# THE POTENTIAL FOR QUALITATIVE METHODS TO ENHANCE HEALTH SERVICES AND OUTCOMES RESEARCH: WHY, WHEN AND HOW?

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# CONTENT OF TODAY'S PRESENTATION

- Relevance of qualitative methods to health services and outcomes research
- Examples of relevant work & publications employing qualitative methods on health services and outcomes research
- Opportunities for training and capacity building at JHU

*"The health services research and management field will not meet its future challenges with quantitative methods alone or with a half-empty tool box."*

Devers, K. (2011) Qualitative methods in health services and management research: pockets of excellence and progress, but still a long way to go. Medical Care Research and Review. 68(1):41-48.

# MY PERSPECTIVE

- Sociologist working on a variety of public health issues for 15 years.
- Roots in qualitative research in health services delivery
- Qualitative and mixed methods specialist. Author of NIH best practices for mixed methods in health sciences report

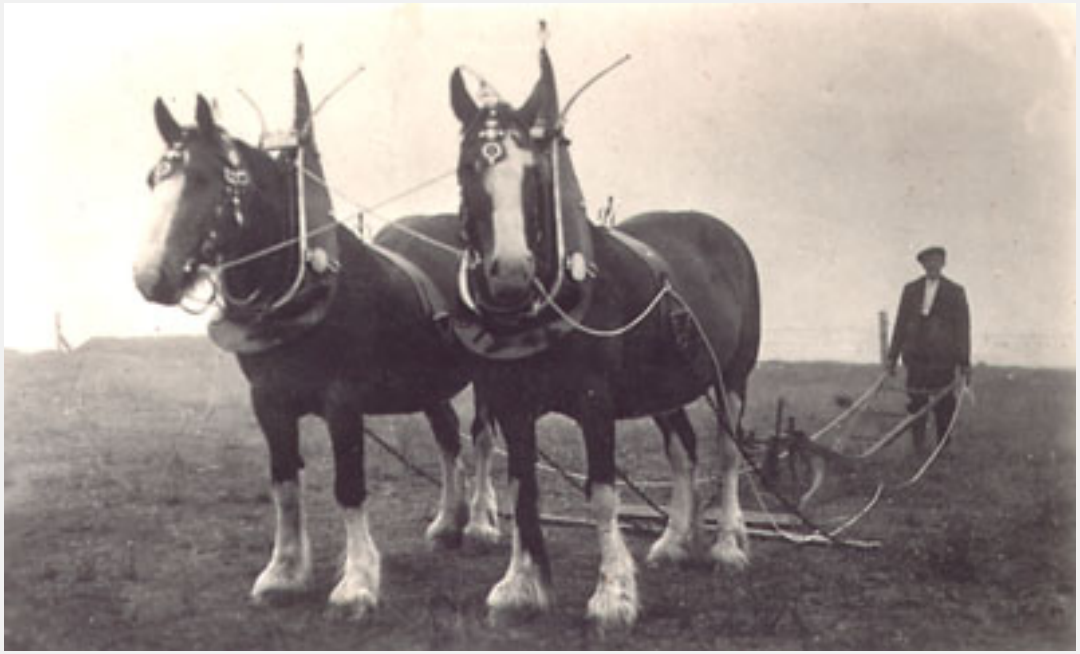
  (http://obssr.od.nih.gov/mixed_methods_research/)
- Investigator on numerous patient-centered projects including with CHSOR faculty

# ONTOLOGY, EPISTEMOLOGY & METHODOLOGY

*….The researcher "approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he or she then examines in specific ways (methodology, analysis)."*

(Denzin and Lincoln, 2003)

*The tool needs to match the job at hand….*



*"The choice between quantitative and qualitative research methods should be determined by the research question, not be the preference of the researcher."*

(Marshall, 1996)

*" Qualitative methods can answer important health services and management questions via a complementary set of methodological tools and rigorous empirical methods."*

(Devers, 2011)

"*Qualitative research is an umbrella term for an array of attitudes towards and strategies for conducting inquiry that are aimed at discovering* ***how human beings understand, experience, interpret and produce the social world***."

Sandelowski, 2004

"*…Qualitative methods are the most appropriate way of ascertaining the experience of subjective symptoms, ensuring that the data are grounded in the patient's language and experience.*"

Hewlett, S. et al (2005) Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. Arthritis and Rheumatism. 53(5): 697-702

*"Renewed interest in qualitative methods can be traced to growing concerns about the* ***gap between what we know and what we need to know about health care financing, organization, delivery, and outcomes****. Scholars have argued that health policy making, research and management could benefit from more in-depth, textured descriptions of* ***what actually happens in practice settings, health care markets and patients' lives****."*

Weiner, B. J., Amick, H. R., Lund, J. L., Lee, S. Y. D., & Hoff, T. J. (2011). Review: use of qualitative methods in published health services and management research: a 10-year review. *Medical Care Research and Review*, *68*(1), 3-33.

# LESS IS MORE AND MORE IS MORE…

- Qualitative research prioritizes detailed data from smaller number of cases
- "Making the facts understandable" – Why do we see the patterns that we do?
- Mechanisms and processes are often key
- Embraces context, rather than trying to control for it, or exclude it

# WHAT KINDS OF QUESTIONS ARE BEST SUITED TO QUALITATIVE METHODS?

- **What?** Questions
  - What are routine practices regarding provision of services in a given location or unit?
  - What do doctors/nurses/administrators see as their role in caring for patients?
- **Why?** Questions
  - Why do patients not adhere to medication regimens?
  - Why are patients happy about the care that they receive in some clinics and not others?
- **How?** Questions
  - How is change implemented in a unit or organization?
  - How do caregivers contribute to medical appointments?

- Not necessarily **Who?** Or **Where?** Or **When?** questions

# PRIORITIZING A PERSON'S PERSPECTIVE….

*"The key to asking questions during in-depth interviewing is to let them follow, as much as possible, from what the participant is saying"*

(Seidman, 2006 p. 81)

*"There is no recipe for the effective question. The truly effective question flows from an interviewer's concentrated listening, engaged interest in what is being said, and purpose in moving forward."*

(Seidman, 2006 p. 93)

# PRODUCTS OF QUALITATIVE INTERVIEWS

- Shared construction between the researcher and the researched
- Reactions to particular prompts
- Accounts or narratives
- Physical product – transcripts or field notes

*This is all very messy data – not direct answers to research questions – still a lot of analysis to do.*

# GROUP INTERVIEWS/ FOCUS GROUPS

- The types of question that are well suited to focus groups are distinct from those suited to in-depth interviews
- Good for eliciting group norms and assumptions
- Allows people to think about/talk about issues and perspectives that might otherwise never occur to them
- Good for initial inquiry and to enrich other data

# HOW ARE FOCUS GROUPS DISTINCT?

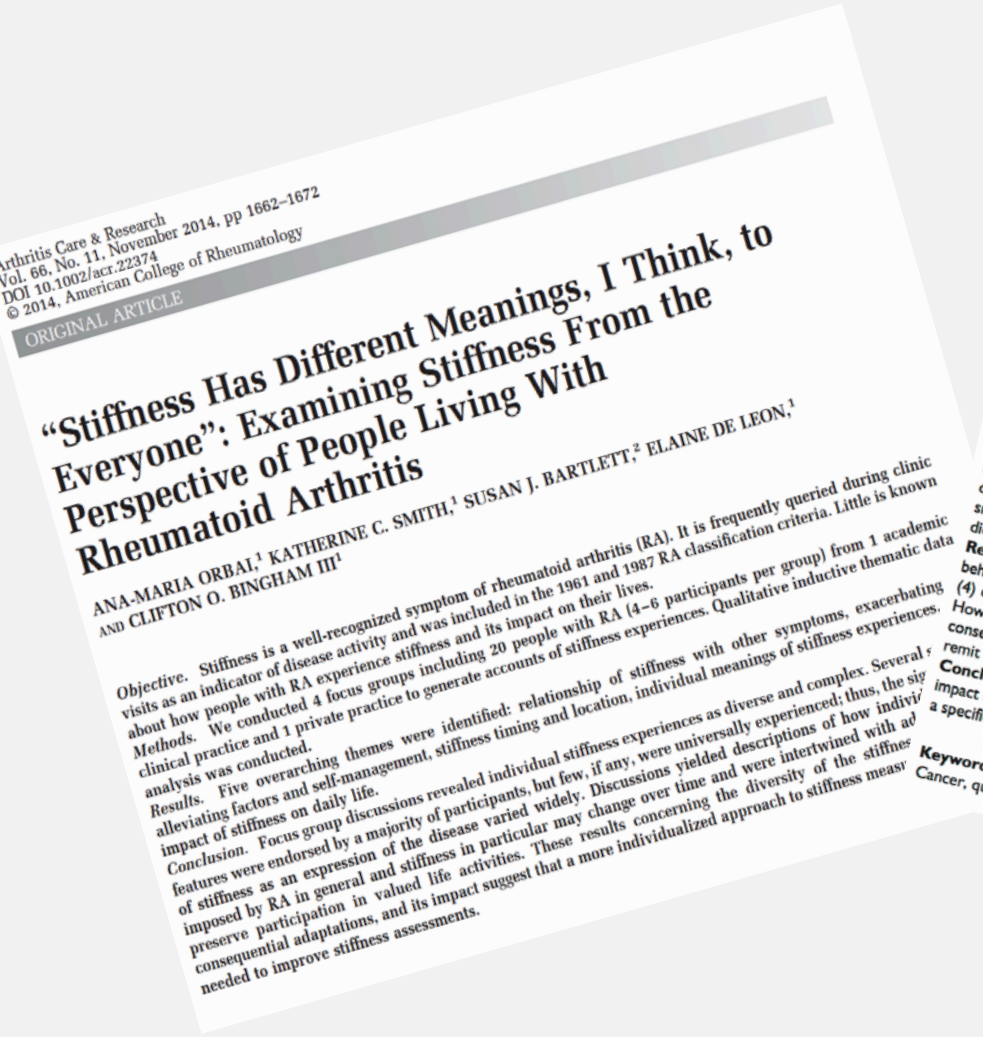
- Dynamic and interactive exchange in a FG produces multiple stories and perspectives
- Generates discussion of similarities and differences – exploration can lead to new areas of enquiry
- *May* not facilitate personal disclosure

(Brown, 1999)

# FOCUS GROUP DATA

- The interactions between group are FG data– group dynamics are key
- The purpose of the group is to facilitate interaction on a given subject
- The group is the unit of analysis
- Contrary experiences and opinions are explored – cohesion & diversity are both valuable
- Can offer insight into how people talk to one another about an issue/concept/event

# 2 EXAMPLE STUDIES



Arthritis Care & Research
Vol. 66, No. 11, November 2014, pp 1662–1672
DOI 10.1002/acr.22374
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ORIGINAL ARTICLE

## "Stiffness Has Different Meanings, I Think, to Everyone": Examining Stiffness From the Perspective of People Living With Rheumatoid Arthritis

ANA-MARIA ORBAI,[1] KATHERINE C. SMITH,[1] SUSAN J. BARTLETT,[2] ELAINE DE LEON,[1] AND CLIFTON O. BINGHAM III[1]

*Objective.* Stiffness is a well-recognized symptom of rheumatoid arthritis (RA). It is frequently queried during clinic visits as an indicator of disease activity and was included in the 1961 and 1987 RA classification criteria. Little is known about how people with RA experience stiffness and its impact on their lives.

*Methods.* We conducted 4 focus groups including 20 people with RA (4–6 participants per group) from 1 academic clinical practice and 1 private practice to generate accounts of stiffness experiences. Qualitative inductive thematic data analysis was conducted.

*Results.* Five overarching themes were identified: relationship of stiffness with other symptoms, exacerbating alleviating factors and self-management, stiffness timing and location, individual meanings of stiffness experiences, impact of stiffness on daily life.

*Conclusion.* Focus group discussions revealed individual stiffness experiences as diverse and complex. Several features were endorsed by a majority of participants, but few, if any, were universally experienced; thus, the sig of stiffness as an expression of the disease varied widely. Discussions yielded descriptions of how indivi imposed by RA in general and stiffness in particular may change over time and were intertwined with ad preserve participation in valued life activities. These results concerning the diversity of the stiffnes consequential adaptations, and its impact suggest that a more individualized approach to stiffness measu needed to improve stiffness assessments.

Original Article

SAGE Open Medicine

## A qualitative study of dietary discussions as an emerging task for cancer clinicians

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SAGE Open Medicine
Volume 4: 1–11
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/2050312116665935
smo.sagepub.com
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**Abstract**

**Objectives:** Improvements in cancer detection and treatment create a need for care that prioritizes acute treatment and ongoing needs. There have been calls to include health promotion in cancer care, but little empirical consideration of the work involved in such an expansion of services. In this article, we adopt a constructionist position to explore clinicians' perspectives on capacity for health promotion, specifically dietary counseling.

**Methods:** Our data result from 33 semi-structured qualitative interviews with members of cancer care teams. All interviewees were affiliated with one of two contrasting medical systems located in Baltimore, MD, USA. Interviews focused on professional roles and responsibilities around health promotion for cancer survivors. We employed both purposive and snowball sampling. We conducted a thematic analysis informed by the sociology of professions literature of discussions of dietary change by provider type.

**Results:** We discuss four emergent themes that relate to the work of providing dietary counseling: (1) prioritization of behavior change in survivorship care, (2) evidence base for dietary messaging, (3) available time and clinical priorities and (4) clinical expertise. Interviewees generally expressed support for the importance of diet for healthy cancer survivorship. However, while there was broad support for dietary change and health promotion, we found little evidence of an emerging consensus on how this work should be accomplished, nor an indication of any occupational group expanding their professional remit to prioritize health promotion tasks.

**Conclusions:** Health promotion is the key to any efficient and effective model of cancer care. Careful attention to the impact of the task on key patient outcomes as well as system capacity for the provision of dietary counseling and its fit with a specific professional remit will be critical for successful integration of health promotion into routine cancer care.

**Keywords**

Cancer, qualitative methods, health care professionals, health promotion, survivorship, semi-structured interview

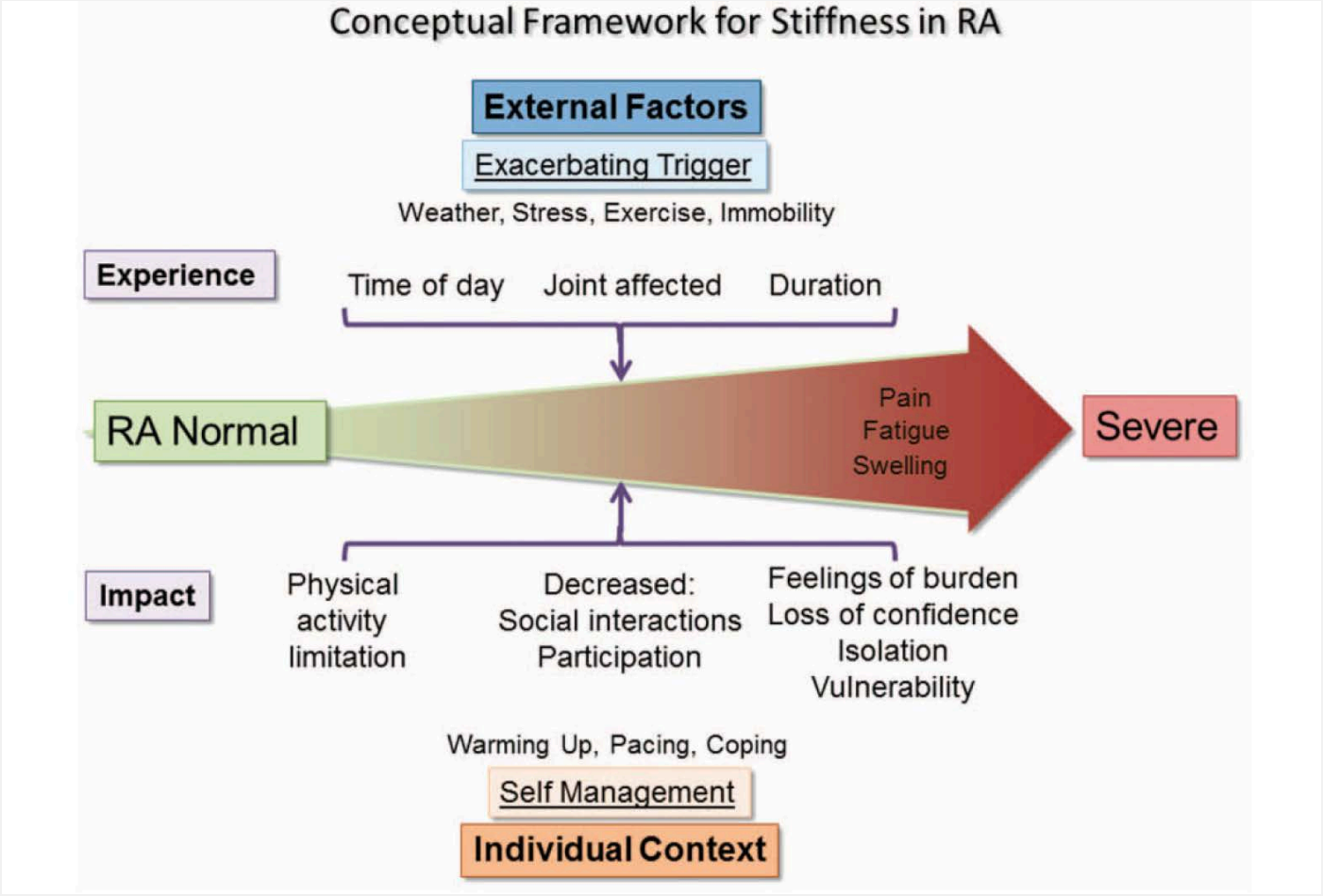
# EXPLORING THE EXPERIENCE OF STIFFNESS AMONG PEOPLE WITH RHEUMATOID ARTHRITIS

- Stiffness is a symptom widely seen as having clinical significance in RA as a signifier of disease worsening or flare.
- Stiffness is difficult to quantify – not directly measurable. Existing measures such as 'morning stiffness duration' may not be universally effective as a measure
- 4 focus groups with patients from an academic rheumatology clinic (n=3) and a community hospital (n=1)
- 20 participants (15 women, 5 men; 17 white, 3 African American)

# EMERGENT THEMES

1. Meaning and experience of stiffness is related to other symptoms (e.g. pain)
2. Exacerbating (e.g weather, inactivity, activity) and alleviating factors (warmth, movement) and self-management (dietary modification, use of tools)
3. Timing and location
4. Individual context and meaning (e.g. 'RA normal')
5. Impact on life (e.g. perseverance, adaptation, dependency, fear, isolation)

# DEVELOPMENT OF A CONCEPTUAL MODEL FOR STIFFNESS IN RHEUMATOID ARTHRITIS



# HEALTH PROMOTION WITH CANCER SURVIVORS

- >15 million cancer survivors in the US; 2/3 of whom will survive 5 years or more post-diagnosis
- Cancer survivors have elevated risks of more cancer and also of co-morbidities. Healthy lifestyle (diet, physical activity, tobacco and alcohol use) is an important aspect of survivorship care
- Evidence regarding current practice is that healthy lifestyle promotion is often not addressed as a part of cancer care. Why? **How do members of the cancer care team understand health promotion and how it relates to their job?**

# DATA COLLECTION AND ANALYSIS

- 33 key informant interviews with members of cancer care teams at an academic medical center and a community hospital
- Modified form of snowball sampling, starting with clinicians on the research team
- Data analysis informed by the sociology of the professions literature in which the ‘professional project’ and ‘jurisdiction’ are key to how the organization of tasks is understood – new tasks are often seen as opportunities for professional growth/expansion

# EMERGENT THEMES

1. The prioritization of behavior change in the care of cancer survivors (general support for the idea)
2. Evidence base for dietary messaging
3. Relating work to available time and clinical priorities
4. Constructing dietary counseling in relation to professional expertise.

# A FEW ILLUSTRATIVE QUOTES

*"They need to learn what a healthy diet is, they need to learn about what a normal portion size is, and they need to learn about exercise, so those are the three things I talk to them about, so ... it takes a minute to do that, so I don't spend hours doing that."* (Urologist, Academic)

*"When I'm seeing someone two maybe three times a year for a 30 minute visit where the primary focus is going to be on surveillance because the reality is that's what they want to see me for ..."* (Medical Oncologist, Breast, Academic)

*"I think the appropriate person might be the primary care doctor. I think probably they have a big role cause that's been their quarterback for years, and hopefully their quarterback for years to come, so that sort of person I think would be the best facilitator."* (Urologist, Academic)

# IMPLICATIONS FOR PRACTICE

- Relatively strong expression of support for the importance of dietary messaging – minimal gains to be made changing the messaging on this
- Stronger evidence around impact of dietary change on cancer-specific outcomes might lead to greater engagement by oncologists
- Little consensus as to how health promotion around diet should be constructed/delivered given current structures
- Shortage of time and expertise identified as barriers – also patients' expectations of oncologists
- Oncology nurses & PCPs identified as possible intervention points for dietary messaging

# TRAINING OPPORTUNITIES IN QUALITATIVE RESEARCH AT JHSPH

Regular term classes

- Concepts in qualitative research for social and behavioral sciences (410.710), 3 credits, Term 2
- Theory and practice in qualitative data analysis for social and behavioral sciences (410.712) 3 credits, Term3

Summer institute courses (June 2017)

- Introduction to qualitative research methods (410.671), 3 credits
- Introduction to qualitative data analysis for public health (410.673), 2 credits

- Center for Qualitative Studies in Health and Medicine listserv and activities. Contact Dr. Susan Hannum (shannum1@jhu.edu)