

Surrogate Decision Making for Hospitalized Older Adults

Alexia M. Torke, MD, MS
Assistant Professor of Medicine, Indiana University
Associate Fellowship Director, Fairbanks Center for Medical Ethics



INDIANA UNIVERSITY

School of Medicine
Department of Medicine
Division of General Internal Medicine and Geriatrics
Center for Aging Research



Regenstrief Institute

IU Geriatrics



Acknowledgments

Research Team

- Chris Callahan
- Greg Sachs
- Paul Helft
- Sandra Petronio
- Patrick Monahan
- Lucia Wocial
- Babar Khan
- Evgenia Teal
- Emily Burke
- Lev Inger
- Annie Montz
- James Slaven
- Steve Ivy
- Kristen Geros

Support

- John A. Hartford Foundation/American Geriatrics Society
- Indiana University Health Values Grant
- National Institute on Aging
 - K23 career development award
 - R01



Ms R.

- A 66 year old woman with a long history of heart failure.
- Has cardiac arrest on hospital day 3. On hospital day 6, she is completely unresponsive.
- The ICU attending approaches the family to discuss changing the goals of care to comfort and withdrawing the ventilator
- The patient's adult children say, "Do everything."



Mr. S

- A 92 year old man with Alzheimer's disease
- Admitted for abdominal pain and found to have a bowel obstruction
- His family gathers at the bedside.
- They ask the surgeon, "Can we just take him home?"



Communication problems are common

- Up to 1/3 of family members report serious problems with communication and decision making (SUPPORT, JAMA 1995;274:1591-8; Baker, Wu, Teno et al, JAGS 2000)
- Almost half of ICU families report conflicts with medical staff (Abbott et al, Crit Care Med 2001;29:297-201)
- Physicians report
 - Disagreement with families about 10% of the time
 - Ineffective communication with families 22% of the time
 - High levels of distress 23% of the time

(Torke et al JGIM 2008)



Outcomes of decision making may be poor

- Surrogate distress
 - There is evidence of distress for many surrogates
Wendler and Rig Annals 2011;154:336-346
 - PTSD symptoms in ICU family members
 - 33% of all family members
 - 48% of those who made decisions (Azoulay AJRCCM 2005)
- Unwanted treatment
 - 41% of those who preferred comfort care reported that care was inconsistent with their preferences (Teno et al, JAGS 50:496-500)



Long Term Research Agenda

- Change the health care setting so that:
 - Family members and physicians are supported when making difficult health care decisions for patients who cannot participate
 - Every physician and family member make the best possible decision under the circumstances
 - Patients receive optimal care
- Design system-based interventions directed at health care providers and family members



Long-Term Research Agenda

Retrospective chart review

Prospective, observational studies

Decisions for Patients with Cognitive Impairment and Dementia (K23)

The Family Inpatient Communication Survey (R01)

Clinical Trial

The Family Navigator (P30, Roybal Center Pilot Funding),
planned R01 RCT



Retrospective Chart Review: Objectives

- To examine:
 - The frequency older, hospitalized adults face major decisions
 - The frequency that surrogates must make decisions for the patient
 - Whether surrogate decision making impacts the process of decision making or the delivery of medical care.



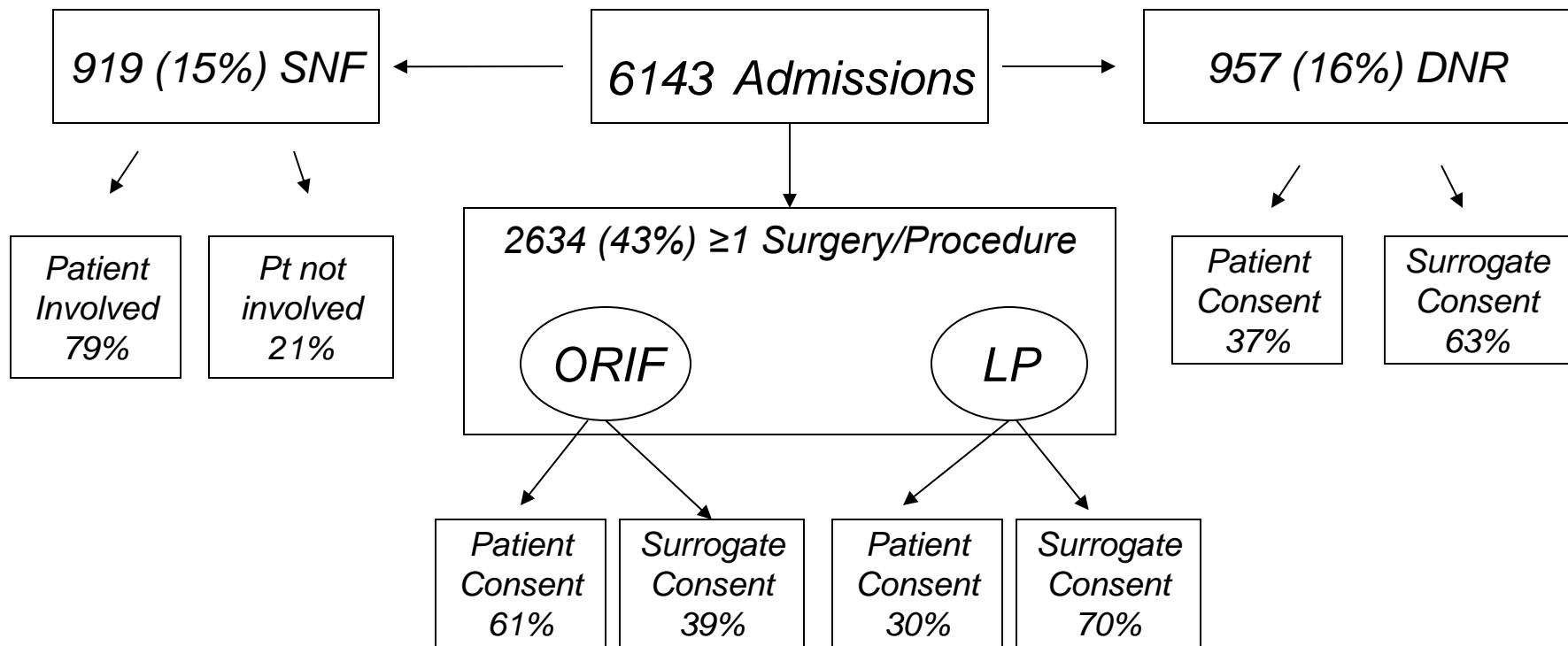
Methods

- **Subjects**
 - Adults age 65 and older
 - Medical and surgical services at Wishard
 - Three-year period (2004-2006)
- **Electronic chart review (Regenstrief Medical Record System)**
 - Patient demographic information
 - Frequency of 3 categories of interventions:
 - Do not resuscitate (DNR) orders
 - Procedures and surgeries (By ICD-9 codes)
 - Lumbar puncture
 - Open-reduction internal fixation of the hip/leg
 - Transfer to a skilled nursing facility (SNF)
- **Review of decisions**
 - Randomly selected 75 charts for each of 4 decisions
 - Identified
 - Frequency of surrogate consent for each DNR order and procedure
 - Who was involved in discussions regarding transfer to a skilled nursing facility



Results

- 3,472 unique patients admitted over the study period
 - 6,129 admissions (65% of admissions were repeat admissions).
- 3410 (56%) of admissions involved at least one of the three major categories of interventions.





Timing of DNR Decision Making

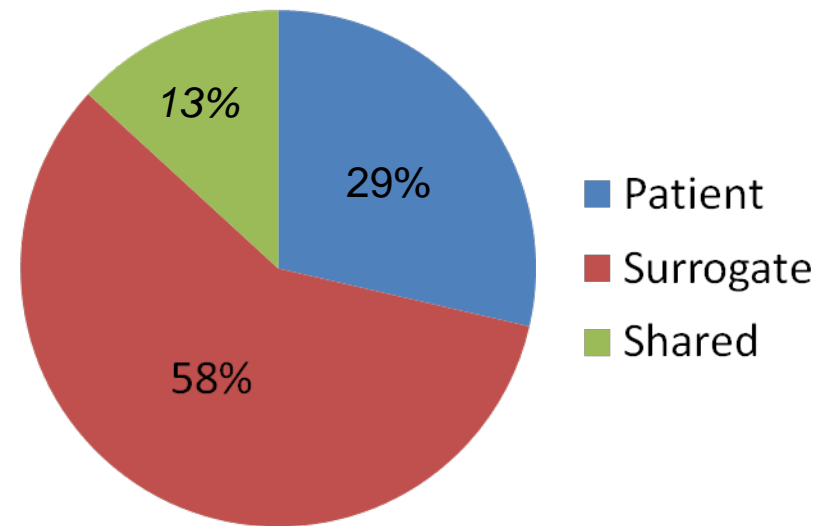
- Electronic chart review
 - Frequency and timing of DNR decisions
 - 668 patients over 3 years
- Text chart review: Who made the DNR decision?
 - Decision maker is a required text field in CPOE system
 - Divided into
 - Patient
 - Surrogate
 - Both



Results

- 3,472 unique patients admitted over the study period
 - 6,129 admissions (65% of admissions were repeat admissions).
- 957 (16%) of patients had a DNR order

Decision Maker



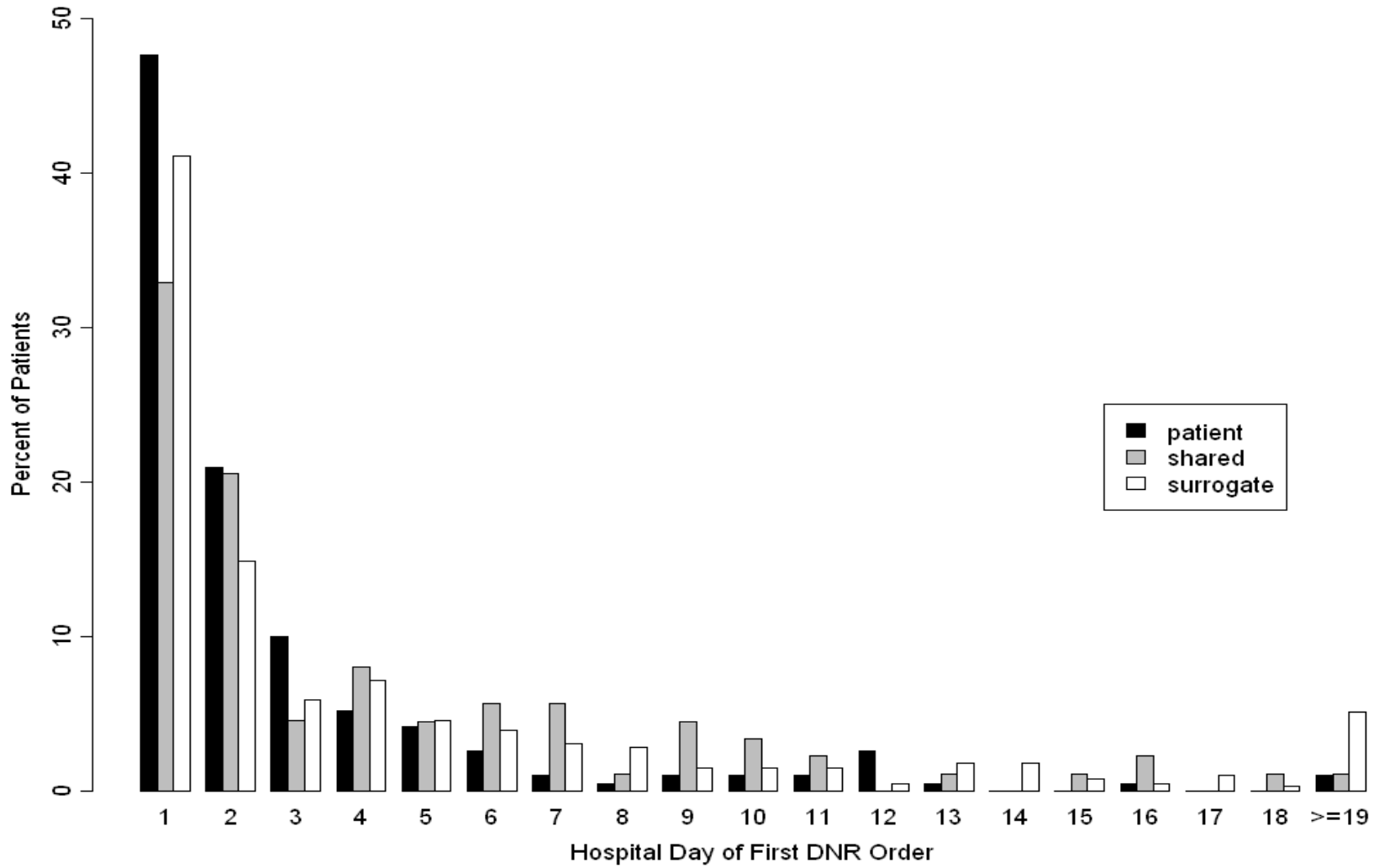


INDIANA UNIVERSITY

Variable	Patient Decisions	Surrogate Decisions	Shared Decisions
Observations	191 (28.6)	389 (58.2)	88 (13.2)
Length of Stay	7.8 days	11.6 days	8.8 days
Age (mean)	77	79	78
Sex (Female)	63%	63%	73%
Race			
African/American	47%	53%	47%
White	50%	43%	46%
Hispanic/Latino/Asian	4%	5%	8%
Any ICU Stay	40%	62%	41%
In-hospital Mortality	9%	34%	14%
Hospital Day of First DNR Order	3.2 days	6.6 days	4.4 days
Days from DNR to death (median)	3.5 Days	1.0 day	4.0 days



INDIANA UNIVERSITY





INDIANA UNIVERSITY

Variable	Patient Decisions	Surrogate Decisions	Shared Decisions
Observations	191 (28.6)	389 (58.2)	88 (13.2)
Length of Stay	7.8 days	11.6 days	8.8 days
Age (mean)	77	79	78
Sex (Female)	63%	63%	73%
Race			
African/American	47%	53%	47%
White	50%	43%	46%
Hispanic/Latino/Asian	4%	5%	8%
Any ICU Stay	40%	62%	41%
In-hospital Mortality	9%	34%	14%
Hospital Day of First DNR Order	3.2 days	6.6 days	4.4 days
Days from DNR to death	3.5 Days	1.0 day	4.0 days



Explanations

- Clinician/surrogate communication is more difficult than communication with patients
- Making decisions for others is more ethically complex than making decisions for oneself
- Surrogates face a more complex emotional burden than patients making decisions for self.



Alternative Explanations

- Some patients may have been stable until late in the hospital stay, when new questions about DNR arose
- Decision making capacity may have changed over the hospital course



Chart Review Summary

- 56% of admissions for patients 65 and older involve a major decision
- Surrogates give informed consent
 - over half the time for DNR orders and LP's
 - commonly for other procedures.
- Patients who require surrogate consent for DNR orders have
 - orders are written later in the hospital course
 - Even though patients are sicker and more likely to die



Limitations

- Retrospective chart review only allowed for the identification of patients who underwent the proposed intervention.
 - We do not have information on interventions that were considered but not undertaken.
- Chart documentation for communication is often incomplete.
- No formal consent process is documented in the hospital chart for transfer from the hospital to a skilled nursing facility.



INDIANA UNIVERSITY

Decisions for Elders with Cognitive Impairment and Dementia (DECIDE)





Prospective observational study

- **Aim 1:** To describe the frequency, characteristics, and clinical context of surrogate decisions for adults age 65 and older on an inpatient medicine service
- **Aim 2:** To identify important determinants of successful communication and high quality decision making from the surrogate's perspective



How common is surrogate decision making?

- Decision Making Capacity

- Single hospital in England
- Administered a structured decision making capacity assessment
- 40% of adult inpatients lack capacity

Raymont et al Lancet 2004

- SUPPORT Study

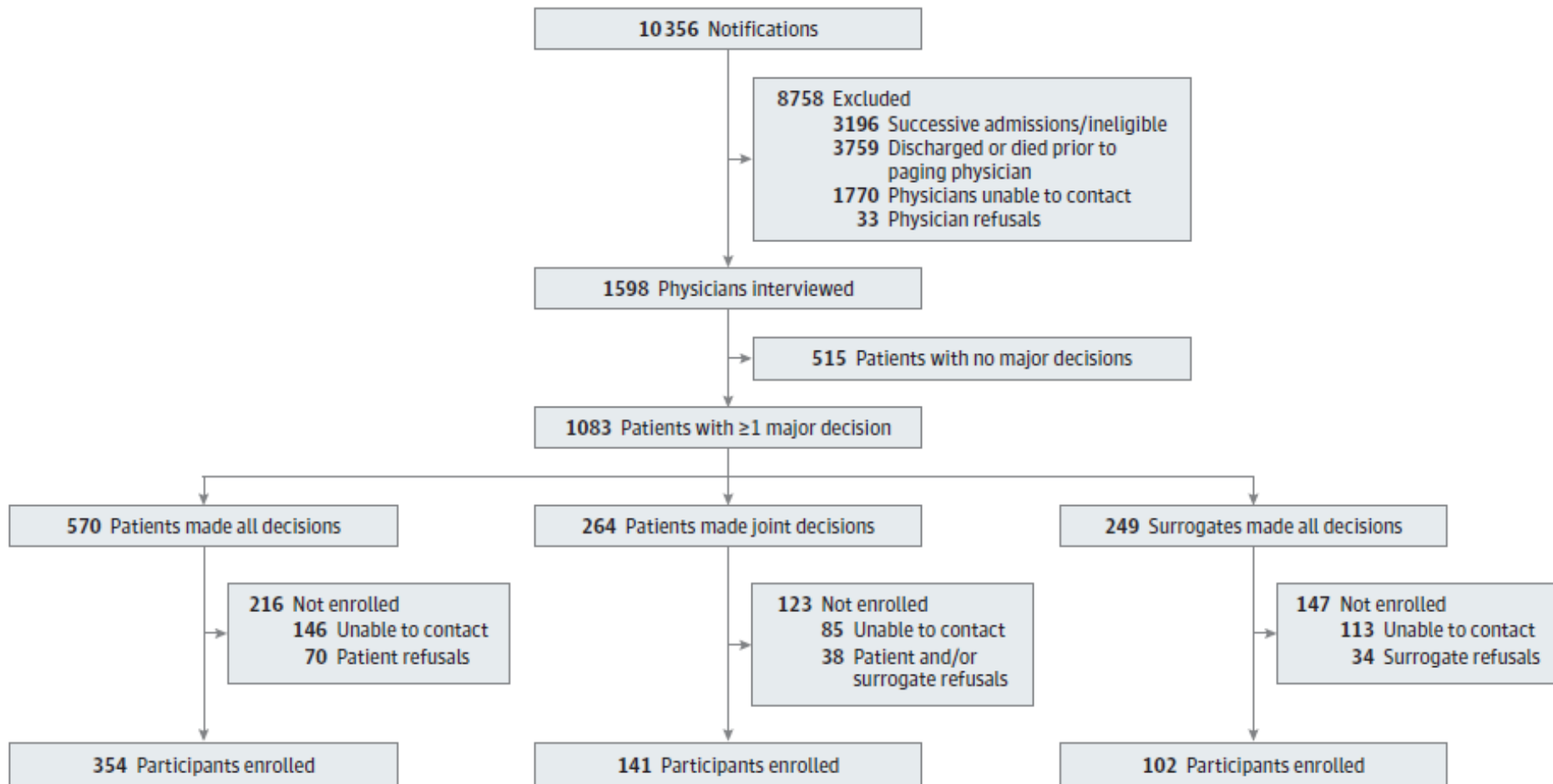
- 40% of patients were unable to participate in decision making

SUPPORT JAMA



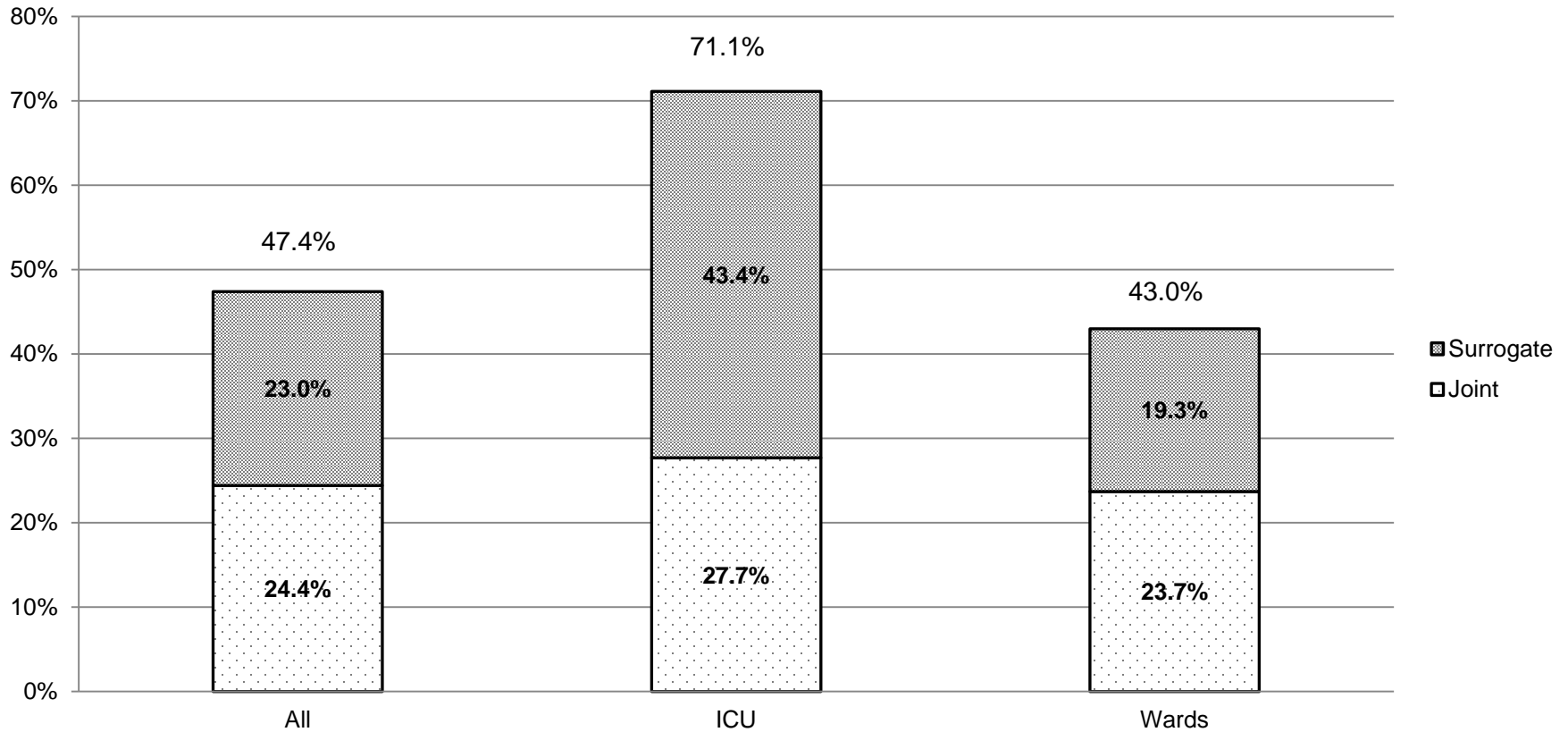
Method

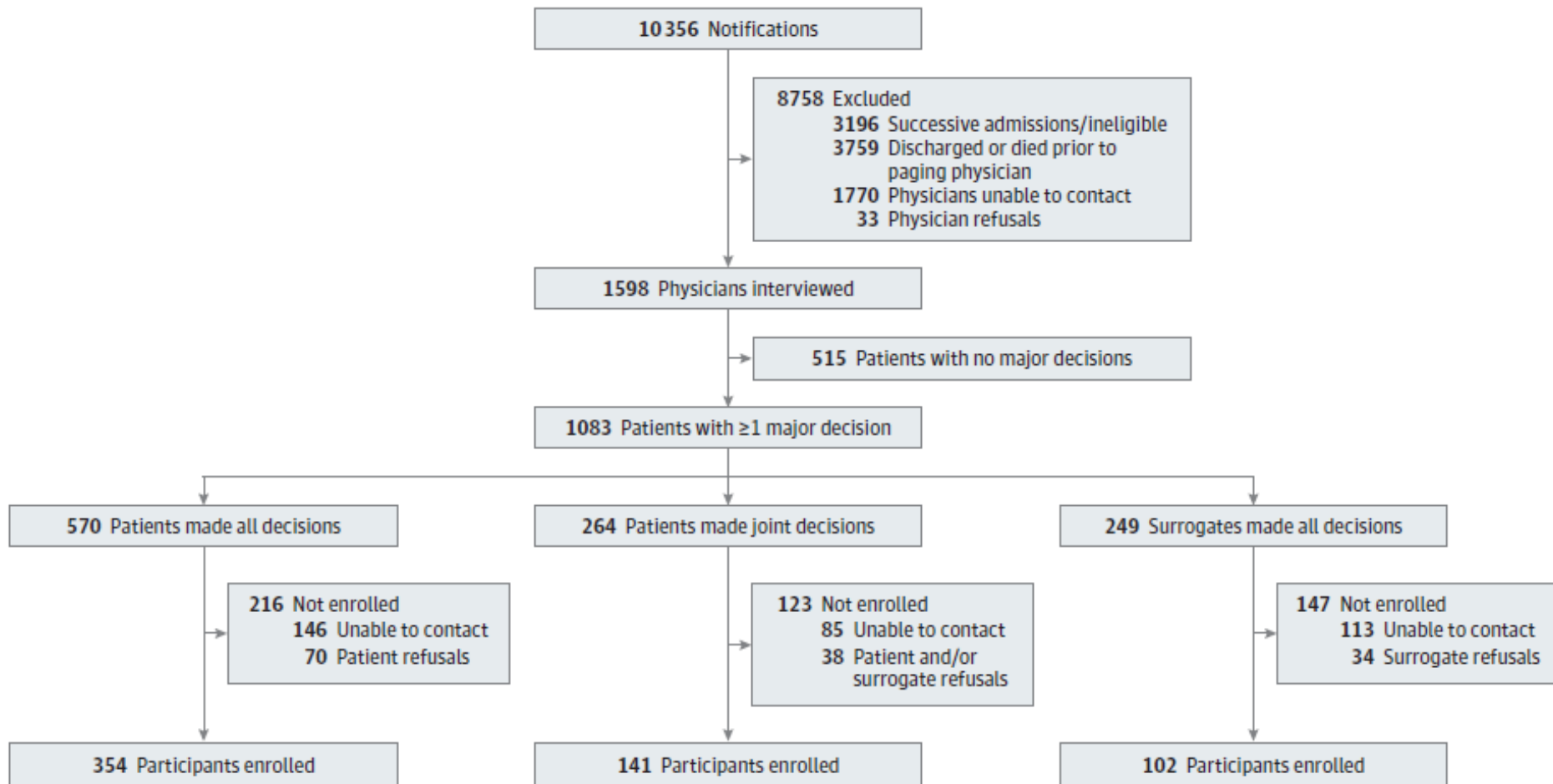
- **Subjects**
 - Patients age 65 and older who are admitted to the medicine or MICU services at 2 Indianapolis hospitals
 - Identified by an automatic email or review of electronic admission lists
- **Physician Screen**
 - Research assistant contacted the patient's primary hospital physician via page
 - To determine
 - whether the patient has faced any major treatment decisions during the first 48 hours of the hospital stay
 - whether a surrogate decision maker was consulted for any decisions
- **Chart Review**
 - Patient demographic information,
 - Clinical information
 - Outcomes
- **Surrogate Interviews**
 - In-depth, semi-structured interview addressing the surrogate's communication and decision making experience.





Frequency for Older Adults







What decisions do surrogates face, by decision maker (n=597)?

Decision	Patient	Surrogate	P value
Life sustaining therapy	44	57	.002
Code status	41	53	.01
Ventilator	1.4	5	.02
Dialysis	1.1	1	.71
Procedures and surgeries	54	49	.21
Endoscopy	10	10	<.001
Central venous line	10	10	<.001
Blood transfusion	7	5	.73
Discharge planning	33	47	<.001
Nursing home/rehab	25	38	.001
Hospice	3	6	.03



Hospital Course and Outcomes

	Patient	Surrogate	P value
Length of Stay, in days median (range)	6 (2-27)	7 (1-40)	<.001
Discharged to Extended Care Facility/Nursing Home	21.2%	40.9%	<.001
In-hospital mortality	0	5.8%	<.001
30-day mortality	1.1%	7.4%	<.001



Making decisions

- Advance Directives
 - 7.4% of patients had a living will
 - 25.0% had a legally designated health care representative
 - No differences in frequency by decision maker.
- Of patients with a surrogate
 - 18% had more than one primary surrogate
- Surrogates were most commonly
 - daughters (59%)
 - sons (25%)
 - spouses (21%)
- Among patients with “joint” decisions (n=141):
 - 54% had all decisions made jointly by the patient and surrogate
 - 46% (10% of all patients) decision maker varied during the first 48 hours



Prospective Study Summary

- Surrogates are involved in decision making for half of hospitalized older adults
 - Ethical models of hospital decision making must incorporate family perspectives and surrogate decision making
 - Nearly half of families are at risk for substantial distress
 - Hospital functions should be redesigned to account for the large and growing role of surrogates



Surrogate/Clinician Communication

- Surrogates are traditionally asked to rely on advance directives and to “speak for the patient.”
- Prior research on surrogate decision making
 - Concordance of patient/surrogate wishes
 - Stability of patient preferences
 - Surrogate distress
- **Surrogates face communication challenges**
 - Form separate relationships with clinicians
 - Manage communication for someone else (the patient)
 - Make decisions while facing stress and other difficult emotions
- These challenges may affect the process and outcomes of decision making



The surrogate's experience: Findings from prior studies

- Understanding information
- Coming to terms
- Obligations to the patient
- Emotional burden
- Family and social networks
- Ethical reasoning
- Making decisions
- Communicating with health care providers
- Looking back at decisions



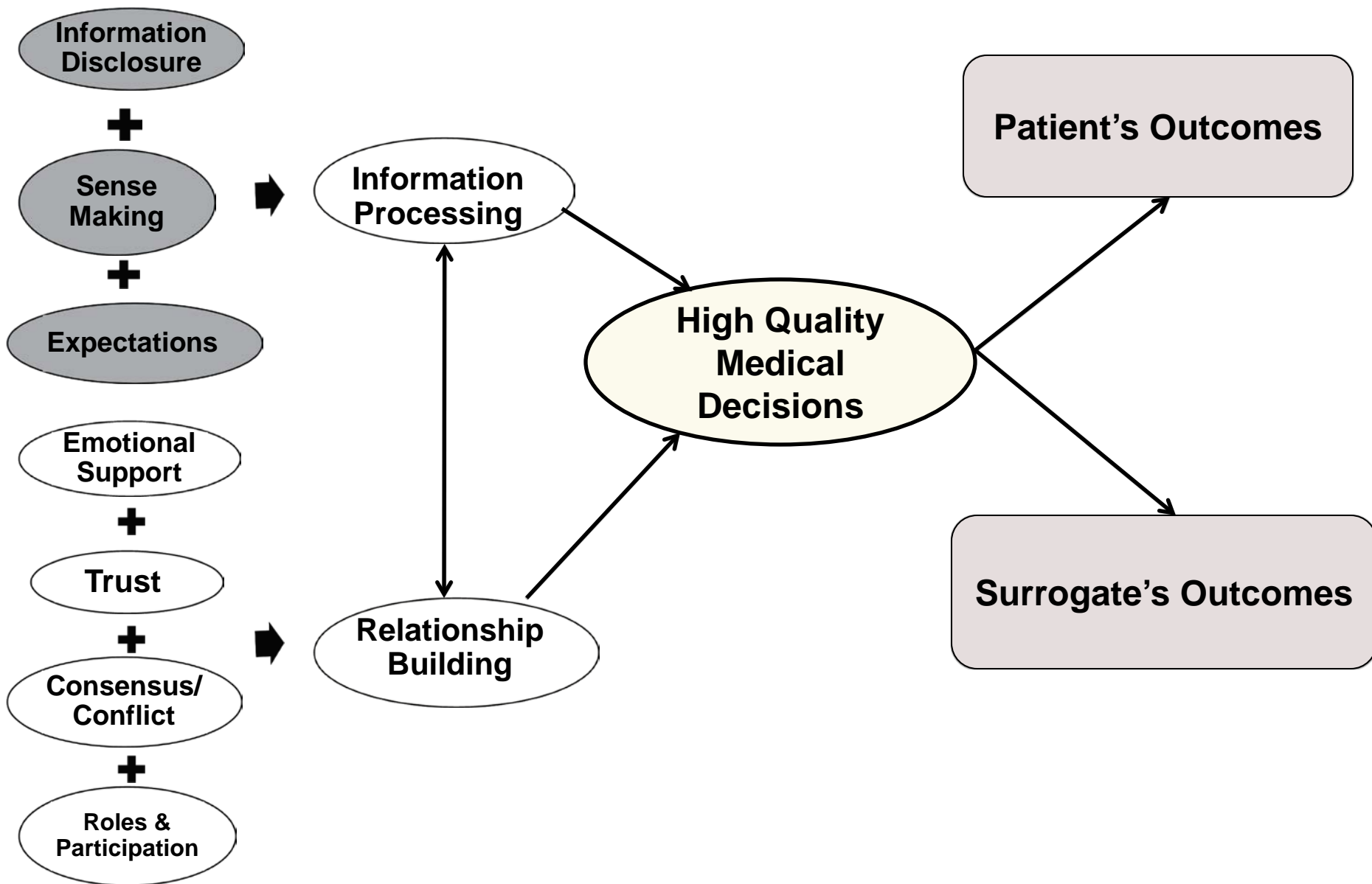
Surrogate Interviews Approach

- Review of literature in fields of communication and medical decision making
- Development of a theoretical model of communication and decision making Torke et al PEC 2011
- Developed a semi-structured interview guide based on the model The interview guide was pilot tested with 5 surrogates and revised.

Surrogate-Clinician Communication

Decision Making

Outcomes





Semi-structured interview guide

Variable	Sample Questions
Introductory Question	Tell me about (patient) and what brought him/her to the hospital?
Information Processing	During the time (patient) was/has been in the hospital, how did you find out what was happening to him/her?
Relationship Building	What were your first impressions of the hospital staff? How did your impressions change over time? Was there anyone at the hospital you could rely on? Tell me about him/her.
Decision making process	One decision that (patient's) physicians have considered is (target decision). What, if any conversations with the doctors or other hospital staff can you recall about this decision?
Possible outcomes	When you look back on this decision later, what will seem most important to you?
Possible interventions	Can you think of anything that could have been done to help you make this decision for (patient)? What, if anything, could have been done to make the hospital experience better for you or (patient)?



Semi-structured Interviews

- Individual interviews with surrogate decision makers who had made at least one major decision for the patient
 - Life-sustaining therapy
 - Procedures or surgeries requiring consent
 - Nursing home placement
- Conducted within one month of making a major decision (2-4 months if the patient has died)
- Audio-recorded and transcribed



Data Analysis

- **Constant comparative method**
 - Alternate between data collection and analysis (iterative process)
 - Read interviews and identify important concepts, or themes
 - Compare new themes with existing theory in order to confirm or refine the theory
- **Coding**
 - Important themes in the data are identified and labeled
 - Develop detailed descriptions of each theme
 - Identify relationships among themes
 - Build new theories or test existing ones



Data analysis

- Conducted by an interdisciplinary team (AMT, CP, SP) using the constant comparative method
- Five interviews independently coded by two investigators (CP, AMT) and used to develop a list of codes and themes
- Subsequent interviews were read by the team but coded by one investigator
- Team meetings after every 3-5 interviews
- Interviews continued until theme saturation.



Participants

(n=35, 759 double spaced pages)

Characteristic	Number	Percent
Female	28	80
Race		
African American	18	51
White	17	49
Relationship		
Daughter	21	60
Son	5	14
Sister	2	6
Spouse	2	6
Other	5	15
Decisions Considered		
Life sustaining therapy	24	68
Procedures/surgery	28	81
Nursing home	14	40



The surrogate's experience

- Decision making is stressful
 - May bring up unresolved grief, family conflict or other difficult emotions



The one thing they kept pushing and adamantly pushing is that we had to make a decision whether they were going to resuscitate her if anything happened because she was in pretty bad shape...It was difficult because we just buried, the two nieces that were there, we just buried their mother on (date) and they had to make the same kind of decision for her.



The surrogate's experience

- Decision making is stressful
 - May bring up unresolved grief, family conflict or other difficult emotions
- Relationship with a “team”
 - Many different clinicians
 - Frequently changing teams



Multiple Clinicians

We usually take her to emergency and there is a team of doctors that is caring for her while she is in emergency. Then it's out of their hands...and once they say she has to stay then it goes to some other doctors...the only thing I knew about those was after she called me, Dr. B called me, that I knew it was Dr. B taking care of her.



Not a Relationship

Well, they seem to be pretty caring. I mean, there's not a relationship, but they do try to explain everything and offer (to) me to ask some questions if I don't understand



The surrogate's experience

- Decision making is stressful
 - May bring up unresolved grief, family conflict or other difficult emotions
- Relationship with a “team”
 - Many different clinicians
 - Frequently changing teams
- Trust



Trust

They have the pain medicine here. It's just a shame that they reluctant to give it to her because they didn't think they were gonna get their money for it, so she had to lay here and suffer the whole time.

You know, I seen what they was telling me, that it was accurate. Everything was getting better and I was glad of that.



What do surrogates need?

- Frequent communication
- High levels of information
- Emotional support



Frequent Communication

One thing I will say is that the staff here, with their having team members and...three different teams for mom, um, they were in contact with me on almost like a daily basis...I was extremely impressed that I had gotten so many calls from a team member from Wishard Hospital.



Information

The nurses were good. The doctors were...spotty at best.....information that was kind of shared haphazardly...mainly by the nurses who were saying that there was some discussion about some kind of procedure.



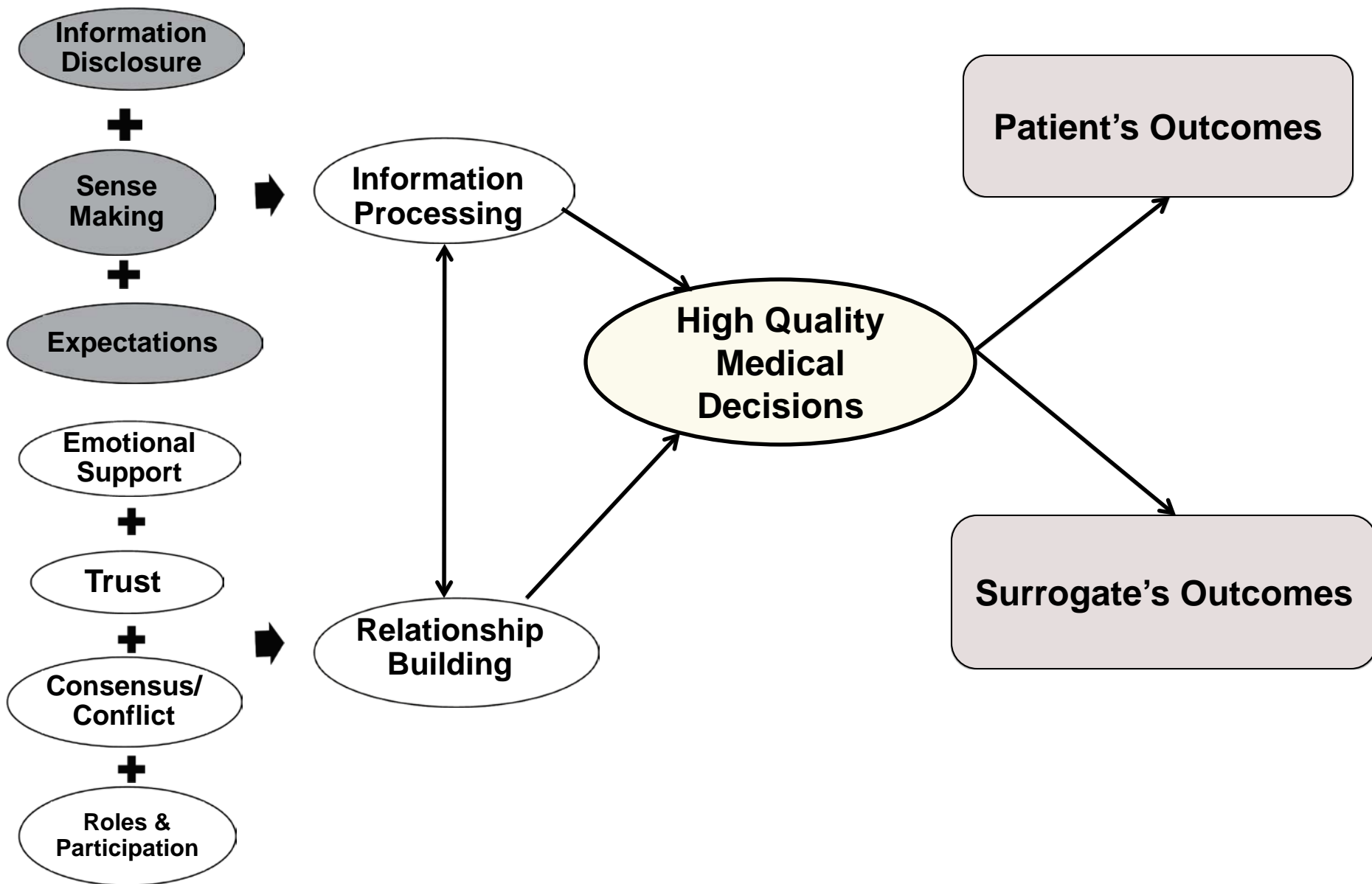
Emotional Support

...taking the time out to really sit there with me to explain that to me, that meant a lot to me cause some doctors they will tell you and explain it to you and then they move on. But she actually, I felt like she really cared about what was really going on with my mom.

Surrogate-Clinician Communication

Decision Making

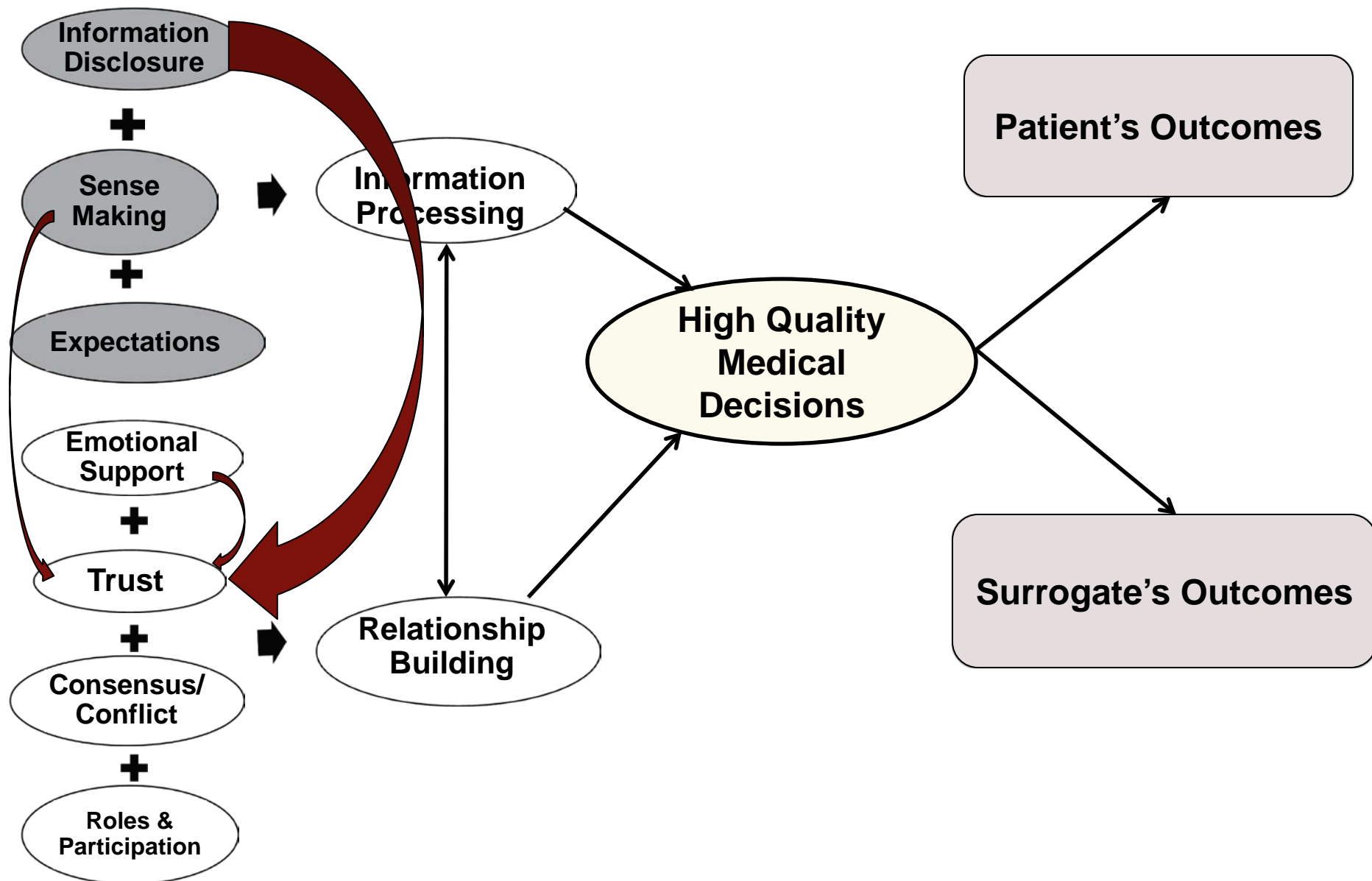
Outcomes



Surrogate-Clinician Communication

Decision Making

Outcomes





Summary

- In the hospital setting, surrogate/clinician relationships are often fragmented and brief
- Surrogates highly value
 - Expressions of emotional support
 - Information
 - Frequent communication
- These decrease the surrogate's distress and increase their trust
- An interdisciplinary approach is accepted by most surrogates



Implications

- We need to revise our understanding of “relationship” between surrogates and clinicians in the hospital setting.
 - Trust and emotional connection can be quickly established
 - Relationships are rarely longitudinal
- Surrogates identify elements of communication that are amenable to intervention



Summary of Research

- For hospitalized older adults, surrogate decision making is almost as common as patient decision making
 - The hospital structure should account for the crucial role of families
- Surrogates commonly face decisions about life sustaining care, procedures and placement
 - Interventions should prepare surrogates for this task
- Surrogate decision making may involve poor communication, surrogate distress and delays in patient decision making
 - Improvements are needed to improve patients care and improve surrogate wellbeing



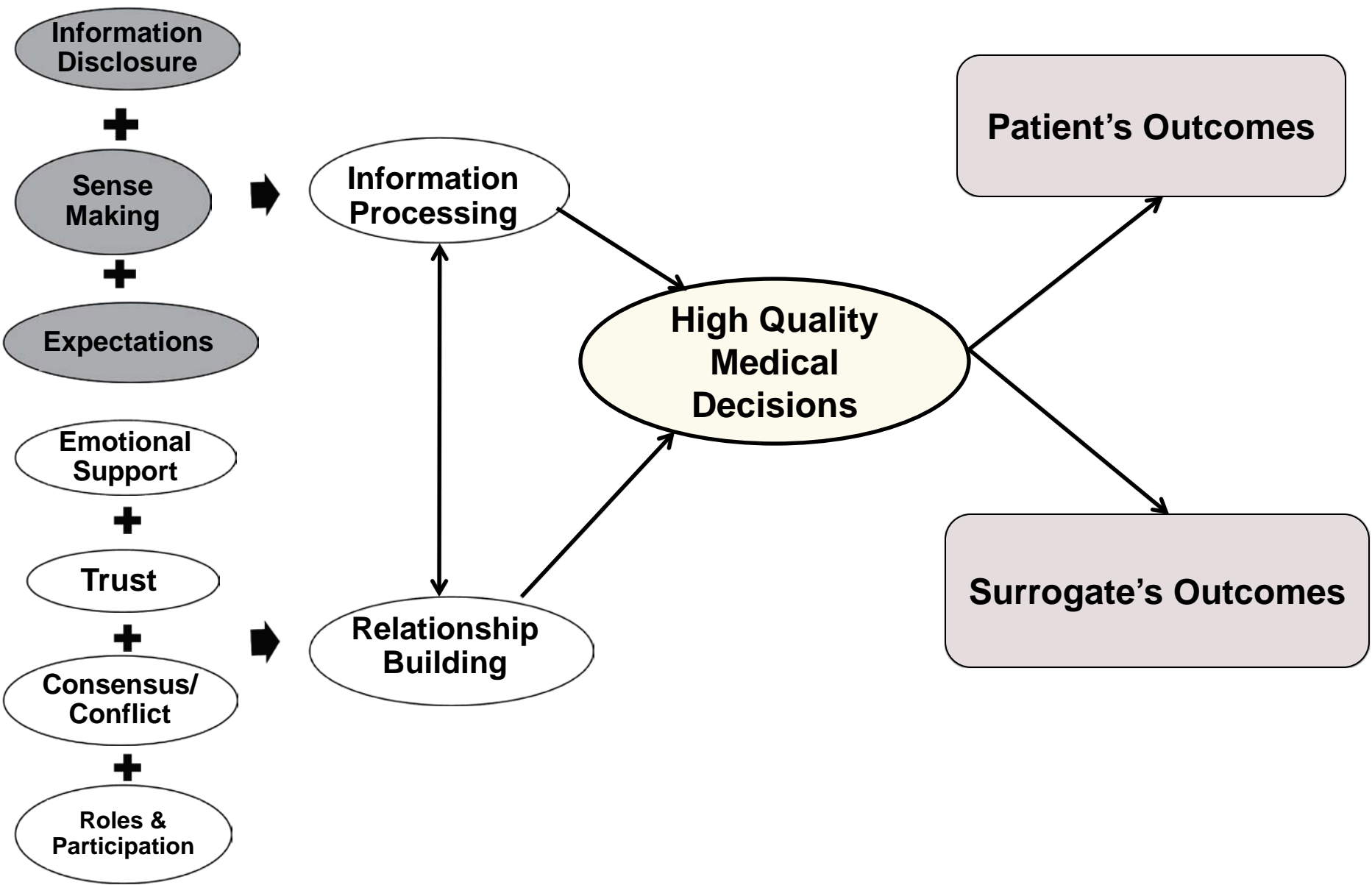
Next Steps

- Further data analysis
 - Religion and surrogate decision making
 - Communication Privacy Management Theory
- Family Inpatient Communication Survey
- The Family Navigator Intervention

Surrogate-Clinician Communication

Decision Making

Outcomes



Information Disclosure

+

Sense Making

+

Expectations

Emotional Support

+

Trust

+

Consensus/
Conflict

+

Roles &
Participation

Information Processing

Relationship Building

High Quality Medical Decisions

Patient's Outcomes

Surrogate's Outcomes



Family Inpatient Communication Survey

- New instrument to measure the quality of surrogate/clinician communication
- Impact of communication on
 - Surrogate outcomes (distress, depression, regret)
 - Patient outcomes (LOS, aggressive care at EOL)



The Family Navigator

- A new nursing role to support families
- Improve communication
 - Information
 - Frequent contact
 - Emotional support
- Improve surrogate outcomes and patient care



FAMILY NAVIGATOR

YOUR FAMILY NAVIGATOR IS HERE TO HELP YOU DURING YOUR LOVED ONE'S HOSPITAL STAY

- Provide Daily Updates
 - Provide Support
 - Communicate
 - Listen
- Provide Resources





INDIANA UNIVERSITY

Questions?