Content Synopsis for Basic Qualitative Inquiry

Jennifer B. Averill, RN, PhD Associate Professor of Nursing, UNM College of Nursing Senior Fellow for NM CARES HD

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NOTE: All photographic images of persons and places were obtained as free downloads from the internet. No person or place was ever identified, and no person or place occurs in the NMCARES HD service area.

Opening Remarks and Dedication

This basic module on *qualitative data generation/collection, management, analysis and interpretation* was prepared for use by a variety of users: (1) researchers who are experienced with statistical/quantitative designs but unfamiliar with the same level of detail for qualitative designs; (2) graduate or post-doctoral students who seek to deepen their understanding of how qualitative research happens; (3) interested members of research grant staff who may have some understanding of the research process in general, but who seek additional knowledge for working with qualitative data they encounter in their communities of interest; and (4) other interested stakeholders, especially people living in the varied communities of interest to research efforts, wherever and whoever they may be.

Several assumptions informed this work: (1) ALL people are entitled to know what research is, why it is done, and for whose benefit; the implication of this is that they may be better informed to at least understand what research is all about, so they may decide for themselves whether or to what extent they want to participate. (2) All people hold knowledge that benefits not only themselves and their communities, but also the work of science, health care, and reducing/eliminating inequities in resources. (3) It is possible to conduct rigorous research while simultaneously respecting, honoring, and benefiting the residents in all kinds of communities. (4) Well-done qualitative research is a complement to additional types and kinds of inquiry; it allows a personal perspective, voice and experiential presence to be a part of all meaningful inquiry designed to describe, explain, predict, enlighten, measure and/or improve life and health for all people. (5) Like all forms of systematic inquiry, gualitative research is always a work in progress, sensitive to the changes, contexts, challenges, priorities, and other factors that comprise the human condition, in all kinds/types of settings. This module does NOT replace a full course in qualitative methods. Rather it opens the door with basic explanations, and then invites interested investigators to take one or more full courses in the design, conduct, and evaluation of qualitative inquiry.

As a long-time qualitative researcher and educator, the author dedicates this work first to the residents and community members of New Mexico and surrounding areas, then to the community of scholars with whom she has worked in both CO and NM over the years. Finally, she dedicates this work to Dr. Robert Williams, PI of NM CARES HD and RIOS net, and the members of the NM CARES Research Core, who have shown themselves to be dedicated, talented and passionate researchers who work to eliminate inequities in health for all people. I salute all of you and thank you for this opportunity to share a small bit of information about how to do qualitative research.

Sincerely,

Jennífer B. Averíll, RN, PhD, author of module

Content Synopsis for Basic Qualitative Inquiry

Created by Jennifer B. Averill, RN, PhD Associate Professor of Nursing, UNM College of Nursing Senior Fellow for NM CARES HD Original Facilitator of the Qualitative Café at UNM

PREFACE

This very basic overview of qualitative inquiry includes a glimpse of the philosophical/conceptual underpinnings of gualitative research, as well as abbreviated, simplified strategies for the generation/collection, management, analysis, and interpretation of qualitative data. It is prepared for use by novice or inexperienced qualitative researchers, with the caveat that for a deeper understanding and the capacity to serve as a PI on a qualitative or mixed methods project, one should take a full course in gualitative methods, covering research design [numerous qualitative traditions exist—e.g., ethnography, grounded theory, phenomenology, etc.], guestion/proposal development, data generation/collection, data analysis strategies, and interpretation of findings. Such courses exist at UNM [both main and north campus] and other research-intensive universities, for on-theground and web-based learners. Users of this simple module are strongly encouraged to locate/identify the qualitative researchers here at UNM and work closely with one or more of them when learning and mastering the techniques described here.



INTRODUCTION: The module is organized into six units of content,

extracted and simplified from a graduate level overview course in qualitative methods taught by this author. A full content outline for that course appears as Appendix D for this module, for readers who may be interested in a more complete description of essential knowledge attached to qualitative inquiry. Also in that same Appendix D are essential and recommended texts for use in understanding the content; numerous additional texts and articles exist for these content areas, and it is likely that many more can be added [by additional qualitative researchers] to this module in the years ahead.

Unit 1: Conceptual and philosophical vision for qualitative research

- Qualitative/naturalistic inquiry emerges from a human science perspective (as compared to the logical-empirical perspective) --> it focuses on human experience, perceptions, and contextual-historical-cultural-embodied interpretations of the human realm. The basis for understanding this scientific distinction can be found in any good graduate course on Philosophy of Science, a foundational slice of content.
- Qualitative work envisions truth as not only scientifically verifiable information, but also [equally] information/beliefs as lived/experienced by people themselves.

- Qualitative inquiry takes place in field settings where people live, work, attend school, or otherwise experience daily life [as opposed to inside a controlled or laboratory setting]. The researcher is a visitor, a "professional stranger" [in the words of ethnographer Michael Agar], not an expert in the setting.
- Knowledge claims are valid when a group or community accepts them as an improvement over previous knowledge, understanding or experience.
- The goal of qualitative research is not generalizability and/or 'proof', but instead meaning, insight and understanding about something or about people's lived experience. It is more about the kind, importance, impact or quality of things, as opposed to the measurement of things.
- Research methods are useful and trustworthy [similar ideas to reliability and validity] to the extent they actually represent what is going on in a community, a group, or a sample of participants, as interpreted/related by the participants themselves.
- Human science and qualitative inquiry hold that all research is communitarian in nature—it engages people in a common/shared effort to better understand, describe, explain, and/or resolve problems and inequities.
- Qualitative inquiry recognizes and advocates multiple (pluralistic) designs, perspectives/voices, methods, and approaches in solving human problems.
- Consistent with the above statement, it is very common for qualitative investigators to work as members of mixed methods teams, to better achieve a more complete picture of what is going on in a community or setting.
- Qualitative work generally takes more time than other types of inquiry because it involves asking many questions, making multiple observations, engaging in reflection and discussion/negotiation with participants, and analyzing many kinds of non-numeric data.
- In Polkinghorne's (1983) words: "All of our knowledge is conditional knowledge, constructed within our conceptual systems, and thus knowledge is a communal achievement and is relative to time and place...(p. 13)...What is called for is getting on with the development of a science without certainty that deepens our understanding of human existence" (p. 281).
- Because qualitative inquiry is as specialized and detailed as quantitative/ statistical work, it is generally not feasible for one researcher to be equally proficient in both types of research. Thus, a research team approach will often produce more significant, reliable findings.



Unit 2: Qualitative designs and ways to generate your research questions

• Some of the best-known qualitative designs include ethnography [several types], phenomenology, grounded theory, and interpretive description. Please see the

Appendix for more detailed explanations for each of these, as well as key readings for best understanding of the origins, purpose, and conduct of each design.

- Qualitative work is not a "one-size-fits-all" design, just as numerous kinds of statistical, quantitative, and epidemiological designs exist. Some commonalities exist among the qualitative designs [see Unit 1 above], but there are important differences and implications for the kinds of research questions asked, as well as the methods used for data management, analysis and interpretation.
- Research questions may be generated by a researcher, but are often refined and shaped—at least in part—by the interests, concerns, and voices of participants in the research process. This happens because participants are seen as experts in their own lived experience, and they may partner with a researcher to explore, explain, change, or understand something.
- Readers are strongly encouraged to take a course in qualitative methods to grasp the substance of these design differences. Otherwise, mistakes can be made in the application of strategies that are poorly informed, understood, and (mis)interpreted. One way of thinking about this is to consider how many different varieties of "automobiles" exist....one risks many problems if s/he treats all automobiles as if they had the same identical structure, requirements for operation, manufacturing standards, styles of production and function, or repair needs. It makes more sense to decide what kind of vehicle is needed, then make a choice that fits the need, the driver's capabilities and budget, and the service requirements that the buyer can manage. Similarly, for most accurate results in qualitative research, readers are encouraged to learn more about this branch of systematic inquiry, and/or work alongside experts in the field.



Unit 3: Entering "the field", collecting and managing qualitative data

- Do the homework first—learn as much as possible about the setting, communities, cultures, and information relevant to participants. This includes thorough literature reviews, epidemiological reviews of health indicators/other data, incidence/prevalence of problems, demographic trends, historical/cultural factors, literacy/health literacy levels, geographic and ecological details, visits with key gatekeepers in the communities of interest, levels/kinds of engagement with community-level problems and with outsiders [eg, researchers, etc.]. Qualitative researchers enter the field not as "experts' with answers, but instead as good listeners/observers, with open minds, cultural/social humility, and more questions than answers. This is congruent with the philosophical intent and orientation to inquiry expressed in the Units above.
- Qualitative data consist of many forms and kinds of information: interviews both individual [for depth and detail] and group [for breadth and the group

perspective]; participant observation in/of daily life; archival data [eg, news accounts, library resources, health care brochures/information--for reading level, language options, eligibility requirements]; arts and artifacts; theater and drama presented by participants; written policies; storytelling experiences, etc.

- Ways to capture/record these data include audiotaping, videotaping, photography, researcher field notes/logs of all activities, use of large tablets/ easels with a common/public view of what is recorded, and many additional strategies for noting, preserving accurately, and holding data considered important to the conduct of the research and the answering of questions. This comprises the transparent audit trail. Obviously, with all of these possibilities, the tension existing between ethical conduct of research and participant data-sharing must be addressed by the researcher. Specific consent forms may be required for the various kinds of data. Researchers are encouraged to evaluate this before launching data generation/collection, so that all IRB requirements are met, and all data considered important by participants are also included in some way that is acceptable to all concerned.
- In earlier times, qualitative researchers tracked all such data using file cards, notebooks, and extensive note-taking. To some extent, depending on setting, participants' preferences, IRB requirements, etc., some of these very old strategies may still be best. For instance, there are participants who do not want to be taped and/or photographed. In such cases, the researcher simply attends deeply to the encounter and conversation, then records her/his field notes afterwards—this is not as accurate, but at times it is the only option. In other situations, we may use an array of smart phones, tablets, digital recorders/ cameras, and laptop computers that aid us in capturing these data. It is the researcher's responsibility to know what is legal, what is ethical, what is permitted by participants, and how to honor all of these considerations.
- The management of data is handled on a case-by-case basis, incorporating elements in the point above this one. But in general, it is helpful to aggregate all field notes, researcher reflections, and additional information into some kind of electronic format....a simple word processing or text filing package is perfectly adequate for this. There is no need to invest in very expensive software to gather, then later process/analyze the data...regardless of what anyone tells you, the real work of managing and especially of analyzing qualitative data is in the mind of the researcher—repeat: the researcher is the instrument, and no software package can make the decisions about how to classify a piece of information, to decide how/why it relates to any other....software is helpful for holding, organizing, moving, collating and preserving data. But the work of interpretation, decision-making, and dissemination is the province of the researcher, in concert with the participants, in whatever way has been negotiated.
- Regarding software: depending on whether the researcher works on a PC or Mac-based platform, there are free, open-source examples of basic software for capturing and organizing qualitative data. One can locate these by doing a Google search online, and the researcher/author writing this module strongly recommends that a novice qualitative scientist do this, rather than assuming that only the most elegant, expensive packages [eg, N-Vivo, Atlas.TI] can do this task. If the reader expects to conduct multiple qualitative studies, s/he is strongly

encouraged to thoroughly explore student versions of those 2 largest, best known packages, then take a course in one or both of them—they are very complex, powerful, and they require considerable training to be proficient in their use. One simpler, long-time package that is available FREE online for only PCusers [does not run on a Mac] is EZ-Text, available online from the CDC—just go to the following link: <u>http://www.cdc.gov/hiv/library/software/eztext/index.html</u>

- Here is the actual description from that CDC page about their EZ-Text qualitative software:
 - Overview
 - "CDC EZ-Text" is a software program developed to assist researchers • create, manage, and analyze semi-structured qualitative databases. Researchers can design a series of data entry templates tailored to their questionnaire. These questionnaires are usually administered during face-to-face interviews with a sample of respondents. A response to a question may be entered into EZ-Text either as a verbatim transcript (e.g., from a tape recording), or a summary generated from the interviewer's notes. Data from respondents can be typed directly into the templates or copied from word processor documents. Following data entry, investigators can interactively create on-line codebooks, apply codes to specific response passages, develop case studies, conduct database searches to identify text passages that meet user-specified conditions, and export data in a wide array of formats for further analysis with other qualitative or statistical analysis software programs. Project managers can merge data files generated by different interviewers for combined cross-site analyses. The ability to export and import the codebook helps to coordinate the efforts of multiple coders simultaneously working with copies of the same database file.
 - Copies of the EZ-Text software and user documentation can be downloaded free of charge from this web site.
 - If you have further questions or problems, please send an email message to: <u>eztext@cdc.gov</u>
- Also at the CDC website are additional free software packages that the reader may find helpful for general or mixed methods research:
 - AnSWR is a software system for coordinating and conducting large-scale, team-based analysis projects that integrate qualitative and quantitative techniques.
 - <u>Epi-Info</u>--Easy form and database construction, data entry, and analysis with epidemiologic statistics, maps, and graphs.
- For Macs, as of June 2013 [when this module was finalized], the reader is encouraged to at least look at a web page called "Chaos and Noise", which describes several open source qual software packages for Macs; see the information at: <u>http://morsla.wordpress.com/2010/09/03/qualitative-analysissoftware-for-mac-a-brief-look/</u>

• NOTE: Remember that web-based information changes constantly, and readers should expect some changes from the links here with the passage of time—keep up with frequent searches for new offerings of software.



Unit 4: Analysis and interpretation of qualitative data

- Readers should use all of the points made in above Units as a basis for moving into qualitative data analysis and interpretation.
- Regardless of the many kinds of qualitative data one generates, it is always fundamentally about the following processes: data generation data display ---> data reduction ---> data analysis and meaning-making/conclusion-drawing ---> assuring the integrity, transparency and accuracy of all processes and findings, including some kind of validation with participants ---> dissemination, in whatever way has been arranged or negotiated with appropriate stakeholders. Stakeholders may include the research team, the academic partners, the community partners [eg, tribes, citizen groups, families, students, providers, planners, important others].
- Qualitative data analysis always consists of trying to make sense of the data, each kind of data by itself, then as a whole, blended package of kinds-of-data [the integration and synthesis of all the data forms-textual, visual, etc., as described above]. Thorne calls this process "from pieces to patterns", holding the activities of organizing, reading/reviewing mindfully, coding, reflection [researcher-is-instrument], thematic derivation and analysis [finding meaning]. The author of this module uses the following scheme of actions for qualitative data analysis, after converting textual data in Word to a software package for analysis [please see Appendix for a more explanatory, detailed version of this sequence]:
 - Detailed reflexive reading of all the textual data, saving relevant, meaningful data and discarding irrelevant data, such as researcher clarifications or an interruption in the conversation (eg, by someone entering the room or a thunderstorm passing by); this is a data-cleaning or culling process;
 - Open coding of the transcripts, in which each line of data is analyzed for meaning, culminating in text excerpts reduced to concise, named segments (eg, cost of prescriptions, problems getting somewhere); at this point data are still organized into individual level responses, such as individual interviews or individual sessions with a group.

- Re-sorting of the identified segments into distinct conceptual categories for additional analysis of commonly coded portions, or secondary coding; this resorting moves the data from individual to collective/overall group data, from which final conceptual elements or codes will be extracted.
- Re-reading, interpretation, and extraction of recurring ideas, patterns of meaning, or language from the coded categories, yielding a final set of codes common across/distilled from all data; and
- Synthesis and integration of the recurrent patterns, emergent across all of the data, into distinct themes, each conceptually unique, yet internally consistent with regard to the research questions; the themes represent propositional statements or linkages among the distinct codes or categories of meaning, as well as study findings. Themes are larger units of meaning than codes, usually in the form of propositional statements.
- An additional/complementary strategy for the display, analysis, and dissemination
 of qualitative data is a matrix...A matrix is a useful technique for organizing final
 themes; it can be created to represent a description of findings, a depiction of
 process, or a set of outcomes generated, consisting of data cells as "crossing
 points", such as across varied participant/stakeholder groups, in response to the
 same research questions, or as particular strategies used by different
 communities, across a common set of disparities or problems. Major points are
 bulleted in a matrix, reflecting synthesis and providing ease of access and
 understanding by multiple stakeholders at varied levels of research literacy.
- Readers are encouraged to read a paper in Appendix E by the author, in which data analysis is presented in more depth and detail.
- Again in a very general, "big picture" vision of qualitative analysis, a useful metaphor both in structure and function is the common funnel:
 - * The broad, open top of the funnel is the gathering place and entry point for data—all kinds of data enter in, each representing a unique kind of knowledge, exemplar, or data source [as described above in Unit 3].
 - * Once combined in the funnel, computer, and/or mind of the researcher, the varied types of data begin their dance of linkages, relational dynamics, and strands of meaning; they swirl together, yet still represent distinct patterns of knowledge and insight.
 - * They undergo intensive reflection and analysis by the researcher, sometimes aided by participants. Gradually, as they move through the narrower portions of the funnel and towards the finish of the study, and by way of data display-reduction-analysis, they coalesce into fewer bits of common meaning and conceptual clarity that cut across all data sources. This journey through the funnel represents the processes of reading-reflection-sequential coding-thematic analysis/derivation described above.
 - * At the point where the findings flow out of the funnel, they represent the collective synthesis, integration, and meaning-making [the "so-what?"] of all inputs. The nuggets are the themes and conclusions articulated by the researcher.





Findings: data interpretation, then dissemination



Unit 5: Issues of representation, evaluation/critique, rigor and presentation

- Relational dynamics, ethical conduct, and negotiations with participants are key processes in insuring representativeness of data/findings.
- Qualitative rigor is achieved by multiple strategies, but is generally referred to as study integrity or trustworthiness. The author's article [see Appendix E] holds specific criteria for rigor used in her rural health research. However, interested readers can find a great deal of additional, enriching literature on qualitative rigor.
- Among qualitative scholars, there exists a tension between allowing participants to decide the extent of quality or rigor, since they provide the raw data for the study in question, and the scientific perspective for verifiable findings based on external criteria....it is the author's perspective that a blending of these views is the best overall solution. The classic work on qualitative rigor was done by Lincoln and Guba (1985), who described the indicators of truth value, applicability, consistency, and neutrality as touchstones of trustworthiness analogous to the familiar reliability and validity we know from quantitative research. The citation for their timeless work is included in the references for this module, at the end of Appendix D.
- The author acknowledges the outstanding contribution to this topic by Dr. Karen J. Lottis, PhD, RN, who graduated two years ago from the UNM College of Nursing, in her dissertation about health care perceptions of indigenous people in British Columbia—Engaging the Liminal. Here is an unpublished excerpt from her work, used with her permission, to discuss qualitative rigor, especially in working with indigenous groups [but the author believes it pertains to any/all participants]:

There is a further level of verification that must occur in a critical/transformative paradigm. Fine, Weis, Weseen and Wong (2003) contend that social responsibility must also be verified, and offer a series of questions designed so that "social analyses might be continually reassessed an (re)imagined" (p. 198):

- 1. Have I connected the "voices" and "stories" of individuals back to the set of historic, structural, and economic relations in which they are situated?
- 2. Have I deployed multiple methods so that very different kinds of analyses can be constructed?
- 3. Have I described the mundane?
- 4. Have some ... participants reviewed the material with me and interpreted, dissented, challenged my interpretations? ...
- 5. How far do I want to go with respect to theorizing the words of informants?
- 6. Have I considered how these data could be used for progressive, conservative, repressive social policies?
- 7. Where have I backed into the passive voice and decoupled my responsibility for my interpretations?
- 8. Who am I afraid will see these analyses? Who is rendered vulnerable/ responsible or exposed by these analyses? ...
- 9. What dreams am I having about the material presented?
- 10. To what extent has my analysis offered an alternative to the "common-sense" or dominant discourse? What challenges might very different audiences pose to the analysis presented? (p. 199-201)

All of these criteria for methodological rigor resonate with Lincoln's (2002) proposed/emergent criteria for doing qualitative research, all of which position the community as arbiter of quality:

- 1. Voice articulation of who speaks, who is silenced or silent, and for what purposes. Voice is interpreted as "resistance against silence" (p. 337).
- 2. Critical subjectivity, in which the researcher and participants share a dialectic, negotiate an interpretation, and determine an action
- 3. Reciprocity, which describes the intensive sharing of information, points of view, reflexive interpretations, and significance for research outcomes and findings.
- 4. Sacredness, which is emerging from a feminist perspective that science "has a sacred and spiritual character" (p. 339), and aims to create relationships of mutual respect, dignity, and appreciation.
- Sharing the perquisites of privilege, a referent to recognition, royalties, or other benefits that may derive from the sharing-writing of research findings. [Lottis, K.J., 2011)



Unit 6: Writing, reflection, conclusion-drawing

- With qualitative researcher-as-instrument, the writing up of findings, conclusions, and meaning/insight achieved is a work of knowledge production.
- Respected educator/phenomenologist Max van Manen said of writing: "Writing is not just externalizing internal knowledge, rather it is the very act of making contact with the things of our world. In this sense to do research is to write, and the insights achieved depend on the right words and phrases, on styles and traditions, on metaphor and figures of speech, on argument and poetic image. And these are values that cannot be decided, fixed or settled, since the one always implies, hints at, or complicates the other."--Max van Manen, in his book Writing in the Dark (p. 237)

* Depending on the level/extent of partnership negotiated with research participants, the writing up of qualitative findings may be something jointly owned, disseminated, or utilized. More often in the current activities of mixed methods research, it is a dimension of overall study findings; it must adhere to the appropriate philosophical and methodological principles of qualitative inquiry, as it is presented in writing, and then again as it is integrated into the complete set of findings, which likely hold a blending of quantitative/statistical, epidemiological, and other types of data.

- As with all research, qualitative conclusions drawn and findings presented represent a moment in time, may change with new information or events, and should always be interpreted cautiously and contextually. If done properly, these findings should bring into the mainstream of scientific inquiry the actual voices, perceptions, priorities, and lived experiences of the various participants we in health care seek to serve, assist, and encourage.
- Dissemination is really of two types, both equally valuable and important: the scientific community expects researchers to publish their work in peer-reviewed sources, present the works at key conferences, and share the knowledge achieved with colleagues, students, funding sources and stakeholders. But of equal importance is the need to take the findings back to the communities and participants who shared it—in whatever forms or forums that the participants request. This might include town/community meetings, inservices, colorful charts, executive summaries written in plain language or the language of residents, photographs, policy seminars before elected representatives and leaders, or selected public venues.
- For the author of this module, the process and outcome of qualitative inquiry fits very well into the approach we know as CBPR, since it invites/evokes all voices to take part in the description, analysis, and resolution of major questions, issues, or concerns. Genuine qualitative research is so much more than "just a few focus groups" added to an otherwise quantitative design....it vividly represents the voices, perceptions and experiences of people living the reality we investigate....thus, being consistent with the true ethical, equity-related, socially/ politically leveling values of naturalistic/qualitative inquiry is essential. Its philosophical/conceptual, as well as methodological principles and methods are not optional, but critical to accurate representation of the people involved.



Appendix A

Qualitative Designs

A Note from Jennifer on Qualitative Research Design(s)

There are at least 2 major ways to think of qualitative research designs: One is to begin with the conceptual/methodological details & differences among the varied traditions or approaches; the second [which is the one I recommend to you at this phase of your work] is to be most concerned with the big picture, or the commonalities overall about qualitative inquiry, with a nod towards the various specialty designs that fall under that larger umbrella. The Richards-Morse text is a brief/foundational sketch of some of those well-known variations & subspecialties. There are additional texts that also do that, including Patton. My overall recommendations for you include the following:

- Read all that is assigned, noting especially the *common threads & ideas that unite all qualitative designs*; this course is not on designs, per se, but on the overview of qualitative research. Designs are simply one part of the whole.
- Identify the common threads, ideas, strategies, or ways of thinking that are common to all of the designs. Thorne & Patton are very good at helping with this; Denzin & Lincoln add a fine depth to this discussion.
- Read about some of the differences across the major designs, noting where they diverge/converge from the overall ideas. At this point, you should not worry about which one is best for you—it is far too early in your own research trajectory. This really is no different from your study of numerous quantitative research designs—you learn about many, but are not expected to choose one until you are much closer to your own proposal. But you are expected to know the general, over-arching ideas, procedures, & ways of thinking for any quant/statistical study—the same is true for qualitative designs.
- When you really want to know the depth, detail, history & scope of particular qualitative designs, do take the time to track down original or primary/major sources for these, rather than rely on others who analyze, categorize, & describe the various traditions/designs, but who do not actually do or innovate them. I have placed a number of these primary sources on our N 607 Recommended List of texts. Now you know why I did not recommend that you purchase any Recommended texts until you determine which if any of them might benefit your own research & scholarship trajectory ;-)!
- There are numerous writers/authors/scholars of qualitative work, & they do not share complete consensus on what the major designs actually are....usually, you will identify ethnography, phenomenology, & grounded theory as strong examples. Richards-Morse present these well known designs as their base of analysis for the text, and include a section on mixed methods designs [our Recommended/Additional readings also have several excellent texts on mixed methods designs*. These* are not the focus of N 607, but we can discuss them as we enter the later weeks of the course, if you are interested & we have the time. There are also other designs that appear in alternative sources/texts. We will spend just a little of our face to face time reviewing these, so that later on, if desired, you can follow up in more depth & detail. *Bottom line*: please relax about trying to take the micro-view across the various qualitative designs. Go for the major ideas & points at this juncture. Thanks!

• Here is a brief synthesis of some of the major qualitative designs, with info drawn from numerous sources in J's library & experience—here's hoping this table may be of some help:

DESIGN	NUTSHELL SYNTHESIS	COMMENTS
Phenomenology	the 'systematic attempt to	Read Husserl, Merleau- Ponty, van Manen, Giorgi, et al. In nursing: Pat Benner, Jean Watson
Ethnography	Studies culture, in all possible settings, groups &	
Grounded Theory	<i>detailed</i> grounding by systematically & intensively analyzing data, often sentence by sentence, or	-

Narrative Research/Analysi	s'Narrative analysis is a variety of orientations to interpreting varieties of discourse, including narrative texts.' (Daiute & Lightfoot, p. xi). 'Narrative can refer to the process of making a story, to the cognitive scheme of the story, or to the result of the process—also called stories, tales, or histories.' (D. Polkinghorne, p. 13 in his text on Narrative Knowing)	Read Polkinghorne, Frank, Kleinman, Cheek, Daiute & Lightfoot
Case Studies	Studies an exemplar or individual case of someone/ something in depth & detail (as opposed to breadth obtained with larger samples); 'case study concentrates on experiential knowledge of the case & close attention to the influence of its social, political, & other contexts' (Stake, in Denzin/ Lincoln, p. 444).	Read R. E. Stake & others who use this approach; can incorporate both quantitative & qualitative data.
Participatory/Action Research	Called by a variety of names across multiple disciplines, <i>participatory research</i> rests on full partnership among stakeholders for the research endeavor, at all phases of work.	Read Freire; Denzin, Lincoln & Smith; Israel et al.; Minkler & Wallerstein; R. Stoeker; E. Stringer, et al. There is increasing presence of this kind of inquiry in nursing research. It is an approach, not a method.
Historiography/Historical Research	Research based on review of historical facts, documents, artifacts, events, & personalities; is often focused on a particular era, individual or issue.	

Hermeneutics	Strictly speaking,	Read Gadamer, Hegel,
	hermeneutics is the study of	
	written text & its	Reeder, Benner, et al.
	interpretation. It is also	
	sometimes called	
	interpretive research; it also	
	is considered to be a branch	
	of philosophy. 'Hermeneutics	
	is like a roadmap for	
	understanding the terrain of	
	language; the signs of spoken	
	& written expressions point	
	out connections between the	
	speaker or the writer & the	
	world in which he or she	
	lives' (F. Reeder, in Sarter, p.	
	194)	
Interpretive Description	'Interpretive description is a	Oriented as a kind of
	strategy for excavating,	general approach to applied
	<u> </u>	nursing practice & its
	disseminating the kind of	research, this strategy is at
	knowledge that sits	once practical, humanistic,
		& relatively simple [as these
	conjecture, but which is of	things go!]. It aims for a
	central importance to the	user-friendly 'middle
	applied	ground' of applied
	disciplines' (Thorne, p. 15)	qualitative logic.

Appendix B

Mixed Methods Designs

ALWAYS NOTE:

- ★ Purpose/intent/aim of the inquiry
- ★ Assumptions, both explicit & implicit
- ★ Conceptual-theoretical foundations & implications
- Operational/methodological foundations & implications
 - ★ Nature & type of research questions that fit
- ★ Appropriate strategies for study integrity/rigor
- ★ Orientation & role of researcher regarding participants
- Consideration of ethics, social justice, equity, representation,
 - voice, & level of participant engagement in the research



Non-Experimental Designs

- ★ Qualitative methods
- May describe, explain, and/or lead to propositions & hypotheses
- Favors emancipatory, aesthetic, personal, ethical, sociopolitical, cultural, ecological, & other knowing/knowledge
- INTENT: Understanding, meaning; involves lived human experience, perceptions, & interpretation
- Data are narrative, visual, archival, performative, and/or arts-based

- Experimental Designs, Quasi-Experimental Designs
- ★ Quantitative methods
 - ★ Hypothesis-testing
- ★ May be predictive
- ★ Favors empirical knowing/knowledge
- ★ INTENT: Generalizability of findings/results
 - ★ Data are generally numeric

Appendix C

Expanded Data Analysis Content

Some General Steps to Follow in Preliminary Data Analysis [JBA]:

The following "very general scheme" is suggested as a way to approach preliminary data analysis. It must be emphasized that in the qualitative paradigm and way of thinking, this is NOT a linear process, is not perfectly predictable, and is subject to modification based on reflection & insight. Why, you may ask, is this so? Because qualitative research aims to accurately capture slices of real life, & translate them meaningfully into research findings. Real life is very "messy" in terms of everyday occurrences. People move through a variety of settings and experiences, hold varied attitudes and mindsets, are influenced by countless variables and events, and clearly defy perfect predictability and prescription. *For that I am so thankful!* All of that means that in doing research qualitatively, we do so with the knowledge that:

- all knowledge & findings are co-created between the participants & the researchers
- everything is tentative & subject to modification, pending a change in thinking, life events, or other unforeseen circumstances/events
- flexibility is absolutely key to obtaining a wide array of data in varied settings, from as diverse an array of participants as we can find
- because this research unfolds as a partnership with community residents & participants, we are always sensitive & responsive to their interpretations of our work; what we think we are discovering or learning may shift as we gain their understanding & insights. Always, THEY are the experts in their own contexts & daily life.
- All that said, we can still be systematic, efficient, and auditable in all of our procedures!

So here is a very general scheme that we will follow as we begin to manage & analyze all of these data. I hope the RA team will find it helpful:

- 1. Read the initial transcripts carefully & thoughtfully
- 2. Listen to the initial transcriptions by the transcriptionist, while simultaneously comparing what is heard on the tapes with what is written as script. It is extremely important to CLEAN the data: that is, to insure the best possible, most accurate fit between what is heard on the tapes & what appears on the transcript. This normally results in an edited set of transcripts, since research team members have a different knowledge base regarding what is on the tape and how it matches the research questions. This step is key since all subsequent coding & interpretation rest on an accurate depiction of what was said during the interviews. Unnecessary, confusing, or obviously irrelevant information on a tape (e.g., a pause because of a telephone ringing, the interruption of the conversation by a 3rd person needing assistance, etc.) may be removed or filed in a separate electronic file entitled "miscellaneous".
- **3.** Once the scripts are edited, find a systematic way to number each line of text on a page. Then print out a set of cleaned, edited transcripts for initial open coding. NOTE: eventually, this step may be revised once everyone is very comfortable

with the *Atlas ti* software; however the most critical thing is for the reader and the data to interact, for the reader to reflect deeply on what is said, & to analyze the significance of the words. NO software can make these judgments for us—we are the instruments. Software is merely an assistant for organizing, storing & grouping data we have assigned to various categories. **PLEASE reread this statement—it is crucial...**

- 4. Read attentively & deeply EACH interview, using brackets, a pencil (since ideas may shift with the reading & thinking), & initial open coding of chunks of text. We are reading for major ideas, concepts, or categories of information. We record these major items to the right of the blocked text, doing so in abbreviated form—usually in single word, or a few brief words or a short phrase. This begins the process of synthesis—the extraction of or distillation of absolutely key words in a larger block of data. It is rather like a mental "funnel", into which a great blob of narrative data are poured, & out of which the reader distills nuggets that capture the essence of what was said. This requires considerable mental energy, focus & ability to concentrate. When you begin to do this, you may only be able to work for brief periods; but with practice, you develop the ability to concentrate in longer blocks of time. But take breaks periodically, so that you are always fresh & ready to engage each transcript openly.
- 5. Once all of the interviews have been individually coded for conceptual categories, we revisit each briefly, to see if we want to collapse any of the categories into fewer categories of distinct information. We continue this process until we are satisfied that all conceptual categories have been extracted from the interviews.
- 6. Now that we have initially coded each interview, we use the computer to help us develop a 3rd set of transcripted data: in this case, we identify, using the numbered lines from each interview, ALL cases of "category x", all cases of "category y", etc. We then pull ALL cases of each code/conceptual category from the interviews (collectively). What we end up with is a new set of transcripts. In this new set, each unique transcript contains ALL instances of each conceptual category or code. We acknowledge that a few things may be double coded, & end up in more than one category. Not a problem! Data are what data are, & not everything stands apart from everything else.
- 7. Now that we have a new set of initially coded transcripts, we repeat the process: print out the commonly coded transcripts & go through a second coding for key/ major ideas& conceptual categories. Again, think of the funnel....this time our "units of analysis" are commonly coded sequences or scripts. From these we synthesize & derive a finer & further set of conceptual categories or codes. The process is the same: read carefully, code segments, then look over each unit (commonly coded set of scripts) for opportunities to collapse or refine essential categories or codes.
- 8. When we complete this process, we are ready to move to a new phase of data analysis: *thematic analysis*. In this, we assemble these secondary/finer codes &

reflect on how they interrelate to each other. The metaphor for this process is the model of a molecule—remember that from a long-ago science class? Consider each "molecule" or atom to be analogous to a secondary/finer code. Thematic analysis is the process of LINKING those individual codes/molecules/atoms in propositional statements. Keys to this process:

- use simple language
- use short sentences
- plan to construct declarative sentences or brief phrases for the propositions; Jennifer will show you some examples of "themes" from her previous work.
- If it is helpful, use diagrams or illustrations to illustrate how the concepts/ideas relate to each other propositionally. Jen likes to use matrix analysis for this phase, as it facilitates the display, comparison, & analysis of emerging findings.
- 9. *Thematic Analysis* is a phase for which we take the emerging findings from our analysis back to the participants for validation. If they "recognize" & agree with what we think we have extracted from the data, we are on target; if we have missed something crucial, we revisit the collection and/or analysis.
- 10. I think this is far enough for the present time in the progression of this research project. There is much more to say & do; but this should help the RA team have a focus, a pathway to follow, & an opportunity to use our collective debriefing sessions as a means of multiple-voice analysis, comparison, & understanding. I suggest you print out this information & keep it handy, so that as we move through the long process of qualitative data analysis, you can always see where in the forest your "tree" might be located! My sincere thanks for your help—this would be immensely difficult without your assistance! And I hope you may learn something valuable from the experience. Take care....see you soon!

--Jennifer

Appendix D

Detailed Content Outline for Qualitative Research: a Course Blueprint, Including a Reference List of Texts

APPENDIX D: Detailed Content Outline for a Basic Qualitative Methods Course [JBA]

Unit 1: Conceptual, paradigmatic, and philosophical issues and perspectives in qualitative/interpretive inquiry; cultivating/creating questions for inquiry

- A. The nature of qualitative inquiry: paradigms, worldviews, perspectives, comparisons to quantitative inquiry
- B. Locating the field [describing 'the field']
- C. Philosophic assumptions
- D. Interpretive frameworks & communities
- E. Generating/creating appropriate questions for interpretive description
- F. Contextualizing your study in the existing literature
- G. SEMINAR QUESTIONS to guide Discussions online [start with these, feel free to add your own questions to the common discourse]:
 - How would you define/describe qualitative inquiry, & how does it differ from quantitative inquiry?
 - Please identify and analyze the several most compelling [to you] paradigmatic points, assumptions, or worldviews that inform qualitative research.
 - What are some of the philosophic roots & origins of qualitative inquiry?
 - What is meant by interpretive description?
 - What is meant by methodological congruence?
 - What is meant by 'the field' in a discussion of qualitative research? Can you provide at least one example of a 'field' for your own research interests?
 - Please offer at least one suitable question from your own interest areas that could be explored using interpretive description.
 - I recognize that this is likely your first graduate course in qualitative research. But from where you are currently, what do you see as the most critical/ important strengths/benefits & weaknesses/limitations for doing this kind of research? You may modify your thinking as we go, but this is a starting point in the Discussion.
- H. READINGS:
 - Patton, all of Part 1 (chapters 1-4)
 - Richards & Morse, chapters 1 & 2
 - Thorne, chapters 1-3 & 6
 - Denzin & Lincoln: scan Parts 1 & 2; then select 2-3 chapters from these sections that interest you—read them & integrate them into our Unit 1 Discussion. You may return at anytime to additional chapters in parts 1 & 2 of this text.
 - For this requirement, you are asked to become familiar with several sources that offer ongoing/periodic resources, articles, and ideas about qualitative inquiry. Please select/choose a minimum of 2 peer-reviewed articles from any of these sources for Unit 1 [& for each of our other Units], choosing material that is current [less than five years old], & that is pertinent to the particular Unit we are studying: Qualitative Health Research (QHR); Journal of Contemporary Ethnography; Social Science and Medicine; Family &

Community Medicine [has occasional articles using one or both of these approaches to research]; any journal listed at <u>http://www.slu.edu/</u>organizations/qrc/QRjournals.html [this is a very rich listing of peer-reviewed journals that are receptive to qualitative research]; or any article listed at Dr. Michael Agar's website: <u>http://www.ethknoworks.com/</u>. Integrate material from these 2 articles into our Unit Discussions, & thank you for citing the 2 articles that you read for each Unit, so that classmates may benefit from each other's choices.

Unit 2: Qualitative designs, strategies and approaches to inquiry

- A. Designing qualitative studies: structure, design, characteristics, process, ethical & IRB considerations
- B. Some of the best known qualitative designs: phenomenological research, grounded theory research, ethnographic research; there are others, which we may mention as we move through the course [e.g., participatory/action research, etc.]
- C. Comparing & contrasting the designs we study here
- D. Introducing & focusing the study, elements of design SEMINAR QUESTIONS to guide Discussions online [start with these, feel free to add your own questions to the common discourse]:
 - Under what conditions might you choose a qualitative design for your research? Why?
 - What are the defining & critical characteristics of a qualitative design (any kind)?
 - Please engage/analyze the several different designs in terms of overall purpose, scope, fit for a clinical or research-related problem or question—I want to see you compare/contrast how a study might look in the various designs. Focus only on design in this Unit—save analysis, etc. for later Units. You might come up with a potential research question, then discuss how it would be addressed in the various designs.
 - Thorne avoids a dialogue about these several designs, & instead focuses simply on descriptive inquiry as an overarching design....how would your research question be addressed if you were using her 'interpretive description' as a design strategy? Please analyze how that may/may not differ from the other several options. I realize this is somewhat a judgment call—it is about the strength & clarity of your arguments

E. READINGS:

- Patton, all of part 2 (chapters 5-7)
- Thorne, chapter 4
- Richards & Morse: chapters 3-4
- Denzin & Lincoln: may review anything you liked in part 2; also read Part III you may scan it, then return for deeper reading on particular chapters; be certain to read well chapters 19 & 23, in Part III

- Recommended—NOT Required: Creswell: chapters 3, 4, several; 5 is optional, but somewhat helpful in clarifying differences among designs
- Please select/choose a minimum of 2 peer-reviewed articles from any of these sources for Unit 2 [& for each of our other Units], choosing material that is current [less than five years old], & that is pertinent to the particular Unit we are studying: Qualitative Health Research (QHR); Journal of Contemporary Ethnography; Social Science and Medicine; Family & Community Medicine [has occasional articles using one or both of these approaches to research]; any journal listed at http://www.slu.edu/organizations/qrc/QRjournals.html [this is a very rich listing of peer-reviewed journals that are receptive to qualitative research]; or any article listed at Dr. Michael Agar's website: http://www.ethknoworks.com/. Integrate material from these 2 articles into our Unit Discussions, & thank you for citing the 2 articles that you read for each Unit, so that classmates may benefit from each other's choices.

Unit 3: Entering the field, generation/collection of qualitative data

- A. Fieldwork strategies, observation methods, qualitative interviewing (there are many variations), documents, photography
- B. The data collection circle/cycle; questions to guide the discussion
- C. Access, rapport, communicative interaction
- D. Engagement with the data, & everything is/are data J
- E. Management & protection of the data
- F. Emergence of arts-based inquiry, arts as data (visual data)
- G. Including a research log/field notes & reflective journal
- H. Comparison of data collection/generation across the several designs
- I. SEMINAR QUESTIONS to guide Discussions online [start with these, feel free to add your own questions to the common discourse]:
 - In terms of qualitative data collection, can you distinguish among the various strategies (variations on observation, interviews, notes & journal)? Please use this opportunity to question, clarify, & understand the similarities & differences among the strategies.
 - What kinds of 'sampling strategies' are used for qualitative inquiry? Please identify & compare them. How/why is this different from what we use in quantitative studies [a critically important question]?
 - What are the advantages/disadvantages of 1:1 interviews compared to group interviews or focus groups?
 - Analyze the similarities & differences between group interviews & focus groups.
 - What information would you expect to put into your field notes or log? How does that differ from information you would place in your reflective journal?
 - Under what conditions might you include visual data (photos, videos, arts, other creations) in your qualitative data collection? How would you address issues of privacy & confidentiality when using visual data?
 - What is meant by 'saturation' of data? This entails conceptual thinking...

- Can you identify & analyze at least 2 strategies for preserving the quality & integrity of qualitative data that are collected for analysis?
- J. READINGS:
 - Patton, chapters 5-7
 - Richards & Morse: chapter 5
 - Thorne: chapter 7
 - Denzin & Lincoln: Scan all of Part IV, returning to more deeply read any 2 of the chapters in part IV, with emphasis on the collection/generation of the data; I recommend chapters 26-29, in particular
 - J's article, a summary of findings for a recently completed rural health study, currently under revision, then more review—focus on the section about collection/generation of data—included for you as a PDF file; additional articles may be forthcoming
 - Any article in a recent issue of Qualitative Health Research (QHR); vol 20, number 5, May 2010—the issue is devoted to focus groups.
 - Please select/choose a minimum of 2 peer-reviewed articles from any of these sources for Unit 3 [& for each of our other Units], choosing material that is current [less than five years old], & that is pertinent to the particular Unit we are studying: Qualitative Health Research (QHR); Journal of Contemporary Ethnography; Social Science and Medicine; Family & Community Medicine [has occasional articles using one or both of these approaches to research]; any journal listed at http://www.slu.edu/organizations/qrc/QRjournals.html [this is a very rich listing of peer-reviewed journals that are receptive to qualitative research]; or any article listed at Dr. Michael Agar's website: http://www.ethknoworks.com/. Integrate material from these 2 articles into our Unit Discussions, & thank you for citing the 2 articles that you read for each Unit, so that classmates may benefit from each other's choices.
 - Instructors' additional notes, to be shared during this Unit

Unit 4: Analysis and interpretation of qualitative data

- A. Data analysis & interpretation
- B. Important questions for discussion
- C. Specific strategies for analysis
- D. Comparison/contrast in analysis across the various designs
- E. Making sense of data-"From pieces to patterns" (Thorne, p. 7): organizing, coding, reflection, thematic derivation/analysis, matrix analysis
- F. Examples of analysis
- G. Preserving the trustworthiness & integrity of the research
- H. Qualitative software—the good, the bad, & the ugly
- I. SEMINAR QUESTIONS to guide Discussions online [start with these, feel free to add your own questions to the common discourse]:

- In quantitative studies, we are accustomed to 'numbers' as our units of analysis; what are the units of analysis (all the various kinds) for qualitative inquiry?
- What are the meanings/definitions of these processes: coding, thematic derivation, matrix analysis, immersion & crystallization?
- What role does software play in qualitative data analysis? What are its benefits? What are its limitations?
- How does the work of data analysis vary across the various designs?
- What do you consider the most challenging aspects of qualitative data analysis? How would you address them directly as a researcher?
- What are several important perspectives or points in the work of data analysis (see ch. 32 in Denzin & Lincoln)?
- What are specific ways that we try to strengthen the analysis and the eventual outcomes/findings?
- What is meant by the term 'thick description'?
- What role does the researcher play in the nature, work & product of qualitative data analysis (this goes beyond entering data into software)?

J. READINGS:

- Patton, chapter 8
- Richards & Morse, chapters 6-9
- Thorne, chapters 8-9
- Denzin & Lincoln, chapters 32, 34, 35 & 37 [any additional chapters that interest you in Parts IV-V]
- 2 PDFs provided for you: my paper again, this time focusing on the data analysis section; excerpt from Clifford Geertz
- Please select/choose a minimum of 2 peer-reviewed articles from any of these sources for Unit 4 [& for each of our other Units], choosing material that is current [less than five years old], & that is pertinent to the particular Unit we are studying: Qualitative Health Research (QHR); Journal of Contemporary Ethnography; Social Science and Medicine; Family & Community Medicine [has occasional articles using one or both of these approaches to research]; any journal listed at <u>http://www.slu.edu/organizations/qrc/QRjournals.html</u> [this is a very rich listing of peer-reviewed journals that are receptive to qualitative research]; or any article listed at Dr. Michael Agar's website: <u>http://</u> www.ethknoworks.com/. Integrate material from these 2 articles into our Unit Discussions, & thank you for citing the 2 articles that you read for each Unit, so that classmates may benefit from each other's choices.

Unit 5: Issues of representation, evaluation/critique, rigor and presentation

- A. Understanding 'representation' and 'voice' in qualitative research
- B. Enhancing the quality, credibility, & rigor of qualitative research

- C. Representation, voice, quality, rigor, & presentation of work across the several designs
- D. SEMINAR QUESTIONS to guide Discussions online [start with these, feel free to add your own questions to the common discourse]:
 - What is meant by 'representation' in qualitative research? How is it achieved, and what is the impact of 'voice' in representation?
 - In quantitative inquiry we refer to reliability & validity when we analyze quality & rigor; what are the analogues or similar ideas in qualitative inquiry? How are they similar to or different from reliability & validity?
 - How do researchers achieve indicators of quality & rigor across the different designs? Pay close attention to similarities & differences.
 - Whose voices are represented in an assessment of rigor? Who has responsibility for the logic and authority of qualitative inquiry? Why is this analysis also a political discourse?

READINGS:

- Patton, chapter 9
- Richards & Morse: chapters 8-9
- Thorne, chapter 13
- Denzin & Lincoln, scan all chapters in Part V, then return/read any 2 that speak to you on the Unit 5 topics
- Cohen & Crabtree, 2008 (PDF); Mykhalovskiy, et al., 2008 (PDF)
- Please select/choose a minimum of 2 peer-reviewed articles from any of these sources for Unit 5 [& for each of our other Units], choosing material that is current [less than five years old], & that is pertinent to the particular Unit we are studying: Qualitative Health Research (QHR); Journal of Contemporary Ethnography; Social Science and Medicine; Family & Community Medicine [has occasional articles using one or both of these approaches to research]; any journal listed at http://www.slu.edu/organizations/qrc/QRjournals.html [this is a very rich listing of peer-reviewed journals that are receptive to qualitative research]; or any article listed at Dr. Michael Agar's website: http://www.ethknoworks.com/. Integrate material from these 2 articles into our Unit Discussions, & thank you for citing the 2 articles that you read for each Unit, so that classmates may benefit from each other's choices.

Unit 6: Writing, reflection, conclusion-drawing

- A. Writing, reporting, reflection & conclusion-drawing as the product of qualitative inquiry
- B. Issues & questions we face in writing up qualitative research
- C. Writing findings across the various designs
- D. The hermeneutic circle & interpretation (Patton)

- E. Dissemination of our findings: public, targeted, specific audiences; kinds of dissemination
- F. Dissemination issues across the several designs
- G. Conceptual clarity, coherence, & simplicity in writing
- H. Blending technique & reason, art & science (Thorne, p. 230)
- I. SEMINAR QUESTIONS to guide Discussions online [start with these, feel free to add your own questions to the common discourse]:
 - How does a researcher's audience impact what/how s/he writes up the findings?
 - How do we achieve a balance & integration between researcher conclusions & those of our participants?
 - In terms of final write-up & conclusion-drawing, what are differences & similarities across the various designs? Reflecting on your own research interests, which of the designs seems a stronger or weaker fit for inquiry (for you)?
 - To borrow an idea from Thorne, how do qualitative researchers successfully blend technique, reason, art & science into a coherent write-up for their work?
 - After all of these readings, questions, & considerations, explain what you see as the future of qualitative inquiry—both in general, & for you as a nurse scientist.
 - How does 'qualitative evidence' fit into this discussion, & how should we apply it in our programs of research?
 - · READINGS:
 - Patton, chapters 8-9 once more
 - Richards & Morse, chapter 10; optional: Chapters 11-12, on writing your qualitative proposal
 - Thorne, chapters 10-12, & 14
 - Denzin & Lincoln, all of Part VI—chapters 43, 44 & the Epilogue by Lincoln & Denzin
 - Morse's work on 'qualitative evidence' (PDF)
 - Please select/choose a minimum of 2 peer-reviewed articles from any of these sources for Unit several [& for each of our other Units], choosing material that is current [less than five years old], & that is pertinent to the particular Unit we are studying: Qualitative Health Research (QHR); Journal of Contemporary Ethnography; Social Science and Medicine; Family & Community Medicine [has occasional articles using one or both of these approaches to research]; any journal listed at http://www.slu.edu/organizations/qrc/QRjournals.html [this is a very rich listing of peer-reviewed journals that are receptive to qualitative research]; or any article listed at Dr. Michael Agar's website: http://www.ethknoworks.com/. Integrate material from these 2 articles into our Unit Discussions, & thank you for citing the 2 articles that you read for each Unit, so that classmates may benefit from each other's choices.

~ ONCE MORE: A very brief synopsis of your texts, to help you organize your thinking/ reading for summer term, including the 3-hour interval we will have together face to face during summer term: Patton: a classic text about qualitative inquiry—what it is, why we use it, how we prepare it, analyze it, & apply it. Patton writes well, has a great sense of humor/wit, & is your basic, most seminal text for this class.

Richards & Morse: a respected reference that details sufficient knowledge & description about several of the most common designs of qualitative inquiry; very useful in a beginning course, when one seeks simply to know a little & understand how the various designs differ/compare, & how to think about, perform, & write up a qualitative project.

Thorne: there are differences across the various designs regarding what we do with our data, how we represent & present it; Thorne recognizes that there is perhaps a general process that underlies all of the designs—interpretive inquiry. Her book represents a fine idea and discussion of how, in a general sense, we process, interpret, & make sense out of qualitative data.

Denzin & Lincoln (Eds.): this is the true 'state-of-the-art' book on what is going on in the deeper thinking, conceptualizing, acting-doing, & interpretation of qualitative research. This book is deep, long, detailed, & represents a level of scholarship & understanding that ANYONE who works with qualitative research needs to be aware of & involved with....it is an intense book. You are getting it because those of us who teach & use qualitative research at the CoN want you to own the seminal text on the topic. You buy a number of quantitative/statistical sources, & since this is the only required qualitative class you must take in your PhD program, we want you to be informed by the best, most influential & effective scholars of that discipline. At a minimum, you should read the Intro, the closing chapter, & other chapters that detail the various designs & methods that comprise the landscape of qualitative inquiry. We will talk more about it when we meet in may in Albuquerque.

Essential Fundamental Texts

Denzin, N.K., & Lincoln, Y.S. (Eds.) (2011). *The Sage handbook of qualitative research (4th ed.)*. Thousand Oaks: Sage. Denzin & Lincoln [Editors/Writers-Authors] represent the cutting edge of critical methodologies in qualitative inquiry.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park: Sage. [NOTE: if you could only own one classic reference for all of qualitative inquiry, this would be that one....Jennifer]

Patton, M.Q. (2002). *Qualitative research and methods evaluation (3rd ed.)*. Thousand Oaks: Sage. This old, but is a timeless classic that brilliantly tells readers about qualitative work and how to do it.

Richards, L., & Morse, J.M. (2007). *Read me first for a user's guide to qualitative methods (2nd ed. or more recent ed.)*.Thousand Oaks: Sage.

Thorne, S. (2008). *Interpretive description.* Walnut Creek, CA: Left Coast Press. This is a wonderfully readable, accessible resource, especially for clinicians who want to add qualitative methods to their toolkit as researchers.

Recommended Texts on Qualitative Research

Agar, M. (1994). *Language shock: Understanding the culture of conversation*. New York: Perennial.

Agar, M. (1996). *The professional stranger (2nd ed.)*. San Diego: Academic Press.

Atkinson, P., Coffee, A., Delamont, J., & Delamont, L. (2007). *Handbook of ethnography* (paperback). London: Sage.

Auerbach, C.F., & Silverstein, L.B.(2003). *Qualitative data: An introduction to coding and analysis.* New York: New York University Press.

Bochner, A.P., & Ellis, C. (Eds.). (2002). *Ethnographically speaking: Autoethnography, literature, and aesthetics.* Walnut Creek, CA: AltaMira Press.

Charmaz, K. (2006). *Constructing grounded theory*. London: Sage.

Cheek, J. (2000). *Postmodern and poststructural approaches to nursing research.* Thousand Oaks: Sage.

Cooper, H. (1998). *Synthesizing research: A guide for literature reviews (3rd ed. Or any later edition)*, Thousand Oaks: Sage.

Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks: Sage.

Daiute, C., & Lightfoot, C. (Eds.) (2004). Narrative analysis. Thousand Oaks: Sage.

•Denzin, N.K., Lincoln, Y.S., & Smith, L.T. (Eds.) (2008). *Handbook of critical and indigenous methodologies*. Los Angeles: Sage.

Denzin, N.K., & Lincoln, Y.S. (Eds.). (2005). *The Sage handbook of qualitative research (3rd ed.)*. Thousand Oaks: Sage. [Note: emphasize chapters on critical ethnography and CBPR/participatory research.]

Denzin, N.K. (2003). *Performance ethnography: Critical pedagogy and the politics of culture.* Thousand Oaks: Sage.
Denzin, N.K., & Lincoln, Y.S. (Eds.). (2002). *The qualitative inquiry reader*. Thousand Oaks: Sage.

Denzin, N.K. (1997). *Interpretive ethnography: Ethnographic practices for the 21st century*. Thousand Oaks: Sage.

Emerson, R.M., Fretz, R.I., & Shaw, L.L. (1995). *Writing ethnographic field notes*. Chicago: The University of Chicago Press. [an old book, but a gem!]

Fetterman, D.M. (2010). Ethnography step by step (3rd ed.). Los Angeles: Sage.

Freire, P. (1997). *Pedagogy of the heart*. New York: The Continuum International Publishing Group, Inc.

Freire, P. (1970). *Pedagogy of the oppressed.* New York: Continuum.

Flick, U. (2006). An introduction to qualitative research (3rd ed.). London: Sage.

Garrard, J. (1999). *Health sciences literature review made easy: The matrix method*. Gaithersburg, MD: Aspen.

Glaser, B.G. (1978). *Theoretical sensitivity*. Mill Valley, CA: The Sociology Press.

Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine Publishing Co.

Grbich, C. (2007). Qualitative data analysis: An introduction. Los Angeles: Sage.

Habermas, J.(1992). *The philosophical discourse of modernity*. [translated by F.G. Lawrence]. Cambridge, MA: MIT Press.

Hart, C. (1998, with additional recent reprints). *Doing a literature review: Releasing the social science research imagination*. London: Sage.

Hegel, G.W.F. (1977). *Phenomenology of spirit*. Oxford: Oxford University Press. [Note: Translated by A.V. Miller, with analysis of the text & foreword by J.N. Findlay]

Herr, K., & Anderson, G.L. (2005). *The action research dissertation: A guide for students and faculty*. Thousand Oaks: Sage.

Husserl, E. (1999). *Cartesian meditations: An introduction to phenomenology.* The Netherlands: Kluwer Academic Publishers.

Israel, B.A., Eng, E., Schulz, A.J., & Parker, E.A. (Eds.) (2005). *Methods in community-based participatory research for health.* San Francisco: Jossey-Bass.

Kleinman, A. (1988). The illness narratives. New York: Basic Books.

Krueger, R.A., & Casey, M.A. (2000). *Focus groups (3rd ed.)*. Thousand Oaks: Sage.

Lewins, A., & Silver, C. (2007). *Using software in qualitative research: A step-by-step guide.* Los Angeles: Sage.

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Appendix E

Priorities for Action in a Rural Older Adults

Priorities for Action in a Rural Older Adults Study

Jennifer B. Averill, PhD, RN

This article reports the findings from a recent study of older adults in the rural southwestern United States and discusses practice and research implications. The aim of the study was to analyze health disparities and strengths in the contexts of rurality, aging, a depressed economy, and limited health resources. Identified themes needing action included sustained access to prescriptions, transportation solutions for older adults in isolated communities, inadequate access to care, poor infrastructure and coordination of services, scarce assisted living and in-home care for frail older adults, and barriers related to culture, language, and economics. **Key words:** *community based participatory research, community and public bealth, critical etbnography, cross-cultural nursing, bealth disparities, rural older adults, social networks*

T HE Healthy People 2020 objectives call for more long-term services, support for older adults and their caregivers, increased preventive services, and effective management of chronic conditions for older adults in rural and urban settings.¹ Approximately 20% of Americans, or 55 million people, currently live in rural communities with fewer than 2500 residents. In general, rural populations experience higher rates of heart disease, cancer, injury-related deaths, diabetes, and depression than do urban populations. Rural communities are also characterized by lower rates of personal income, educational attainment, health insurance coverage, access to emergency and specialty care services, and reported health status of adults than are urban communities.²⁻⁴ Data are scarce regarding the perspectives of rural older adults in New Mexico, a culturally diverse state, with the third highest poverty level among states and a

statewide poverty rate of 18.1%.⁵ Even less is known about the health care perceptions, experiences, and contextual issues of rural older adults in southwestern New Mexico on the US-Mexican border, afflicted by the decline of the copper mining industry and struggling to meet the needs of successful aging in place.

Deeper understanding of these collective perceptions, social determinants, and contexts of health emerged from an examination of the social ties and networks that characterize the rural communities, linking all stakeholders, especially regarding older adults. These networks were analyzed in the context of overall findings, informed by the ideas summarized in the Table.

Building on findings from a pilot study, this current qualitative study analyzed health disparities and strengths in the contexts of rurality, aging, a depressed economy, geographic isolation, cultural tensions, and limited resources for health and social services among multicultural rural older adults in 3 counties in the southwestern United States. The focus was on the older adults perspectives and perceptions of health and health disparities, in their own words. This article reports the findings from the study and suggests implications for practice and research initiatives.

The pilot study was smaller, encompassed one large rural county in the same study

Autbor Affiliation: College of Nursing, University of New Mexico, Albuquerque.

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Correspondence: Jennifer B. Averill, PhD, RN, College of Nursing, MSC09 5350, 1 University of New Mexico, Albuquerque, NM 87131 (javerill@salud.unm.edu).

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Sources	Foundations	Interpretation/Process	Impact/Outcome
Waldrop ⁶ ; Kauffman ⁷ : Santa Fe Institute, complexity theorists	People tend to organize according to needs, purpose; collaboration/ adaptation of networks occurs in cells, organisms, humans, communities, and systems	Observation, interviews, assessments, verification	<i>Understanding</i> these networks strengthens interventions in business, social health services, politics, funding
Wheatley ⁸⁻¹⁰ ; Wiles et al ¹¹	<i>Community/network is</i> <i>the human web of</i> <i>connection</i> , perseverance, and resilience	Social discourse, re-engagement of people in their communities	<i>Resolution</i> of problems, social civil activism, and work for change
Greenhalg ¹² ; Kotelchuck et al ¹³	<i>Core concepts</i> : interpersonal communication and influence; partnership	Use social activity surveys to map social networks	<i>Innovations,</i> <i>evidence, change;</i> meet community needs, improve social determinants of health, policy
Grbich ¹⁴	Understanding <i>patterns</i> of interaction is key	Identify people, assess relational dynamics/ power, produce a graphical analysis, confirm/adapt with data over time	<i>Insight</i> regarding key linkages, patterns, group behaviors over time
Holmes and Joseph ¹⁵	<i>Social participation</i> improves older adults health, works as a protective factor	Provide network of services, opportunities for affiliation/dialogue	<i>Improvements</i> in morbid- ity/mortality, self-managed illness, symptoms
Madison ¹⁶	<i>Performance</i> as social behavior gives insight to people's priorities, actions, motives	Analyze actions, communication patterns, scenes (contexts), agents (persons), agency (means, tools, instruments), and purpose (aim/objective)	Accurate interpretation of human actions, what they mean, and how we may support or help

Table. Perspective on Social Networks: Foundations, Interpretation, Impact/Outcome

area, and utilized the same methods as the study reported here. Results showed that participants' definitions of health varied with socioeconomic status and included avoidance of contact with the health care system, obtaining needed medications, remaining independent, a sense of spiritual belonging, eating wisely, and exercising moderately. Older adults identified the major concerns of escalating prescription costs, inadequate access to care, and social isolation.¹⁷ However, existing strengths and assets were also identified: older adults knowledge about sustaining health in austere conditions and caring for the sick using simple measures; an existing group of dedicated professional providers applying their best efforts and knowledge to the challenge of health care; and a preexisting community-based action group working to decrease fragmentation of services, streamline delivery of services, and work with legislators on funding priorities.¹⁸ Rural studies in other settings have identified similar findings, with some regional and cultural variations.^{4,19,20-27} However, variations in cultural groups, patterns of immigration/migration, impact of specific local politics and economies, available resources, and the particular social networks in play result in important differences among rural settings. It cannot be assumed that all are the same, and no work has been documented about the health-related perceptions of this group of multicultural older adults.

CONCEPTUAL FOUNDATION

The theoretical background for this study drew strongly from community-based participatory research (CBPR), which may be interpreted as both a theoretical approach to research and a set of specific strategies for conducting investigations. The participatory sequence formulated by Stringer of Looking, Thinking, and Acting was used.^{19,28,29} Each step of Stringer's sequence corresponds to a key research phase of this work. The completed study can be characterized primarily as Looking: recognizing, gathering, defining, and *describing* the situation. The next phase will move beyond description to frame the quantitative constructs, measures, and models that are critical to the *Thinking* phase, which is more focused on explanation than description. Out of Looking and Thinking come Act*ing*, and this phase will correspond to a large, definitive evaluation, to be submitted as a future intervention project, targeting the interventions and services identified in the upcoming Thinking phase.

DESIGN AND METHODS

Critical ethnography and CBPR

The study design blended critical ethnography and CBPR. Critical ethnography combines descriptive ethnography, communicative interaction, and critical analysis of contextual factors,^{30,31} as well as strategies commonly used in CBPR.^{32,33} The focus was on the discovery, interpretation, and translation/application of *local knowledge* to practice, rather than on testing hypotheses. Community residents were the experts in the description, analysis, and interpretation of their own cultures, lifestyles, and ways of engaging the health care system, public or private.

Critical ethnography and CBPR echo what Denzin and Lincoln³⁴ refer to as "the merger of indigenous [local] and critical methodologies"^(p2) with the essential attributes of ethical inquiry, respectful engagement, transformative potential for inequities, and direct pertinence to the needs of the community. On the basis of a dialogue and partnership between the researcher and community members/participants throughout all research activities, CBPR was a natural extension of critical ethnography, the intent of which was to identify, analyze, and resolve important health or social problems.³⁵⁻³⁷

Sample and setting

Consistent with CBPR principles, a subset of interested key informants in each county made up the community advisory board (CAB) for the project. The CAB followed all phases of research, asked questions, and responded to questions from me. Working through the CAB, using purposive sampling²⁸ of private and public health care organizations, the study included 64 participants across 3 rural counties (12 men and 52 women). Fourteen women and 5 men self-identified as Hispanic, and 38 women and 7 men self-identified as non-Hispanic whites. Of the 64 participants, 40 were 65 years or older. The remaining 24 informants were adult family members, providers, or other community-dwelling

adults who in some way influenced the health care system (public or private) for rural older adults groups. Although I attempted to include a sample that represented the demographic profile of the region, my final sample did not completely match the approximately 50:50 split between Hispanics and non-Hispanics in the local demographics, possibly because larger numbers of Hispanic residents were difficult to reach through the contacts that I used in the study and because few providers and other agency personnel were Hispanic. It was not possible to precisely document differences in poverty levels between men and women in the study region, but sources have noted that women usually make up 65% of the rural poor at least 65 years of age; widowed women are even more likely to be poor than married women.^{19,29} In the state of New Mexico, 16% of all persons 65 years or older live in poverty, compared with 14% nationwide. In terms of age, 24% of all females and 22% of all males in the state live in poverty, compared with 20% and 18% nationally, respectively.³⁸

The older adults in this study diverged into 2 major groups: (1) individuals who were born in the region, who had lived and worked locally all their lives (having been mine workers, ranchers or ranch hands, farmers, or railroad workers), and who averaged 4 to 7 years of education (with just 2-3 individuals who had graduated from high school or a local college); and (2) retirees from elsewhere in the United States, who came to the region because of its mild climate, lower cost of living, and nearly constant access to outdoor adventures.

Though widely dispersed, the counties were all located in a region of high desert and mountainous terrain, with few major highways, 4 definitive seasons, and significant distances between towns or cities. In fact, major cities were no closer than 80 miles away in 1 county and even further in the remaining 2 counties. I selected the 3 counties on the basis of distinctive features of demographics, history, and settlement patterns to note similarities and differences in health care challenges. The immense geographic area and the scarcity of large population centers directly impacted the capacity of older adults to obtain needed services.

Procedures

Specific methods used for this study were establishment of trust with public and private sector agencies, ethnographic fieldwork and interviews (one-to-one and in groups), field notes and a reflective journal, participant observation, photography, and archival review. Approval was granted for this study by the University of New Mexico Health Sciences Center's institutional review board, and all data were collected with signed, informed consent forms from participants.

Establishment of trust with stakeholders

Having previously learned of the region's geographic, demographic, and socioeconomic features,³⁹ I spent 3 to 5 days in each county prior to data collection, connecting with key stakeholders. The stakeholders represented public and private organizations, including managers, providers, and key personnel in hospitals, home health and hospice agencies, senior meal sites, administrative offices, and local groups (community health councils, volunteer centers, and colleges with health care programs). These contacts were gatekeepers for the older adults and directed me to participants for subsequent interviews. I met with the CAB each time I visited the region.

Ethnographic fieldwork and interviews

Ethnographic interviews were the centerpiece of data generation, taking place in homes, agencies, clinics, senior meal sites, and even automobiles. I asked a combination of open-ended, descriptive, structural, and contrast questions.^{40,41} I queried older adults for their definitions of health and perceptions about health care experiences with providers, services, and facilities; specific issues or problems that concerned them about health care for rural older adults; strategies for managing health care dilemmas and challenges; strengths, resources, and barriers existing in the present system; what else was important to them that we had not yet thought to ask; and (supporting CBPR) how they would like to see the information get used in their communities.

English was the language of choice for most informants, although a translator was required for several interviews. Most of the interviews were tape-recorded and later transcribed or were documented in field notes when individuals preferred not to be audiotaped.

Field notes and reflective journal

Field notes captured the daily activities, communications, and encounters in a log, tracking dates, times, types of actions, miles traveled, and specific sites (agencies, homes, communities or towns, centers, libraries, and stores). For interviews where the participant did not want to be audiotaped, the notes contained my summary and synthesis of key points in the discussion.⁴² Simultaneously, I kept a reflective journal that allowed me to explore dilemmas, problems, unanswered questions, emerging ideas, potential topics for future interviews, and deeper levels of insight and awareness about the overall study.⁴³

Participant observation, photography, and archival review

Honoring ethnographic traditions, work as a participant observer allowed me to live briefly in the daily lives of participants.³⁶ I joined them for meals; went with them to appointments; sat with them as case workers, nurses, and others performed assessments and evaluations; and visited them in their homes, neighborhoods, and senior centers.

Adding a visual component through photography forged the conceptual link for "realworld contexts to understand how culture impacts on cognition."⁴⁴ The pictures of older adults and settings depicted a more detailed and personal portrait of the older adults for care providers, planners, and policy makers who influence the resolution of health disparities in rural settings.⁴⁴⁻⁴⁶

I reviewed and documented archival data, such as historical records at local libraries (to note past cultural and settlement/migratory patterns); eligibility brochures and pamphlets at local agencies (noting readability levels, language options, and financial requirements); local newspapers (to see trends in *public voice* when analyzing health care and other services for rural older adults); and Web site information presented by various community groups. These data were part of the contextual scene for the older adults and constituted an important dimension of the total picture.

Data analysis

Procedures used to analyze the data included sequential coding, thematic analysis, matrix analysis, and strategies for methodologic rigor. Although not a linear process, the fundamental actions for analysis of the interview data, field notes, and researcher's journal are summarized as follows⁴⁰: (1) detailed reading and open coding of the transcripts; (2) resorting of the identified segments into distinct conceptual categories for additional analysis of commonly coded portions, or secondary coding, yielding a final set of codes common across all data; and (3) synthesis and integration of the recurrent patterns, emergent across all of the data, into distinct themes, or propositional statements/linkages among codes/patterns.^{40,41}

Congruent with the philosophies of critical ethnography, CBPR, and public health nursing, I applied 5 criteria for study integrity and quality⁴⁷⁻⁵¹: *transparency, partnership, precision, evidence,* and *compassion. Transparency* refers to clarity, auditability, and ease of seeing, following, exploring, and querying research activities for all stakeholders. *Partnership* refers to a condition of consistent collaboration with community advisors in a joint effort and being community engaged in all phases of work. *Precision* refers to practice of exactness, accuracy, correctness, and care in all details of research design and process, with

attention to all phases of action and interaction. *Evidence* means anything that presents as useful data (empirical, aesthetic, political, etc), such as documents, measurements, artifacts, art works, objects, clues, substantiation, and signs/indicators. *Compassion* refers to consistent benevolence, empathy, humanness/humanity, civility, patience, kindness, and acts of conscience for all concerned.

The criteria were achieved by (1) efforts to check the findings against contradictory evidence and explore for variations throughout all phases of the inquiry^{28,41}; and (2) the overarching idea that research should reflect empathic, compassionate relationships with respondents; community-centered dialogue; professional, personal, and political commitment in support of change and equity; and an orientation to human caring ethics.^{48,50,52}

RESULTS

Key themes and definitive issues for action identified by the older adults included (1) the need to consistently manage prescription costs; (2) gaps in transportation between isolated communities and health care resources; (3) inadequate access to primary and specialty care; (4) poor social infrastructure and coordination of services; (5) scarce assisted living and in-home care for frail older adults; and (6) barriers related to culture, language, and economics. Literature addressing problems for older adults in all settings, both above and below the poverty level, suggests that the issues identified here are not unique to the rural southwest. However, the severity of health disparities, access, transportation, and other barriers is greater in geographically isolated, economically poor settings, such as the rural counties in this study.^{1-5,19,20-23}

Community assets were also identified, including (1) local health councils, (2) volunteer groups, and (3) a regional medical center in 1 county. Again, themes generally resembled findings from other rural health studies,^{2,20-23,33,53} yet manifested in unique ways because of the geographic location, a particular blend of cultures, and the economics of the southwestern US-border region. The themes also supported evidence presented in Healthy People 2020, Institute of Medicine (IOM) reports on rural health, and the National Rural Health Association, regarding the most challenging problems for community-dwelling rural older adults.^{1,3,20,24,26}

Affording and maintaining prescriptions

Given that the median age of community residents in the region continues to rise, that income levels for all residents tend to be lower than the national average, and that older people generally have multiple chronic conditions, managing prescription expenses was a major concern. People told stories of having to choose among groceries, rent, or a prescription. In addition, many of the older people, especially those 80 years and older, did not drive because of lost vision, mobility, ability to afford a car, and/or the service of nearby relatives to drive them. Participants told me that they routinely skipped medications, cut them in half, or went without, using instead a variety of home remedies (eg, drinking more water, taking herbs, eating certain foods, or practicing a ritual of prayer) to manage their symptoms and diseases.

Respondent voices echoed this theme in their own words. According to a senior volunteer who helped bring a grant-funded medication assistance program to homebound older adults, "We're not hitting all the people who need this help [for obtaining their medications]. Some don't return, can't do the paperwork, or don't reapply after the 3 months. So some aren't getting what they should to be healthy." A retired elementary school teacher told me, "My friends all go to Mexico for it [medicines]." A homebound, wheelchairbound older woman who depended on others for her groceries, medications, and other services said, "I know what they mean when they say, well, this month I'll buy the medicine, I guess I won't next month If I have enough for my medicine, I get lower foods or no food." A man who cared for his seriously ill

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wife alone added, "Well, we have our troubles, and uh, the distance to go for it [their prescriptions] is too much, so we just don't do it." And, finally, from an older adult who also participated as a member of the local health council: "The whole thing for drugs is hard. They didn't have co-pays before, and now they're paying 10 bucks. That's a lot harder and it's a lot to pay when you're on a fixed income."

Transportation gaps

In a region dominated by great distances between towns, providers' offices, and other sources of health and social services, families have been separated by economic hard times and the need to find work at a distance from home. An informant who directed a large public agency commented,

For some older people ... they're either too old to drive or not safe to drive, even if they have a driver's license. I don't know if I want them out on the streets and roads. If they have a license and they're safe, they usually don't have a car.

A locally funded senior transport van briefly served several of the larger rural towns. However, eligibility requirements excluded people living a long distance from the towns. In addition, physical capacity to be ambulatory and go to pick-up points, available time for drivers to assist people who required more help, and costs passed on to van users limited access to transportation. A lay health worker observed:

People have told me they often miss their appointments because they [van drivers] are never there on time, or they don't give 'em enough time to make it to the appointment on time to see the doctor. And then they have to pay 5 bucks or 7 bucks to use the van. They don't have it.

Care access

Care access problems for older adults usually involved too few primary care providers and specialty providers; providers who could not speak the language the older adults spoke; and/or providers who left before establishing meaningful relationships with them. According to a retired participant who also worked as a senior volunteer, "I do think people fall through the cracks to the tracks. A large number don't have medical coverage or even get medical attention or dental care, eye care, or prescriptions at all."

There were exceptions to the overall findings because some retirees entering the region lived in the more populous communities, closer to providers and necessary services. For the most part, this retiree group held higher educational attainment than locals who had worked in mining and agriculture, were more likely to have supplemental health and prescription insurance, and were more likely to gather in large social groups at senior centers, community-based activities, and planned recreational activities. However, a care provider for a home health agency commented,

We see too many of these older couples move out here from wherever. They do okay for a few years. Then one of them either dies or gets real sick, and their families are far away. It leaves the other one alone. They don't know the doctors here, or they don't like the ones who talk with an accent. And they don't know what to do, where to go. But they can't seem to get into the idea of finding a primary provider and getting referrals, especially into hospice. Sometimes they are too afraid. They don't trust people, they don't have extra insurance, and sometimes they even die alone at home.

Thus, an unanticipated finding was the growing need for palliative care and assisted living options so that people could remain at home for life.

Patchwork service network

During the study, it became obvious that work was needed to accurately document exactly which agencies offered what services; what the various eligibility requirements were; what funding sources supported the programs; what kind of strategic planning, if any, had occurred to keep programs sustainable into the future; what plans existed for linking to other services and programs in the region; how specific information about health and social services would be disseminated, communicated, assessed for adequacy, evaluated for effectiveness, and revised in response to analysis and critique; and how the necessary personnel levels could be maintained or expanded. Consultations with the CAB supported these impressions. As one older adult council member commented, "Sometimes our right hand doesn't know what the left one is up to."

At times, the stories were quite sad, like the one told by a long-time home care nurse:

We had a patient, she lived alone in the mountains east of town. She'd been sent home from the hospital and we could not get to her for a week, with holidays and the weather. When I finally could go, we found her dead in a tub of water. She tried to give herself a bath, nobody was there to help her, and she died. We don't know if she had a heart attack or what.

In another case, a public agency charged with coordinating a network of federally funded senior services had just 1 lay caseworker for an enormous service area. Bicultural and bilingual, she was responsible for performing all intake and follow-up assessments on homebound seniors receiving services through that office. She commented, "I see a lot of old people who could use wheelchairs, ramps, and bars in their homes. But there's no way to get them there. And some live pretty far away from town, you know."

Scarce assisted living options

Throughout the study and since its completion, the need for assisted living options has grown as a theme for residents and research partners. With a swelling older population, the need for affordable housing expands. In part because of the depressed local economies, scarce opportunities exist for either institutional assisted living or agingin-place and at-home care alternatives. An older adult who lived alone said, "There's this homeless grandmother and grandfather around. They get sick and don't have a place to go." Interviews with care managers, care providers, agency administrators, senior volunteers, community health councils, and other informants from the various senior centers revealed the greatest gap in senior care to be for those who need help with activities of daily living, meal preparation, symptom management, and medication regimens. A manager of a local senior center noted, "There's this huge need for something in between, you know, retirement housing or assisted living, or even hospice. Places people can go that are not nursing homes. And most long-term places are full and not open to admissions."

Nationally, Hawes and colleagues²⁴ proposed that assisted living as it is currently implemented in the Unites States is likely not to serve the needs of frail rural older adults. Byok and colleagues⁵³ found that in New Hampshire, citizen forums on the need for palliative care argued in favor of more services in rural areas and requested that more research funding be set aside for this topic. A longtime home care nurse in my study remarked, "We see people who shouldn't even be in the home, don't have any family here, but we can't get them placed in a long-term care facility, and the hospital won't take 'em 'cause they're not really acute." Since the National Institute of Nursing Research invites proposals on palliative and end-of-life care, this finding represents a potentially valuable opportunity for rural health researchers to influence community-based care for rural older adults.

Barriers of culture, language, and economics

For older residents of these rural communities, often lacking adequate health insurance coverage, prescription benefits, educational attainment, health literacy in any language, capacity to adjust to the fast pace of busy health care centers and clinics, patience with impatient others (office staff, assistants, and health care providers), and persistence to keep pushing for what is needed, their situation has become dangerous, disconnected from care and advocacy, and so unpleasant that avoidance becomes the strategy of choice. In fact, when I asked what people considered the key definition of health and staying healthy, they overwhelmingly responded, "Avoiding contact with the health care system!"

Barriers to care exist around cultural misunderstandings, language deficiencies of both patients and providers, and the economics of purchasing health care, prescriptions, and other related services. The values of each distinct group are based on their birthplaces, the socioeconomic status of their own and similar families, experiences of their parents and ancestors, immigration patterns in respective generations, and the roles they have held in local society and community life. At one senior center, I noted strong differences between some of the native-born Hispanic older adults and the ones who migrated from Mexico in the last 20 years. A Hispanic woman born in the region more than 80 years ago said, "Those people from Mexico are not like us. And they don't think like us, we don't like them very much, but they're here."

Letting go of earlier norms when providers knew all the families and treated them as additional family members is difficult for people in their twilight years, especially when they perceive that no one cares who they are, what they think, or how they truly feel. In the words of one informant, "It's just hurry up, tell me what's wrong, and pay before you go." At a meal site in a former mining town, a group of miners' widows sat together for their daily lunches and traded stories about how each one was getting along. One of them said, "We pretty much do for ourselves, and we don't need much help. Anyhow, they [health care providers in their region] don't know us anymore."

In addition, English has always been a second language for some residents, and if they attained less than a high school level of education, they suffer frustration at the inability to either understand or discuss a complex health problem—a striking example of health literacy deficits. Many of the providers speak only English or have come from another country, speaking neither English nor Spanish clearly enough for the older adults to understand. Thus, it was not unusual to hear people say that the providers "never understand me, and I don't understand what they are saying." These findings resemble results obtained by Torres,²⁵ Borders,²⁶ and Guo and Phillips²² involving other Hispanic populations.

Economically, many older adults have spent their lifetimes being frugal because they never earned enough money to generate savings and were raised to value saving whatever income they earned. They have little to spend and are reluctant to spend for things they consider minimally helpful. Complicating matters is the lack of case managers or navigators for both public and private organizations, limiting use of agencies and fragmented services. One informant said,

If you look at access, as they get older, the access to care is going down. And especially among Hispanics, who are about 50% of our population. We're not sure why. Maybe some have no extra money or don't like the way appointments work these days, or just feel uncomfortable getting out of their homes.

The manager of a publicly funded health service stated, "Sometimes, older people put off health care—it's a change in personal and family culture to use preventive services."

Assets and strengths

Although the challenges to even basic care for the older adults are considerable, rural communities displayed impressive strengths and assets alongside the problems. A closer look at the assets is warranted because before designing solutions, an inventory of what is and is not working well should take place. The strengths will play a key role in interventions aimed at reducing or eliminating inequities. The assets could be summarized as (1) individual peers, family members, and caregivers/providers; (2) community-wide advocacy groups and centers; and (3) an array of rural values that inform the older adults behavior, outlook, and belief systems.

For older adults living alone, select individuals comprised the lifeline and human connection in daily survival. Examples of these individual contacts included peers who lived close enough to visit by walking or watching out their windows, family members who lived with an older adult or nearby, neighbors who had known the older person for a long time, a visiting nurse, a case worker, a social worker, a priest, or a local police officer on patrol. If available, such visitors were often the only source of contact with the outside world, asking such simple questions as "How are you doing?" or "Have you eaten today?" A visitor might notice a new health problem, a lack of available food or heat, a need for home repair, or simply a need for human contact.

Importantly, the presence of a small dog or cat was often the most treasured asset in the daily life of an older person. On more than one occasion, I heard someone say of his or her pet, "If it weren't for him [her], I'd have nobody to talk to or love." The pets were family members to them. Without question, this network of both formal and informal individuals was a pivotal asset to a number of rural older adults living alone in the more remote communities.

For each of the 3 counties, at least 1 community-wide advocacy group, senior center, senior meal site, or other organization constituted a helpful asset in terms of health promotion, common voice, or quality of life. One county in the study had an active community health council, made up of local residents across the lifespan, representing the interests of all age groups, schools, businesses, health care providers, a local university, a network of senior centers, senior meal sites, a volunteer group, and some faith-based initiatives for assisted living.

Finally, assets and strengths of older residents, regardless of their heritage, culture, or history, nearly always included a set of rural values that infused all areas of their daily life, including the challenges of aging in remote communities. I summarized the core values as resiliency, diligence, autonomy, and spirituality, echoing similar values identified in other rural studies, yet manifest in a way particular to the desert southwest, near an international border.²⁷ The older adults were resilient because in discussing their health, their definitions of health, their view of our health care system, and how they kept themselves active daily, they emphasized that they simply did what they needed to do-get up, get work done, take care of themselves and others, clean up their dwelling, fix meals, stay busy, communicate with people, and remain engaged in the flow of daily life. They spoke of cardiac, endocrine, pulmonary, orthopedic, psychological, economic, family, workrelated, transportation-related, and other challenges, but always brought the conversation to the present moment and the fact that they had made it this far, could still handle some things on their own, and planned to do so as long as possible.

Diligence and autonomy were the twin pillars of their approach to daily demands of personal care, chores, attention to family members, pets, and local activities. In the words of a woman who taught school for many years, "We worked every day, and we didn't take money unless we got it done." Laziness, inactivity, or refusal to try and do something useful with their waking hours never seemed an option. They made it clear that no one else was responsible for their happiness.

When I asked what was most important to them in their lives and in their aging, they usually responded that some kind of *spiritual* or *religious orientation* was central to health. The majority spoke of a particular church or a daily ritual of prayer, "quiet time to think," or of simply being outdoors to enjoy nature. The key seemed to be a connection to something larger than themselves and beyond the routines of daily living.

Coaxing from this group of resilient, independent older adults a definition of health proved difficult, because for them, health and how one stays healthy are synonymous. Rather than try and redirect them in terms of language, I allowed them to tell me what mattered most about health and/or staying healthy. Accustomed to a lifetime of daily responsibilities, most participants defined *health* as avoiding the health care system, along with the ability to get out of bed each morning and remain active. One gentleman said, "I hope it don't get to where I have to live with somebody. I don't like to be a burden or have somebody tell me what to do." A retired nurse added, "Health is keeping a good weight, staying active with walking and whatever. And a proper diet. And a spiritual life with daily prayer and meditation."

LIMITATIONS OF STUDY

While providing rich documentation of participants' perceptions and ideas, the study had several limitations. As a lone outsider conducting the investigation in a vast rural locale, the researcher likely missed finding additional data sources and informants who might have added breadth and depth to the insight achieved. The trend toward team science will insure that all future investigations will consist of multiple investigators. Also, any outsider will hear and observe only part of the whole picture surrounding the lives and health care dilemmas of community-dwelling older adults. Future studies should include a local community member as part of the research team, to increase the likelihood of more complete understanding and data capture.

In addition, the critical ethnographic/CBPR strategy yielded narratives, experiences, and observations that could only happen in sustained fieldwork, with few restrictions on time, distance, or setting to generate the qualitative data. Yet, missing from this study were concurrent opportunities to garner epidemiological or statistical parameters of older adults health that might have strengthened the conclusions and findings. Those data will be planned into future studies in the region.

CONCLUSIONS AND IMPLICATIONS

Practice and research implications are necessarily at the level of the rural community (as opposed to individuals), involving local residents/CAB, agency representatives, and researchers as partners. The implications are that (1) community partners must be multidisciplinary and multicultural, combining lay, professional, and retired participants; and (2) evaluation criteria will blend researcher participant strategies and mixed research methods in a negotiated effort. Given that this study was exploratory, using critical ethnographic and CBPR methods, it is not feasible to predict with certainty or clarity exactly what interventions or evaluation strategies will be employed in future studies. CBPR requires that when a new phase of work begins, the research team will need to meet with community stakeholders to revisit priorities for action, brainstorm best methods for implementing interventions (blending mixed-methods science with community preferences), analyze limitations and local/cultural considerations, engage in self-reflection on the completed and suggested research/practice, and design a partnership model for all research activities. 30-34, 36, 37, 47, 49, 50, 52, 54

All research aimed at developing specific interventions and actions will necessarily involve the input and partnership among community advisors, advocacy groups, multiple disciplines and professions (from the sectors of health care, business, education, technology, and government), and researchers, a conclusion supported by the IOM.³ Not only is this kind of multivoiced team-building essential from the perspective of rural communities but also it is increasingly a requirement of national funding agencies. On the basis of findings, emphasis will likely be on care management for older adults across settings, including palliative care in the community and home.

Within the context of community preferences and priorities, interventions should include the guidelines for rural health care suggested by the IOM³ and Healthy People 2020¹: greater emphasis on population health; core services in primary care, mental health care, dental care, long-term care, caregiver support services, preventive services, and emergency services; local and regional service links; community voice and engagement in determining services; multidisciplinary and collaborative teams of providers, managers, community members, and leaders; financing options that fit rural communities; and health information technology infrastructure.³

Evaluation regarding the merit of any future research will blend both research team perspectives and the viewpoints of community members. As Lincoln⁵⁰ observed,

I label it [research] communitarian because it recognizes that research takes place in, and is addressed to, a community; it is also accurately labeled because of the desire of those who discuss such research to have it serve the purposes of the community in which it was carried out, rather than simply serving the community of knowledge producers and policymakers.^(p334)

As a result, the communities where the work will take place have the authority and support to develop their own criteria for success in upcoming studies.

Finally and importantly, it is important to reprise and examine the importance of complexity science, social capital, and social networks as overarching conceptual touchstones in the current program of rural studies. Moving from the general to the more specific observation, I suggest the above ordering of ideas is most plausible as explanatory pattern. The work of Santa Fe Institute scientists such as Waldrop,⁶ Kauffman,⁷ and others^{55,56} posited that humans in all settings tend to organize, collaborate, and pool their resources for solving problems, communicating important information, and meeting challenges. Furthermore, they proposed that the tendency to organize and collaborate for the common good was inherent to individual cells, organisms, people, communities, and systems. Their musings came about after intensive observation, tracing of historical events, interviews/conversations, assessments/tests/modeling of various kinds, and verification over time and multiple data sources. The implications of their arguments center on the interplay of predictability and uncertainty or chaos. Is it possible that the impetus to connect with others is a matter of both physiology and mind, of instinct,

motivation, and even survival? Binder and colleagues⁵⁷ would argue affirmatively on this point. For investigators studying human communities, implications are that taking time to observe, verify, and document patterns of human actions, interactions, and networks could strengthen the impact of specific/targeted interventions in social health services, business and fiscal negotiations, policy, and politics. This thinking frame resonates with critical ethnography and CBPR, especially as I prepare for next phases of work in partnership with the rural communities.¹⁶

From complexity theory, it is easy to move into an analysis of social capital, an idea central to complex human communities, but with abundant/variable definitions in the literature.⁵⁸ Polkinghorne⁵⁹ and Bourdieu/Wacquant⁶⁰ suggested that human capital encompassed at least 4 domains of assets: economic (money, property), cultural (goods, services, education), social (networks, acquaintances, power dynamics), and symbolic (legitimization). I consider all of these dimensions relevant to understanding the rural communities, and study findings provide nascent descriptions of them. Future work should build on these preliminary insights, adding pertinent empirical measurements to better assess our capacity for effective interaction and intervention to help resolve or manage problems for rural older adults.

Abbott cautioned that too often in studies blending surveys with health indicators, investigators try to link social capital with human health in communities.⁵⁸ However, often missing in this effort are reliable, valid measures linking the concepts evidentially. He calls for empirical evidence (as opposed to proxy data) to establish conceptual and experiential/actual clarity about social capital. If one accepts this notion, then qualitative studies with analyses of the social networks, communication strategies, and effectiveness of partnerships are helpful in establishing operational definitions and accurate metrics for social capital.^{12,16} In the current study, I informally assessed the effectiveness, depth,

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and consistency of partnerships among the community stakeholder groups (eg, senior centers, private hospitals, community health councils, and volunteer groups) and between myself and the various groups to be moderately successful-good in the number of contacts between the individual/group stakeholders and me, the quality of our discussions and problem solving, and in the mutuality of purpose; not as good in consistency over time, capacity to somehow capture, analyze, and leverage the things we collectively learned for future benefit. Although that is imprecise in quantification, it is useful in establishing basic understanding, insight, and knowledge about how human networks operate in the region. It means that in next phases of work, the research team will have a reasonable idea about whom to contact, how to communicate with the various groups, and the best strategies for engagement. I have a decade of work in the region,^{17,18} and a few of the current community partners have been part of that sustained effort, even as new ones arrived and some departed or died during the interval. Thus, knowing where to start in new stages of work is not a mystery, with specific personal contacts maintained (by telephone, e-mail, and occasional site visits) during and between actual research activities. The aims of this study did not specifically include an analysis of social networks. However, in the spirit of Abbott's⁵⁸ suggestions, next studies should include ethnographic data on the relationships between social networks and social support (SNSS); social support and reciprocity; SNSS and social capital; and the impact of SNSS on the effects of social capital on health.

Out of complexity science and social/other capital in human communities comes the

more specific idea of social networks, those webs by which people directly identify, recognize, communicate, and influence daily life, manage stressors for the collective interest, and engage with external entities.^{9,11,14} I propose the ideas presented in the Table as key to describing and utilizing social networks. From the macro level of our existence to the micro level of everyday actions and interactions, the social ties people establish, nurture, sever, or otherwise influence are critical to our well-being and ability to survive. Human resilience, hardiness, adaptability, relational capacity, patterns of interaction, and social participation in meaningful activities depend on our social networks-with each other individually, significant others (people and pets), providers of health/social services, community members who help shape political/economic/educational agendas, and even investigators-informal and formal networks make a crucial difference.^{8,11-16} Successful social ties appear to strengthen the health, vitality, and quality of life for rural older adults and for others. In this study, the quotations from participants spoke to the role of social networks in keeping people less isolated, more connected to others in their surroundings, and to a greater purpose in their lives. At least one of the stories told of what happens in the absence of such linkages, when someone died alone at home. In a national and local context of scarce economic resources, the social capacity of the communities, especially involving lonely older adults who may not be as mobile as they once were, is critical to their level of health and belonging. Deliberate inclusion of a focus on the nature, quality, and effectiveness of social networks in these rural communities will therefore be intrinsic to future phases of inquiry.

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