Advance Care Planning Conversations: The Family Perspective

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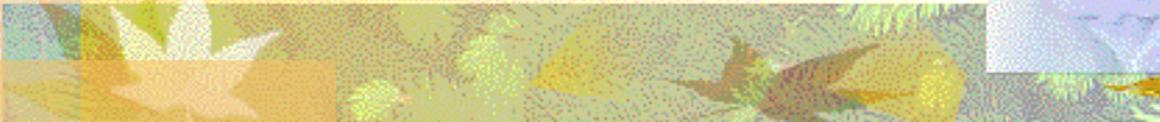
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How I came to choose this topic?

Nephrology nurses encounter ethical issues daily in their clinical nursing practice, such as:

- Renal nurses described the appropriateness of initiating and stopping dialysis as being the most common ethical conflict in their practice, frequently causing moral dilemmas and in some instances moral distress

  (Redman, et al., 1997)

- Patients ask if stopping dialysis is considered suicide?

- Patients often indicate they are ready to stop dialysis but continue for the sake of the family who are not able to let go

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Nephrology nurses encounter ethical issues daily in their clinical nursing practice con't…

- Patients and families not realizing that stopping dialysis or receiving a short trial of dialysis are treatment options

- Lack of patient/family understanding of what are conservative care and palliative care treatments

- Families inability to 'let go' often valued over patient suffering

- Healthcare providers feeling ill equipped to have conversations about dying and death

- The Medical Model appears to value quantity of life over quality of life

Key Concepts in the Study

1. The Family
2. The trajectory of Endstage Renal Disease (ESRD)
3. Healthcare provider (HCP)-Client Relationship
4. Advance Care Planning (ACP) in End-of-Life (EOL) Care

These 4 topics were central to the study. Their meaning was examined from the perspectives of the literature, the study participants, and from my researcher, professional, and personal perceptions.

Key Concept: The Family

Family was defined as: *who they say they are. The patient was included in all references to family unless otherwise indicated*

- Are an integral part of patient/family centered care

- Are significantly affected by the illness trajectory

- How the family experiences the impact of the illness determines how effectively they will manage it
  (Knafl & Gilliss, 2002; Öhman & Söderberg, 2004; Strauss, et. al, 1984; White, et. al, 2004)

- Often experience a position of silent bystander, feeling powerless & helpless in their caregiver role from both an unpredictable disease & overburdened healthcare system

- Most families feel unprepared to make decisions about EOL care issues

Key Concept: Trajectory of ESRD

- ESRD is a "family focused journey" (White, et al., 2004, p. 373)

- A long process of disability and decline prior to death

- Filled with uncertainty and complex decision making opportunities

- Its course is unique for every individual and family

- "Revolving door syndrome" illness exacerbations & frequent hospitalizations enhance uncertainty of death
  (Winzelberg, Patrick, Rhodes & Deyo, 2005, p. 293)

- Families' lives transform with each change in ESRD treatment modality

- The threat of death is a constant companion lurking in the shadows of families' subconscious (Calvin, 2004)

Key Concept:
Healthcare Provider (HCP)-Client Relationship

- Families are also HCPs' clients

- Families are dependent on HCPs for support, assistance and direction throughout the illness trajectory

- As patient's health deteriorates = $\uparrow$need for more frequent & consistent communication

- A general lack of readiness from all parties to address the topic of death & EOL care issues

- Clients who turn to HCPs for answers, direction & support with questions about death & EOL issues all too often encounter a closed door   (Dunbrack, 2005; Levine & Zuckerman, 2000)

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Key Concept: Advance Care Planning

ACP was defined as: a comprehensive process of planning ahead for health care decisions that may have to be made by an appointed representative or a (temporary) substitute decision maker in the event of incapability of the individual

([Health Region A], 2007)

- International consensus from HCPs in the value of having ACP conversations   (Blank & Merrick, 2005; Gunda, Thomas, & Smith, 2005; WHO, 2004)

- The challenge is in determining how and when EOL care discussions and decision-making should occur

- Many HCPs believe they are protecting patients by delaying or avoiding such conversations   (Song, 2004)

- Engaging in ACP does not take away patients' hope but rather transforms it   (Davison & Simpson, 2006; Song, 2004; Steinhauser et al., 2000)

Key Concept: Advance Care Planning

If no consensus on the objectives of ACP, the content of its conversations and associated documents exists then how are HCPs able to determine whether they are asking the correct questions, using the best methods to collect this data or accurately interpreting the findings?

(Kolarik, et al., 2002)

Study Overview

Problem Statement

Hemodialysis patients, their families and HCPs are in a unique position to begin the ACP process early in their illness trajectory, revising it when the patient's health status, prognosis and treatment modality changes. Such an approach enables everyone to understand how the family situates and contextualizes the illness experience thus creating an opportunity for a smooth transition into planning for EOL care

Study Overview

Purpose of Study

To explore, from family members' perspectives, the experience of participating in a facilitated ACP conversation with a loved one: the hemodialysis patient.

Research Question

"How do families of hemodialysis patients experience advance care planning conversations?"

Clarification of Study Terminology

- The word "patient" was chosen over the word "client" to represent the individual receiving care from either the family or healthcare providers.

- Endstage Renal Disease (ESRD) represents stage V of chronic kidney disease, when remaining kidney function is less than 15% (glomerular filtration rate < 15 cc/minute). If a life sustaining treatment (such as dialysis or transplant) is not sought soon the resulting body system complications caused by a build up of toxins, and fluid and electrolyte imbalances will eventually cause death

    (Candela & Parker, 2006;National Kidney Foundation, 2000b)

- There are two types of dialysis treatments: peritoneal dialysis and hemodialysis. This study focuses on hemodialysis treatments only. Hemodialysis is a process of cleaning a person's blood of toxins and impurities, and rebalancing some electrolytes, fluid, and acid-base using a special machine. The standard routine is a 4-hour treatment 3 times weekly for the remainder of a person's life. Typically, treatments take place in an outpatient clinic requiring healthcare professionals from a variety of disciplines to oversee various aspects of the treatment

    (Kidney Foundation of Canada, 2006; Thomas, 2002)

Clarification of Study Terminology

- The term "end-of-life" (EOL) in this study and thesis is used in broad context. It is meant to include all decision-making in the last days, months, or even years of an individual's life   (Hammes & Briggs, 2004)

- Facilitator is defined as a person who, as part of a group, encourages discussion and other activity without directing it or controlling it actively
(Barber, 2004, p. 531)

- Advance Directive for health or personal care consists of instructions given by a capable person, often in written form, about their wishes for health care treatment and/or personal care in the event that they become incapable of giving informed consent. The advance directive may appoint a proxy who will assume responsibility for ensuring that the person's wishes are respected   (Dunbrack, 2006, p. 25)

Clarification of Terminology

- A Representative is chosen and appointed by a capable adult through a Representation Agreement. This person must also: be an adult, be capable, have been in touch with the incapable adult in the past year, have no known dispute with the adult, and be willing to abide by the duties of a temporary substitute decision maker

([Health Region A], 2007)

- Temporary Substitute Decision Maker (TSDM) is appointed by a health care provider after an adult has lost capability and a health care decision needs to be made; chosen from the following in order: spouse, either by marriage or common law relationship (even very short term) and including same sex relationships, adult child (children equally ranked) parent (parents equally ranked) brother or sister (siblings equally ranked) any other relative by birth or adoption

([Health Region A], 2007)

Literature Review

- End-of-life (EOL) Care
  - In Canada
  - Endstage Renal Disease (ESRD)
  - Hemodialysis (HD)
- Death
- Components of Advance Care Planning
  - The influence of culture
  - Advance Directives (AD)
  - Decision-making
  - Family as Substitute Decision-Maker (SDM)
  - Role of an ACP Facilitator
  - Communication and its Breakdown
    - Between HCP-Client, HCP-HCP, Patient-Family

Gaps Remaining in the Literature

- Little research has focused directly on how patients and their families experience ACP conversations in the context of chronic illness, ESRD and HD.

- Minimal exploration of both the meaning of death and dying or its experience in ESRD and HD from patient, family and HCP perspectives

- The notion of there being 'stages of readiness' in the ACP process.

- Little research examining when is the right time to introduce ACP conversations into the illness trajectory of ESRD.

- Little research is available on the perspectives and needs of nephrology nurses' in ACP or EOL care. The majority of the literature focuses on oncology and palliative care nurses.

Methodology
Qualitative Research Approach

A Focused Ethnographic study

Postmodernist Critical Theory
(Theoretical Perspective)

Relevance of Methodology Chosen

Ethnographic research:

- Researcher is immersed in the field of study over a long period of time examining human behaviour and social interactions

- Has its origins in cultural anthropology. It is about acquiring cultural knowledge of a person's own society   (Germain, 1986)

- Appreciating the world through the participants' eyes and what they perceive as meaningful   (Roper & Shapira, 2000)

Focused Ethnography:

- Allows the researcher to select a behaviour, belief or problem *(ACP)* and study its meaning in a specific context/amongst a specific group of people *(Families in Hemodialysis)*

- Is used to develop nursing knowledge and practice   (Mueck, 1994, p. 198)

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Theoretical Perspective of Methodology:
Postmodernist Critical Theory

- Acknowledges the complexity and influence that multiple cultural and religious beliefs have on family structures and how family members explain their "illness narrative"   (Wright & Leahey, 2005, p. 30)

A cultural influence is: North American society and the health care system are generally uncomfortable talking openly about death and dying, and in planning for it.

- It is about digging beneath the surface of social life to uncover the assumptions, masks and [contradictions of the underlying reality] that keep us from a full and true understanding of how the world works

(McCormick, 2003, p. 39)

Digging beneath the surface: As families reflected on their ACP conversation, they considered their individual and collective experiences, and were able to share what meaning, value and impact the conversations had on them.

Data Collection Methods

1. In-depth semi-structured interviews

2. Participant Observations during interviews

3. Fieldnotes

    I.e. documenting the who, what, when, where & how of each interview. Noting (non)verbal cues.

4. Situating myself as an Ethnographer

    I.e.being a **nephrology nurse** provides an **'insider's view** into understanding ESRD & being a **researcher** provides an **'outsider's view** as an observer & analyzer of social interactions

5. Reflexivity

    I.e. self-reflecting on what & how my personal biases, prejudices or misconceptions before, during & after data collection/analysis potentially influence the research

Setting

- In-centre hemodialysis unit in a large urban tertiary hospital in BC

- ACP part of patient care

- Access to ACP Facilitators

- 4 out of 5 family interviews took place in participant's home. One family interviewed during HD session

- ACP Facilitator interviewed twice on site

Sampling Process

Purposive Sampling:

- Deliberately selecting participants who appeared knowledgeable about the research topic and/or had experienced the topic first hand

Recruitment:

- Posters & information leaflets available on the unit advertising study
- Nephrologist spoke with eligible patients informing them of the study

Inclusion Criteria:

- English-speaking
- At least 19 yrs of age
- Able to provide informed consent
- HD patient currently receiving HD treatment in the specific unit
- Had involved at least one family member in their ACP experience, worked with an ACP facilitator and had filled out the specified ACP workbook

The Sample

Eligible Population on HD Unit at time of Study

- 8 HD patients and their families
  - 5 Families agreed
  - 1 HD Patient died
  - 1 HD Patient's renal function recovered
  - 1 family declined. The patient indicated interest but family "not ready to revisit topic at this time"

Sample Size

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

Study Participant Characteristics

- Held different positions in the family
  - I.e., (common law) husband or (surrogate) daughter
- Varied in ages from 30 years old to mid 80s
- All participated in one family interview
- Patient had been on HD from < 6 month up to 3yrs

Sample of Interview Questions

1. Can you tell me what it has been like for you, as a family, to participate in an ACP conversation? What kinds of thoughts did you have at first and have they changed over time?

2. Could you start at the beginning and describe for me what was happening in your lives when you had your first ACP conversation?

3. Has participating in these discussions affected how you view kidney disease and hemodialysis? Can you tell me more about this?

4. Based on your experience with this topic, what sort of advice would you give me in how my family might approach this same issue?

5. What are the things that we, as a family, should consider if we were to talk about this topic?

6. Knowing what you now know about this topic, what advice would you give to the staff in the hemodialysis unit about how they should talk about or think about this issue? What were some helpful and unhelpful things you experienced yourself and as a family that you would ask them to consider?

Revisiting the Research Question

"How do families of hemodialysis patients experience advance care planning conversations?"

Study Findings

2 Major Themes

1. The ACP Process

2. Communication Breakdown

Study Findings
First Major Theme: The ACP Process

Subthemes of the ACP Process:

1. ***Initial Reactions***

2. ***Timing***

3. ***Readiness***

   a. Matter of fact about death

   b. Talking out loud about death

   c. Facing mortality

   d. Anticipating fear in the other person's response

4. ***Finding Meaning in the Experience***

Study Findings
First Major Theme: The ACP Process

5. *Study Participants' Perspectives on the Resources Provided to Facilitate the ACP Process*

   a. The Role of the Facilitator
   b. The Role of the Workbook

6. *Family Advice about the ACP Process*

Study Findings:
First Major Theme: ACP is a Process

- ACP is an invaluable experience offering "peace of mind" (1-2-12).

- Every HD family (patient and family members) should be provided with the opportunity & encouraged to go through the process. Each member has a different set of needs.

- It facilitates a positive experience in working through future health crises & at the time of the patient's death.

- Often brought family members closer together, having a renewed appreciation of the remaining time left as a family.

"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" (1_1_1391-1395).

Study Findings:

First Major Theme: ACP is a Process

- Enabled family members to share their challenges in witnessing their loved ones' declining health making their experience 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, it just, diminished, you know, it's gone" (5_7_1425-1461).

- Expressed an appreciation for having their parent make an advanced care plan in which the burden of decision-making was no longer completely theirs.

"It's ideal if I can meet with them together. It's like amazing cause you see the lights going on. The relief on the family member's face as they hear. Gee, I don't have to answer that question. My mother just answered it for me" (1_ACPF_898-910).

Validation of Findings with the Literature
ACP is a Process

- It is unrealistic to expect patients and their Substitute Decision Makers (SDM) to provide accurate reflective responses when presented with hypothetical life and death scenarios. Particularly when discussions regarding values, beliefs and wishes were not previously discussed.

- Families are but one player in ACP.

- Each member (patient, family, HCP) brings their individualized perspectives to the table, including past history and current context.

- Each person's set of needs and values about the process affect how they participate in ACP.

(Chambers-Evans, 2002; Ditto, et al., 2001; Fagerlin et al., 2001; Fried et al., 2003; Meeker & Jezewski, 2005; Pruchno, et al., 2005; Tulsky, 2005)

Study Findings:
1. Subtheme: Initial Reactions to the Conversation

Participants found themselves asking:

- What is ACP?
- Is this the right timing in my life to address this question?
- Am I ready to have a conversation about it?

Participants familiar with the topic:

"It did not come out of the blue"; "not bothered"

Participants unfamiliar with the topic:

"Eye-opening"; "it really hit me"; "signing a death warrant"

Study Findings:
2. Subtheme: Timing of the Conversation

Integral throughout all stages of the process was the need for time to:

- Assess the individual's 'readiness' to engage in a conversation
- Work through the process individually then collectively
- Time needed to create and sustain a meaningful experience

Families needed time to:

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

"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…" (1_2_683).

Validation of Findings with the Literature
Timing of ACP Conversations

- An <u>in</u>effective time for initiating EOL care dialogue is when the individual is critically ill and family stress is at its peak.

- Consensus from the literature suggests creating a process whereby a series of conversations occur over time at particular points, starting early and continuing throughout the illness trajectory, involving at least one if not all health care team members in varying capacities.

(Curtis, 2000; Davison & Simpson, 2006; Jezewski et al., 2003 Jezewski et al., 2005; Song, 2004)

Study Findings:

3. Subtheme: Readiness

- Readiness to address the notion of death & dying, and to engage in an ACP conversation.

- It changes throughout the process and must be continually reassessed prior to moving forward.

- Not just about patient and family readiness. Are the staff and ACPF ready both <u>personally</u> and <u>professionally</u> to talk about death and mortality?

Study Findings:
3. Subtheme: Readiness
a. Being Matter of Fact About Death

- Readiness to acknowledge meaning of death & talk about it

- Human beings are mortal but people make a conscious choice in whether or not they chose to face their mortality

"You're born and you die" (2_4_124).

"If death happens right away, it's much easier then when you see your mother in this condition" (1_2_49).

"I guess a lot of people just aren't comfortable talking about it...you're going to die at some point and hope that you're comfortable when you go" (2_2_169-175).

Study Findings:
3. Subtheme: Readiness
     b. Talking out loud about Death

- It transforms a person's inward thoughts outward, into reality where they cannot be retracted.

- Identifying what death means to you in the context of your current life, then sharing these thoughts with another person.

Study Findings:
3. Subtheme: Readiness
c. Facing Mortality

- HD patient's had to face their mortality while family members had to face the patient's mortality.

- Several participants were matter of fact about death but still struggled to face their mortality.

"Facing your mortality that's all it is and that's what hits you" (1_2_1264).

"If you haven't thought of it, it's time you start" (3_5_1250).

"Sure it's hard but [it] has to be done. Now we know what we want" (1_1_1898).
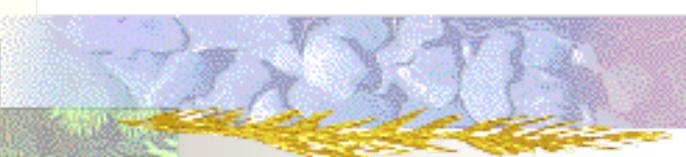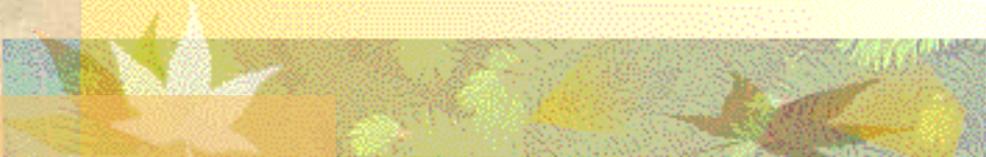
Validation of Findings with the Literature
Facing Mortality

"In fearing death, what people are actually afraid of is the end of living by not being able to complete one's life plans and the process of dying. It is the fear of losing control, enduring suffering and/or debilitation" (Pollin & Golant, 1994, p.237).

Study Findings:

3. Subtheme: Readiness

     d. Anticipating Fear in the other person's response

■ 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" (2_3_244-249).

Study Findings:
4. Subtheme: Finding Meaning in the illness experience

- An opportunity for completing a life review ("legacy work") that highlighted hopes and unaccomplished life goals.

- Living with HD confirms the reality of having a terminal disease, requiring permanent life sustaining treatment, and the potentiality of death (mortality).

- Expressing fear of the unknown in how the patient might die 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, it was just so horrendous for me because that's when it showed your mortality" (1_2_42-53).

Study Findings:

5a. Subtheme: Participants' Perspectives on the ACP Facilitator Role

The ACP Facilitator needs to be…

- Approachable, non threatening

- Flexible, open-minded & non-judgemental

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

- Encourage one to address their fears

"This is how it is and [the ACPF] really made sure we got the point. Don't walk away, like if you…kind of don't get it…Like [the ACPF] wanted to make sure we understood 100%" (4_7_3095).

Study Findings:
5a. Subtheme: Participants' Perspectives on the ACP Facilitator Role con't…

- Have time to revisit the topic, keep track of where families are at in the process and check-in from time to time to ensure they are moving forward.

- Consistently follow up with all members.

- Encourage patients to involve their families.

- Be available to act on the moment when patient status or something else in the family changes, opening up the opportunity for new discussion given the current circumstances.

These suggested characteristics resonate with the literature by Dunbrack, 2006; Jezewski & Meeker, 2005.

Validation of Findings with the Literature Being an ACP Facilitator:

- Is not the sole responsibility of one HCP or one profession.

- Is a collective decision by the team, patient and family that is based on their existing relationships, available resources and most appropriate personality fit.

(Chambers-Evans, 2002; Doukas & Hardwig, 2003; Kovacs, 2006; Marchand, 2005; Schwartz & Perry, 1999).

Validation of Findings with the Literature

HCPs' perspectives on the issues & current barriers to implementing the ACPF role effectively include:

- Lack of time to engage in ACP conversations

- Lack of consensus on when to start them and who to include

- Lack of professional training, educational and support resources to accompany these conversations

- Overcoming personal discomfort with subject matter

- Improving personal listening skills

- Honouring patient wishes even when they may conflict with own

- Requiring clarification of role responsibilities

Chambers-Evans, 2002; Doukas & Hardwig, 2003; Kovacs, 2006; Marchand, et al., 2005; Schwartz & Perry, 1999

Study Findings:
5b. Subtheme: Participants' Perspectives on the ACP Workbook

- A good resource and valuable tool
- Makes you talk about ACP, providing context, direction and a method of instigating the conversation

Noted challenges:

- Several participants commented on having to be "well educated" to comprehend the necessary yet complex medical terminology & its implications

- Participants indicated how easily the terminology can be misinterpreted if a HCP is not present to ensure comprehension

- Participants stressed the importance of having the ACPF present to ensure clarity and provide additional examples to support their interpretations

Study Findings: ACPF Observations…

- Finding the workbook incorrectly filled out
- Finding out that someone else had filled it in for the patient

"People, they don't always read the whole thing...say they've chosen, "I want to have life support no matter what." And yet the way I have come to know the patient, it doesn't seem consistent with the way they view life. So then, [what] I have done [is] I will go back and read [it through with them verbatim]. They seem to jump in and select an answer without having read the introduction" (2_ACPF_427-434).

- **Part of the ACPF's role then is to question any discrepancies, review the document in its entirety, ideally with as many members present, to ensure everyone understands what decisions have been documented.**

Study Findings:
6. Subtheme: Participant Families' Advice to Others about the ACP Process…

- Do not assume what the other person's wishes are, or that everyone involved is of the same understanding

- It is imperative that this exploration of understanding be done up front well in advance of a health crisis

- Conversations should happen when everyone is healthy, calm and can think clearly

- 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

Study Findings
Second Major Theme:
Communication Breakdown

Subthemes: Communication breakdown in the family's illness trajectory, had 3 distinct timeframes…

1. **Interactions with HCPs prior to Kidney Disease**
2. **Interactions with HCPs during ESRD**
   a. Having a chronic illness
   b. Experiences in the HD unit

Study Findings
Second Major Theme:
Communication Breakdown

Subthemes: Communication breakdown in the family's illness trajectory, had 3 distinct timeframes…

3. **Communication breakdown in the context of the ACP process**

   a. Discomfort in talking about death
      - Macro level in society and medical system
      - Meso level in the HD unit
      - Personal level both professionally and personally

   b. Positive Change
      - Increased invitations for staff to attend HD patients' funeral
      - Memory Tea to honour memory of deceased HD patients

Study Findings:

1. Subtheme: Participants' experiences prior to Kidney Disease

- Families described feeling "kept in the dark" by not being provided with:

  > I.e. explanations for long waits, decisions of care made by HCPs

- Families felt they were often left scrambling to put makeshift plans for discharge together without adequate time, resources or supportive guidance to do so.

- Families needs are often overlooked.

Outcome is…. *families' experiences have left permanent impressions of mistrust and broken faith in the system.*

Study Findings:
2. Subtheme: Participants' experiences of living with ESRD & HD

- In society, participants often described trying to maintain a 'healthy' & 'normal' appearance that often created prejudice in others who may have doubted the extent to which the illness actually was affecting the individual.

- Living with constant stigma.

- Families must be strong advocates for the patient.

- Families described feeling burdened by the responsibility of communication being left up to them to initiate, particularly if they were unable to attend dialysis sessions.

Study Findings:
2. Subtheme: Participants' experiences with ESRD & HD

Families described:

- the challenges in relying on the patient for updates when their cognition was often compromised by uremia, anemia and other complications

- communication occurring mostly between HCP and patient unless they ensured their involvement

- feeling isolated and 'out of the information loop'

- "knowledge is power"-families often did not understand the whole of ESRD or what to anticipate in the illness trajectory

- If the patient does not feel the need to communicate things to the family they are left in the dark but are often still expected to make decisions without knowing the whole story

Study Findings:
3. Subtheme: Participants' experiences with ACP

- Families/patients lack of awareness of the existence of ACP on the HD unit or what this term meant.

- The need for the HCP to establish a professional rapport and trust prior to engaging in an ACP conversation.

- Both the patient and family should be introduced to ACP and offered the opportunity to engage in a conversation.

Study Findings:
3. Subtheme: Communication Breakdown in ACP
a. Discomfort in Talking about Death

- This discomfort prevents patients, families and HCPs from openly posing questions, discussing their concerns or expressing any trepidations

"A culture of death denial prevails in dialysis units among renal staff, patients and families" (Dinwiddie et al., 2003, p.3).

- Staff's paternalistic (protective) approach does more harm than good

- One participate felt isolated as she worked through the deaths of her peers. Mostly hearing of them through the "gape vine" rather than first hand.

"There's got to be a warmer way of talking about [death] instead of leaving everybody out in the cold you know" (2_4_1218-1222).

Study Findings:

3. Subtheme: Communication Breakdown in ACP
b. Positive Change

The ACPF and I (as an HD nurse) have noticed:

> ➢ Increased invitations for renal staff to attend HD patients' funeral

The following event was just getting started on the HD unit when the study was coming to a close:

> ➢ Hosting a Memory Tea to honour the memory of deceased HD patients in which family, other HD patients and renal staff were invited to attend

Study Limitations

- My professional and political stance

    I.e. my preconceived assumptions, personal biases, prejudices

- Participant observations limited to interviews and not in the field

- Small sample size

- Encountering only one negative case

- Limited number of family member positions

    I.e. would the son or wife of an HD patient have a similar experience compared with the study participants?

- Lack of multi-ethnic study sample

    I.e. only one non-Caucasian participated in study

Study Conclusions

1. ACP is a valuable experience that every HD family should be offered the opportunity of completing

2. ACP provides a safe and supportive environment for exploring future health uncertainties

3. ACP enables individuals to face mortality and find meaning in the illness experience

4. The ideal time to initiate an ACP conversation is when everyone's health is stable and people are calm in order to think clearly

5. The role of facilitator is pivotal to the success of the ACP process

Study Conclusions

6. Understanding the medical terminology contained in ACP related documents is complex and should be supported by a facilitator to determine individual comprehension

7. Communication breakdown with HCPs continues to be present at all stages of the illness trajectory

8. Death remains a "taboo" topic on this HD unit

9. Communication with the family about EOL care & ACP wishes cannot be left up to the patient, as it is met by multiple barriers

10. Many families want to be more involved in the patient's care and want to experience improved communication with the healthcare team throughout the HD illness trajectory

Implications of Study Findings

1. Implications for Individual Practice
2. Implications for Patient Education
3. Implications for Organizational Structures and Policy
4. Implications for Further Research

Implications for Individual Practice

1. Explore what personal meanings you attribute to dying and death. Self-reflect on how these perceptions influence your professional practice.

2. Study participants described how they staff discomfort in talking about dying and death impeded client care and reinforced that it is not an acceptable topic for discussion.

3. Do not be afraid to ask about EOL care issues. Focus on creating an environment conducive to exploring this topic.

4. Consider what ethical concerns are present in everyday practice and learn how to articulate the ways in which these issues impact delivery of care. Encourage staff to have round table discussions that begin to address these matters.

Implications for Individual Practice

5. Collaborate with families and commit to continuous open and effective communication. Families want to be offered the option to engage regularly in dialogue.

6. Avoid making assumptions about how a family is managing rather contact them and ask. Families ask HCPs not to assume that :

    a. all patients are reliable resources for conveying information back to the family. Information often gets miss communicated or misunderstood if the patient is ill at the time of receiving the information/education

    b. if families have not contacted them they are managing well and do not have concerns or they would be in touch

    c. families do not want to talk about dying and death or that patients do not want to know about the deaths of their HD peers

Implications for Patient Education

1. Consider developing more family focused resources.

2. Continue encouraging and supporting both the patient and family to explore the meaning of their hemodialysis experience, the notion of death, facing mortality, and learning how to articulate what quality of life means to them.

3. Consider providing families with a more formal introduction to hemodialysis.

4. Consider developing a process for assessing the family's individual and collective needs, devising a plan of care involving everyone that can be revisited frequently throughout the illness trajectory.

Implications for Organizational Structures and Policy

1. ACP program sustainability and success requires a full commitment to a collective approach that is being simultaneously implemented from the organization's administrative level to the individual practice of front line staff. It cannot be done 'off the side of ones desk'.

2. Consider how ACP is being implemented at a local level and system wide given the study participants' identified barriers of staff discomfort with dying and death, communication breakdown, and the lack of patient/family awareness of ACP on the unit.

3. The practice philosophies of hospice palliative care and the chronic disease care model with family centered care at its core foster ACP. How does the organization's current practice philosophy foster ACP?

Implications for Further Research

1. Consider assessing whether the findings from this small study resonate with the greater HD patient/family population.

2. Study participants indicated their lack of awareness of ACP being available on the unit. Consider investigating the effectiveness of current communication strategies and what are the impeding factors.

3. Consider evaluating how patients and families are completing the ACP workbook and what their understanding is of the complex medical terminology.

4. Consider evaluating how HD patients, their families and staff perceive the effectiveness of current communication pathways, tools and resources on the unit.

Implications for Further Research

5. Consider evaluating how effectively HD families' individual and collective needs are currently being met on the unit.

6. Consider initiating an examination of the staff's current attitudes and level of comfort in addressing HD related EOL care issues and their perceived role within it.

7. Consider evaluating how HD patients and staff experience the death of other HD patients on the unit.

8. Consider examining the renal staff's perspectives on both EOL care related issues and other ethical concerns then determining how they are affecting nursing practice.

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References

- Barber, K. (Ed.). (2004). *Canadian Oxford Dictionary*. Ontario, Canada: Oxford University Press Canada.

- Blank, R. H., & Merrick, J. C. (Eds.). (2005). *End-of-Life decision making: A cross-national study*. Cambridge, Massachusetts: The MIT Press.

- Brown, H., Rodney, P., Pauly, B., Varcoe, C. & Smye, V. (2004). Working within the landscape: Nursing ethics. In J. L. Storch, P. Rodney & R. Starzomski (Ed.), *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice* (pp. 126-153). Toronto, Ontario: Pearson Education Canada Inc.

- Calvin, A. O. (2004). Haemodialysis patients and end-of-life decisions: A theory of personal preservation [Electronic Version]. *Journal of Advanced Nursing*, 46, 558–566. Retrieved Sept. 4, 2007.

- Chambers-Evans, J. (2002). The family as window into the world of the patient: Involving patients and families in the decision-making process [Electronic Version]. *CJNR*, 34, 15-31. Retrieved August 26, 2007.

References

- Curtis, J. R., Patrick, D. L., Caldwell, E. S. & Collier, A. C. (2000). Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. [Electronic Version]. *Archives of Internal Medicine*, 160, 1690-1696. Retrieved August 16, 2007

- Davison, S. N., & Simpson, C. (2006). Hope and advance care planning in patients with end stage renal disease: qualitative interview study [Electronic Version]. *BMJ*, 333, 868-869. Retrieved January 18, 2007.

- Dinwiddie, L., Pfettscher, S., Kitsen, J., McCarthy, S., & Danko, H. (2003). ESRD workgroup Final Report Summary on end-of-life care: recommendations to the field. (Research brief). *Nephrology Nursing Journal, 30*(5), 59-67.

- Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dresser, R., Fagerlin, A., Gready, R. M., Houts, R. M., Lockhart, L. K., & Zyzanski, S. (2001). Advance directives as acts of communication: A randomized controlled trial [Electronic Version]. *Archives of Internal Medicine*, 161, 421-430.

References

- Doukas, D. J., & Hardwig, J. (2003). Using the family covenant in planning end-of-life care: Obligations and promises of patients, families, and physicians. *JAGS, 51*(8), 1155-1158.

- Drought, T. S., & Koenig, B. A. (1996). Advance directives: Changing our expectations [Electronic Version]. *Chest*, 110, 589-591. Retrieved August 3, 2007.

- Dunbrack, J. (2005, March). *The information needs of informal caregivers involved in providing support to a critically ill loved one: A synthesis report prepared for Health Canada*. Ottawa, Ontario: Health Canada. Retrieved on August 20, 2007 from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2005-info-caregiver-aidant/2005-info-caregiver-aidant_e.pdf

- Dunbrack, J. (2006, August). *Advance care planning: the glossary project final report*: Health Canada. Ottawa, Ontario: Health Canada. Retrieved August 20, 2007 from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2006-proj-glos/2006-proj-gloss_e.pdf

References

- Fagerlin, A., Ditto, P. H., Danks, J. H., Houts, R. M., & Smucker, W. D. (2001). Projection in surrogate decisions about life-sustaining medical treatments [Electronic Version]. *Health Psychology*, 20, 166-175.

- Fried, T. R., Bradley, E. H., & Towle, V. R. (2003). Valuing the outcomes of treatment: Do patients and their caregivers agree? [Electronic Version]. *Archives of Internal Medicine*, 163, 2073-2078.

- Germain, C. (1986). Ethnography. The method. . In P. L. Munhall & C. J. Oiler (Eds.), *Nursing research: A qualitative perspective* (pp. 147-162). Norwalk, CT: Appleton-Century-Crofts.

- Gunda, S., Thomas, M., & Smith, S. (2005). National survey of palliative care in end-stage renal disease in the UK [Electronic Version]. *Journal of Nephrology, Dialysis and Transplantation*, 20, 392-395.

- Health Region A. (2007). *Planning in advance for your future healthcare choices*. Retrieved November 26, 2007, from health regions website.

References

■ Jezewski, M. A., & Meeker, M. A. (2005). Constituting advance directives from the perspective of people with chronic illnesses. [Electronic Version]. *Journal of Hospice & Palliative Nursing*, 7, 319-327. Retrieved 29 March 2006.

■ Jezewski, M. A., Meeker, M. A., & Schrader, M. (2003). Voices of oncology nurses: What is needed to assist patients with advance directives [Electronic Version]. *Cancer Nursing*, 26, 105-112. Retrieved August 30, 2007.

■ Knafl, K. A., & Gilliss, C. L. (2002). Families and chronic illness: A synthesis of current research [Electronic Version]. *Journal of Family Nursing*, 8, 178-198. Retrieved August 31, 2007.

■ Kolarik, R. C., Arnold, R. M., Fischer, G. S., & Tulsky, J. A. (2002). Objectives for advance care planning [Electronic Version]. *Journal of Palliative Medicine*, 5, 697-704.

■ Kovacs, P. (2006). Family-centered care: A resource for social work in end-of-life and palliative care [Electronic Version]. *Journal of Social Work in End-of-life & Palliative Care*, 2, 13-27. Retrieved August 21, 2007.

References

- Larson, D. G., & Tobin, D. R. (2000). End-of-Life conversations: Evolving practice and theory [Electronic Version]. *JAMA*, 284, 1573-1578.

- Levine, C., & Zuckerman, C. (2000). Hands on/hands off: Why health care professionals depend on families but keep them at arm's length [Electronic Version]. *Journal of Law, Medicine & Ethics*, 28, 5-18. Retrieved August 26, 2007.

- Marchand, L., Fowler, K. J., & Kokanovic, O. (2005). Building successful coalitions to promote advance care planning [Electronic Version]. *American Journal of Hospice & Palliative Medicine*, 22, 437-441. Retrieved September 5, 2006.

- Martin, D. K., Thiel, E. C., & Singer, P. A. (1999, January). A new model of advance care planning: Observations from people with HIV [Electronic Version]. *Archives of Internal Medicine*, 159, 86-92.

- Mc Cormick, J. (2003). Synopses of theories. In *NURS 512: Experiences of health, illness and healing*. Victoria, BC: University of Victoria.

References

- Meeker, M. A., & Jezewski, M. A. (2005). Family decision making at end of life [Electronic Version]. *Palliative and Supportive Care*, 3, 131–142. Retrieved September 10, 2007.

- Muecke, M. A. (1994). On the evaluation of ethnographies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 187-209). Thousand Oaks, CA: Sage Publications.

- Öhman, M., & Söderberg, S. (2004). The experiences of close relatives living with a person with serious chronic illness [Electronic Version]. *Qualitative Health Research*, 14, 396-410. Retrieved August 31, 2007.

- Ollife, J., & Mroz, L. (2005). Men interviewing men about health and illness: Ten lessons learned. [Electronic Version]. *Journal of Men's Health & Gender*, 2, 257-260. Retrieved July 30, 2007.

- Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods* (7 ed.). Philadelphia, PA: Lippincott Williams & Walkins.

- Pollin, I., & Golant, S. K. (1994). *Taking Charge: Overcoming the challenges of long-term illness*. New York: Times Books.

References

- Pruchno, R. A., Lemay, E. P., Field, L., & Levinsky, N. G. (2005). Spouse as health care proxy for dialysis patients: Whose preferences matter? [Electronic Version]. *The Gerontologist Journal*, 45, 812-819.

- Redman, B. K., Hill, M. N., & Fry, S. T. (1997). Ethical conflicts reported by certified nephrology nurses (CNNs) practicing in dialysis settings [Electronic Version]. *ANNA Journal*, 24, 23-33. Retrieved January 10, 2006.

- Rodney, P. (Personal Communication, September 21, 2005).

- Roper, J. M., & Shapira, J. (2000). *Ethnography in nursing research.* Thousand Oaks, CA: Sage Publications.

- Schwartz R. D., & Perry, E. (1999). Medical family: a new view of the relationship between chronic dialysis patients and staff arising from discussions about advance directives [Electronic Version]. *Journal of Women's Health & Gender-Based Medicine*, 8(9), 1147-1153. Retrieved August 10, 2007.

- Singer, P. A., Martin, D. K., Lavery, J. V., Thiel, E. C., Kelner, M., & Mendelssohn, D. C. (1998). Reconceptualizing advance care planning from the patient's perspective [Electronic Version]. *Archives of Internal Medicine*, 158, 879-884.

References

- Song, M.-K. (2004). Effects of end-of-life discussions on patients' affective outcomes [Electronic Version]. *Nursing Outlook*, 52, 118-125. Retrieved October 10, 2006.

- Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers [Electronic Version]. *Ann Intern Med*, 132, 825-832. Retrieved August 10, 2007.

- Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Suczek, B. & Wiener, C. L. (1984). *Chronic Illness and the Quality of Life* (2nd ed. ed.). St. Louie, Missouri: C. V. Mosby Company.

- Tulsky, J. A. (2005). Beyond advance directives: Importance of communication skills at the end of life [Electronic Version]. *JAMA*, 294, 359-365.

- White, N., Richter, J., Koeckeritz, J., Munch, K., & Walter, P. (2004). "Going forward": Family resiliency in patients on hemodialysis [Electronic Version]. *Journal of Family Nursing*, 10, 357-378. Retrieved August 30, 2007

References

- Winzelberg, G. S., Patrick, D. L., Rhodes, L. A., & Deyo, R. A. (2005). Opportunities and challenges to improving end-of-life care for seriously ill elderly patients: A qualitative study of generalist physicians [Electronic Version]. *Journal of Palliative Medicine*, 8, 291-299. Retrieved August 30, 2007.

- World Health Organization. (2004). A glossary of terms for community health care and services for older persons WHO Center for Health Development Ageing and Health Technical Report, [Electronic Version], Volume 5 from http://whqlibdoc.who.int/wkc/2004/WHO_WKC_Tech.Ser._04.2.pdf

- Wright L. M., & Leahey, M. (2005). Theoretical foundations of the Calgary family assessment and intervention models. In *Nurses and families: A guide to family assessment and intervention* (4 ed., pp. 57-78). Philadelphia: GF. A. Davis Company