AGAIN – Aligning Goals Addressing Individual Needs

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Study Participation

Physicians, Family Caregivers, Patients and Staff at Sunnybrook Family Health Team

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Background

- A growing number of people are living longer with multi-morbidities (CIHI, 2011)
  - Use more health care services and are more likely to experience fragmented care than the general population (Corser, 2011)
- Few decision making supports for these people and their care providers (e.g., clinical practice guidelines) (Upshur, 2008)
  - Goal setting has been recommended as a decision support tool but only 48% of Canadian seniors discuss treatment goals with health professionals (CIHI, 2011)
- When goals are driven by health professionals they may not be congruent with patient and family caregiver goals (Bogardus et al, 2001)

Objectives

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1. Examine ***goals of care for the patient*** from the perspectives of patients, their informal caregivers and primary care providers
    (a) Examine extent of ***alignment*** of the three perspectives on goals for the patient

2. Describe the ***frustrations*** *that* patients, their family caregivers and primary care providers experience in the health care system

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Methods

- **Setting**
  - Sunnybrook Family Health Team (Toronto, ON)
- **Inclusion criteria for patient participants**
  - 65+
  - > 2 morbidities
  - Informal caregiver
  - English speaking
  - Willing to be approached by Research Associate

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Methods

Study Design

- Qualitative Description

Data Collection

- Semi-structured interviews
- Data collection tool
  - Semi structured interview guide (Kuluski et al., 2013)
    - » Open and closed ended questions
    - » Patient, caregiver and physician versions

Sampling

- Purposeful sampling

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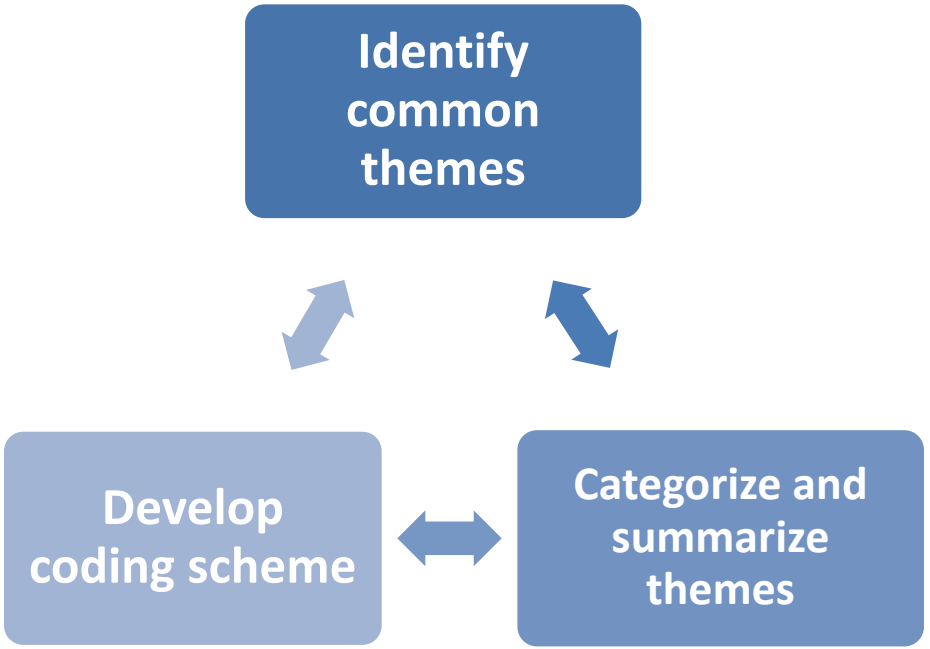
Methods

Data Analysis

- ***Quantitative data***
  - Descriptive statistics
  - Measures of central tendency
  - SPSS version 17
- ***Qualitative data***
  - Qualitative description (Sandelowski, 2000)
  - NVIVO9



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Sample Demographics

RESULTS

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Sample Characteristics

Patients (n = 28)

- **56% male**; average age **82.3 years**; 67% married, **70% more than high school education**; **96% Caucasian**; **85% can support self financially**; **70% live with someone else**; average # **morbidities** 4.61

Caregivers (n = 28)

- **82% female**; **mean age 70.5**; **61% spousal caregivers**

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Patient, Caregiver, and Primary Care Physician Goals of Care

RESULTS

Patient Goals

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Example Quotes: Patient

Health Maintenance

"just to keep doing what I am doing basically..."

Health Improvement

"My goal is to bring down my blood pressure."

Behavior Change

"To lose weight and to exercise."

Preparation for Future Needs

"I've got to either get somebody in here to stay, to live with me, or go to a care facility. And I prefer to stay here and get somebody to come in. End of story."

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Caregiver Goals

- Health Maintenance
- Health Improvement/ Symptom Management
- Preparation for Future Needs
- Continue Role as a Caregiver
- Keeping the Care Recipient Safe
- Helping the Care Recipient Maintain Dignity

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Example Quotes: Caregiver

Health Maintenance

"His mobility is something that's very important to him. Our grandchildren, our family is very important. And because we have a summer cottage that is sort of a gathering point of all the family, it's important to him and to me too to be able to assemble there and do things."

Health Improvement/Symptom Management

"I think pain control is a big issue."

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Example Quotes

Preparation for Future Needs

"trying to convince her that it's a safer way that she can do things independently instead of she looks at it as something that's showing people she's an invalid, shall we say."

Continue Role as a Caregiver

"So my goal certainly is to support him to go to all of his appointments and to keep track of his health, and to feed him well."

"I think to keep calm and don't lose my temper and a few other things like that."

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Example Quotes

Keeping the Care Recipient Safe

"My goal is for him to be safe. Because he doesn't walk, I'm concerned that if he tries to get out of bed or forgets that he can't walk they he might have a fall".

Helping the Care Recipient Maintain Dignity

"But as she has said on many occasions, she would like to die with dignity. I think she realizes she's sort of at the latter stages of her life now"

Physician Goals

- Health Maintenance
- Health Improvement/ Symptom Management
- Preparation for Future Needs
- Keeping the Care Recipient and Caregiver Safe

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Example Quotes: Primary Care Physician

Health Maintenance

"And he had the stroke. So he's now living at home with his wife and doing well. So it's just maintaining his independence and comfort at home, I would say."

Health Improvement/ Symptom Management

"Right now is we have to currently figure out why he's just having acute decline in his mobility. So that's the big goal, is figuring out what's causing this. Which I haven't unearthed and neither have a few specialists."

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Example Quotes: Primary Care Physician

Preparation for Future Needs

"I also would say the big thing would be to sort of prepare him as his dementia worsens, for both him and his wife, who's not my patient but I'm conscious that it has a huge impact on her."

Keeping the Care Recipient and Caregiver Safe

"So safety is a big concern for him. He lives with his elderly wife who's the primary caregiver. So she's at huge caregiver burnout risk there."

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Little alignment when looking across triads

Patient	Caregiver	Physician
"Staying alive...to stay positive and upbeat..."	"...help with the memory loss, improving memory, he still enjoys social contacts..."	"So safety is a big concern for him. He lives with his elderly wife who's the primary caregiver. So she's at huge caregiver burnout risk there. And most recently, he's always had sort of outbursts of anger where he would, you know, hit things or throw things but not directed at her. But more recently she expressed some concern that, you know, he may actual direct it at her; so I guess my goal of care is to try to come up with a good long term care plan".

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Alignment/Misalignment

Alignment tended to occur when patients had….

- stable health
- a very specific symptom or acute exacerbation

Misalignment tended to occur when patients had….

- unstable, fluctuating health problems
- cognitive decline
- Needs that extended beyond their current care environment

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Patient, Caregiver, and Primary Care Physician Challenges

RESULTS

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Patient Frustrations

Poor Communication	• Poor feedback from providers • Between healthcare providers
Lack of Coordination	• Planning care difficult with multiple providers • e.g. scans, blood work, procedures
Turnover of Medical Trainees	• Consistent providers • Streamline assessment
Long Waits	• Scheduling appointments and feedback • Waiting for clinic appointment
Frustrated with Themselves, Symptom or Disease	• Decision making • Identifying solutions to health problems • Frustrated with disease or themselves

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Patient Example: Lack of Coordination/Communication

"And I knew I was going to have another CT scan with (Specialist MD's name) in April so I tried to get the system to put the 2 scans together because they were the bladder and the aneurism…I was trying to eliminate 2 scans and have 1 do the job of both... First of all, (Specialist MD's name) wouldn't do it. He wouldn't return my call even. And then when I got on the table, when I went to the room that morning to get the CT scan, they said that they couldn't do it because it hadn't been asked for."

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Caregiver Frustrations

Poor Communication	• Poor feedback from providers • Between healthcare providers
Lack of Coordination	• Planning care difficult with multiple providers • Need a “point person” for management
Turnover of Medical Trainees	• Consistent providers • Streamline assessment
Long Waits	• Scheduling appointments and feedback • Waiting for clinic appointment
Frustrated with Patient, Symptom, or Disease	• Non-adherence to treatment • No direct solutions

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Caregiver Example: Decision-making

"You want the expert in a given area to be addressing a certain thing. You want the person that is best trained in that area. And there's no question about that. But somehow you want them also to look at the other aspects... And that's hard to achieve because we do need the specialities. We do need the expertise in a narrow way. But we need the whole picture. And that's where I think the old-fashioned family doctor comes into play."

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Primary Care Physician Frustrations

Poor Communication	• Poor feedback from specialist physicians • “Too many cooks in the kitchen”
Access to care	• Unmet needs due to inaccessible services
Frustrated with Patient, Symptom, or Disease	• Non-adherence to treatment • No direct solutions • Poor self-management

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Primary Care Physician: Inaccessible Services

"When you have a patient in heart failure, it's incredibly frustrating to try to manage them as an out-patient... It's a huge health system issue. Like she shouldn't have to go to the Emergency Department… When you know that somebody is heading to Emergency, there's a point where you could intervene before. And if there was a way to consult like urgently, I think you could avoid a lot of hospitalizations."

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Conclusions

- Despite commonalities at the aggregate level → little congruence in patient- caregiver-physician goals
  - particularly for patients with unstable health and changing care needs
- Patients, caregivers and family physicians shared many common frustrations (e.g. wait times, lack of coordination) → highlighted different perspectives on these issues
  - Wait time for patient = decline in health, issues with decision making
  - Wait time for caregiver = time from work
  - Wait time for physician = waiting for specialist input

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Future Research

- How can goal setting be embedded into regular primary care practice?
  - How can expected role differences be reconciled in the goal setting process?
- Opportunities to scale existing approaches to care delivery for complex patients (beyond patient-physician consultations)
  - IMPACT clinic (Upshur et al, 2013)
  - GRACE model (Boult, 2009)
  - Increased access to specialists (Liddy et al., 2011)

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Thank You

QUESTIONS & COMMENTS

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