

FAMILY MEMBERS AT THE BEDSIDE: THEORY, SCIENCE, RECOMMENDATIONS

▶ Janine Carr, PhD, RN

▶ Theory of Family Vigilance

▶ Anita Catlin, DNSc, FNP, FAAN
& Carrie Maloney, MSN

▶ Needs of Family Members
at the Bedside of
Oncology Patients

▶ Michelle Camicia, CCRN,
PhD in Progress

▶ Needs of Family Members
at the Bedside of Patients
Rehabilitating from Stroke

▶ Barbara Lutz, PhD, RN

▶ Measuring Family
Caregiver Readiness

SYMPOSIUM

- ▶ **All examined family needs from different perspectives**
- ▶ **Used each others work before and after we met**
- ▶ **You will find we all had similarities**
- ▶ **Discharge to home is a significant crisis**
- ▶ **Barbara and Michelle are continuing this work**

THEORETICAL PERSPECTIVE ON FAMILIES AT THE BEDSIDE

Jeanine Carr, PhD, RN
Associate Professor
University of Vermont

MIDDLE RANGE THEORY

- ▶ Developed around a concept of interest such as family vigilance
- ▶ “...the ideas of middle range theory are simple yet general and more than empirical generalizations”
- ▶ (Liehr & Smith, 1999).

CONCEPT SYNTHESIS

- ▶ **A strategy for developing concepts (Walker & Avant, 2011)**
- ▶ **In this case based on data from qualitative research.**





CATEGORIES OF MEANING

- ▶ **Commitment to care**
- ▶ **Resilience**
- ▶ **Emotional upheaval**
- ▶ **Dynamic nexus**
- ▶ **Transition**

Commitment to Care

- ▶ Love
- ▶ Protection
- ▶ Advocacy
- ▶ Solicitude
- ▶ Involvement
- ▶ Watching

Resilience

- ▶ Taking care of oneself
- ▶ Perseverance
- ▶ Maintaining hope

Emotional Upheaval

- ▶ Uncertainty
- ▶ Anxious living
- ▶ Life and death decisions

Dynamic Nexus

- ▶ Relationships with family and friends
- ▶ Relationships with health care providers

Transition

- ▶ Lifestyle
- ▶ Role
- ▶ Daily rhythm
- ▶ Comfort
- ▶ Space



Commitment to Care

Advocacy Love Responsibility Solitude Involvement Watchin



Resilience

Caring For Self

Perseverance

Hope



Emotional Upheaval

Anxiety/Shock

Uncertainty

Life and Death Decision



Dynamic Nexus

Relationships with
Family and Friends

Relationships with Health
Care Providers



Transition

Lifestyle/Role

Daily Rhythm

Comfort

Space

Statement Synthesis

- ▶ A strategy aimed at specifying relationships between two or more concepts based on evidence...

(Walker & Avant, 2011).

Resilience is related to commitment to care

(Resilience is a personal characteristic that influences one's ability to care).

Dynamic nexus is related to emotional upheaval

(The strength of the dynamic nexus can influence extent of the emotional upheaval).

Dynamic nexus is related to transition

(The strength of the dynamic nexus can impact whether or not there is a healthy transition).

Emotional upheaval is related to transition

(How one manages emotional upheaval impacts the family member's transition).

THEORY SYNTHESIS

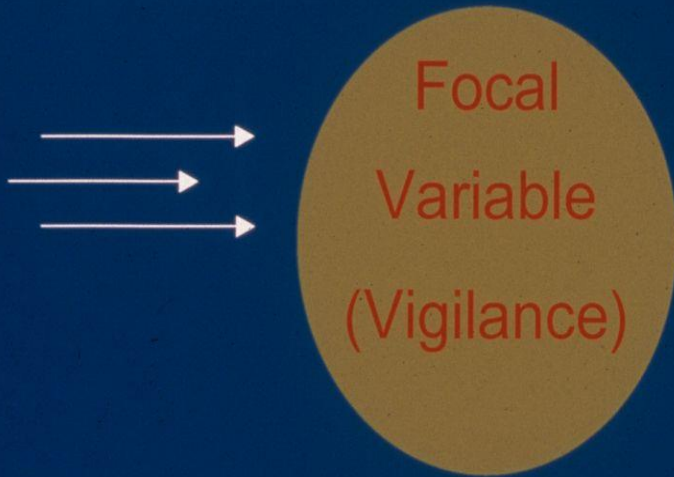
**A strategy aimed at
constructing theory,
an interrelated system of ideas
from empirical evidence...
(Walker & Avant, 2011).**

THEORY SYNTHESIS

- ▶ Commitment to care and resilience are related and necessary components for family members to engage in the experience of vigilance.
- ▶ The experience of vigilance generates emotional upheaval and a dynamic nexus.
 - ▶ If emotional upheaval and dynamic nexus are effectively managed, a healthy transition occurs.



Outcome



Determinant

From: Walker, L.D. & Avant, K.C. (1995). Strategies for Theory Construction in Nursing. Norwalk, CT: Appleton & Lange.

Middle Range Theory of Family Vigilance



Outcome

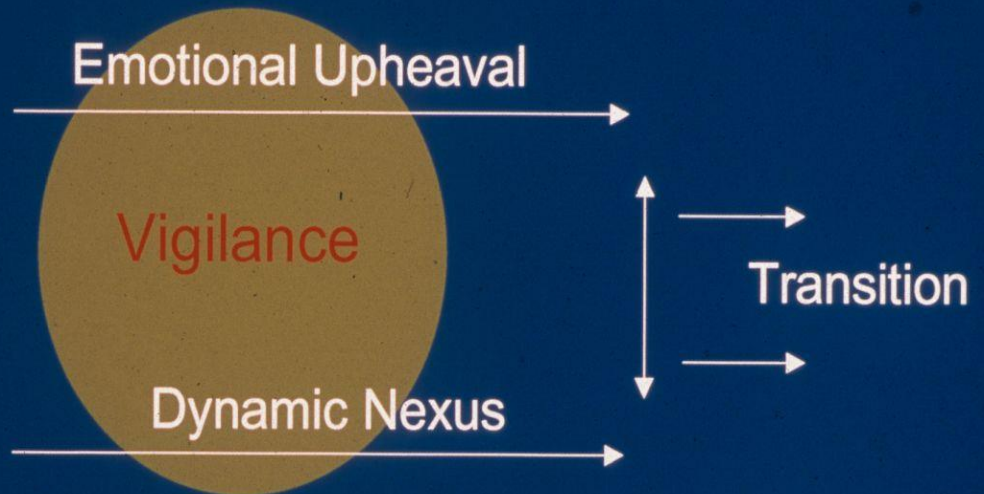
Commitment
To Care



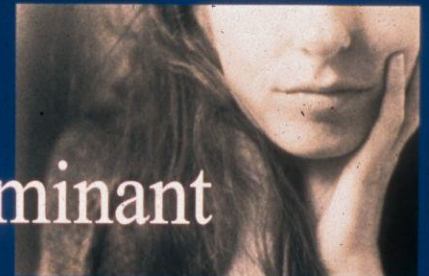
Resilience



Vigilance



Determinant



POSSIBLE RESEARCH QUESTIONS

- ▶ Are resilient individuals more able to make a commitment to care?
- ▶ Does a strong dynamic nexus result in less emotional upheaval?
- ▶ Does a strong dynamic nexus result in a healthy transition?
- ▶ Does management of emotional upheaval result in a healthy transition?

IMPLICATIONS FOR NURSING PRACTICE

- **Recognize the family's commitment to care and empathize with the family**
- **Assess and identify ways to strengthen family members' resilience**
- **Moderate family members' emotional upheaval**
- **Communicate effectively and influence other health care providers to communicate effectively and support family members**
- **Assess support systems and intervene with family members' support networks**



Sigma Theta Tau 2015

- ▶ *Determining Family Needs on an Oncology Hospital Unit*
- ▶ *Using Interview, Art & Survey*



RESEARCH TEAM

Anita Catlin, DNSc, FNP, FAAN

Marilee Ford, RN, BSN, MA, Clinical Educator

Denise Laws, MSN, DNPc, Director CEPI

Carrie Maloney, MSN, Asst. Nurse Manager

Kaiser Santa Rosa Nursing Research Council

**Donna Lamke, FNP; Deborah Ginn, BSN,
Wendy Gaus, MSN**

APPRECIATION

- ▶ Funded by the Daisy Foundation, Patrick Barnes Grant and
- ▶ Nursing Administration of Kaiser Foundation Hospital Santa Rosa
- ▶ Consultant Barbara Cullen, MFT, Executive Director of Willmar Family Grief and Healing Center



PURPOSE

- ▶ Move to Patient and Family Centered Care
- ▶ Unsure what needs were of family members who sit at the bedside
- ▶ Funding for oncology patient family exploration by Daisy Foundation
- ▶ Approved by Regional Institutional Review Board

RESEARCH QUESTIONS

- ▶ What are the needs of family members of oncology patients at the bedside in our hospital?
- ▶ Will art create an environment that allows for improved articulation of personal needs?
- ▶ Which needs are ranked highly by family members and are we meeting these needs?

STUDY AIM

1. To learn how we can improve the quality of care we offer to family members of our oncology patients?

TRIANGULATED STUDY

OPEN ENDED INTERVIEW

**ART THERAPY 'DRAW A
BRIDGE'**

**FAMILY INVENTORY OF
NEEDS (FIN)**

Kristjanson et al, 1995

INTERVIEW

- ▶ **Manager/ANM discussed with family**
- ▶ **Family member over 18 and spoke English**
- ▶ **Signed Consent**
- ▶ **Called interviewer**
- ▶ **Private taped recorded and transcribed interviews**
- ▶ **Keep interviewing until no new data (saturation at 19)**
- ▶ **Hard to focus family member on him/herself**

ART PROCESS



- Introduce materials
- Other people have told us that by drawing a picture of a bridge with you on it, it will help you to formulate your thoughts.
- Draw a bridge going from where you are now, to where you might be sometime in the future.
- Place yourself on the bridge
- Describe your bridge and what surrounds it

FAMILY INVENTORY of NEEDS (FIN)

- Instrument developed by Kristjansen, Atwood & Degner (1995)
- Validity established via expert panel and matched family need findings with other like instruments
- Reliability of Cronbach alpha of .83
- 20 questions which participant answers on a scale of 1 to 10.

DEMOGRAPHICS

Age	Range 18-85; median 56-65
Gender	Male 40% Female 60%
Relationship	Spouse 50%, Parent 17%; Sibling 11%; Fiancé 11%; Adult Child 11%
Caregiver Outside of Hospital	Yes 90%, No 10%
Length of Time	Less than 1 year 40%, 1-3 Years 27%, over 10 years 33%
Number of Hospitalizations at Bedside	Range 1-10 or more; median 3

THEMES IDENTIFIED

by family members

- ▶ **NEED FOR PHYSICAL COMFORT**
- ▶ **NEED FOR EMOTIONAL SUPPORT**
- ▶ **NEED FOR CULTURAL UNDERSTANDING**
- ▶ **FAMILY MEMBERS HELP**
- ▶ **NEED FOR PAIN RELIEF**

PHYSICAL COMFORT



- ▶ **010** It is the overnight part that is important. I am given blankets and made comfortable while I am here, because my wife will not let me leave her.
- ▶ **008:** There is a bathroom in the room but I am not allowed to use it..., but at night when I have to pee I have to walk all the way out and all the way back.

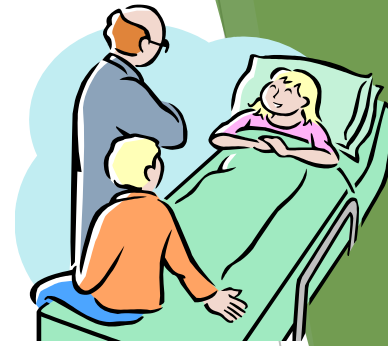
FOOD



010 They bring me a tray so I don't have to leave the bedside. They bring 3 meals a day. That is good because I don't live in this town, if I had to leave for meals it would take an hour and my wife does not want me to leave.

003 I am not eating very well because everything in the cafeteria is so expensive. The Kaiser food is expensive. I need to be looking after my own nutrition more but I really can't afford it.

VISITING RULES



► 003: And it is good that you let children come up. Two of the grandkids came to see him. He was ready to give up. He said “I always fought ,but I just don’t care anymore.” I said “I’ll give you something to care about. Here’s 2 reasons why you can’t give up.” They crawled up in bed with him. I’m glad they allow children.

CULTURAL RECOGNITION

▶ 007: I felt they were prejudiced against us. They hung a sign on our door saying “Only 2 visitors allowed.” (Teary) We are 10 kids, and 25 grandkids. And he is our FATHER. We need to be with him. We cannot leave his side. Neither he nor my mother speak English. We take turns staying with him.



I CAN'T THINK OF MYSELF WHEN MY LOVED HAS PAIN

- **Participants expressed that it was hard to think of themselves when their family member was suffering**
- **Unrelieved pain at home becomes need for ER visit and admission when unmanageable at home**
- **Worries family caregivers that they won't/can't cope**

UNRELIEVED PAIN

▶ #006: We tried our best, but we were not able to control her pain. She came in to the ED. Even though we have a selection of pain medications, it is so hard to see somebody you care about suffering and you can't do anything to control it. I know she has had her pain addressed here, I am more afraid of what I will do when she comes home. Me being competent to do pain management

▶ #016: This woman is in so much pain that it makes me want to pull my hair out. What if she has pain in the middle of the night? I'll be on my own. It will be rough. In other words, I'm disoriented. I don't know where to go.

A PLACE TO GO



- ▶ 010-a garden, somewhere to go, just to have an area in the hospital as an area for the family caregivers

- ▶ 002: I was thinking about somewhere to go. Like one place I went they had like a prayer room, a chapel. And another place had a Zen room. It would be so helpful to have a little alcove to go to. Some type of spiritual place. You don't need a lot of space, just somewhere with a focus on spirituality, it might help.



INCORPORATING ART INTO RESEARCH

- Questions that interviewers can use to deepen the inquiry
- Awareness of potential issues for caregiver
- Needs that cannot be articulated can sometimes be drawn
- Opens participant to emotional expression



(Work)
ie \$

Me
wife

Note:
Bridge is
broken

Samsara
(CANCER)
Babylon

Nirvana

lake of
fire

H₂O



STUDY DATA FROM FIN - NEEDS MET 15/20

- Feel that professionals care about the patient
- Know exactly what is being done to the patient
- Know what treatment the patient is receiving
- Have explanations given in terms that are understandable
- Know why things are done for the patient
- Have someone concerned with my health
- Know the names of the professionals involved in the patient's care
- Help with the patient's care

Needs met = Needs met more than 80% of the time on the FIN

DATA FROM FIN - UNMET

- **Have information about what to do for the patient at home. (only 39%)**
- **Know when to expect symptoms to occur (40%)**

Challenges = Need met 60% or less on FIN

**FIN Survey: Less than 50% knew what symptoms to expect
Less than 40% knew what to do at home.**

We educated the staff nurses that, "Yes, family members could shower." We put in a new shower area on a unit that did not have one. With the grant money and matching funds, we purchased 500 prepackaged bags of hygiene supplies from the ____ company. We now give this bag with a comb, razor, shampoo, toothbrush, and toothpaste to any family member who is staying the night. The bags are labeled "A Gift from the Nursing Research Committee." We rewrote a hospital policy to allow use of patient toilets.

Inconsistency related to hygiene

desire for lists and maps.

A research team member created an orientation book for the patients. It had maps of the hospital and the outside locations, with lists of restaurants, hotels, and drug stores. Pamphlets about the Ethics Committee, the Palliative Care Committee, and other resources were included. These are now being distributed on the medical-surgical units.

spiritual support avenues were lacking.

loved ones were experiencing severe pain.

We have hired both a Palliative Care and a Hospital Chaplain. Plans are underway for an area for meditation and reflection room in the coming year.

This is being addressed as a quality project with our Pain Committee, Inpatient Palliative Care Team and Oncology Department nurses and physicians.

The Needs of Family Members at the Bedside of Stroke Patients

**Sigma Theta Tau
International**

2015 Conference

Michelle Camicia, MSN, CRRN, CCM

**Director, Kaiser Foundation
Rehabilitation Center, Vallejo, CA**



Research Team



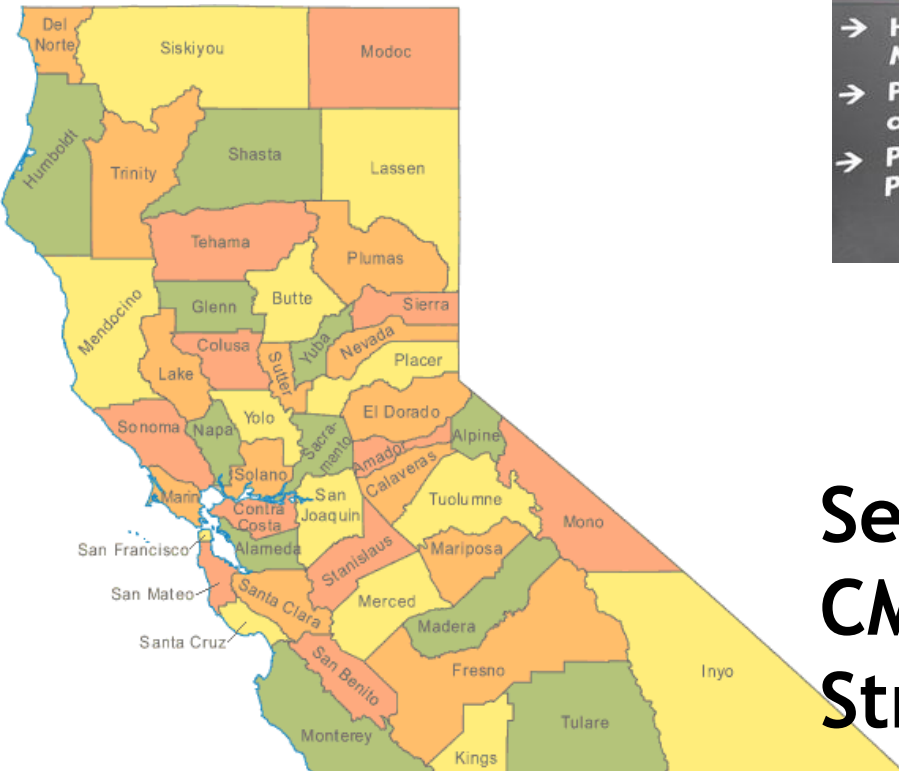
Principal Investigator:
Anita Catlin, DNSc, FNP, FAAN
Consultant, Ethics and Research
Kaiser Permanente Santa Rosa & Vallejo, CA

Co-investigators:
Michelle Camicia, MSN, CRRN, CCM
Nina Markoff, Masters in Social Work Intern

Objectives

1. Share study design and findings from the Family Needs Study
2. Discuss recommendations on how to improve care based on findings





Serve ~700 stroke pts/year
CMI 1.5-1.7
Stroke ALOS=15.1

BACKGROUND

- Study conducted at Kaiser Permanente Santa Rosa with oncology patients
- Limited studies available on needs of family members of stroke patients in an inpatient setting



RESEARCH QUESTIONS

1. What are the needs of family members of stroke patients at the bedside in the rehabilitation unit?
2. Will art therapy lead to an improved understanding of family needs?

Study Aim

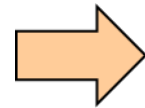
To learn how we can improve the quality of care we offer to families whose family member has a stroke in our hospital.

Study Process

Staff Nurses identify family members who might be interested in participating.

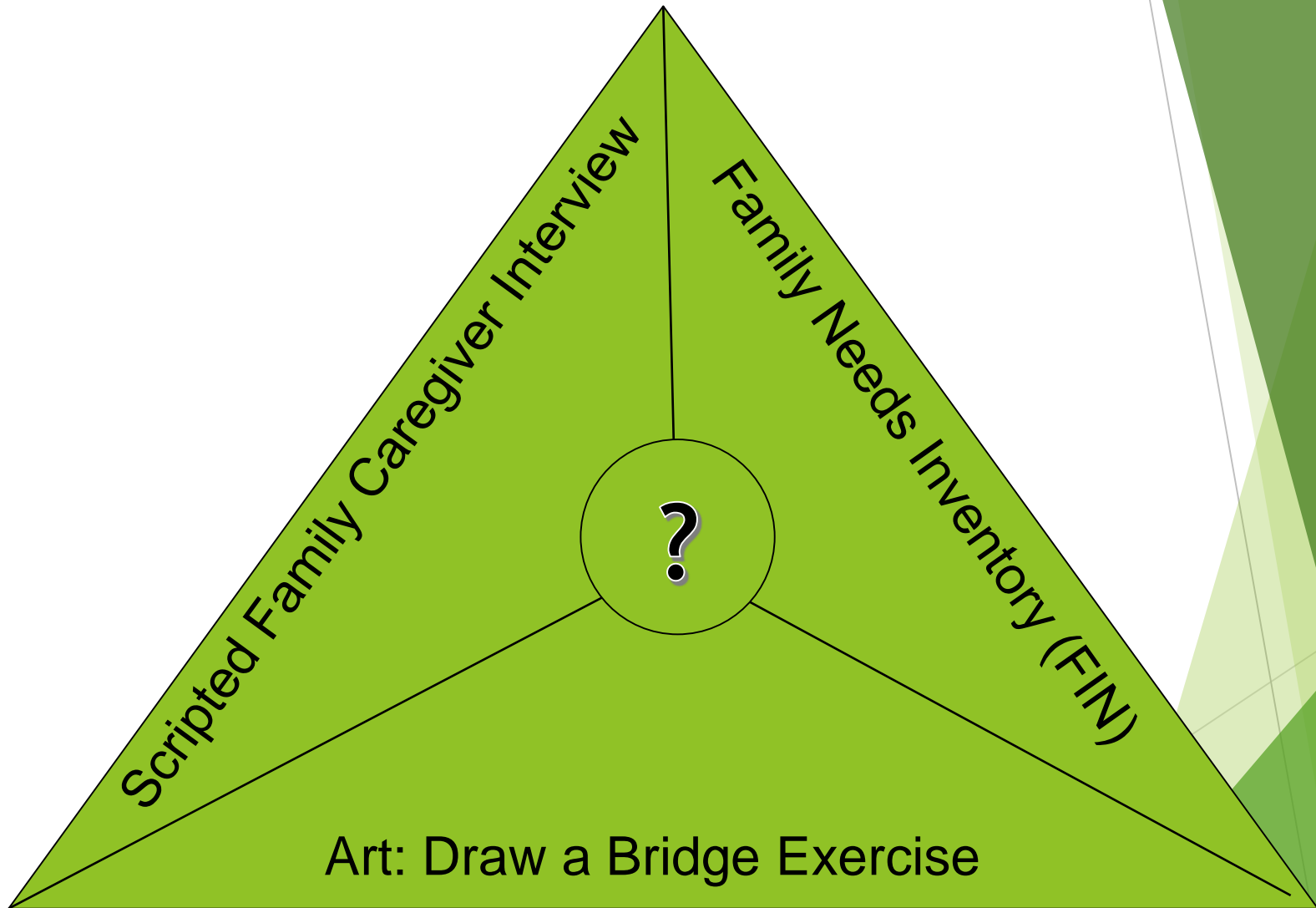


Director speaks with family member, explains study, & if interested, obtains signed consents. Potential appointment times determined.



Interviewer conducts interview, art, & survey

Triangulated Study Design



Measures

Scripted Family Caregiver Interview

- Reaffirm permission to tape & review study
- “We are trying to plan better care for family members who are at the bedside of our patients. We know your ____ had a stroke & you are involved in ____ care.
- “Our study today, however, is about you. We want to hear about the care you need while you are at the bedside & what can be done as we build family centered care program to best serve our families.”

MEASURES

INTERVIEWING IN QUALITATIVE RESEARCH

Questions develop as the data comes in.

If several families talk about need for food, communication, etc., these can be used as prompts for future interviews.

Ask, watch, reflect and listen

Interview ends when family member agrees that he/she has told us what they feel and are satisfied when we reflect back what we have heard.

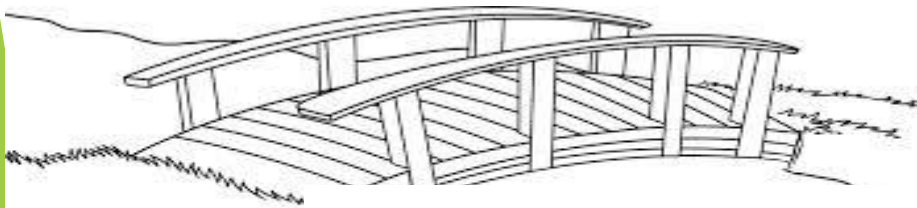
Measures

Family Needs Inventory (FIN)

- Instrument developed by Kristjansen, Atwood & Degner (1995)
- Validity established via expert panel & matched family need findings with other like instruments
- Reliability of Cronbach alpha of .83
- 20 items with a scale of 1-10 identifying if needs are met or unmet.

ART: DRAW A BRIDGE

- A projective technique for assessment in art therapy described by Ronald Hays & Sherry Lyons (19981)
- Indicates how an individual who is going through a difficult change may be experiencing that change
- Can be used to enhance communication & therapeutic change in a therapeutic session



*Interviews for qualitative research
can be therapeutic in & of themselves.*

MEASURES

ART PROCESS



- Introduce materials
- Other people have told us that by drawing a picture of a bridge with you on it, it will help you to formulate your thoughts
- Draw a bridge going from where you are now, to where you might be sometime in the future.
- Place yourself on the bridge
- Describe your bridge & what surrounds it

Data Collection & Analysis

Collect data until saturation of findings is reached & no new information is revealed.

- **FIN** analyzed
- **Interviews** transcribed & coded using naturalistic inquiry method. (Miles and Huberman, 1994)
- **Art**
 - Drawings reviewed by research team.
 - Art Therapist reviews drawings & provides additional insights.

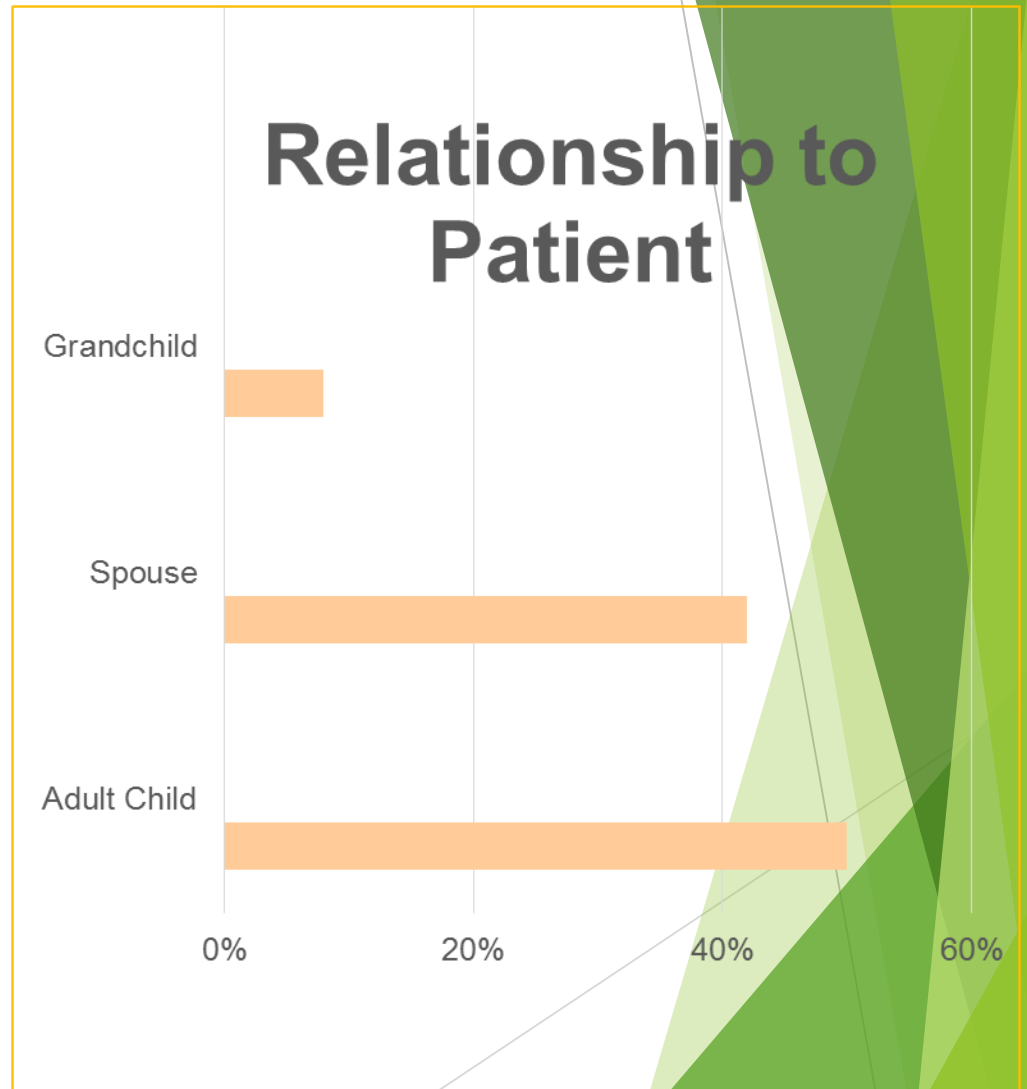
Participants

N = 12

Male 33%

Female 67%

Age 18 - 85
(50% 46-65)



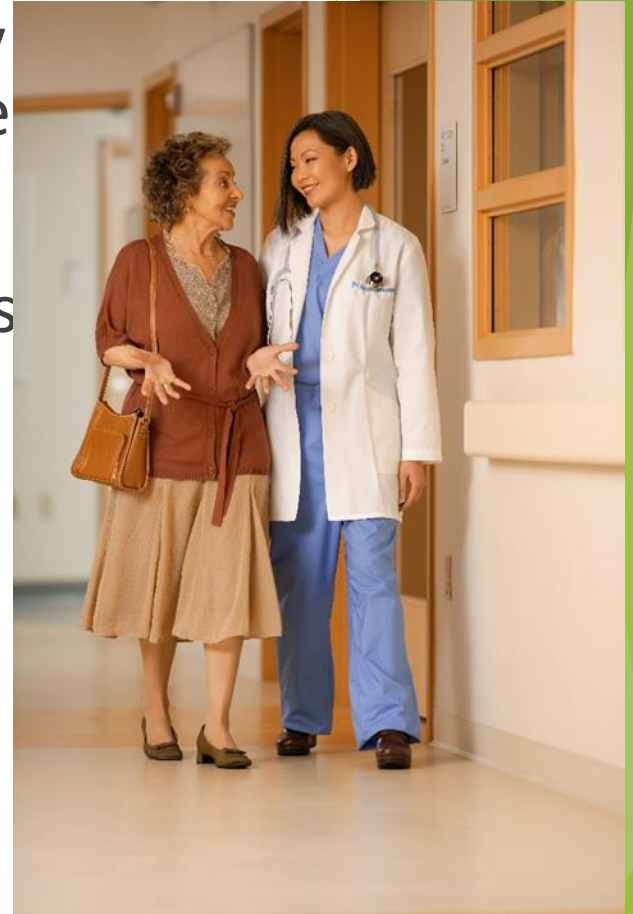
Results: Family Needs Inventory

Scale item	Category Endorsed (%)		
	Unmet	Met	Skipped
Have information about what to do for the patient at home	25%	58%	17%
Know when to expect symptoms to occur	25%	58%	17%
Have someone concerned with my health	25%	67%	8%
Told about changes in the treatment plan while they are being made	8%	83%	8%
Know what symptoms the treatment or disease can cause	8%	83%	8%

RESULTS

QUALITATIVE: THEMES

- Knowing what to expect when they go home (preparation for discharge)
- Communication with care providers
- Physical comfort & self care
- Having someone care about them/provide emotional support
- Trust in care provided



Theme

Knowing what to expect when they go home

“If I had it my way, I think I'd rather have her in here a little longer, so that we feel a little more comfortable caring for her at home”

“When I could tell my fears about what I was afraid - about taking him home, because he's a big man, how do I take care of this person without him hurting himself?”

“We bring him home on Wednesdays, what do we do next? Do we just live? I don't know.”

Theme

Physical Comfort & Self Care

“Sometimes I'm just emotionally drained and I don't know what to do. ...Sometimes at night when she finally goes to sleep I get a chance to lay down, and I just collapse in the chair.”



“I think I've had three showers since I've been here. Otherwise...I go into the washer room and I take a sponge bath every so often and wash my hair in the sink. So, it's been very unpleasant.”

Theme

Communication

“One point of contact with some extremely quick turnaround time would be best...a point person that no matter what even if they can't tell you anything, calls you and tells you...we need acknowledgement.”

“It might be a good idea to force family member or the couple of them to sit down with...somebody who knows all the facts but can massage it through.”



“The communication needs to be a little stronger with the family members that are going to be the ones ultimately giving the patient the care once they get out of here.”

“Once I knew that he was physically ok, that they were taking care of him, I could start absorbing the things that people were giving me like information. I think at first it felt like there was a whole bunch of things coming at once and I really didn't know what to feel throughout.”

Theme

Trust



“They make me feel like I don't have to spend the night because I really do trust these ladies and gentlemen who are taking care of my mom.”

Theme

Caring about them/Emotional Support



“As far as dealing with my mother, nobody asked me how I was holding up or nothing like that; I never talked to anybody about that... That might be something, yeah, that should be focused on.”

Results: What we need to keep doing

Family-centered environment

- Open visitation
- Feeling welcome & included in the patient's therapies

Trust

- The most frequent theme
- All participants felt that team members were skilled & “really cared”



Results: What we need to keep doing

Family-centered Environment

“Another thing that was nice was the puzzles in the family room...and having that room to be able to go there - we'd eat dinner with him, that was very nice.”

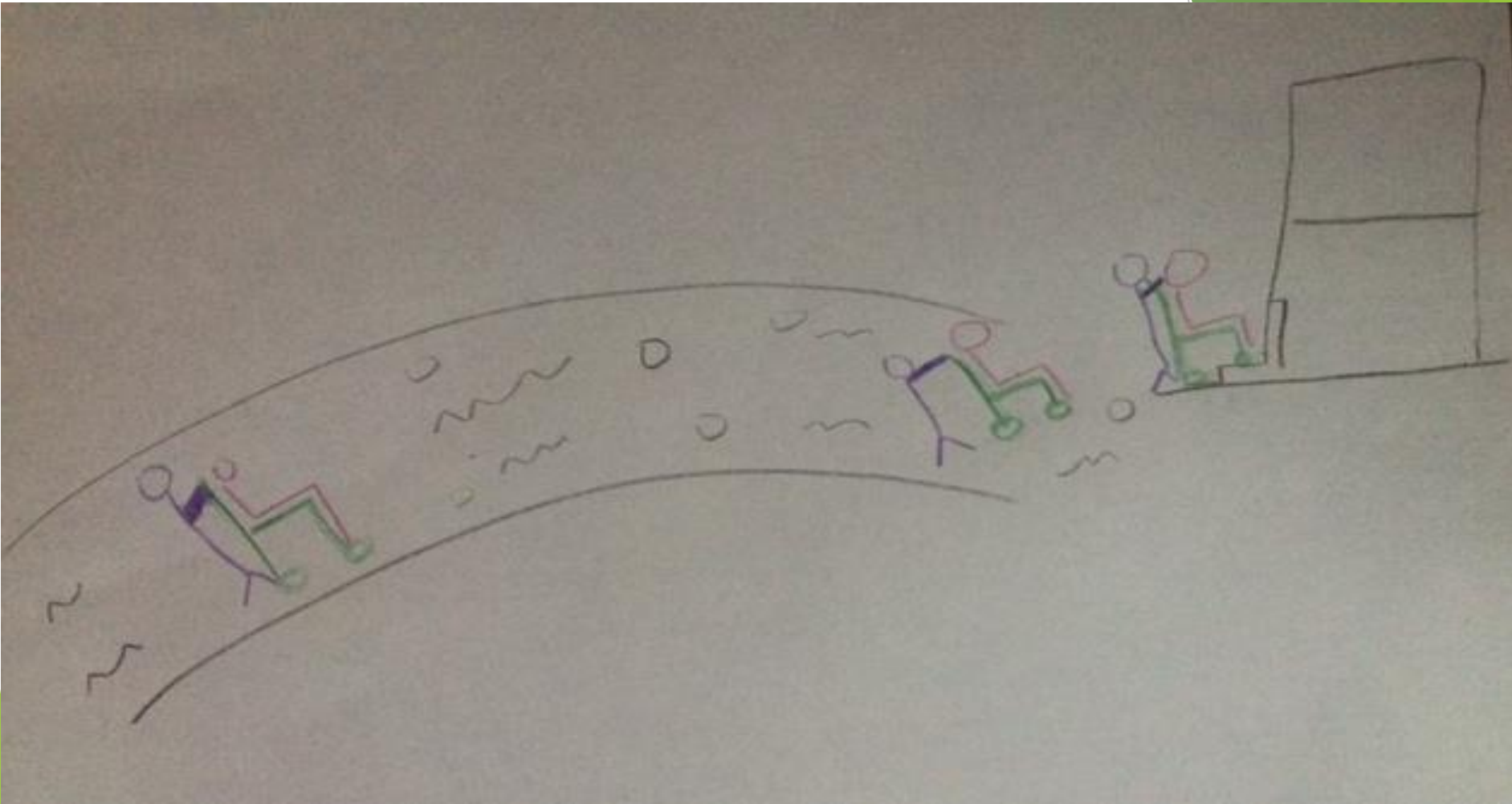
Everyone has been really nice; it's like a family environment. ...They go above & beyond just to make me feel comfortable. They opened up the family lounge for me one night when I came in at 4:30 am.”



“I was surprised they would let me stay the night & that there were no visiting hours, cause they would have had a fight on their hands.”

“I heard a lot of repetitive & support from other fields & the fact that they're so willing to let you sit in & watch everything & explain things was a real support.”

Results: Art



The Draw a Bridge method did seem to inspire deeper communication and emotional expression in some participants.

INCORPORATING ART INTO RESEARCH

- Questions that interviewers can use to deepen the inquiry
- Awareness of potential issues for caregivers
- Needs that cannot be articulated can sometimes be drawn
- Opens participant to emotional expression



Implications

- Proactive solutions to providing family members with emotional support
- Instill hope through interactions with interprofessional team
- Provide for physical needs
 - Promote acquisition of food
 - Provide comfortable sleeping chair
 - Communicate availability of shower
- Implications for future research:
 - Need for studies to determine the effectiveness of interventions to support family members at the bedside in a rehabilitation and other settings
 - Study other populations (e.g. traumatic brain, spinal cord injury) to compare results

LIMITATIONS

- Due to the small sample size, no statistical significance can be determined from the FIN scale data
- Convenience sampling of family present
- Resisting the interest to fix problems



Thank you

for your attention & for being part of this journey to improve care & outcomes for people who experience stroke & their families!

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Assessing & Addressing the Needs of Stroke Survivors and Family Caregivers Across the Care Continuum

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▶ Research Team Extraordinaire

- ▶ Mary Ellen Young, PhD
- ▶ Kerry Creasy, MSN, ARNP
- ▶ Christa Cook, PhD, RN
- ▶ Crystal Martz, MSN
- ▶ Jenny Hoeg, BS

In absentia

- ▶ Kim Cox, PhD, ARNP
- ▶ Lydia Eisenbrandt, MS
- ▶ Undergraduate
Honors Students



Purpose of Research

- ▶ **Understand the experiences of stroke survivors and their family caregivers as they move through the care continuum**
- ▶ **Identify gaps in needs assessment of stroke survivors and their family caregivers**
- ▶ **Identify strategies for addressing post-discharge unmet needs of the family unit**

BACKGROUND

- ▶ ~4 million stroke family caregivers (NAC & AARP, 2009)
- ▶ Stroke occurs suddenly
- ▶ Family members have to assume a new role quickly with limited time for preparation
- ▶ Needs vary as they move through the continuum of care to home
- ▶ Need to tailor our interventions to meet their changing needs

IMPACT OF STROKE - CAREGIVERS

- ▶ **Factors that influence CG health**
 - ▶ **SS functional level**
 - ▶ **Physical & cognitive**
 - ▶ **Availability of support & other resources, e.g. financial**
 - ▶ **Approach to problem solving**
 - ▶ **Socialization / connectedness**

IMPACT OF STROKE

- ▶ Needs of stroke survivors (SSs) & their caregivers (CGs) vary as they move through the continuum of care from onset to home
- ▶ Need to tailor our interventions to meet their changing needs
 - ▶ Focus on the Family Unit
 - ▶ Consider long-term needs of SSs and their CGs

METHODS

▶ **Grounded Theory**

▶ **40 caregivers & 38 patients**

▶ **Semi-structured interviews**

▶ **During rehab**

▶ **Within 6 months post-discharge**

▶ **Data analyzed by research team**

▶ **Dimensional analysis**

▶ **Constant comparative analysis**

TRUSTWORTHINESS

- ▶ **Rigor Theoretical sampling**
 - ▶ **Maintaining an audit trail**
 - ▶ **Member checks**
 - ▶ **Verification**

STUDY PARTICIPANTS

▶ Caregivers

- ▶ Spouses, adult children, children-in-law

- ▶ 73% female 2/3 spouses

- ▶ Age range: 29-83

▶ Stroke Survivors

- ▶ 72% ischemic strokes

- ▶ 55% male Age range: 51-84

▶ Ethnicity

- ▶ 78% white 18% African American

- ▶ 4% Other

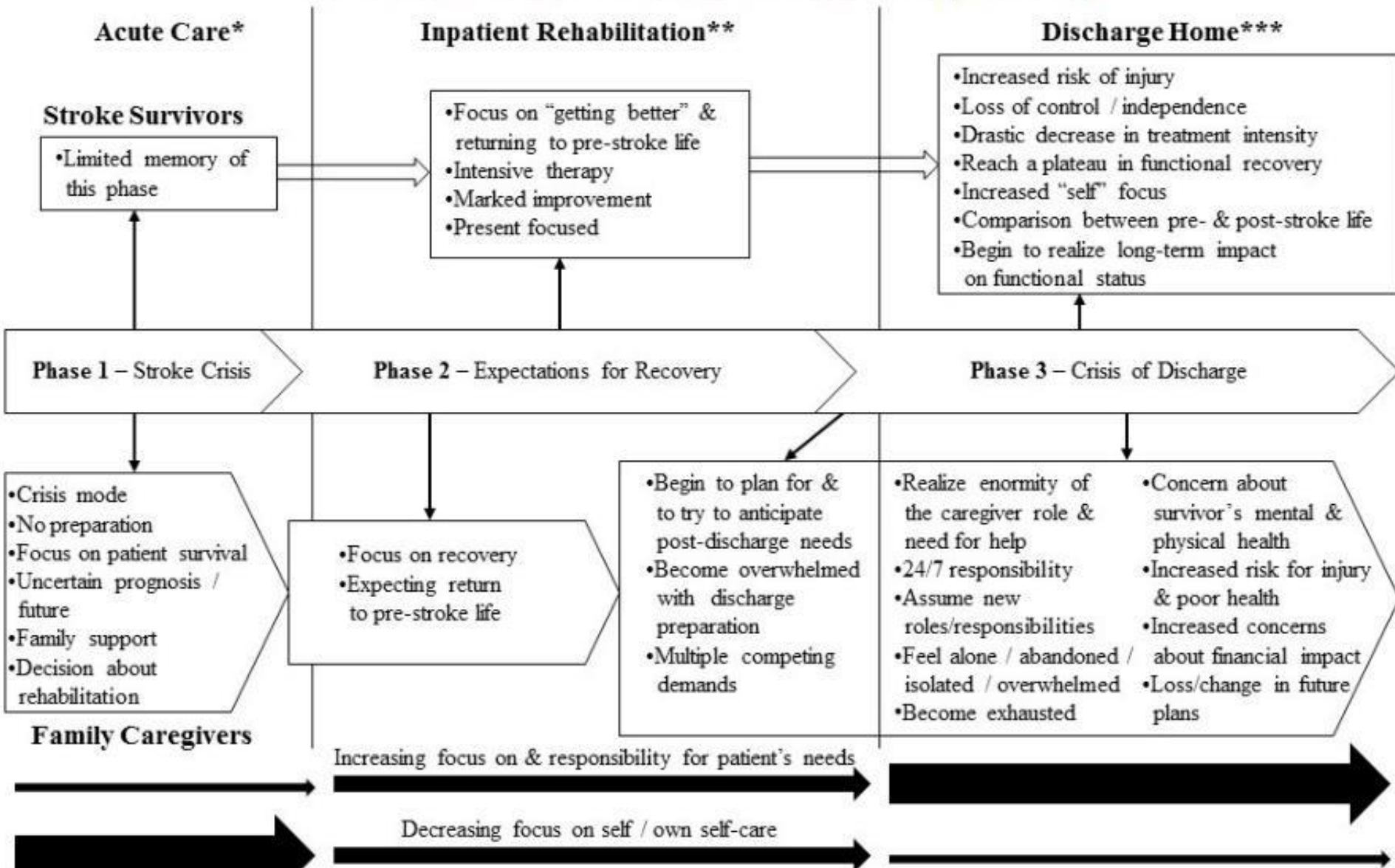
- ▶ Admission FIM™ range: 18-73

FINDINGS

- ▶ Developed 2 conceptual models
 - ▶ Stroke Crisis Trajectory
 - ▶ To understand the experience of caregivers and stroke survivors throughout the continuum of care
 - ▶ Lutz, B.J., Young, M.E., Cox, K., Martz,, C., & Creasy, K.R. (2011). The crisis of stroke: Experience of patients and their family caregivers. *Topics in Stroke Rehabilitation* 18(6), 786-797.

- ▶ **Improving Caregiver Readiness**
 - ▶ **To identify**
 - ▶ **Gaps between caregiver capacity and stroke survivor needs**
 - ▶ **Strategies to address gaps**
 - ▶ Under review: Lutz, Young, et al. *Disability & Rehabilitation*
 - ▶ Camicia interested in carrying forward work

Lutz Model: Stroke Crisis Trajectory

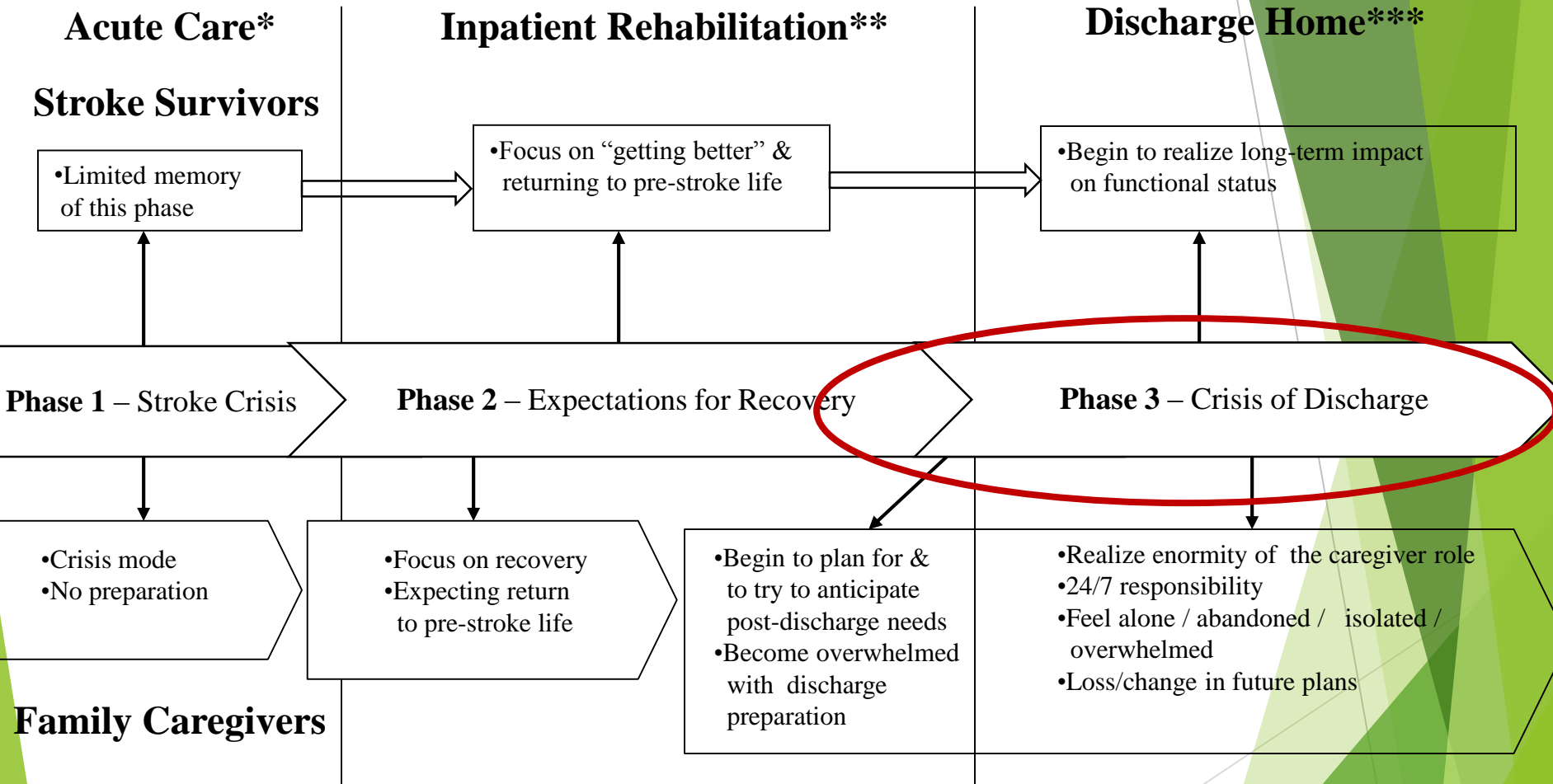


Reprinted with Permission: Lutz, B.J., Young, M.E., Cox, K., Martz,, C., & Creasy, K.R. (2011). The crisis of stroke: Experience of patients and their family caregivers. *Topics in Stroke Rehabilitation* 18(6), 786-797.

*Average length of stay, U.S.: 4.9 days; Study Sample: 8 days; **Average length of stay, U.S.: 18 days; Study Sample: 23 days;

***Study Sample: through the first month post-discharge

Stroke Crisis Trajectory (condensed)



*Average length of stay, U.S.: 4.9 days; Study Sample: 8 days; **Average length of stay, U.S.: 18 days; Study Sample: 23 days; ***Study Sample: through the first month post-discharge

WHAT FAMILY MEMBERS TOLD US

- ▶ Discharge home is a time of crisis
- ▶ Transition home is often fraught with unforeseen complications
- ▶ Training in rehab often does not translate well to home
- ▶ Need assistance in learning to “manage” new life

WHAT FAMILY MEMBERS TOLD

US

- ▶ Feel
 - ▶ Overwhelmed
 - ▶ Isolated
 - ▶ Abandoned
 - ▶ Alone
- ▶ Are grieving
 - ▶ Loss of future
 - ▶ Loss of relationship
 - ▶ Loss for their loved one
- ▶ Don't realize what they have committed to

WHAT FAMILY MEMBERS TOLD US

- ▶ Are conflicted
- ▶ They want to care for their loved one, but can't believe all the changes
- ▶ Lose a sense of self
- ▶ Don't feel included
- ▶ "They didn't tell us what to expect"

HOW DO WE ADDRESS THIS GAP?

- ▶ **Careful systematic assessment**
 - ▶ **Patients' needs post-discharge**
 - ▶ **Family members' capacity for assuming caregiver role**
- ▶ **Prioritize gaps in capacity**
- ▶ **Develop strategies to address gaps**

FAMILY/CG ASSESSMENT DOMAINS

- ▶ **Commitment**
 - ▶ **Strength of relationship**
 - ▶ **Willingness to take on CG role**
 - ▶ **Proximity**
- ▶ **Pre-Existing Factors**
 - ▶ **Existing health issues**
 - ▶ **Pre-illness roles & responsibilities**
 - ▶ **Home environment accessibility**

Family/CG Assessment Domains

- ▶ **Resources**
 - ▶ Internal, external, informal
 - ▶ Pre-illness CG experience
- ▶ **Ability to sustain role long-term**
 - ▶ Self-care strategies
 - ▶ Insight
 - ▶ Prognosis
 - ▶ Boundaries

FAMILY/CG ASSESSMENT DOMAINS

▶ Crisis Response

▶ Grief

▶ Loss

▶ Anxiety

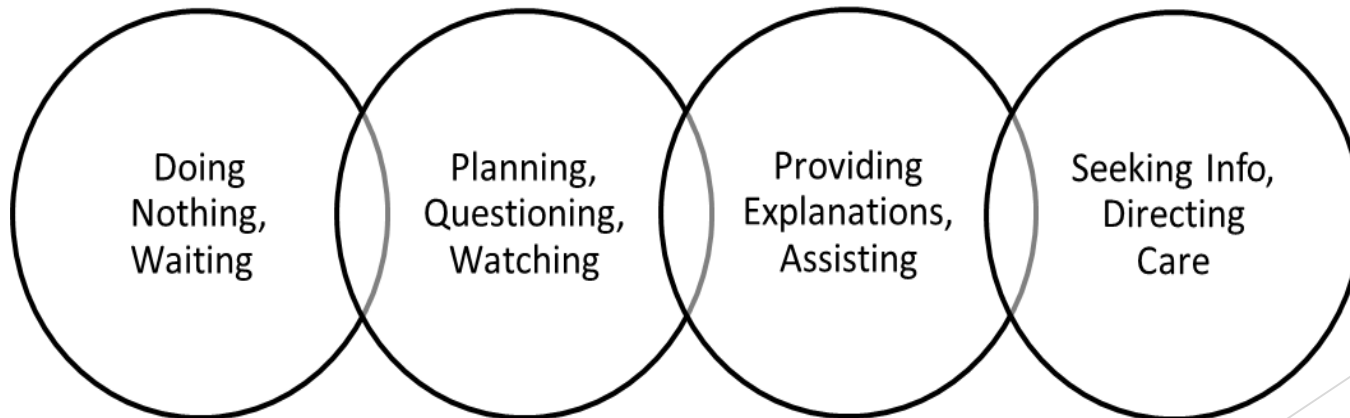
▶ Depression

Reference: Young, M. E., Lutz, B. J., Creasy, K. R., Cox, K. J., & Martz, C. (2014). A comprehensive assessment of family caregivers of stroke survivors during inpatient rehabilitation. *Disability and Rehabilitation*.

Other Considerations

- ▶ **Pre-illness life**
- ▶ **Family / caregiver interaction styles with patient and providers**

Passive ←————→ Active



Reprinted from: Creasy, K.R., Lutz, B.J., Young, M.E., Martz, C., & Ford, A. (2013). The Impact of Interactions with Providers on Stroke Caregivers' Needs. *Rehabilitation Nursing*, 3, 88-98. PMID: 478739

DEVELOPING A PLAN TO ADDRESS GAPS

- ▶ Compare patient needs to caregiver capacity and commitment
- ▶ Identify gaps between needs and capacity/commitment
- ▶ Prioritize gaps
- ▶ Develop a plan

Developing a Plan to Address Gaps

- ▶ Likely topic areas
 - ▶ Activating resources
 - ▶ Readyng the home environment
 - ▶ Securing appropriate equipment
 - ▶ Coordinating multiple appointments
 - ▶ Coordinating additional/other responsibilities
 - ▶ Planning for self-care
 - ▶ Consider need for a grief/crisis management intervention
 - ▶ Refer to family counseling as needed
 - ▶ Caregiver skills training
 - ▶ Medication management
 - ▶ Physical care
 - ▶ Transfers

Model of Improving Caregiver Readiness

Contextual Factors
Caregiver Interactive Style with Healthcare Providers & Care Recipient
Pre-Stroke Life

During Acute Care & Rehabilitation

Risk Assessment Profile:
Matching Caregiver &
Patient Needs

Patient Needs Assessment

- Physical & Cognitive Functional Status
 - ADL
 - IADL
- Co-Morbidities
- # of Medications
- Diet
- Appointments
- Age

Identifying Gaps in Match

Caregiver Readiness Assessment

- Commitment
 - Strength of Relationship
 - Willingness
 - Proximity
- Capacity
 - Pre-Existing Factors
 - Existing Health Problems
 - Pre-Stroke Roles/Responsibilities
 - Pre-Stroke CG Experience
 - Home Environment Accessibility
 - Resources
 - Internal, & External
 - Informal & Formal
 - Financial
 - Ability to Sustain
 - Strategies for Self-Care
 - Boundaries
 - Crisis Response
 - Grief, Loss, Anxiety
- Long-term Implications of Stroke
 - Prognosis
 - Insight

Developing a Plan to
Address Gaps &
Prepare Caregiver

During Rehabilitation &
Transition Home

Caregiver Preparation

- Activating Resources
- Readyng the Home Environment
 - Modifying the home
 - Securing appropriate equipment & supplies
- Providing Skills Training in Patient Care in the Home
 - Managing medications
 - Providing physical care
 - Performing safe transfers
 - Managing behavioral & emotional issues
 - Providing therapies
 - Implementing fall prevention strategies
- Training for Case Management Role
 - Coordinating care across settings
 - Managing multiple appointments
 - Attending to other responsibilities
- Planning for Self-Care
 - Identifying health maintenance strategies
 - Identifying strategies for respite

**If gaps cannot be addressed,
consider other discharge options**

Caregiver
Readiness

INTERVENTION STRATEGIES

- ▶ Use anticipatory guidance
- ▶ Interventions to better prepare caregivers and other family members
 - ▶ Include the family (usually primary CG) and patient (when possible) in team conversations
 - ▶ Assist CGs with strategies to plan / organize / coordinate/ manage
 - ▶ Help them to identify AND activate resources
 - ▶ Provide caregiver skills training
 - ▶ Recommend home adaptations
 - ▶ Discuss plans for self-care and respite
 - ▶ Implement crisis management interventions / referral to family counseling during rehab and post-discharge
 - ▶ Be an advocate even after discharge
- ▶ Need transitional care interventions to help “bridge the gap”

FINAL THOUGHTS

- ▶ Many of our patients cannot go home without the help of family
- ▶ What are we doing to promote the health and well-being of the entire family?
- ▶ What strategies can we implement to better assess and address the needs of family members (especially those who are taking on the role of primary caregiver)?
- ▶ Goal should be to maintain/promote/restore health of the family unit.
- ▶ Family members / caregivers should be included and engaged in the process
- ▶ We need to time our interventions to patient and caregiver needs

“Nothing about us without us”

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BALDWIN



“And do you take Goldie, to be your lawfully wedded primary caregiver?”

Thank You!!!

Questions

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