

A Comprehensive Approach to Improving Stroke Family Caregiver Readiness

BARBARA J. LUTZ, PHD, RN, CRRN, PHNA-BC, FAHA, FARN, FAAN



Justus-Warren Heart Disease and Stroke Prevention Task Force
NC Stroke Advisory Council
Stroke Coordinators Meeting – 1/24/2024

Acknowledgements & Disclosures

Acknowledgement:

Michelle Camicia, PhD, RN, CRRN, CCM, NEA-BC, FAHA, FARN, FAAN

- Director of Operations, Kaiser Foundation Rehabilitation Center
- Owner: PATH2Caregiving, LLC

Disclosures:

Barbara Lutz , PhD, RN, CRRN, PHNA-BC, FAHA, FAAN

- McNeill Distinguished Professor of Nursing
- University of North Carolina-Wilmington
- Current Funding: PCORI & NIH
- Owner: PATH2Caregiving, LLC

No off-label use will be discussed.



Objectives

- Identify gaps in assessing readiness of family caregivers for post-discharge care.
- Describe development of the Preparedness Assessment for the Transition Home (PATH) instrument
- Discuss development of the Catalogue of Interventions associated with the PATH instrument and implementation of the program in clinical care
- Review “Lessons Learned”



Silos of Stroke Care

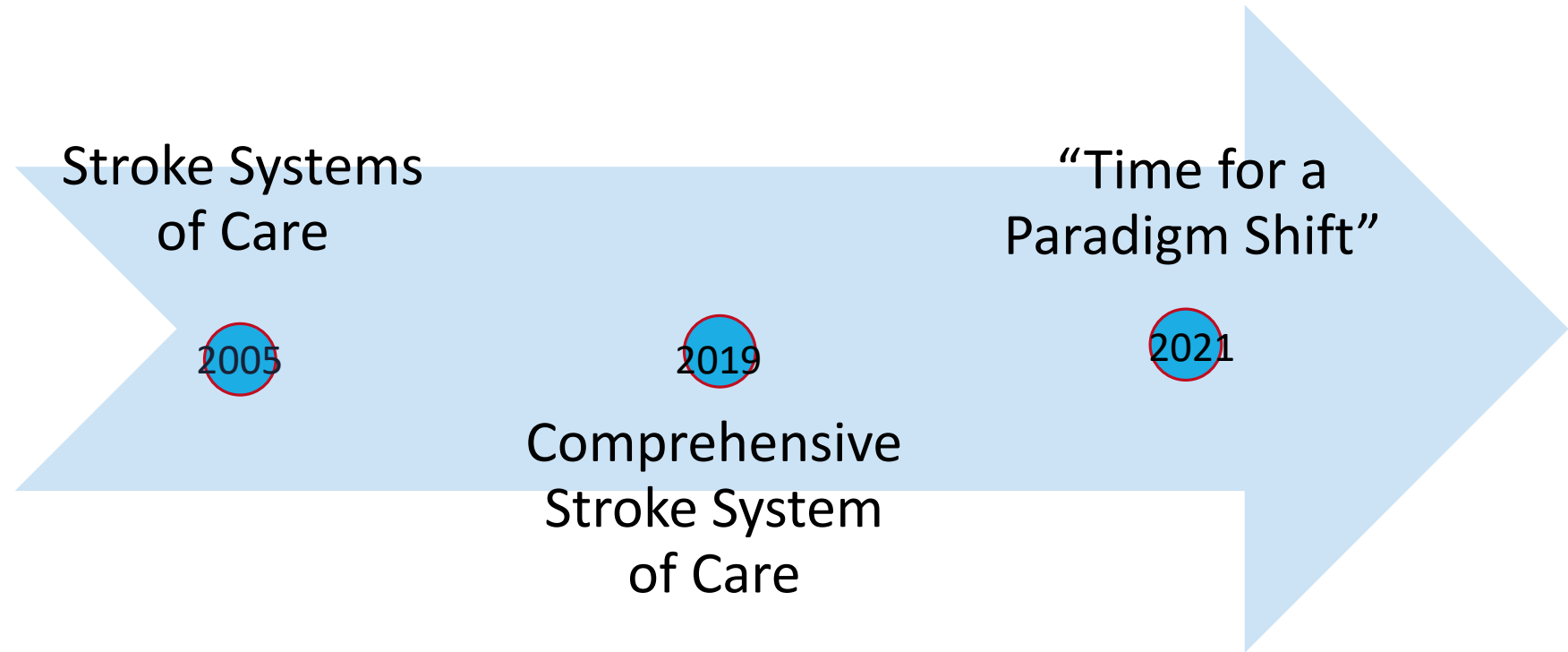
Acute Care

Post-Acute Care

Home



Background



Duncan PW, Bushnell C, Sissine M, Coleman S, Lutz BJ, Johnson AM, Radman M, Pvrü Bettger J, Zorowitz RD, Stein J. Comprehensive stroke care and outcomes: time for a Paradigm Shift. *Stroke*. 2021;52:385–393. doi: 10.1161/STROKEAHA.120.029678

Background

Stroke 2021

TOPICAL REVIEW

Section Editors: Janice L. Hinkle, RN, PhD, CNRN, and Elaine Miller, PhD, MN, BSN

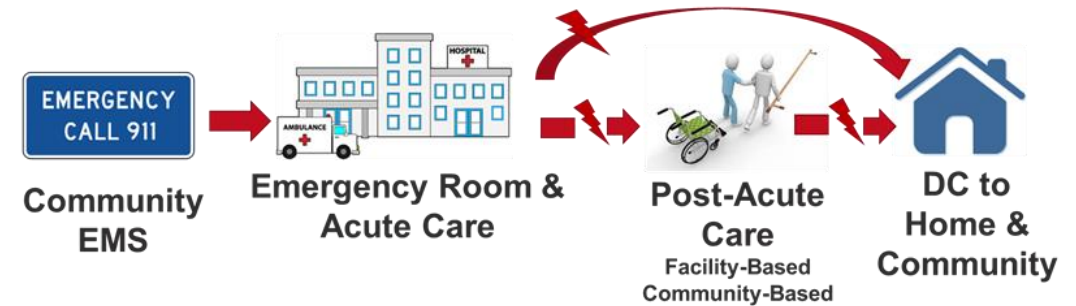
Nursing's Role in Successful Stroke Care Transitions Across the Continuum: From Acute Care Into the Community

Michelle Camicia , PhD, RN, CRRN, CCM, NEA-BC; Barbara Lutz , PhD, RN, CRRN, PHNA-BC; Debbie Summers , MSN, RN, ACNS-BC, SCRNP, CNRN; Lynn Klassman , MSN, APN, CCRN, CCNS, CNRN; Stephanie Vaughn , PhD, RN, CRRN

- Establish a system of coordinated and seamless comprehensive stroke care across the continuum and into the community by reframing the paradigm to include the PAC delivery system
- Implement a validated caregiver assessment to systematically identify gaps in caregiver preparedness and develop a tailored caregiver/family care plan
- Establish a family care plan with tailored interventions based on assessed needs of the stroke survivor and family caregiver and monitors quality outcomes
- Use evidence-based teaching and communication methods to optimize stroke survivor/caregiver learning
- Implement a stroke nurse liaison role

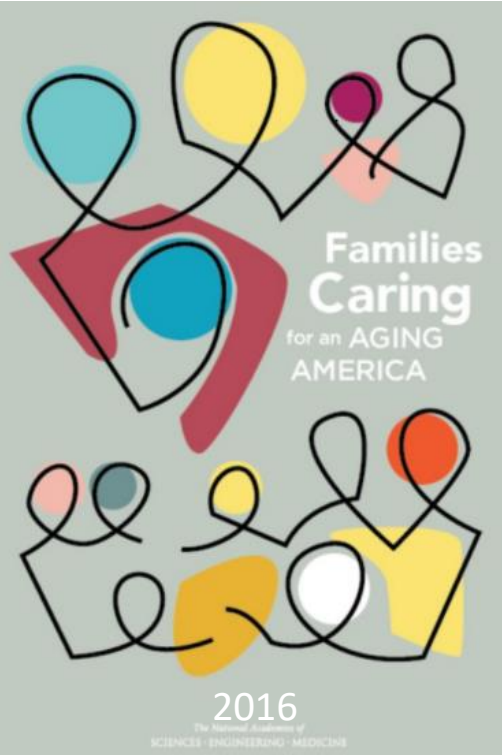
Transition to Home

- One of the most vulnerable times for patients with stroke and caregivers
- Smooth/seamless transitions optimize health and QOL outcomes
- However...
 - Quality of transitions is widely variable
 - Caregivers often feel abandoned and alone
- High quality transition planning:
 - Requires clear and frequent communication across IP team
 - Can be facilitated by a transition specialist or stroke nurse liaison/navigator
 - Understanding of
 - Caregiver capacity and commitment
 - Influence of culture/ethnicity/race/religious preferences/gender identity & SDOH



**Approx. 50% of stroke pts are discharged to facility-based care and ~50% to home
Of those discharged home only about ½ received PAC**

Guidelines Recommending Needs Assessment for CGs



Available online at www.sciencedirect.com



NURS OUTLOOK 000 (2022) 1-9



www.nursingoutlook.org

AARP Public Policy Institute

2019

Publications · Issues · Initiatives · Experts · Events · Data · About PPI



Valuing the Invaluable 2019 Update: Charting a Path Forward

by Susan Reinhard, Lynn Friss Feinberg, Ari Houser, Rita Choula, Molly Evans, **Public Policy Institute**, November 14, 2019

2022

Categorizing national caregiver recommendations to support family caregivers and address unmet needs

Barbara J. Lutz, PhD, RN, CRRN, PHNA-BC, FAAN^{a*},
 Patricia A. Tabloski, PhD, GNP-BC, FGSA, FAAN^b,
 Toby A. Turner, DHA, MSN, AGPCNP-BC, FAAN^c
^aSchool of Nursing, University of North Carolina-Wilmington, Wilmington, NC
^bWilliam F. Connell School of Nursing, Boston College, Chestnut Hill, MA
^cCollege of Nursing, Walden University, Minneapolis, MN

Understanding Caregiver Readiness

BARBARA J. LUTZ, PHD, RN, CRRN, PHNA-BC, FAHA, FARN, FAAN



The Gerontologist
cite as: *Gerontologist*, 2017, Vol. 57, No. 5, 880–889
doi:10.1093/geront/gnw135
Advance Access publication November 5, 2016



Research Article

Improving Stroke Caregiver Readiness for Transition From Inpatient Rehabilitation to Home

Barbara J. Lutz, PhD, RN, CRRN, FAHA, FAAN,^{*.1,2} Mary Ellen Young, PhD,³ Kerry Rae Creasy, PhD, ARNP,² Crystal Martz, MSN, RN,² Lydia Eisenbrandt, MA,¹ Jarrett N. Brunny, MPH,³ and Christa Cook, PhD, RN, MPH²

¹School of Nursing, University of North Carolina-Wilmington. ²College of Nursing, University of Florida, Gainesville. ³College of Public Health and Health Professions, University of Florida, Gainesville.

Development of an Instrument to Assess Stroke Caregivers' Readiness for the Transition Home

Michelle Camicia^{1, 2}, PhD, RN, CRRN, CCM, NEA-BC, FAHA, Barbara J. Lutz³, PhD, RN, CRRN, APHN-BC, FAHA, FNAP, FAAN, Theresa Harvath¹, PhD, RN, FAAN, Katherine K. Kim¹, PhD, MPH, MBA, Christiana Drake¹, PhD & Jill G. Joseph¹, MD, PhD, MPH

Abstract

Purpose: The study purpose was to develop a measure to assess stroke caregivers' commitment and capacity to assume the caregiving role prior to discharge.

Design: Participants were caregivers of stroke survivors in an inpatient rehabilitation facility.

Methods: A sequential, multimethod approach, which included item generation from qualitative data, review of items by expert clinicians, cognitive interviews to determine response format ($n = 22$), and item clarity ($n = 20$), and an analysis of pilot data were utilized.

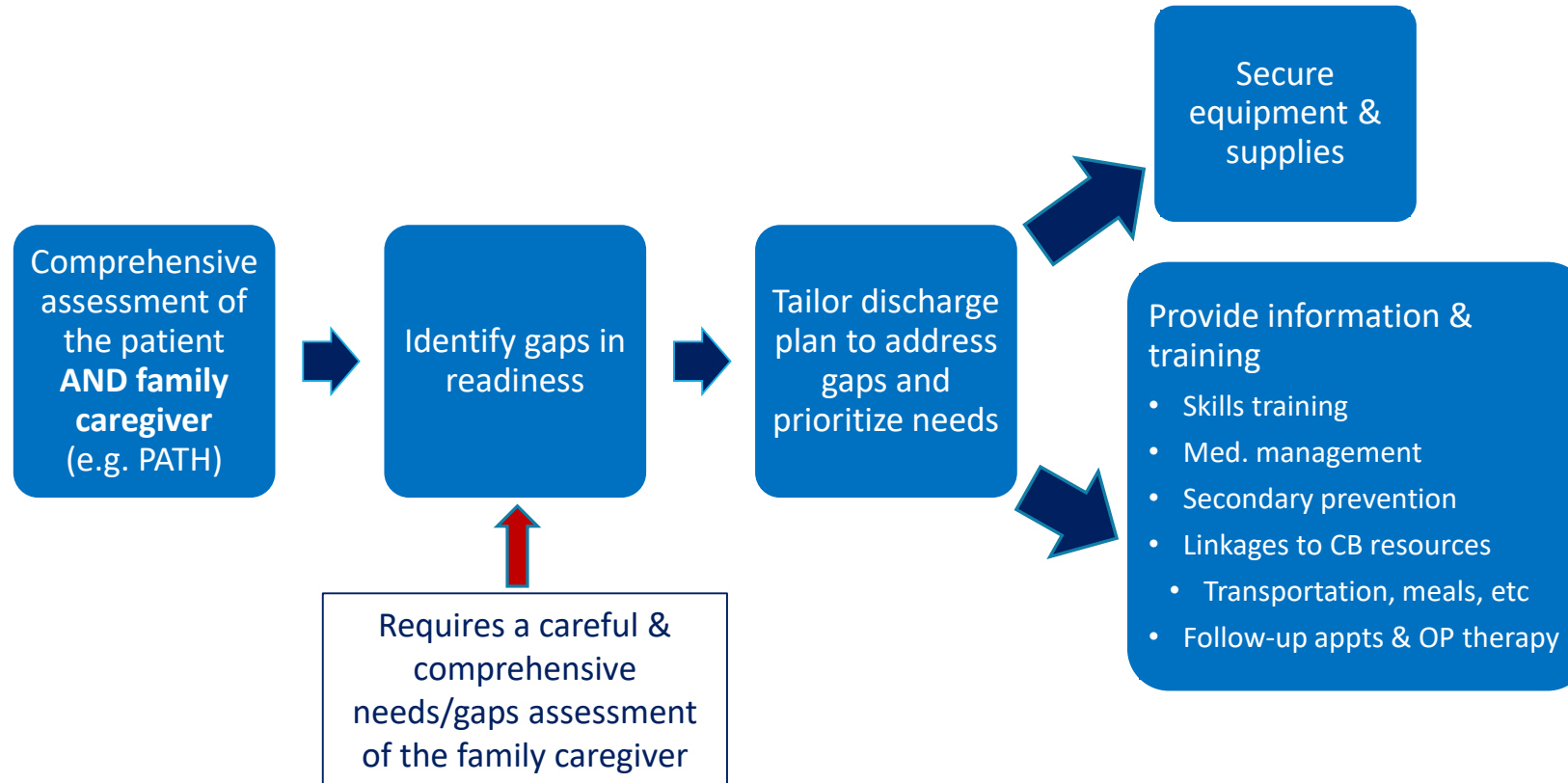
Findings: Cognitive interviewing provided information to improve item clarity.

Conclusion: This instrument development approach resulted in the Preparedness Assessment for the Transition Home After Stroke (PATH-s), a 26-item self-report instrument. The PATH-s represents the domains of the *Model of Caregiver Readiness*, upon which the instrument was developed.

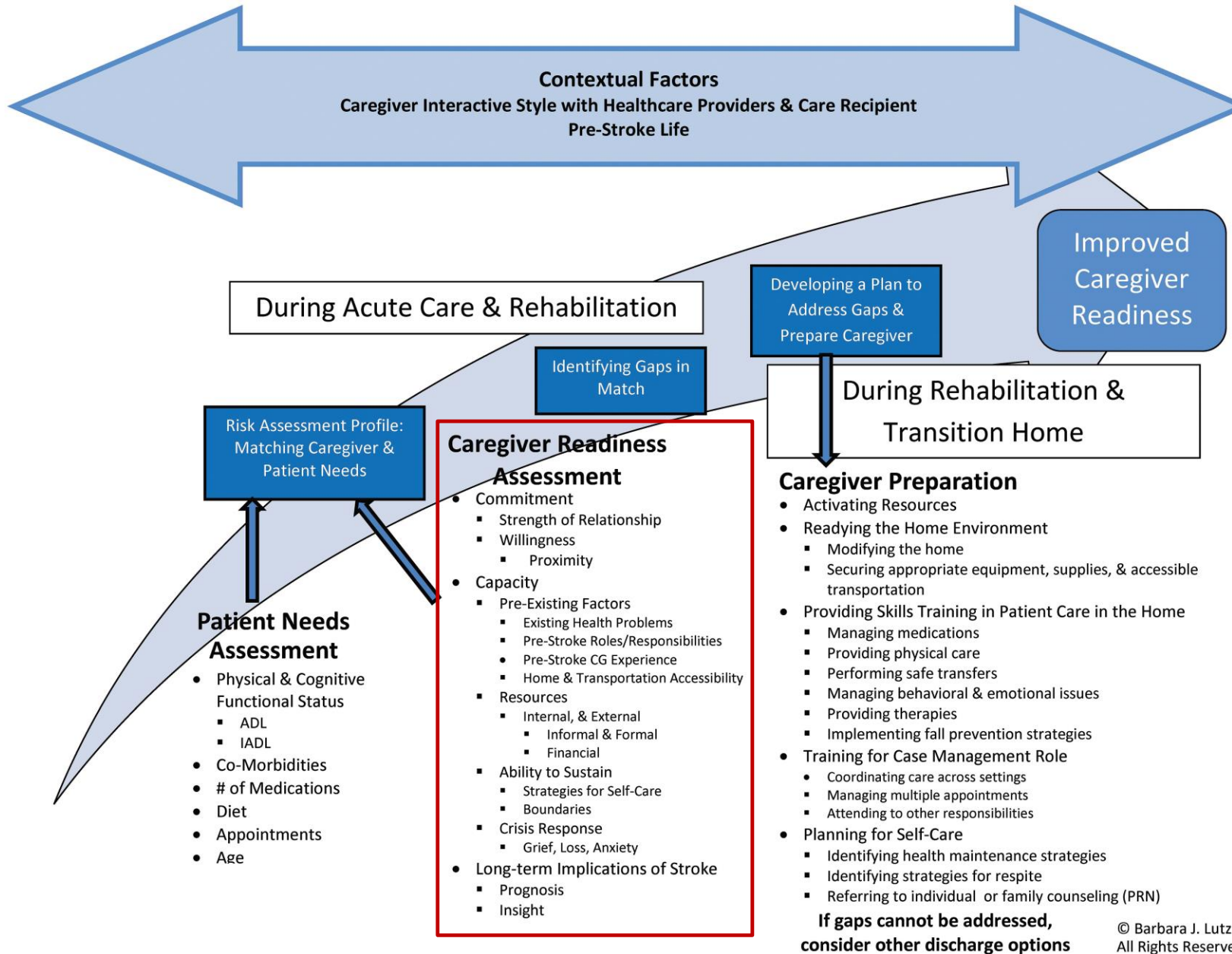
Clinical Relevance: The PATH-s, once further validated, may guide healthcare providers in the development of tailored care plans to address identified gaps and better prepare caregivers for the transition home.

Keywords: Care transitions; caregiver education; discharge planning; family caregiving; stroke.

Components of Transition Plan



Improving Caregiving Readiness Model



Improving Caregiver Readiness: Domains & Sub-Domains

Commitment

- Strength of relationship
- Willingness to perform caregiver role

Capacity

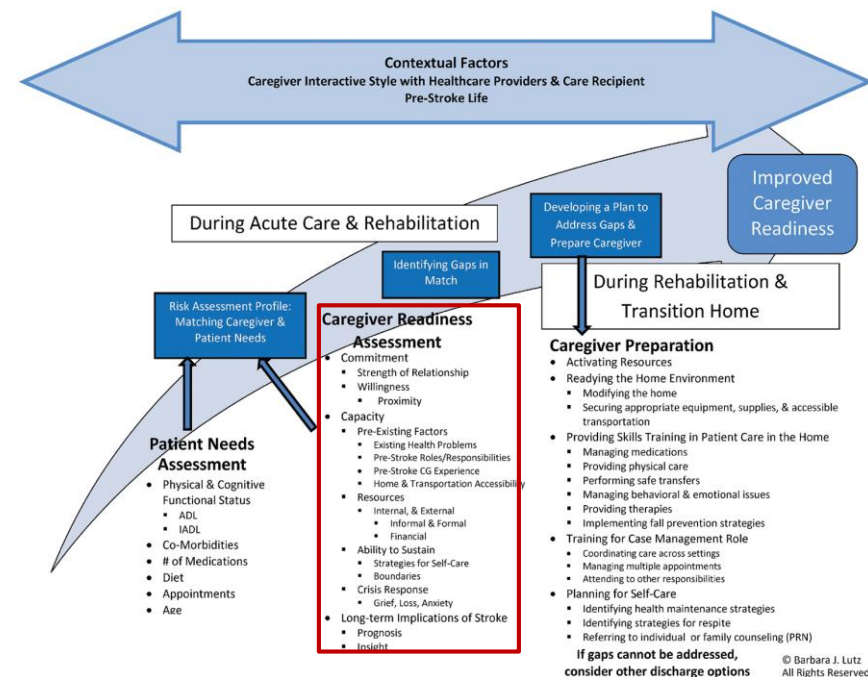
Pre-existing factors

- Health problems
- Pre-stroke roles/responsibilities
- Pre-stroke caregiver experience
- Home and transportation accessibility

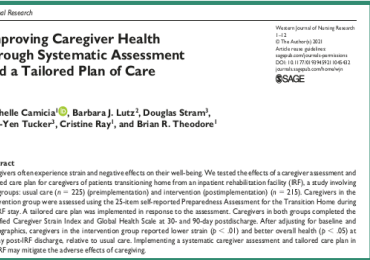
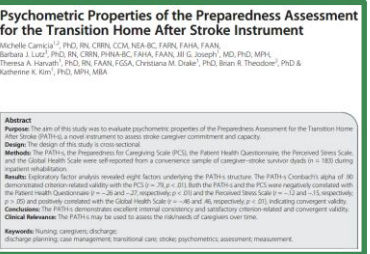
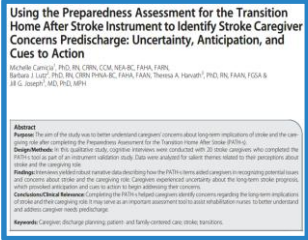
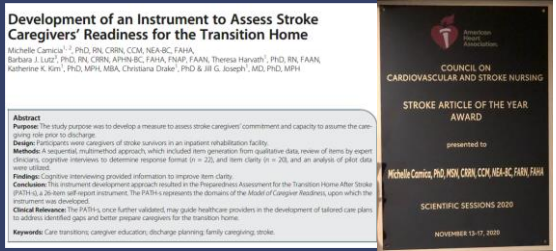
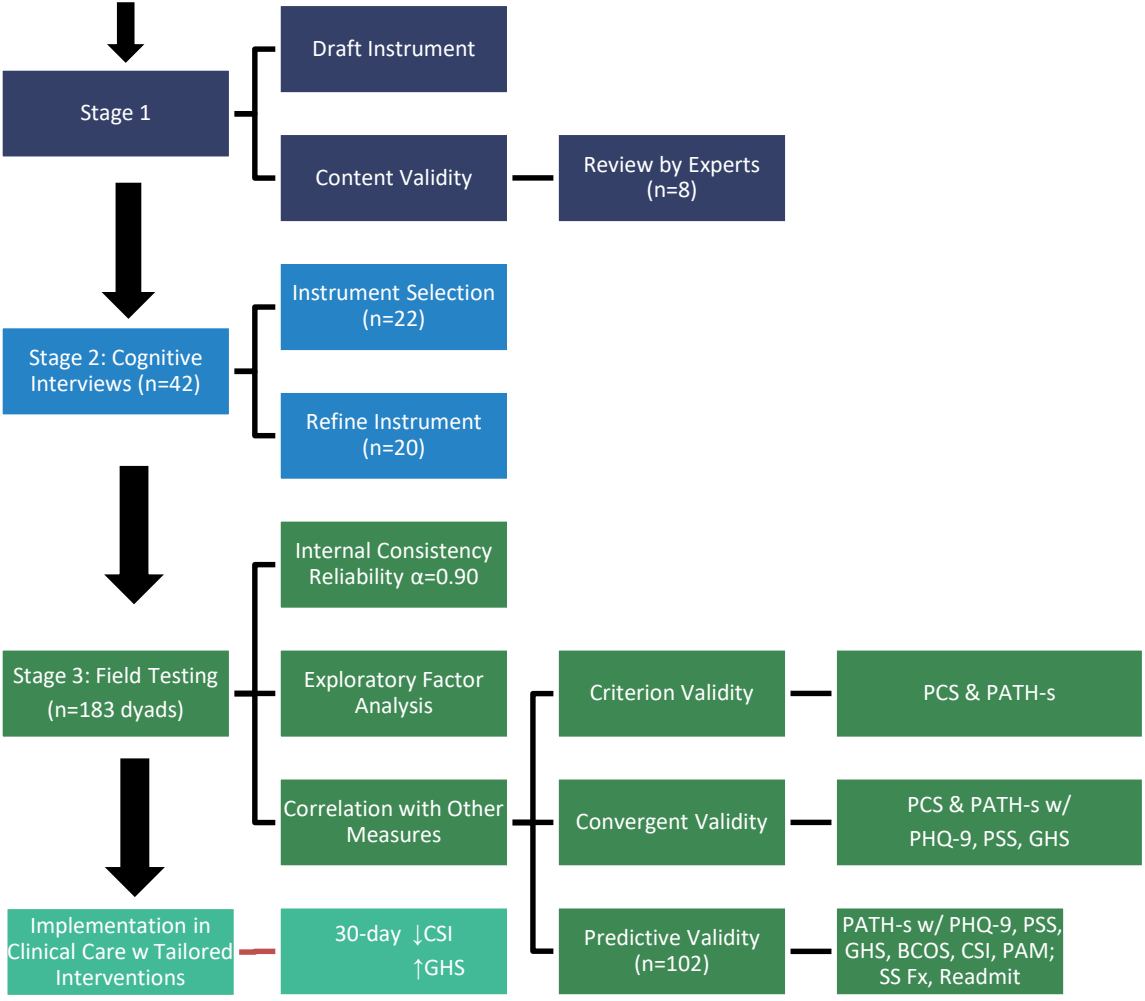
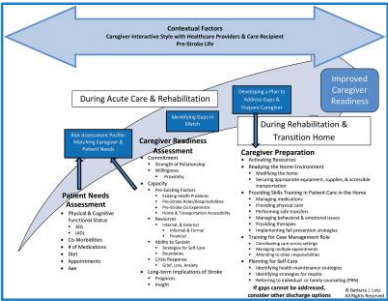
Capacity

Internal & external resources

- Informal support
 - Formal support
 - Financial
- Ability to sustain
Responding to stroke
- Dealing with crisis of stroke
 - Long-term implications



PATH Caregiver Assessment Development



Development of the PATH[©]

(Preparedness Assessment for the Transition Home)
A Pre-Discharge Caregiver Assessment Tool


- 25-item instrument
- Developed with input from
 - Stroke survivors and their family caregivers
 - Case managers
- Theoretically-based in “Improving Caregiver Readiness” model
- Addresses national priorities for assessing caregiver needs
- Designed to assess caregiver readiness to provide care post-discharge
 - To guide development of discharge care plan
 - To be completed during inpatient care
- Originally developed for stroke population; validated by caregivers of patients with other disabling conditions

PATH[©]

Question	Description	Score	Answer Choices
Q1	How much do you understand about the patient's expected recovery over the next 6 months?	2	I have little understanding about the patient's expected recovery over the next 6 months.
Q2	How much do you understand about how the patient's injury/illness will affect your lives over the next 6 months?	3	I understand some about how the injury/illness will affect our lives over the next 6 months.
Q3	How much do you understand about what you need to do to get things ready before the patient goes home?	2	I understand a little about what I need to do to get ready before the patient goes home.
Q4	How much do you understand about what assistance the patient will need with personal care (such as bathing, using the toilet, dressing, and moving around) when he/she goes home?	2	I understand a little about what assistance the patient will need with personal care when he/she goes home.
Q5	How much experience have you had providing physical help with personal care (such as bathing, using the toilet, dressing and moving around) for someone who has an injury/illness or other disability?	1	I do not have any experience providing physical help with personal care for someone who has an injury/illness or other disability.
Q6	How prepared are you to provide the patient assistance with personal care (such as bathing, using the toilet, dressing and moving around) when he/she goes home?	2	I am a little prepared to provide the patient assistance with personal care when he/she goes home.
Q7	How willing are you to provide personal care (such as bathing, using the toilet, dressing, and moving around) for the patient when he/she goes home?	3	I am willing to provide some personal care for the patient.

Participant Interviews

- Conducted multiple studies over several years
 - Conducted more than 100 interviews with stroke survivors and their caregivers
 - Identified domains and sub-domains of caregiver readiness
 - Helped to clarify tool items and format
- Worked with experienced case managers for content validity of the tool

 *The Gerontologist*
cite as: *Gerontologist*, 2017, Vol. 57, No. 5, 880–889
doi:10.1093/geront/gnw135
Advance Access publication November 5, 2016

OXFORD

Research Article

Improving Stroke Caregiver Readiness for Transition From Inpatient Rehabilitation to Home

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Development of an Instrument to Assess Stroke Caregivers' Readiness for the Transition Home

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Abstract

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Findings: Cognitive interviewing provided information to improve item clarity.

Conclusion: This instrument development approach resulted in the Preparedness Assessment for the Transition Home After Stroke (PATH-s), a 26-item self-report instrument. The PATH-s represents the domains of the *Model of Caregiver Readiness*, upon which the instrument was developed.

Clinical Relevance: The PATH-s, once further validated, may guide healthcare providers in the development of tailored care plans to address identified gaps and better prepare caregivers for the transition home.

Keywords: Care transitions; caregiver education; discharge planning; family caregiving; stroke.

Impact of Completing the PATH

Caregivers:

- Recognized uncertainty
- Provoked anticipation
- Identified cues to action to begin to address concerns with rehab team

Using the Preparedness Assessment for the Transition Home After Stroke Instrument to Identify Stroke Caregiver Concerns Predischarge: Uncertainty, Anticipation, and Cues to Action

Michelle Camicia¹, PhD, RN, CRRN, CCM, NEA-BC, FAHA, FARN,
Barbara J. Lutz², PhD, RN, CRRN PHNA-BC, FAHA, FAAN, Theresa A. Harvath³, PhD, RN, FAAN, FGSA &
Jill G. Joseph³, MD, PhD, MPH

Abstract

Purpose: The aim of the study was to better understand caregivers' concerns about long-term implications of stroke and the caregiving role after completing the Preparedness Assessment for the Transition Home After Stroke (PATH-s).

Design/Methods: In this qualitative study, cognitive interviews were conducted with 20 stroke caregivers who completed the PATH-s tool as part of an instrument validation study. Data were analyzed for salient themes related to their perceptions about stroke and the caregiving role.

Findings: Interviews yielded robust narrative data describing how the PATH-s items aided caregivers in recognizing potential issues and concerns about stroke and the caregiving role. Caregivers experienced uncertainty about the long-term stroke prognosis, which provoked anticipation and cues to action to begin addressing their concerns.

Conclusions/Clinical Relevance: Completing the PATH-s helped caregivers identify concerns regarding the long-term implications of stroke and their caregiving role. It may serve as an important assessment tool to assist rehabilitation nurses to better understand and address caregiver needs predischarge.

Keywords: Caregiver; discharge planning; patient- and family-centered care; stroke; transitions.



[Write a Review](#)

On-Demand Webinar: Assessing Family Caregivers Using the PATH Instrument

Product Summary/Description:

Family caregivers are central to successful discharge home for patients receiving inpatient rehabilitation services; yet their needs and concerns are often not assessed. Completing and documenting a comprehensive caregiver assessment has become a national priority.

In this webinar, Dr. Camicia and Dr. Lutz will describe the background, theoretical basis, and development of the Preparedness Assessment for the Transition Home after stroke (PATH-s) tool. Strategies for implementation in inpatient rehabilitation facilities will be discussed. Examples of successful integration of the PATH-s tool in the clinical setting will be described.

www.rehabnurse.org/pathtool

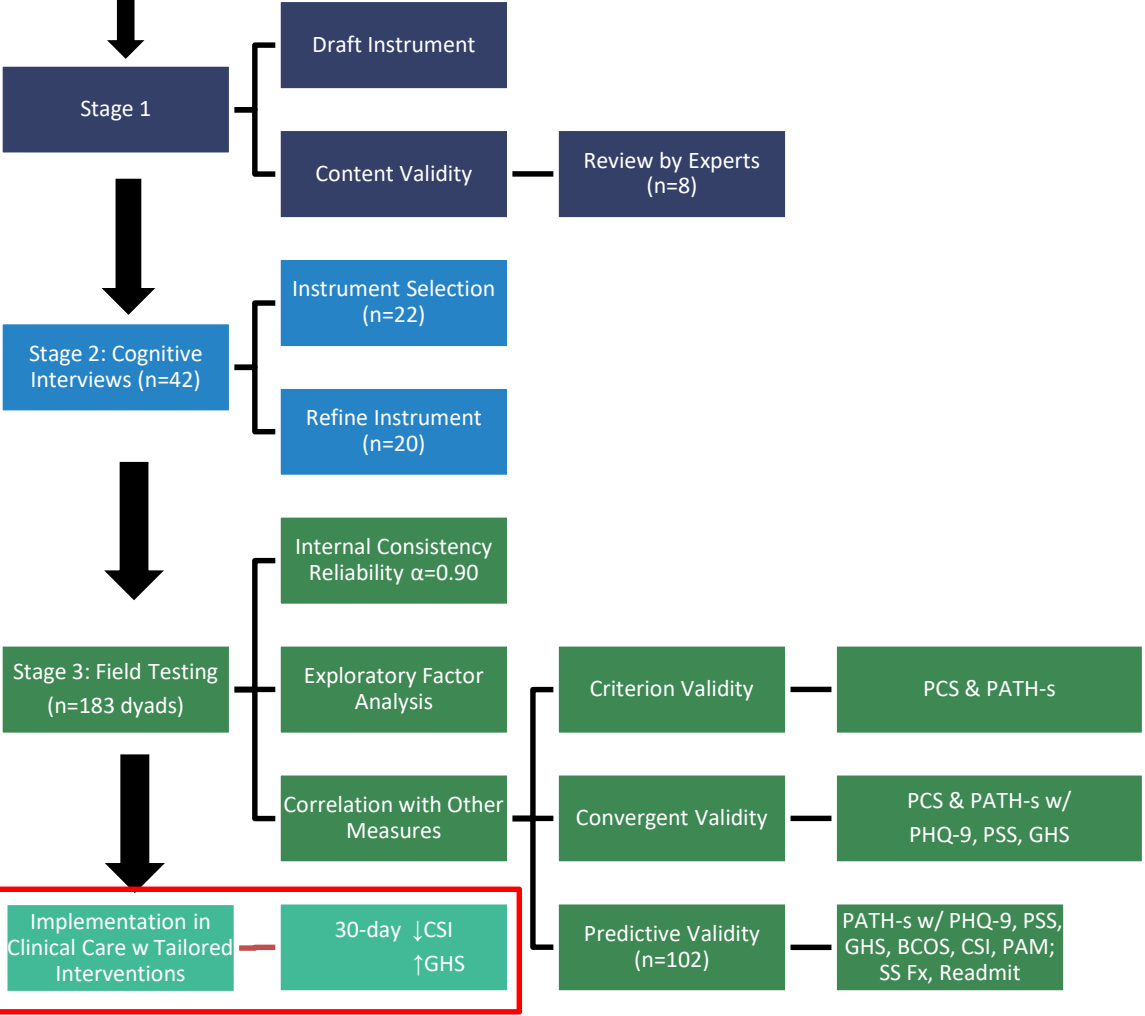
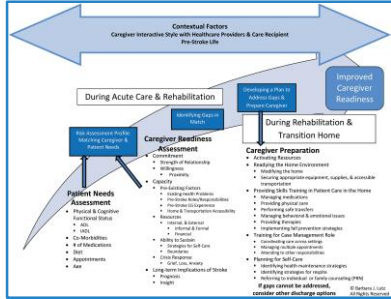


List Price: Free

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PATH Caregiver Assessment Development



Development of an Instrument to Assess Stroke Caregivers' Readiness for the Transition Home

Michele Camicia^{1,2}, PhD, RN, CRN, CCM, NEA-BC, FAHA, Barbara J. Lutz³, PhD, RN, CRN, APN-BC, FAHA, FANP, FAAN, Theresa Harvath⁴, PhD, RN, FAAN, Katherine A. Kim¹, PhD, MPH, MBA, Christina Drake¹, PhD & Jill G. Joseph¹, MD, PhD, MPH

Abstract
Purpose: The study purpose was to develop a measure to assess stroke caregivers' commitment and capacity to assume the caregiving role prior to discharge.
Design: Participants were caregivers of stroke survivors in an inpatient rehabilitation facility.
Methods: A conceptual, multistep approach which included item generation from qualitative data, review of items by expert clinicians, cognitive interviews to determine response format (n = 25), and item clarity (n = 20), and an analysis of pilot data were utilized.
Findings: Cognitive interviewing provided information to improve item clarity.
Conclusions: This instrument development approach, included in the Preparedness Assessment for the Transition Home After Stroke (PATH-s), is a 20-item self-report instrument. The PATH-s represents the domains of the Model of Caregiver Readiness, upon which the instrument was developed.
Clinical Relevance: The PATH-s, once further validated, may guide healthcare providers in the development of tailored care plans to address identified gaps and better prepare caregivers for the transition home.
Keywords: Care transitions, caregiver education, discharge planning, family caregiving, stroke.

**COUNCIL ON CARDIOVASCULAR AND STROKE NURSING
 STROKE ARTICLE OF THE YEAR AWARD**
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 Michele Camicia, PhD, RN, CRN, CCM, NEA-BC, FAHA, FAAN
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 NOVEMBER 13-17, 2020

Using the Preparedness Assessment for the Transition Home After Stroke Instrument to Identify Stroke Caregiver Concerns Predischarge: Uncertainty, Anticipation, and Cues to Action

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Abstract
Purpose: The aim of the study was to better understand caregivers' concerns about long-term implications of stroke and the caregiving role after completing the Preparedness Assessment for the Transition Home After Stroke (PATH-s).
Design/Methods: In this qualitative study, cognitive interviews were conducted with 20 stroke caregivers who completed the PATH-s as part of an instrument validation study. Care were audio-taped and notes were taken related to their responses about stroke and the caregiving role.
Findings: Interviewees expressed four primary concerns describing how the PATH-s items added caregivers' recognizing uncertainties and concerns about stroke and the caregiving role. Caregivers expressed uncertainty about the long-term stroke prognosis, which impacted caregivers' ability to care for stroke survivors following their recovery.
Clinical Relevance: Understanding the PATH-s helps caregiver identify concerns related to the caregiver's expectations of stroke and the caregiving role. This may be used as an important assessment tool to assist rehabilitation nurses to better understand and address caregiver needs predischarge.
Keywords: Caregiver, discharge planning, patient and family centered care, stroke, transition.

Psychometric Properties of the Preparedness Assessment for the Transition Home After Stroke Instrument

Michele Camicia^{1,2}, PhD, RN, CRN, CCM, NEA-BC, FAHA, FANP, FAAN, Barbara J. Lutz³, PhD, RN, CRN, APN-BC, FAHA, FANP, FAAN, Jill G. Joseph¹, MD, PhD, MPH, Theresa A. Harvath⁴, PhD, RN, FAAN, TGA, Christina M. Drake¹, PhD, Brian R. Theodore¹, PhD & Katherine A. Kim¹, PhD, MPH, MBA

Abstract
Purpose: The aim of this study was to evaluate psychometric properties of the Preparedness Assessment for the Transition Home After Stroke (PATH-s), a 20-item self-report to assess stroke caregiver commitment and capacity.
Design: The design of this study is cross-sectional.
Methods: The PATH-s, the Preparedness for Caregiving Scale (PCG), the Patient Health Questionnaire, the Perceived Stress Scale, and the Global Health Scale were self-reported from a convenience sample of caregiver-stroke survivor dyads (n = 183) during inpatient rehabilitation.
Results: Exploratory factor analysis revealed eight factors underlying the PATH-s structure. The PATH-s Cronbach's alpha of 0.96 demonstrated excellent internal consistency with the PCS (r = .79, p < .01). Both the PATH-s and the PCS were negatively correlated with the Patient Health Questionnaire (r = -.26 and -.21, respectively, p < .01) and the Perceived Stress Scale (r = -.12 and -.15, respectively, p < .05) and positively correlated with the Global Health Scale (r = .46 and .46, respectively, p < .01), indicating convergent validity.
Clinical Relevance: The PATH-s demonstrates excellent internal consistency and satisfactory criterion-related and convergent validity.
Keywords: Nursing, caregivers, discharge, discharge planning, care management, transitional care, stroke, psychometrics, assessment, measurement.

Original Research

Improving Caregiver Health through Systematic Assessment and a Tailored Plan of Care

Michele Camicia¹, Barbara J. Lutz², Douglas Stram¹, Lue-Yen Tucker¹, Cristine Ray¹, and Brian R. Theodore¹

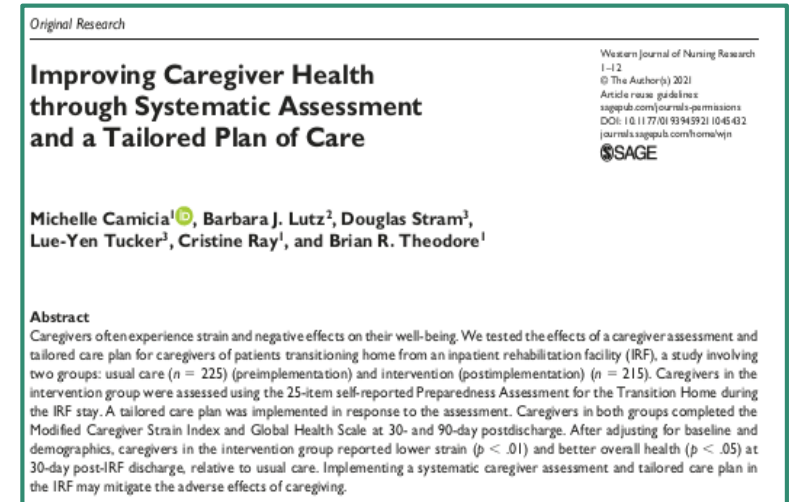
Abstract
 Caregivers often experience strain and negative effects on their well-being. We tested the effects of a caregiver assessment and tailored care plan for caregivers of patients transitioning home from an inpatient rehabilitation facility (IRF), a study involving two groups: usual care (n = 255) (preimplementation) and intervention (postimplementation) (n = 215). Caregivers in the intervention group were assessed using the 25-item self-reported Preparedness Assessment for the Transition Home during the IRF stay. A tailored care plan was implemented in response to the assessment. Caregivers in both groups completed the Modified Caregiver Strain Index and Global Health Scale at 30- and 90-day postdischarge. After adjusting for baseline and demographics, caregivers in the intervention group reported lower strain (p < .01) and better overall health (p < .05) at 30-day post-IRF discharge, relative to usual care. Implementing a systematic caregiver assessment and tailored care plan in the IRF may mitigate the adverse effects of caregiving.

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 Address correspondence to:
 mjcamicia@uconn.edu
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 @SAGE



Improving Caregiver Health through Systematic Assessment and a Tailored Plan of Care

Camicia, M., Lutz, B.J., Stram, D., Tucker, L.Y., Ray, C., & Theodore, B.R. (2022). Improving caregiver health through systematic assessment and a tailored plan of care. *Western Journal of Nursing Research*. 44(3):307-318. doi: 10.1177/01939459211045432



Deemed an “exemplary” program by the ANCC Magnet Recognition Program™ and the Commission on Accreditation of Rehabilitation Facilities (CARF) International



Kaiser Permanente Northern California Care Delivery System

21 acute care hospitals

Regional Inpatient Rehabilitation Facility

Owned/operated SNF + Contracts

Home Health Agencies

4.1 million health plan members

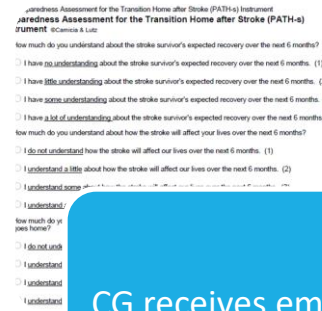


Funded by:
Kaiser Permanente Northern California
Community Health Program

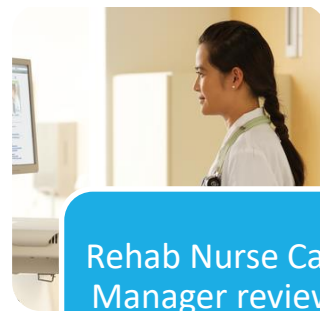
The Intervention: Caregiver Assessment & Plan of Care



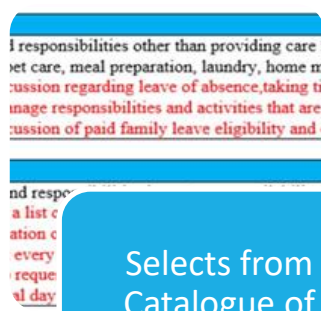
Identify Caregiver & obtain email address



CG receives email & completes PATH assessment



Rehab Nurse Case Manager reviews results & identifies items w/ score ≤ 2



Selects from Catalogue of Interventions & to develop CG Plan of Care



Case Manager reviews Plan of Care & Interprofessional Team implements

Identifies specific areas to target interventions

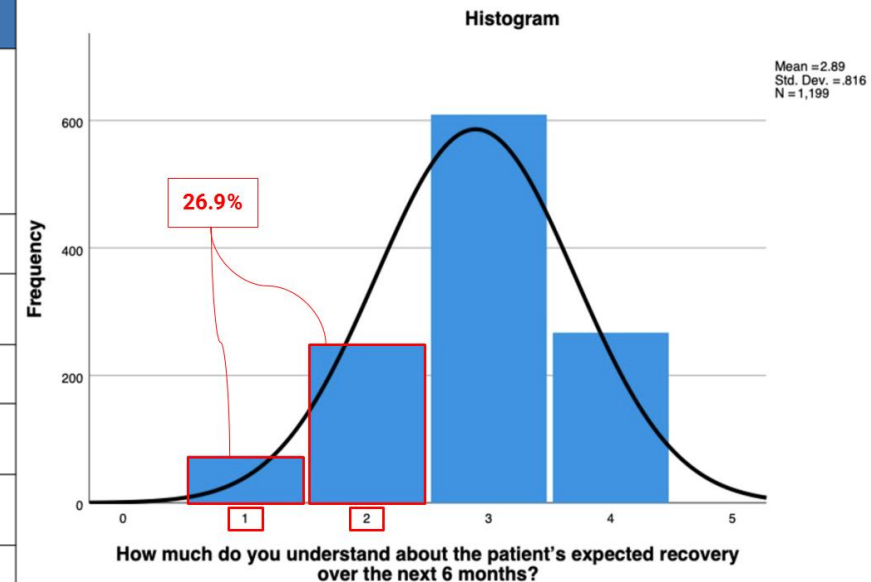
Q1	How much do you understand about the patient's expected recovery over the next 6 months?	2	I have little understanding about the patient's expected recovery over the next 6 months.
Q2	How much do you understand about how the patient's injury/illness will affect your lives over the next 6 months?	3	I understand some about how the injury/illness will affect our lives over the next 6 months.
Q3	How much do you understand about what you need to do to get things ready before the patient goes home?	3	I understand some about what I need to do to get ready before the patient goes home.
Q4	How much do you understand about what assistance the patient will need with personal care (such as bathing, using the toilet, dressing, and moving around) when he/she goes home?	2	I understand a little about what assistance the patient will need with personal care when he/she goes home.
Q5	How much experience have you had providing physical help with personal care (such as bathing, using the toilet, dressing and moving around) for someone who has an injury/illness or other disability?	1	I do not have any experience providing physical help with personal care for someone who has an injury/illness or other disability.
Q6	How prepared are you to provide the patient assistance with personal care (such as bathing, using the toilet, dressing and moving around)?	2	I am a little prepared to provide the patient assistance with personal care when he/she goes home.

Q7	How willing are you to provide personal care (such as bathing, using the toilet, dressing, and moving around) for the patient when he/she goes home?	3	I am willing to provide some personal care for the patient.
Q8	How much time will you have to provide personal care for the patient when he/she goes home?	2	I will have a little time to provide personal care for the patient.
Q9	Do you have any health problems (for example difficulty bending or stooping, back or joint problems, heart issues, memory, depression, anxiety or other health challenges)?	3	I have a few health problems.
Q10	Do you think your health problems will affect your ability to provide care for the patient?	4	I do not think my health problems will affect my ability to provide care.
Q11	Do you have family and/or friends who are capable of providing help with the patient's personal care (such as bathing, using the toilet, dressing, and getting in and out of bed)?	2	I have a few family and/or friends who are capable of providing help with the patient's personal care.
Q12	Do you think these family and/or friends will be available to help with the patient's personal care when needed?	3	I think these family and/or friends will sometimes be available to help when needed.

PATH Question 1:

Family caregivers' understanding of patient prognosis: The prevalence of gaps in caregiver understanding and the interventions recommended to improve caregiver preparedness

ITEM	INTERVENTION	DELIVERY
<p>Question #1: How much do you understand about the patient's expected recovery over the next 6 months?</p> <p>1 – I have <u>no understanding</u> about the patient's expected recovery</p> <p>2 – I have <u>little understanding</u> about the patient's expected recovery</p> <p>3 – I have <u>some understanding</u> about the patient's expected recovery</p> <p>4 – I have <u>a lot of understanding</u> about the patient's expected recovery</p> <p>No Intervention Delivered</p>	<ul style="list-style-type: none"> Basic injury/illness education. Types of stroke and areas of brain, associated functional deficits, and severity. Provider who has rapport and understanding of deficits provides education in lay terms tailored to area of brain and implication. Direct to "I'm on My Way" Resource, Patient Pal App or Binder. Suggest participation in caregiver peer forum, "Caregiver Tea," Stroke or Spinal Cord Education Class. Provide "Healing into Possibility" video link. 90-day follow up Care Tool examples with similar kinds of stroke, Brain Injury, or Spinal Cord Injury. Support hope. Discipline-specific patient and caregiver education per area of expertise and profession/scope of practice. Provide education on importance of maintaining mobility to support continued engagement in ADLs (i.e., home exercise program, daily stretching, education on tone and spasticity management). Provide education (verbally or via handout) on impairment level, progress, and suggestions. 	<p>PM&R Education / In-Person</p> <p>Nurse Case Manager Education / In-Person</p> <p>Nurse Case Manager Education / In-Person</p> <p>Nurse Case Manager Education / Media</p> <p>Nurse Case Manager Education / In-Person</p> <p>OT, PT, ST Education / In-Person</p> <p>OT Education / In-Person</p> <p>ST Education / In-Person / Handouts</p>



Development of a Tailored Plan of Care in Response to the PATH

MD	<ul style="list-style-type: none">● Provide basic education about condition verbally, written materials and video, on-line● Review severity and associated functional deficits.● Discuss medical and functional prognosis
CM	<ul style="list-style-type: none">● Direct to "I'm on My Way" Resource, Pt Pal App or Binder● Suggest participation in caregiver peer forum "Caregiver Tea", Stroke or Spinal Cord Education Class● Provide Healing into Possibility video link for patients with brain injury/stroke● UDS spider 90 day follow up Care Tool examples w/ similar kinds of stroke- Brain Injury or Spinal Cord Injury. Each pt. may do better/worse (mean scores from UDS).
MSW	<ul style="list-style-type: none">● Support Hope
PT,OT,ST	<ul style="list-style-type: none">● Discipline specific patient and caregiver education per area of expertise and profession scope of practice● Provide education on impairment level, progress and suggestions
RN	<ul style="list-style-type: none">● Encourage family/caregiver participation in all nursing care needs whenever possible



Physician Note Examples

Dispo: caregiver (wife Donna) scored low on PATH question 1. Will discuss prognosis with caregiver on CGT day (5/14/23)



Dispo: caregiver (wife Donna) scored low on PATH question 1. Discussed diagnosis, risk factors, short and long term prognosis with Donna today 5/14/23. All questions were answered, and Donna verbalized understanding.

Development of a Tailored Plan of Care in Response to the PATH

5. How much experience have you had providing physical help with personal care (such as bathing, using the toilet, dressing and moving around) for someone who has a disability?

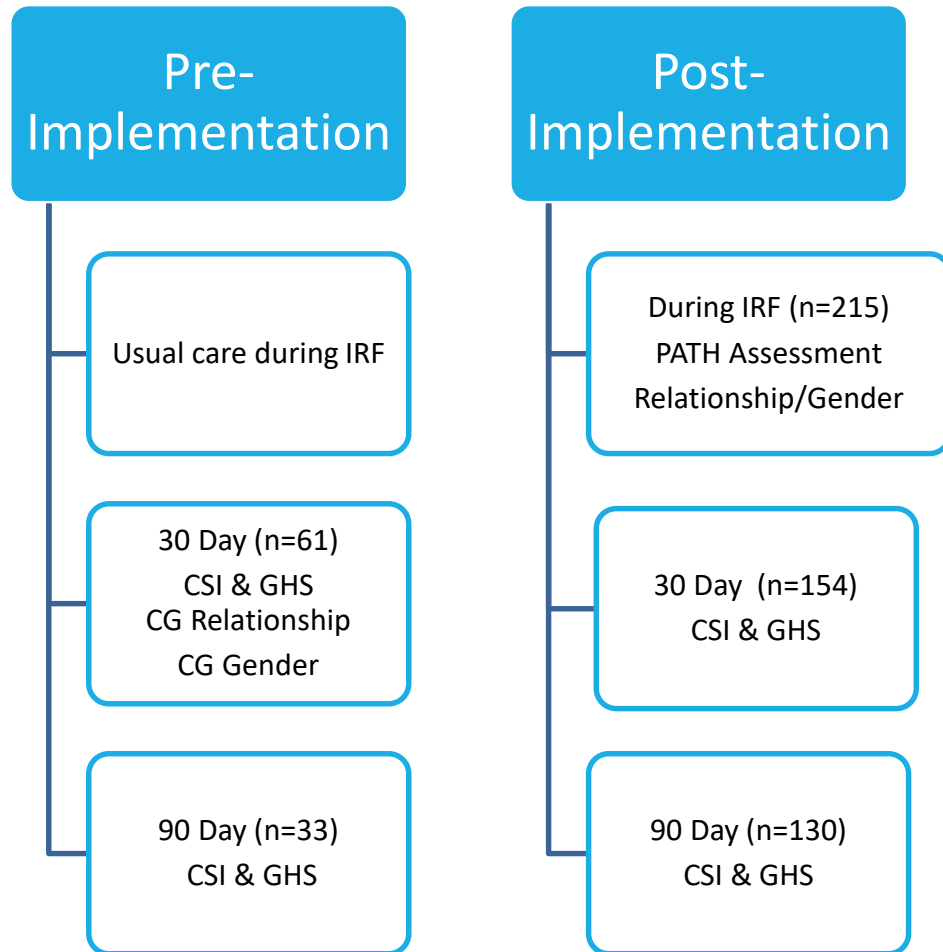
CM	<ul style="list-style-type: none"> • Assist with scheduling their time during rehab so can be present for observing care and attend to self-care and other personal required activities/commitments (e.g. outstanding physician visits and other personal needs/obligations) • Encourage to observe others to identify improvement across trajectory • Offer Family Conference, Therapeutic Overnight Pass, ADL Apartment or stay in patient room after completion of caregiver training
PT,OT	<ul style="list-style-type: none"> • Urge to observe transfers and other care including morning and evening care

20. Will there be any accessibility problems for the patient getting around in the house or using the toilet or shower (for example, the width of doorways, stairs, ramp access) in the home where she will be living?

CM	<ul style="list-style-type: none"> • Discuss options for sleeping/living on entry level • Explore options for alternative living location as needed
MSW	<ul style="list-style-type: none"> • If rent, determine if owner will allow home modifications • If HOA, identify if ramp or other modifications permitted
PT,OT	<ul style="list-style-type: none"> • Consider energy conservation techniques with stairs as needed and for home adaptive devices that may be beneficial • Educate on adaptation of home environment to accommodate impairment vs major home renovation (functional vs ADA adaptation) • Review home evaluation and provide recommendations for modifications and DME to increase home accessibility and safety



CG Data Collection: Email survey via secure DatStat



PATH=Preparedness Assessment for the Transition Home

- 25-items
- CG commitment & capacity
- Higher score=more prepared

CSI=Modified Caregiver Strain Index

- 13-items
- Measure strain (financial, physical, psychological/emotional, social & personal)
- Lower score=less strain

GHS=PROMIS Global Health Scale

- 10-items
- Assesses overall physical/mental/ social health, pain, fatigue, overall QOL
- Higher score=better overall health

Caregiver Characteristics

Pre-implementation

Majority Female

Majority Spouse

Majority >\$75k/yr

45% White

Majority married

Post-implementation

Majority Female

Majority Spouse

Majority >\$75k/yr

45% White

Majority married

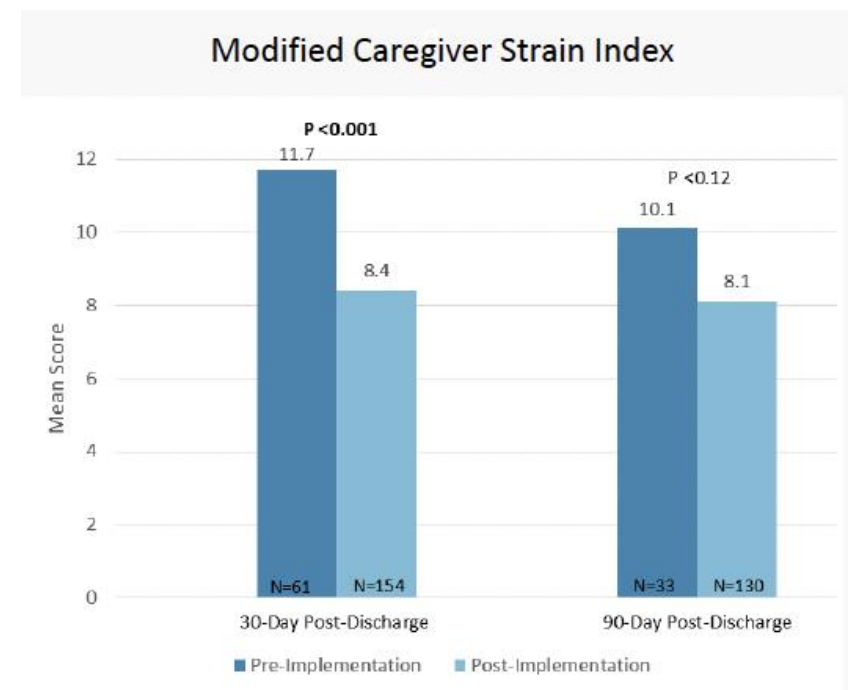
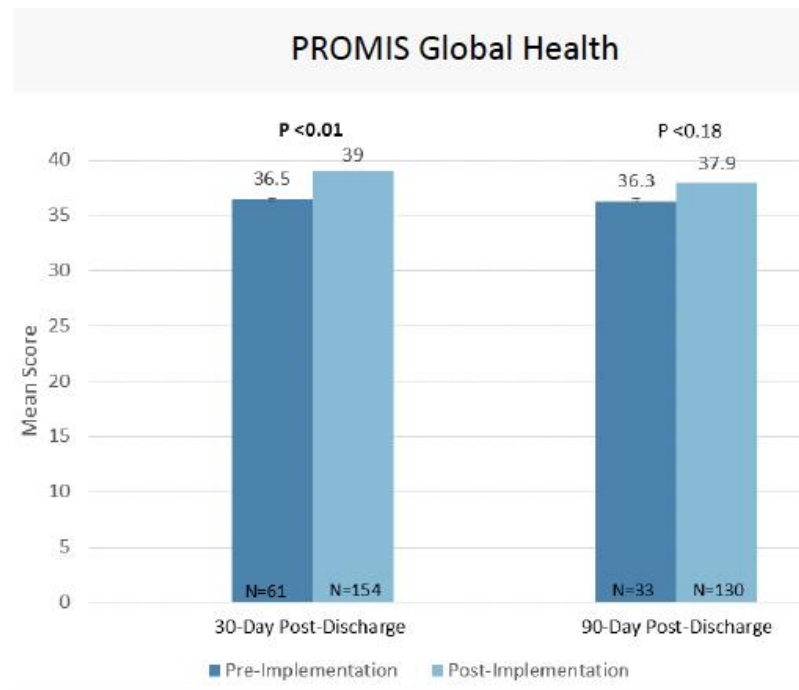
More white, married, spouse completed 90-day

Patient Characteristics

- Age (majority >65)
- Gender (majority male)
- Race
- Marital status
- Census median household income
- Length of stay
- Onset days
- D/C self-care score
- D/C mobility score
- 30-day readmission
- N=136 (63%) Stroke

Unadjusted Results

	Pre-implementation		Post-implementation		p
	N	Mean (SD)	N	Mean (SD)	
30-day PROMIS GH	61	36.5 (7.0)	154	39.0 (5.3)	0.006
30-day Caregiver Strain	61	11.7 (6.3)	154	8.4 (5.6)	<0.001
90-day PROMIS score	33	36.3 (6.3)	130	37.9 (6.4)	0.184
90-day Caregiver Strain	33	10.1 (6.8)	130	8.1 (6.7)	0.122



Adjusted Results

	Post-implementation change		
	Adj. estimate*	S.E.	p
30-day PROMIS Global Health	2.033	0.934	0.031
30-day Caregiver Strain Index	-2.898	0.932	0.002
90-day PROMIS Global Health	1.420	1.268	0.265
90-day Caregiver Strain Index	-1.289	1.362	0.346

- linear regression model adjusting for CARE Tool score, caregiver gender, caregiver relationship, patient census tract median household income, patient age, patient race, length of stay, and onset days.

Limitations

- Insured population
- Assessment limited to English-readers
- 90-day pre-implementation under-powered
- Are the results due to simply due to the CG completing the assessment?

Discussion

- Conducting a comprehensive caregiver assessment can
 - Help caregivers anticipate potential issues not previously considered
 - Highlight potential resource needs
 - Provide a “map” to help caregivers and nurses work together to address issues prior to discharge
- A comprehensive program to address the needs of caregivers results in 30-day post-IRF D/C
 - ↓ caregiver strain
 - ↑ caregiver health
- More research is needed to evaluate the long-term needs of caregivers across the trajectory of caregiving

Discussion & Implications

The PATH © tool

- Is theoretically-based
- Is psychometrically & clinically valid and reliable to assess the needs of family caregivers
- Can be used to better tailor family care plans to
 - Address unmet needs
 - Better prepare caregivers for post-discharge responsibility
 - Tailor educational offerings and resource referrals
 - Address needs of diverse populations
 - Improve patient and family outcomes

Implementation considerations

Mode of PATH survey administration

Documentation in the Medical Record

Language Barriers

Buy-in from IP Team

Leadership Support

Technology Support

Future Directions

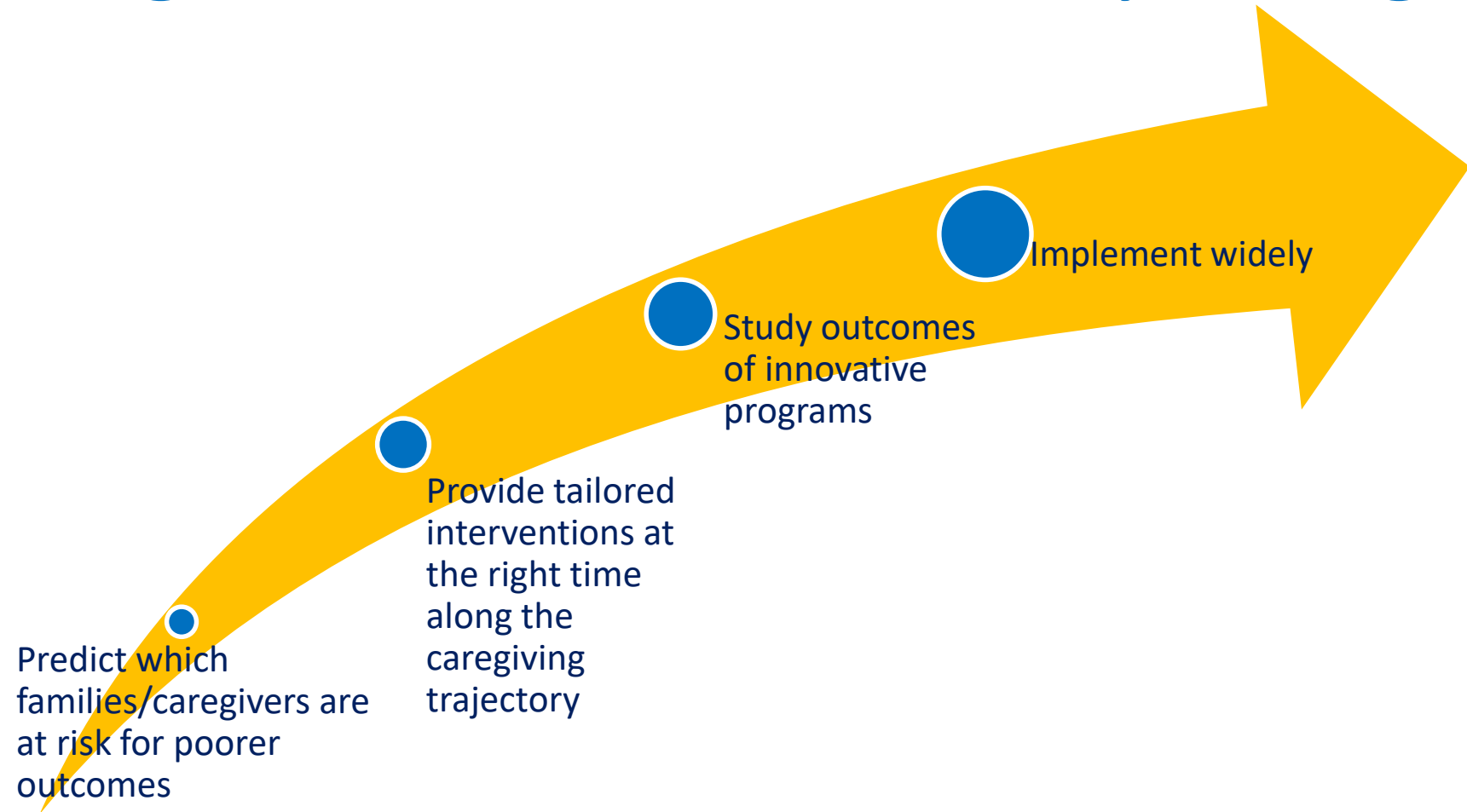
Interprofessional catalogue of interventions



Tele-health interventions



Improving Care for Stroke Family Caregivers



PATH-7[©]

1. How prepared are you to provide the patient assistance with personal care (such as bathing, using the toilet, dressing and moving around) when he/she goes home?
2. Do you have any health problems (for example difficulty bending or stooping, back or joint problems, heart issues, memory, depression, anxiety or other health challenges)?
3. Do you have other roles and responsibilities other than providing care for the patient (for example: work, volunteer work, childcare, pet care, meal preparation, laundry, home maintenance and yard work)?
4. Do you have other people (for example co-workers, your church, a club or social group) who will be able to help you with your other responsibilities (for example: work, volunteer work, childcare, pet care, meal preparation, laundry, home maintenance and yard work)?
5. Will there be any accessibility problems for the patient getting around in the house or using the toilet or shower (for example, the width of doorways, stairs, ramp access) in the home where he/she will be living?
6. Will the patient have accessible transportation (e.g. car that he/she can get in and out of, someone to drive, Paratransit, etc.) that he/she can use to go places (e.g. the doctor, grocery store)?
7. Thinking over the past year, how much conflict have you had in your relationship with the patient?

Conclusions

Assessing and addressing the needs of family caregivers

- Is a national priority
- Is recommended by several national organizations
- Promotes Family-Centered Care
- Facilitates development of a family-focused, tailored care plan

An integrated CG assessment and tailored plan of care:

- Facilitates care focused on the family, not just the patient
- Helps to promote and facilitate safe and effective care transitions
- Is crucial for delivery of high-quality care

PATH-s (stroke specific):
www.rehabnurse.org/pathtool

PATH (all populations):
www.path2caregiving.org

Available upon request

Webinars

On-Demand Education

CE Now!

Online CRRN Review

Professional Rehab Nursing

Intro to Rehab Nursing

Restorative Nursing

Evidence-Based Practice Resources

Publications

Rehabilitation Nursing Journal (RNJ)

ARN Pulse Newsletter

Practice Tools

Specialty Practice of Rehab Nursing Core Curriculum, 8th ed.

Continence Care

Competency Model

ARN-CAT

Safe Patient Toolkit

White Papers

Evidence-Based Rehab Nursing Interventions

PATH-s Instrument

Career Center

Collaborative Resources

COVID-19 Resources

Rehab News

PATH-s is a freely accessible, evidence-based tool designed to assess caregiver's preparedness to transition stroke patients home

The **Preparedness Assessment for the Transition Home after Stroke (PATH-s)** instrument was developed by Michelle Camicia and Barbara Lutz in response to the ARN White Paper, "The Essential Role of the Rehabilitation Nurse in Facilitating Care Transitions" (Camicia et al., 2014). The PATH-s was developed from the theoretical framework, "Improving Stroke Caregiver Readiness Model" (Lutz et al., 2017). The PATH-s instrument is a 25-item self-administered clinical assessment of caregivers developed to assess caregivers' commitment and capacity prior to IRF discharge, before they have assumed the caregiving role (Camicia et al., 2020). Camicia, Lutz, Harvath and Joseph (2021) identified that completion of an instrument such as the PATH-s may aid caregivers in recognizing potential issues and concerns about the caregiving role and provoke anticipation and cues to action to begin addressing their concerns prior to IRF discharge. The PATH-s demonstrates good reliability and validity (Camicia, Lutz, Joseph, et al, 2021).

The PATH-s instrument has been implemented with a corresponding catalogue of interventions (The PATH2Caregiving Program). Several manuscripts are in development to illustrate the clinical benefits of this program. Further, a version of the instrument for use in the general inpatient rehabilitation population, the PATH, has demonstrated reliability (Cronbach's $\alpha=.90$) and is available from the authors upon request (contact information provided below).

The PATH-s has been translated into Chinese, Indonesian, Italian and Vietnamese languages. Validation of the instrument in these languages is underway.

To download this free tool, complete a brief informational form. Upon completing the form, you will achieve access to a PDF document download.

[DOWNLOAD PATH-S](#)

Learn more about this tool, its authors, and how it was developed

Webinar Presentation

In 2021 PATH-s authors Dr. Michelle Camicia and Dr. Barbara Lutz presented a livestream webinar titled "Assessing Family Caregivers using the PATH-s Instrument." During the webinar, Dr. Camicia and Dr. Lutz describe the background, theoretical basis, and development of the PATH-s tool. Strategies for implementation in inpatient rehabilitation facilities are discussed and examples of successful integration of the PATH-s tool in the clinical setting are explained. Upon completing the activity, which offers the opportunity to earn 1.25 CNE credits, participants will be able to:

- Recognize the importance of assessing caregiver preparedness
- Understand the theoretical foundation for the PATH-s instrument
- Identify strategies for administration of the PATH-s instrument

[VIEW THE WEBINAR](#)

“Everyone took such great care of (patient).

They also took great care of me.

*They made sure I thought of all the things I
needed to think about.*

*There is so much to think about and so many
things to do to get everything ready for him to
come home.*

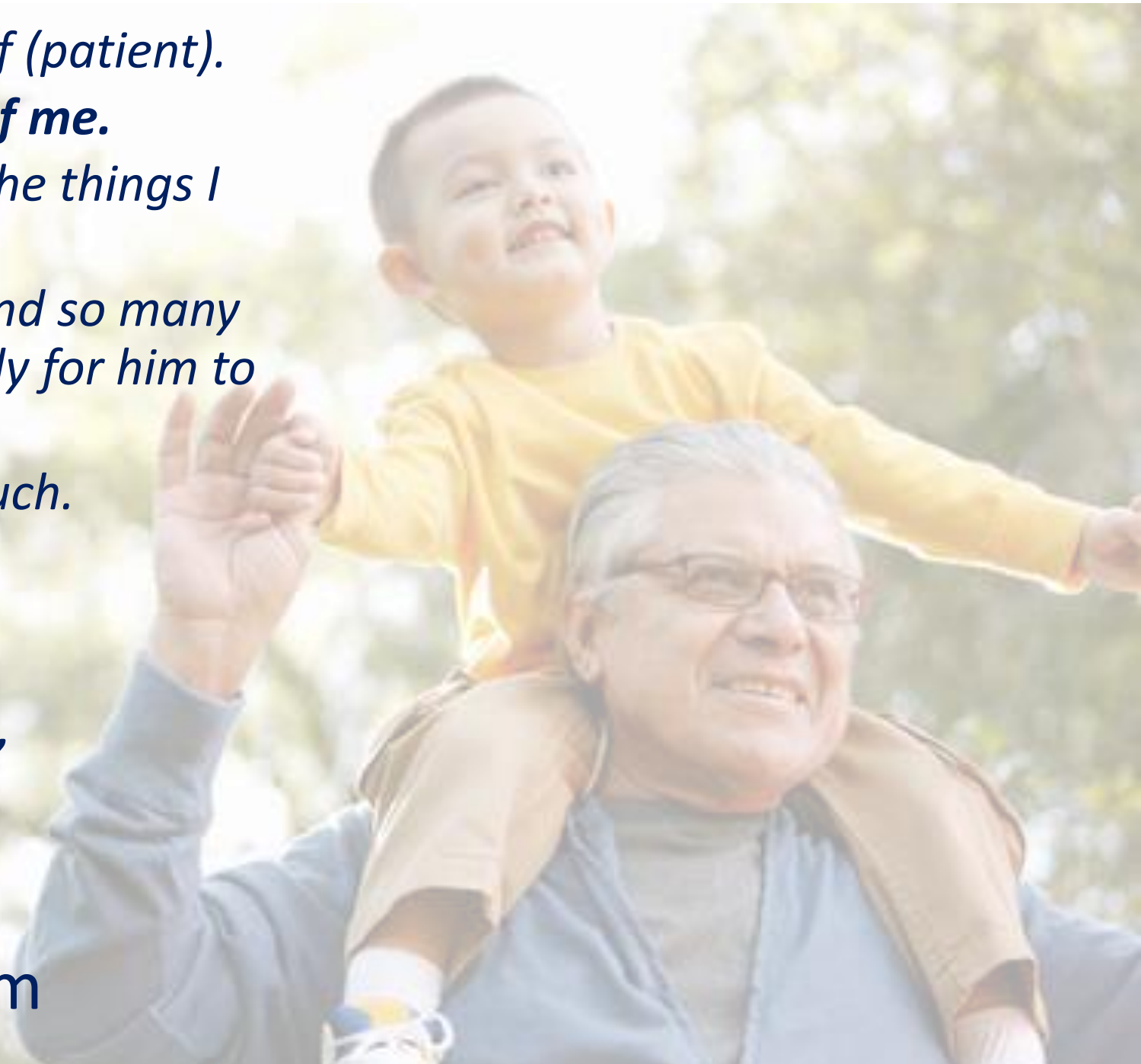
Everyone taught me so much.

I am so grateful.”

***“What a great idea
to care about me too.”***

bjlutz@gmail.com

mecamicia@gmail.com



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