
- Grandparent
- Grandchild
- Anyone else related by birth or adoption to the adult
- Close friend
- A person immediately related to the adult by marriage
- Public Guardian & Trustee as a last resort

Hierarchy of decision makers in new legislation

- Written, signed by 2 lay witnesses or 1 lawyer /notary
- Restrictions on who can witness an Advance Directive
- Cannot be:
  - A person providing care or services for compensation,
  - A child, parent, employee or agent of the adult
  - A person who is not an adult
  - A person who does not understand adult’s form of communication unless translation provided

Witnesses Required for Instructional Directive

Discussion

- When should ACP be introduced?
- Suggest some benefits of having ACP conversations with patients and their family members.
- How can ACP help with someone who CAN speak for him/herself?
- Why might patients and/or family members not want to engage in ACP conversations?

Table Talk Questions

- Do you see any barriers to facilitating ACP conversations in your clinical setting?
- What could look different in your healthcare setting?
- How could resources be allocated to facilitate the conversations; training and education?
- Consider educating clinicians in the Respecting Choices® Disease Specific PCACP intervention.

How can you facilitate ACP in your clinical setting?

- Encourage and support ACP conversations as early as possible in the continuum of care
- Set achievable goals for initiating ACP conversations
- Identify methods for sustaining ACP facilitation within the healthcare system

Three Take-Home Messages

Engaging Staff About ACP

One Program’s Efforts to Promote ACP in the Clinical Setting

Karen Mahoney

- ACP Pilot in 2004
- Unit Champion was extremely helpful
- Several staff took the ACP Facilitator Course (FH wide)
- Units without an ACP Champion? Clinical Realities
- Need for staff to develop comfort and skills in introducing ACP to patients and families
- DVD production

Chronology

- Aims:
    - To clarify the purpose of ACP
    - To distinguish ACP from EOL
    - To engage staff to reflect on barriers and benefits
    - To develop the comfort and skills required to *introduce* ACP

- What the DVD is *not*:
    - An ACP facilitator course

Starting the Conversation: ACP Training DVD