"Where do we go from here?" Frustrating Care Experiences from the Perspectives of Complex Patients, their Caregivers, and Family Physicians

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Acknowledgements

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Study Participation

Physicians, Family Caregivers and Patients at Sunnybrook Family Health Team (Toronto, ON)

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Background

- Seniors with multimorbidity has increased (CIHI, 2011)
  - Greater acute care use, longer emergency department stay
  - Later years (> 80), average 7.7 conditions, 8.2 medications (Vegda, 2009)

- Aging at Home Strategy → Self-manage within community
  - Fragmentation of Care (Corser, 2011)
    - Primary care + Specialists + Community Providers
  - Few clinical practice guidelines (Upshur, 2008)

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Objectives

Primary Objectives

Describe the ***frustrations*** that complex seniors, their informal caregivers, and primary care physicians experience while achieving their goals of care

Rationale

Important to understand if seniors can self-manage and what barriers currently exist

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Methods

Study Design

- Mixed Methods
- Qualitative Description (Sandelowski, 2000)

Data Collection

- Semi-structured interviews
- Open and closed ended questions
- Standardized scales

Sampling

- Convenient, purposeful sampling

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Methods

- **Setting**
  - Sunnybrook Family Health Team (Toronto, ON)
- **Inclusion criteria for patient participants**
  - 65+
  - > 2 morbidities
  - No mental or physical incapacity
  - Informal caregiver
  - English speaking
  - Willing to be approached by Research Associate

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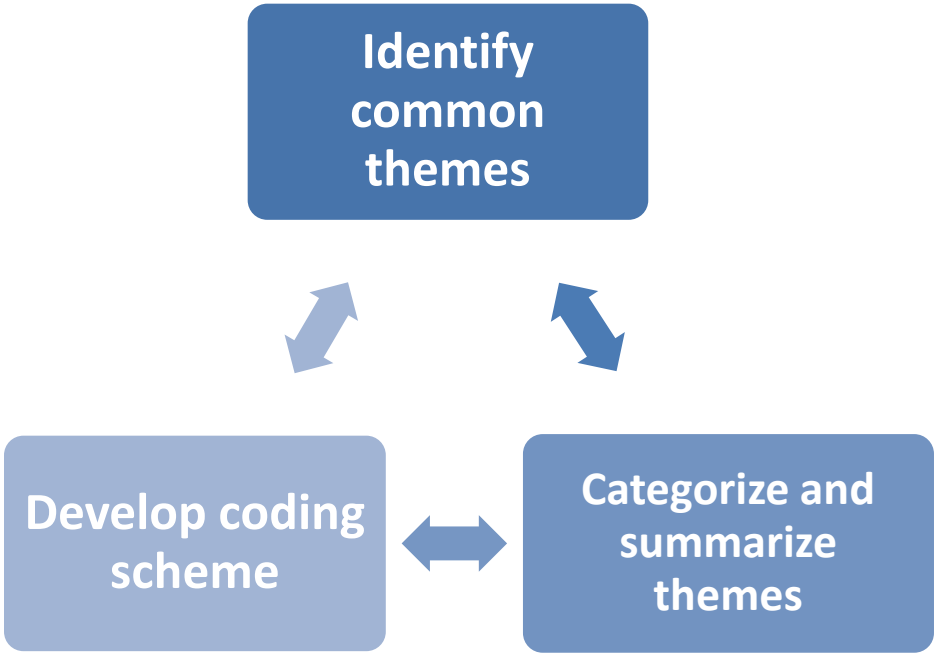
Methods

Data Analysis

- Qualitative data managed via NVivo9 (QSR International)
- Thematic Content Analysis (Green & Thorogood, 2009)



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Patient, Caregiver, and Primary Care Physician Demographics & Themes

RESULTS

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Patient & Caregiver Demographics

	Patient (n = 27)	Family Caregiver (n = 27)
Age	82 (67-96 years)	70.5 (50-91 years)
Sex		
Male	56%	21%
Female	44%	79%

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Patient Demographics con't (n = 27)

	Percent (%)
Martial Status	
Married	67
Other	33
Education	
High School or less	30
More than High School	70
Live Alone?	
Yes	30
No	70
Type of Home	
Single/Family Home	70
Apartment	15
Retirement Home	7
Other	7

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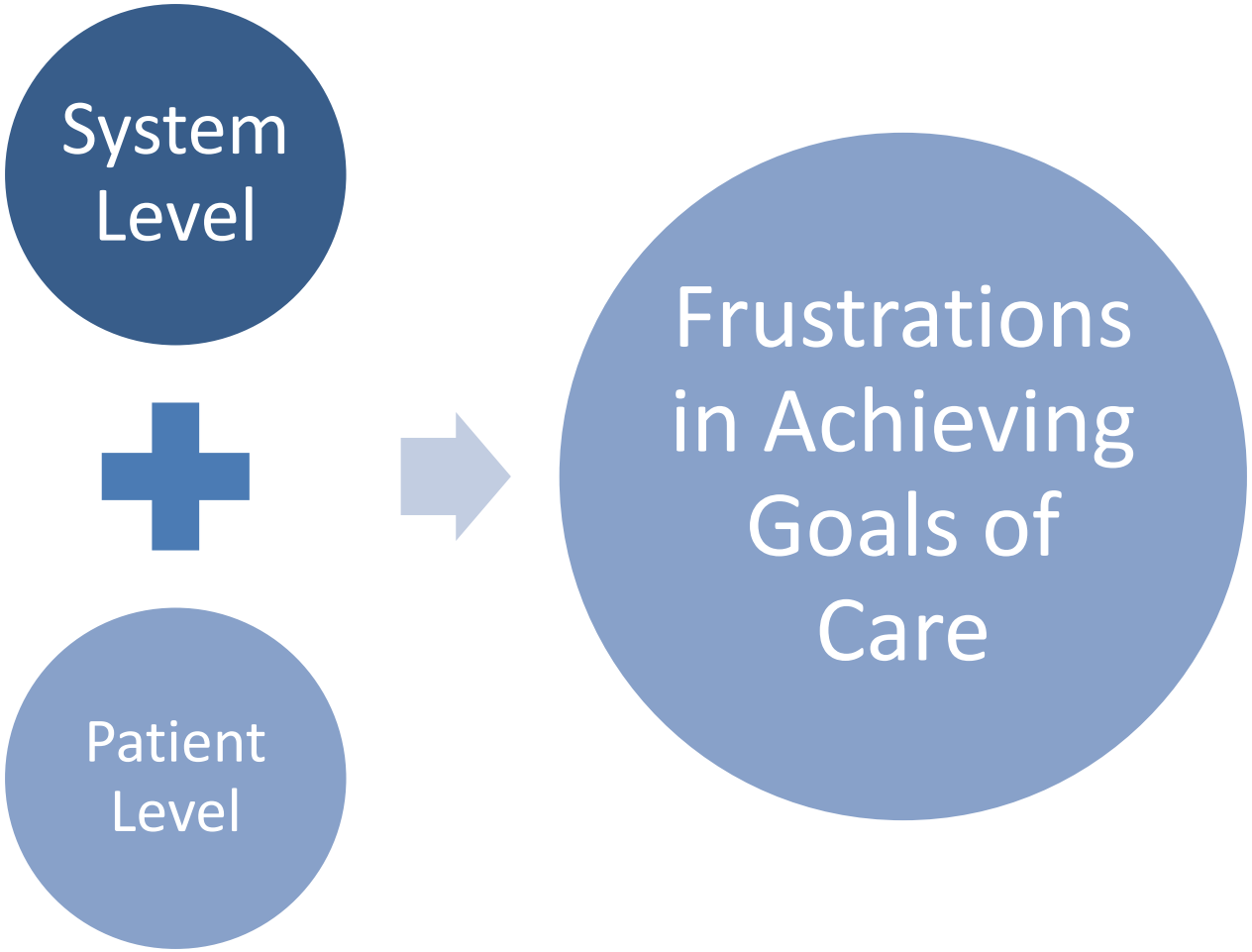
Frustrations: Overview



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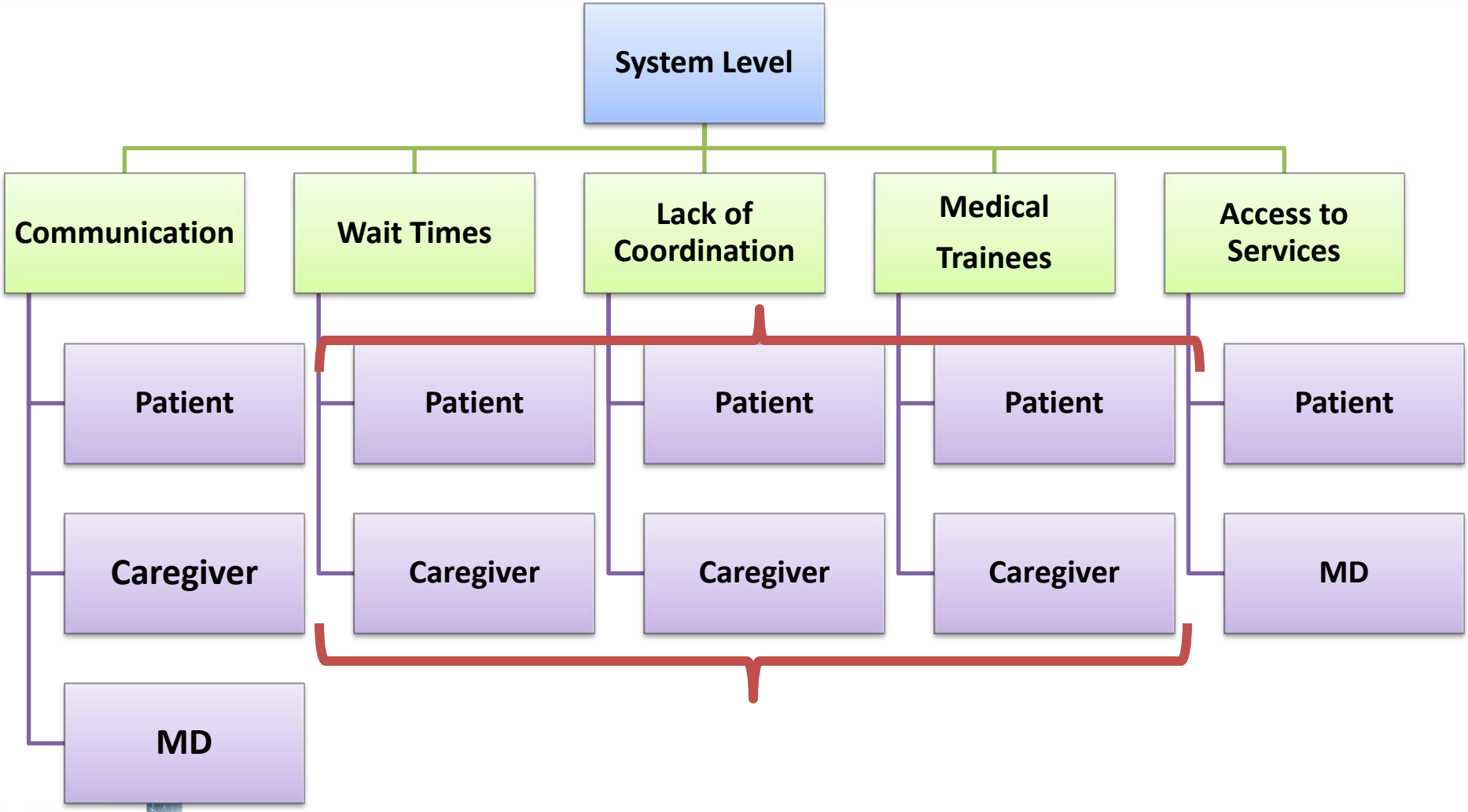
System-Level Frustrations



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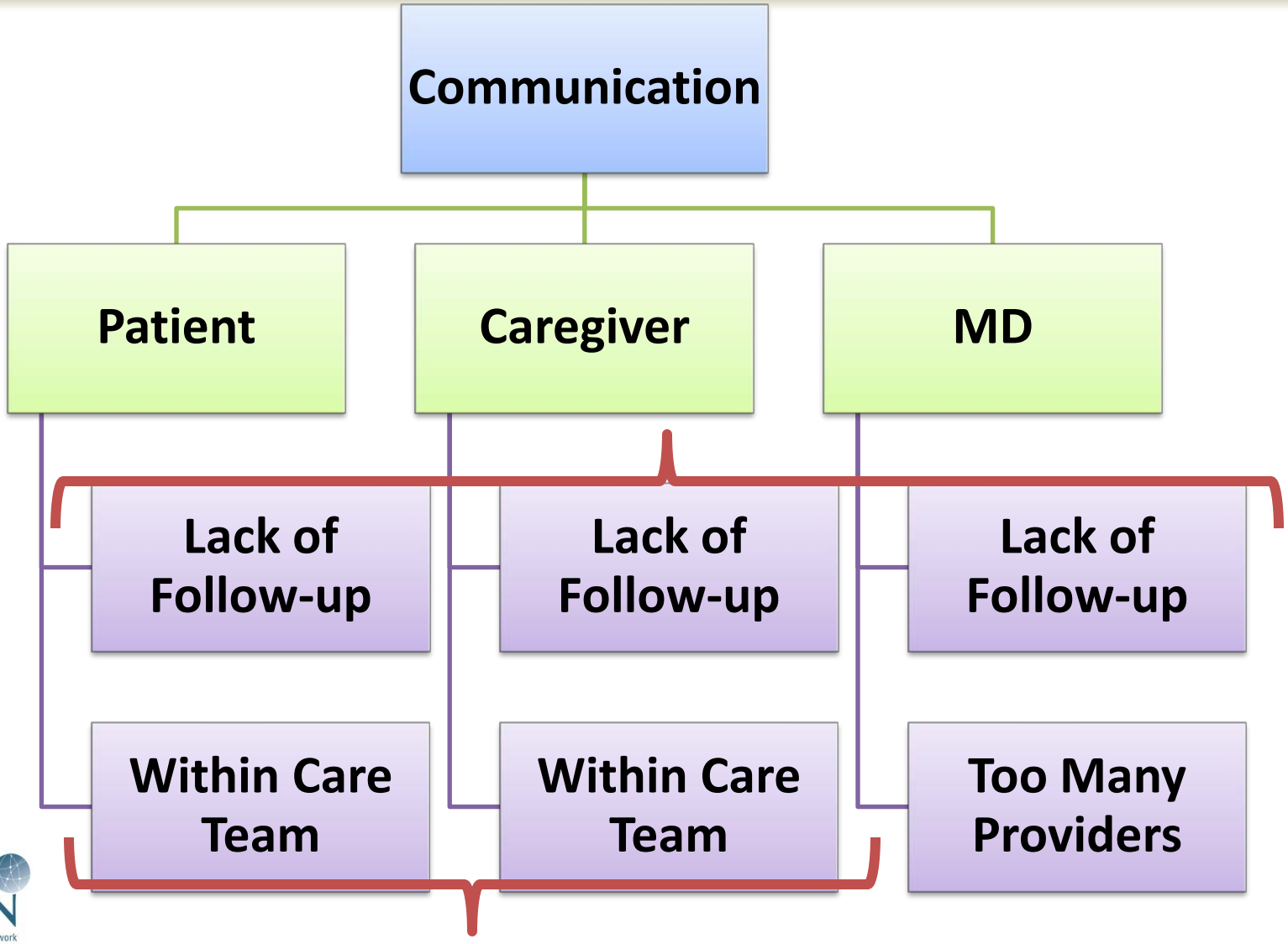
System-Level Frustrations: Communication



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Lack of Coordination/Communication: Patient

"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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Communication: MD

"I think with her, like I said, too many cooks in the kitchen is sort of my frustration with her... I feel this with the specialists. Like the physiatrist orders another test and another thing and another. And for what purpose? You know, I find we do too many investigations without standing back and asking her what do you want?"

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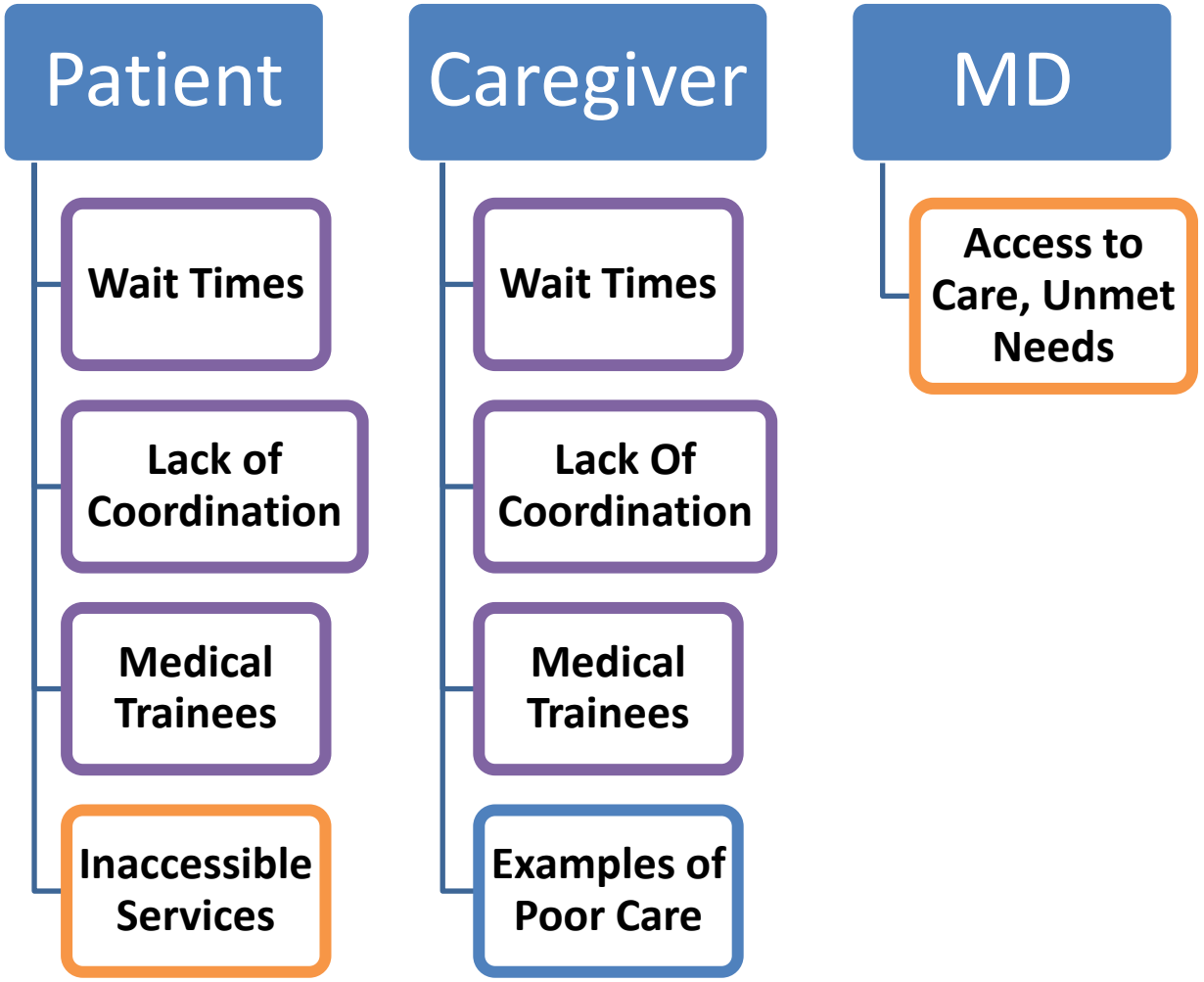
System-Level Frustrations: Con't



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Wait Times: Caregiver

"As a family caregiver, you can spend an awful lot of time sitting in waiting rooms. And you know, when you also have to make some money, it's kind of hard to be doing that… and not only does it cost a fair amount of money to park but it's very tiring for her. She's 93, you know…But it's a morning out of your life or an afternoon out of your week that is very tiring for her."

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Unmet Needs: MD

"Once they need CCAC, they don't seem to get as much as they really need. I mean that's true across the board. They'll come in for an hour a week and help you with a bath. And if you don't need help with a bath, they don't come in. So it's the patients who can bathe no problem, they can manage all their IDLs, other ADLs, but they need help with their IADLs. They may need help with the food shopping. They may need help with food prep. That stuff is hard to get support for…"

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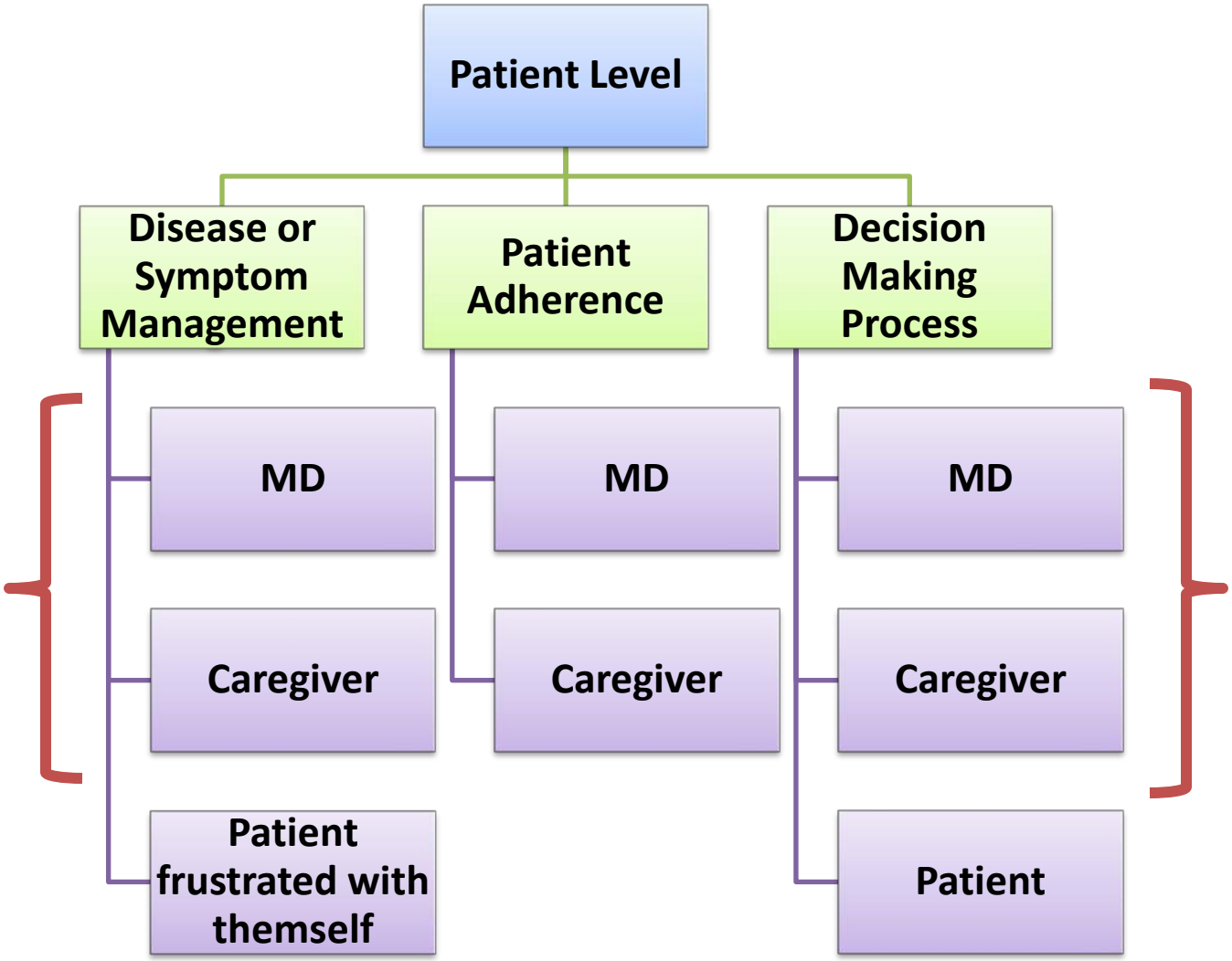
Patient-Level Frustrations



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Decision Making: Patient

"And now the doctor called me at home, or the nurse said the doctor wants to call your drugstore to increase my Lipitor because my cholesterol is up. So you see, this is where you get really in a frustration. I don't know how to describe how it makes you feel because you're damned if you do and you're damned if you don't. I will not take a pill that's affecting my liver. Therefore I don't know if I'm doing the right thing."

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Patient Adherence: Caregiver

"Well, he has been offered many times, both from [name of hospital] and from CCAC, physiotherapy… No, not the system because…I think it's from depression, his lack of willingness to do these things that might have helped him along the road. His attitude is very negative, and that's frustrating to deal with."

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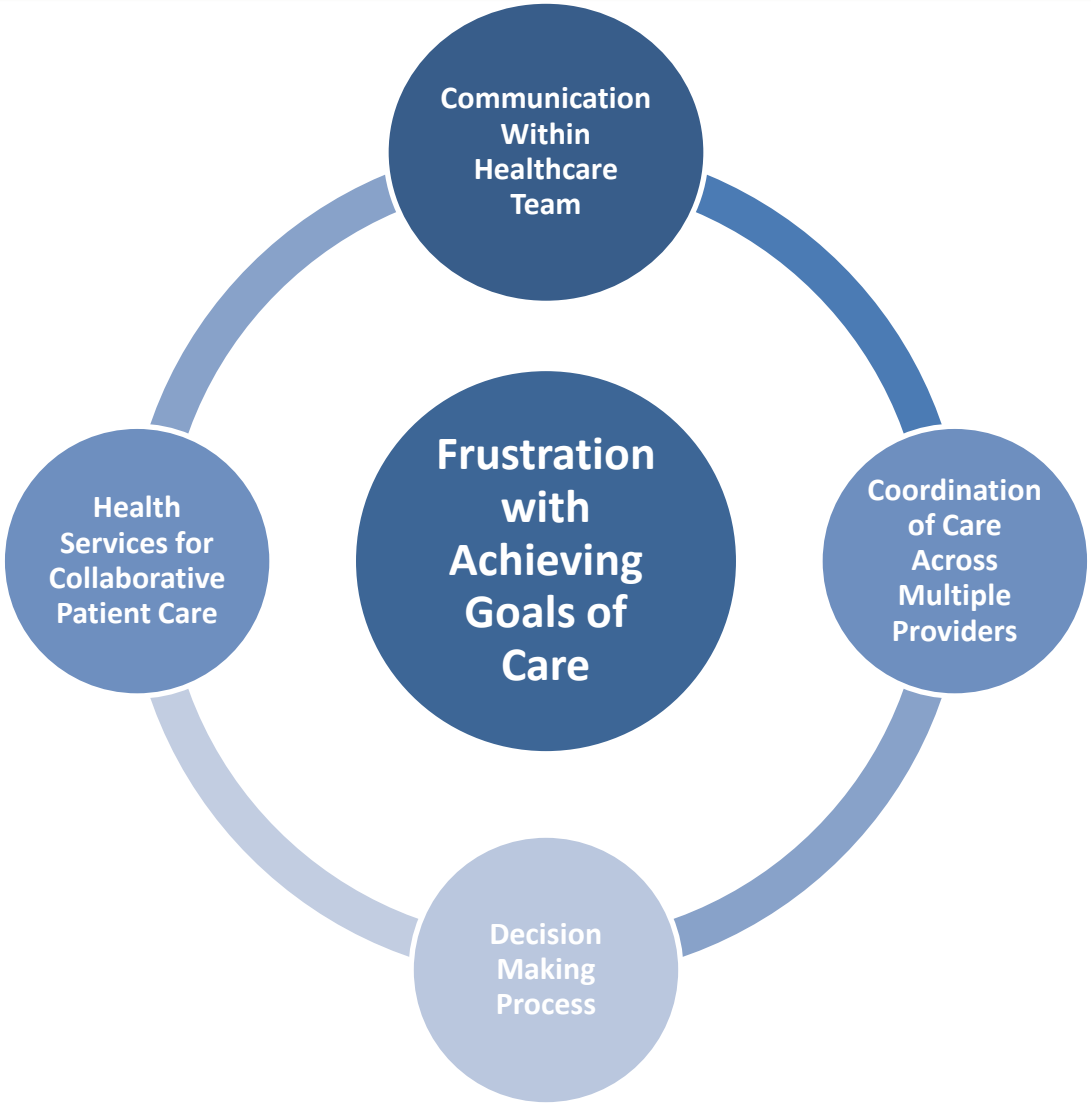
Summary of Findings



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Implications

Patient-Centered Care	• Teaching hospital environment • Fragmented care across disciplines
Self-management	• Caregivers and primary care physicians burdened with both patient- & system-level frustrations • Patient non-adherence • Decision making
"Big Picture"	• Acute- vs. long-term goals • What's important to the patient

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Thank You

QUESTIONS & COMMENTS

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Not Frustrated: MD

"No. I'd say no, from my perspective… More independent and driven, yes. He does a lot of my work for me in a sense. I mean he really does. I don't have to go at the specialists and nag at them. He does it for me. So that's great. Thank you."

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