

Who is the Person behind the Patient?

The use of Person-Centered Data through Narrative Integration into the Electronic Health

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Land Acknowledgement

- Cheyenne
- Arapahoe
- Ute
- Apache
- Ute
- Comanche
- Kiowa
- Lakota
- Pueblo
- Shoshone



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Overview and Objectives

Describe key components of person-centered palliative care

Illustrate the development/design/implementation of a co-created person-centered narrative intervention (PCNI) into the EHR

Summarize barriers/facilitators to implementation of the co-created person-centered narrative intervention (PCNI)

High-Quality High-Value Care

Eight Domains

Structure and Processes of Care

Physical Aspects of Care

Psychological and Psychiatric Aspects of Care

Social Aspects of Care

Spiritual, Religious, and Existential Aspects of Care

Cultural Aspects of Care

Care of the Patient Nearing the End of Life

Ethical and Legal Aspects of care



<https://www.nationalcoalitionhpc.org/npc/>



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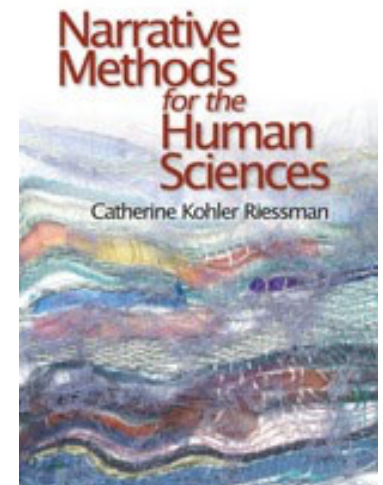
Narrative is...

Layman term: *Story*

Academic term: *Narrative*

Meaning Making

- Strategic
- Functional
- Purposeful



(Riessman, 2008)



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Aim

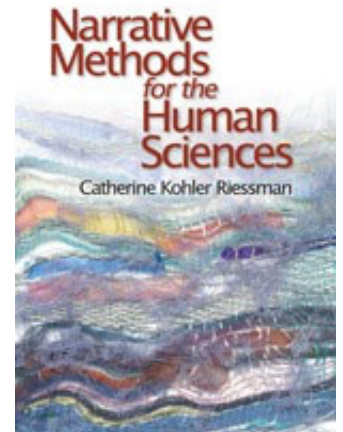
Describe categories and analyze patterns of psychological, social, and spiritual experiences of healing/suffering for African Americans elders living with serious illnesses

Method

Descriptive design

Narrative Analysis Methods

- Thematic analysis
- Structural analysis



(Riessman, 2008)



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Results

African American elders' serious illness experiences:
Narratives of “God did,” “God will,” and “Life is better”

- Spirituality
- Internal strengths

Coats H, Crist J, Berger A, Sternberg E, & Rosenfeld A. (2015). African American elders' serious illness experiences: Narratives of “God did,” “God will,” and “Life is better.” Qualitative Health Research, 27,(5); 634-648. doi:10.1177/1049732315620153. PMID: 26701962



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Results

Narrative methods turned to intervention

- Ruby—pseudonym
- 72-year-old Female
- Heart Failure (14 years)
- Hospitalized 4 times
- Critically ill requiring ventilator support



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Research Goals: *Building a program of research*

How can narratives be used practically in a clinical environment?

How would these narratives be captured and then reflected for the healthcare team?

What effects would the integration of narratives into the EHR have for persons, families, and clinicians in the health care system?

Clinician

Person=Patient

System

Family



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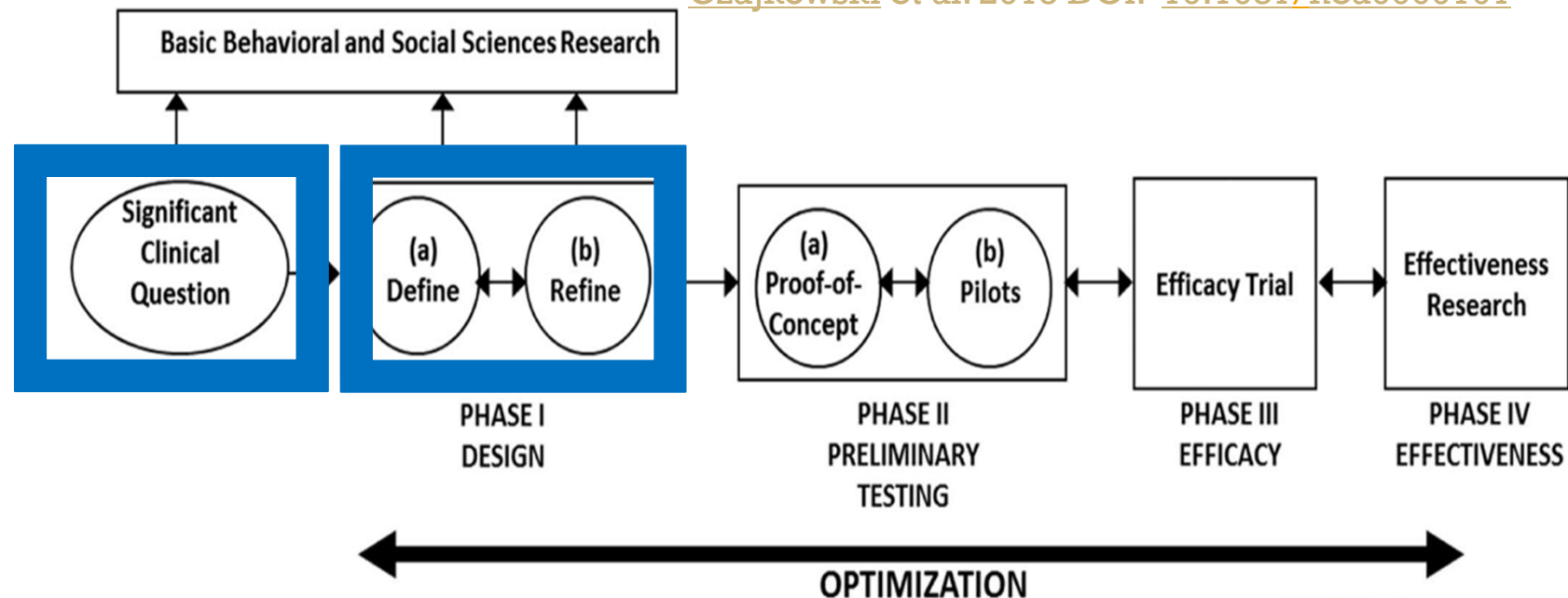


NIH/NINR K99/R00

Pathway to Independence Award

ORBIT MODEL for BIOBEHAVIORAL INTERVENTION

Czajkowski et al. 2015 DOI: [10.1037/hea0000161](https://doi.org/10.1037/hea0000161)



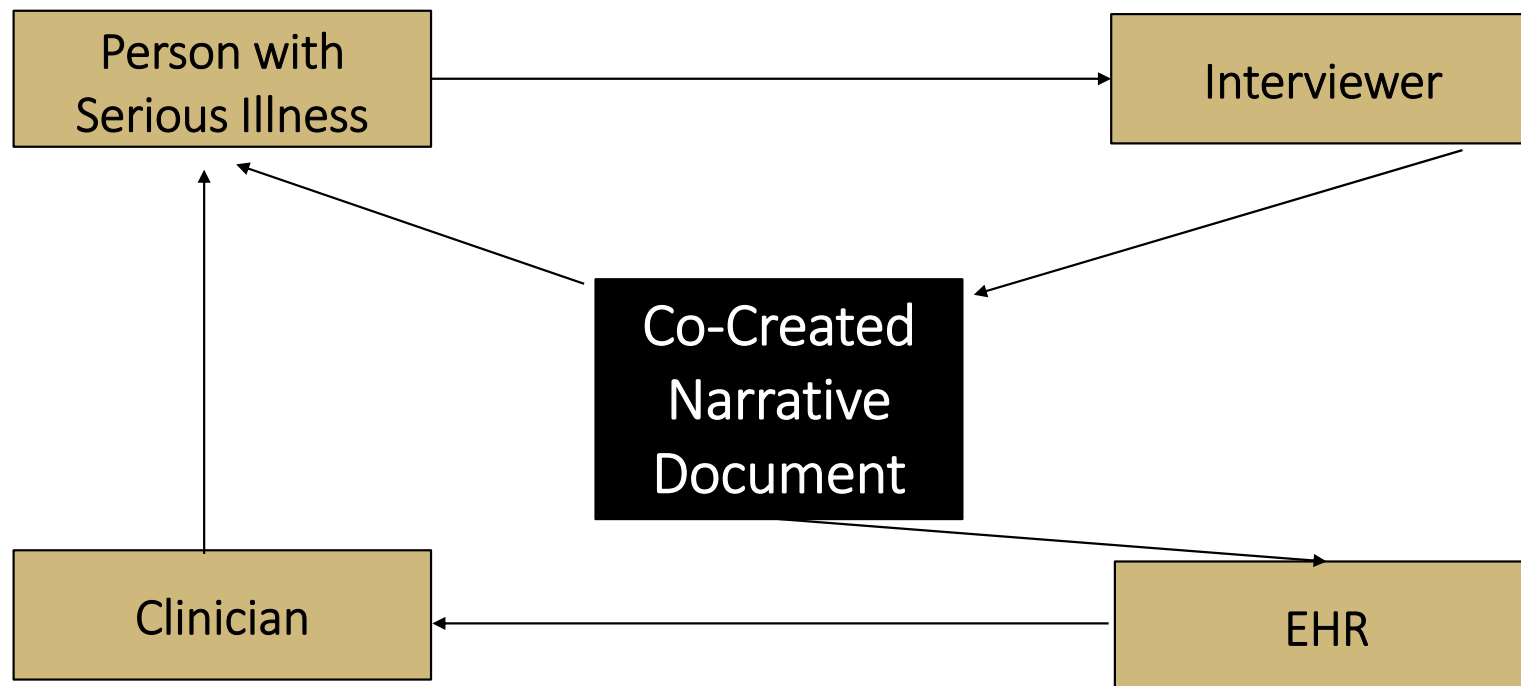
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PCNI: Person-Centered Narrative Intervention



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NIH/NINR K24 NR015340 PI: A. Doorenbos



Feasibility Study

- Identify barriers and facilitators influencing the implementation of a co-created patient narrative intervention
- Assess the acceptability/usability of the patient's narrative from the perspective of key stakeholders—the patient and acute-care bedside nurse



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Methods

Consolidated Framework for Implementation Research (CFIR) <https://cfirguide.org/>

- Implementation design
- Domains
 - Process of implementation
 - Intervention characteristics
 - Outer setting
 - Inner setting
 - Characteristics of individuals



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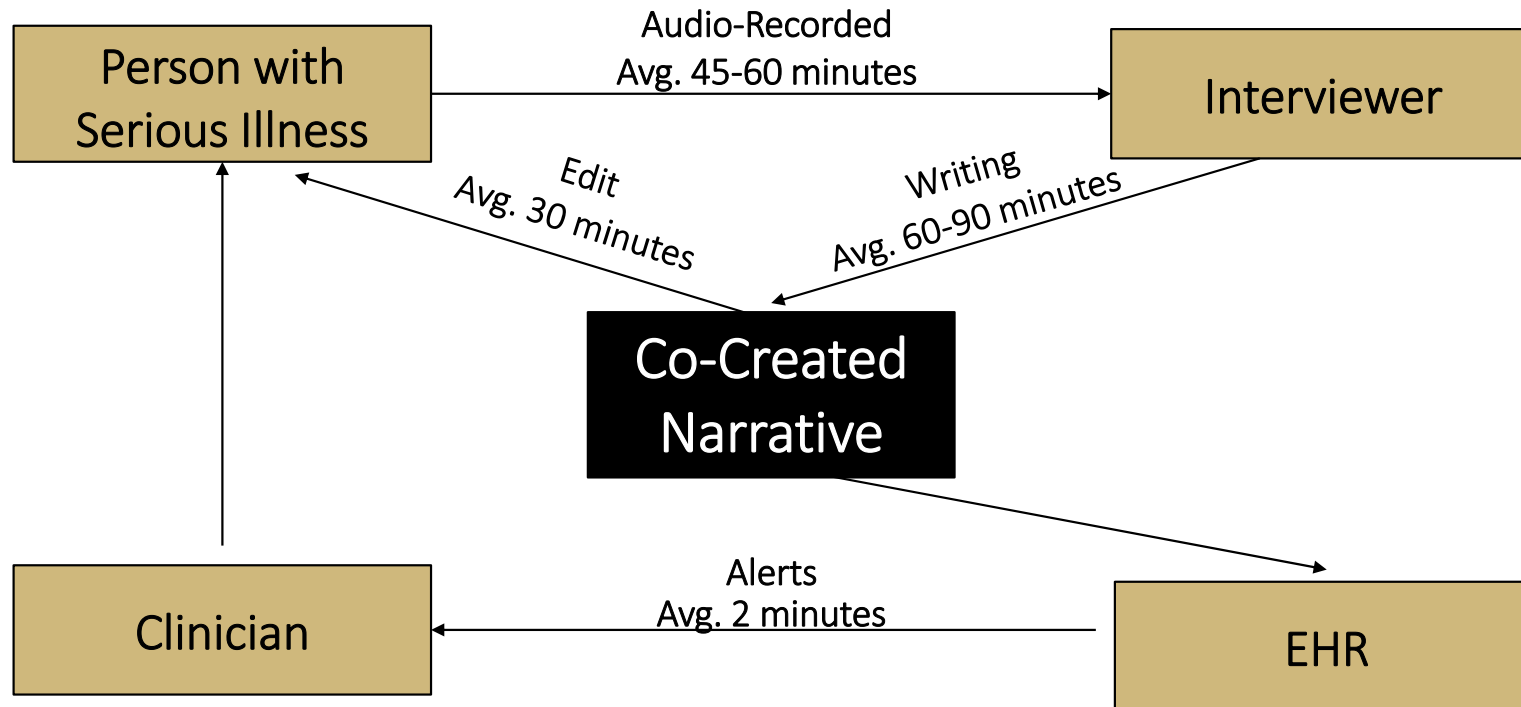
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Results

Intervention Characteristics



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Results: Nurses



<https://medicafuturist.com/the-future-of-nurses-superheroes-aided-by-technology>

- Understanding
- Helpful
- Learn what he values most in his life
- Personable
- Easier to talk about difficult and challenging issues
- Connected dots for me



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Results

- Feasible
- Acceptable
- Usable: System Usability Survey(SUS)= 89.71 (0-100)
 - Item 5= 56 (0-100)

Coats H, Meek PM, Schilling LM, Akard TF, Doorenbos AZ.(2020). “Connection”: The Integration of a Person-Centered Narrative Intervention into the Electronic Health Record: An Implementation Study. Journal of Palliative Medicine, 23 (6), <https://doi.org/10.1089/jpm.2019.0376>.

Bennett, CR, Shive, N, Coats, H. (2020). What Mattered Then, Now, and Always: Illness Narratives From Persons of Color. Journal of Hospice and Palliative Nursing, 22 (5):392-400. PMID: 32740304.



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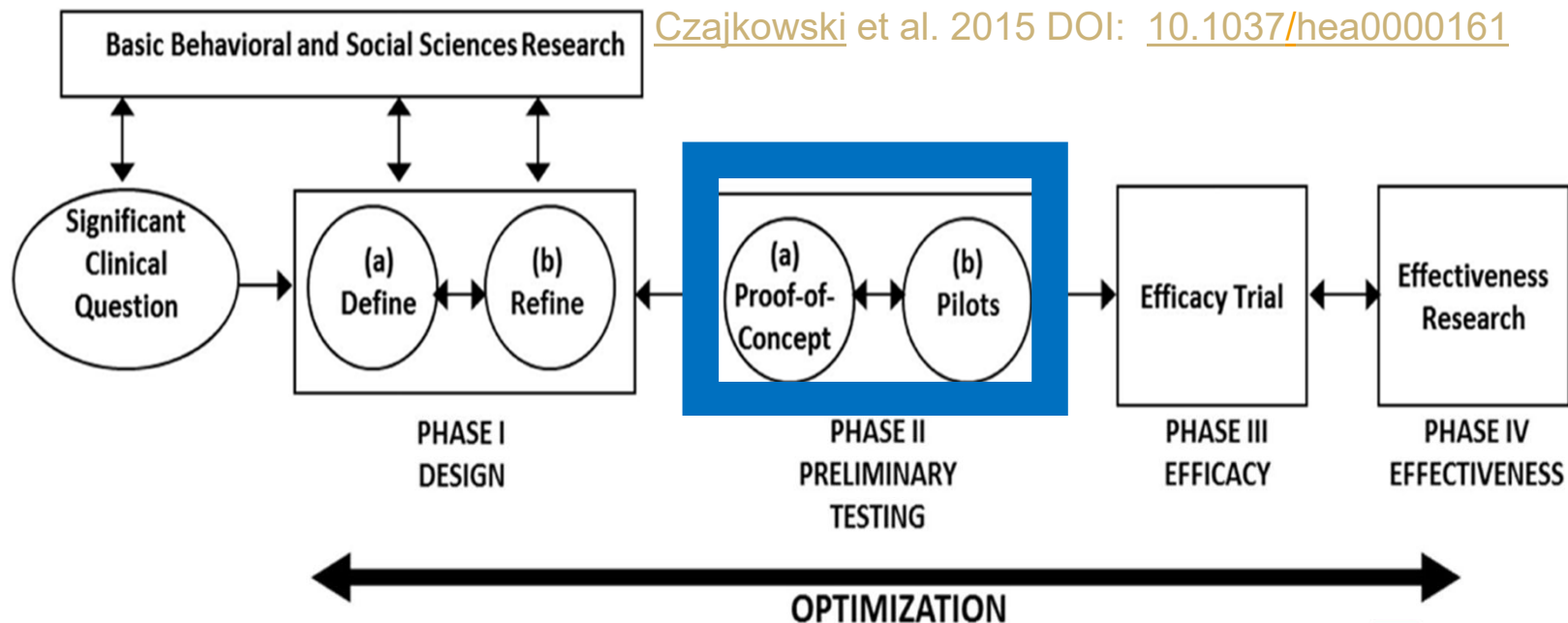
Results: Improved Integration

The screenshot displays the Epic Systems interface for a patient named Carolyn Cdtest. The left sidebar contains patient demographics: Female, 74 y.o., 5/18/1945, MRN: 9305043, Bed: PLMU-PU 931-01, Code: Not on file (no ACP docs), and Service: Pulmonary. Below this is a search bar and a list of actions including 'Review patient's story'. The main content area shows the 'Summary' tab selected, with sub-tabs for Overview, Summary of Care, Event Log, Intake/Output, and Patient Story. The 'Patient Story' sub-tab is active, showing a 'Patient Story Note' with the text: 'Get to know your patient. Carolyn has created a patient story. The Patient Story is a patient created personal story of key life events both medical and non-medical that enables clinicians to understand what matters to the patient.' The bottom of the screen shows the copyright notice '© 2020 Epic Systems Corporation'.

NIH/NINR K99/R00

Pathway to Independence Award

ORBIT MODEL for BIOBEHAVIORAL INTERVENTION



R00 Aims

Aim 1: Outcome Measures: Compare the effects of the narrative intervention to usual care using person-centered outcomes

Quality of communication

PROMIS 29 profile

PROMIS Psychosocial Illness Impact

Aim 2: Process Measures: Establish acceptability, feasibility, and usability of the narrative intervention

Coats H, Shive N, Doorenbos AZ, Schmiede SJ. (2020). Integration of Person-Centered Narratives into the Electronic Health Record: Study Protocol. Nursing Research, 69(6): 483-489. DOI: [10.1097/nnr.0000000000000463](https://doi.org/10.1097/nnr.0000000000000463) PMID: 32740306.



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Clinical Trials: NCT04118569



Future Directions

Building a program of research

Putting the whole person back in the center of their care

Development and testing of person-centered narrative interventions

Delivery of more person-led culturally sensitive care

Empower persons to be heard

Thanks

Persons and their families
who have shared their stories

Mentors

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HPNA

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Advancing Expert Care in Serious Illness