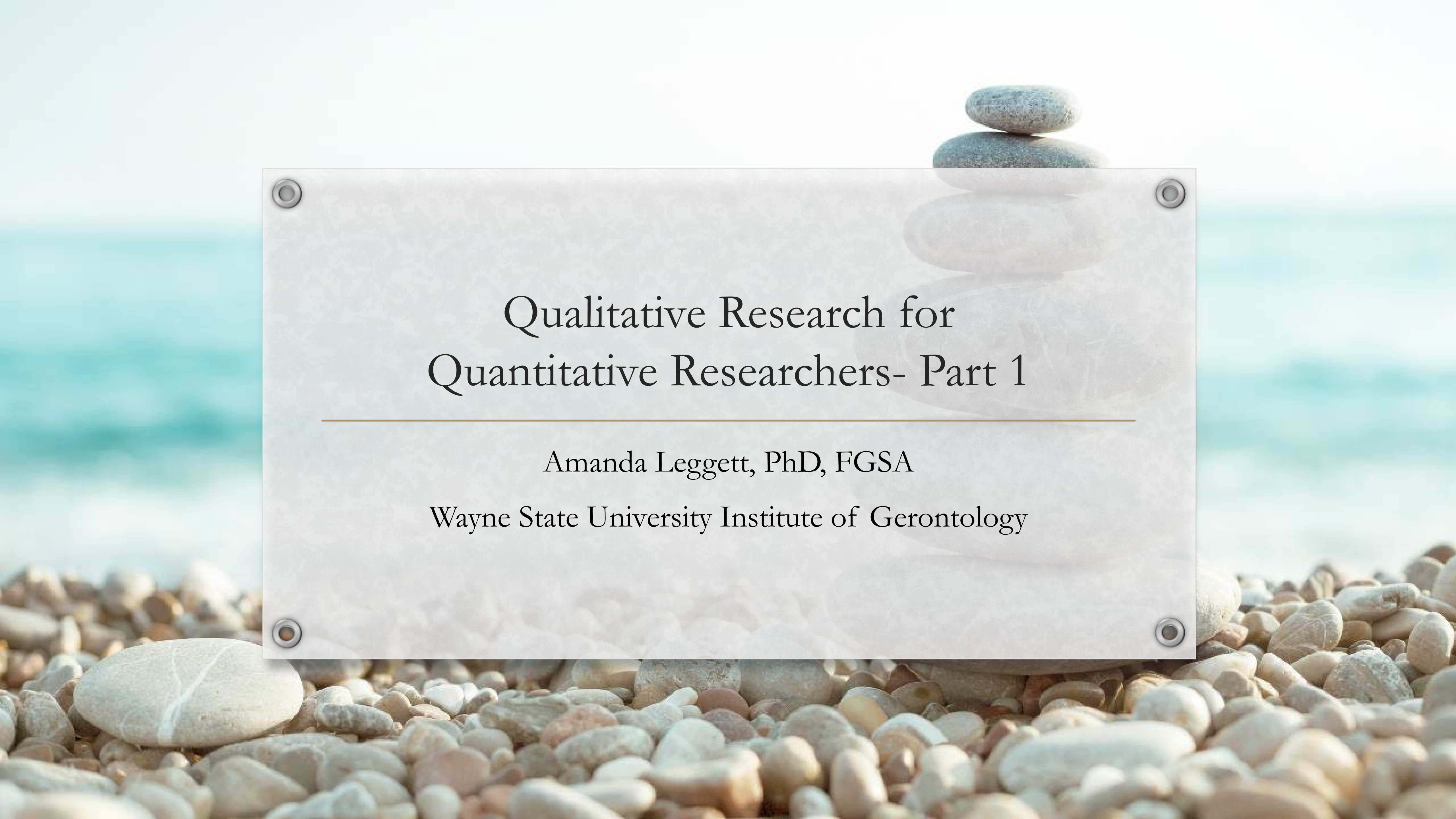


Qualitative Research for Quantitative Researchers- Part 1

Amanda Leggett, PhD, FGSA

Wayne State University Institute of Gerontology

What’s your question?

Deductive vs. Inductive Reasoning

- Theory
- Hypothesis
- Observation
- Confirmation

- Observation
- Pattern
- Hypothesis
- Theory

Research Questions

- Quantitative
  - Questions are closed ended
    - Questions relate to specific variables
    - Hypotheses predict specific relationships between variables
  - Predict causal relationships
  - Describe characteristics of a population
- Qualitative
  - Questions are more open ended
    - What? How?
  - Describe or explain relationships
  - Describe individual's experiences

(Mack, Woodsong, MacQueen, et al., 2011)

When Qualitative Data is Most Helpful

- Understand something better on which little is known; exploration to understand what to study
  - E.g., What variables might we want to later test?
- Gain new perspectives, understand a complex situation that is rapidly changing
- Understand participants perspectives, reactions, and interpretations
- Garner in-depth detail that may be harder to convey quantitatively
- When we are looking for data rich with insight and detail
- Develop a new theory based on lived experience
- (Morse & Richards, 2002; Strauss and Corbin, 1990)

👍 Pros and Cons 👎

- Garner rich data and descriptions to facilitate understanding of phenomena
- Adaptable and flexible, questions can be altered through the research process
- Samples are smaller- saturation is the goal rather than generalizability

- Less generalizable and more specific to sample
- Subjectivity- researchers are interpreting data and may be influenced by biases
    - Qualitative methods aim to minimize this

Methodological Designs and Orientations

In-Depth Interviews and Focus Groups

- **In-Depth Interviews:**
  - Open/unstructured, semi-structured interviews, or structured/standardized- allowing interviewer to probe or follow-up for more information or sticking to a set guide
    - Open ended questions, probing questions
    - Good for sensitive topics

- **Focus Groups:**
  - Moderator interviews a group of 5-10 people
  - Group interaction can facilitate engagement and clarify both individual and shared perspectives

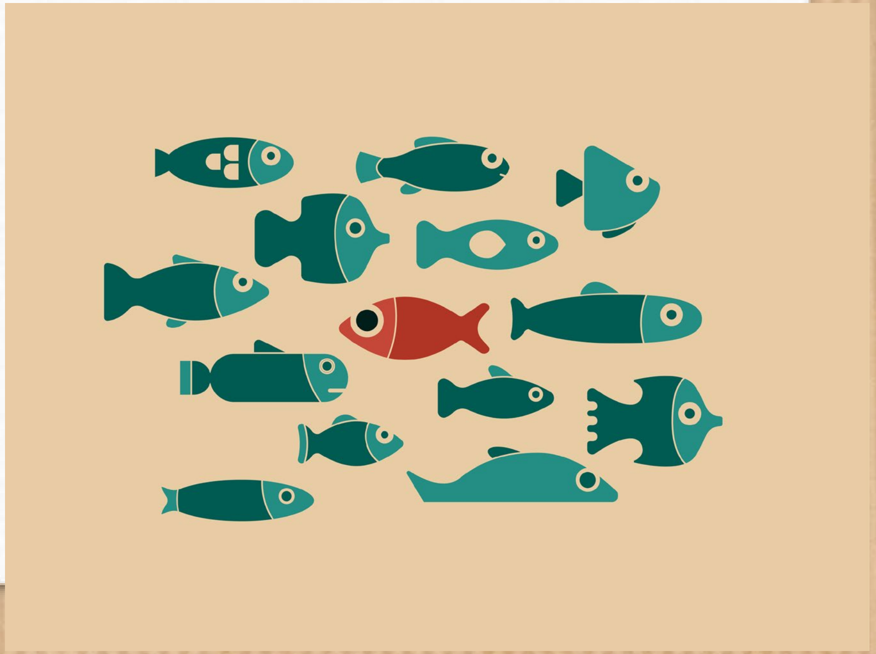
Designing Questions and the Interview

- As with survey design, keep wording simple and easy to understand
- Avoid bias in your responses
- Avoid double barreled and double negative questions
- Reinforce the interviewees responses
- Test your questions
- Consider cultural/power dynamics in the interview context
- Talk less, smile (listen) more
- Be prepared for emotions

(McGrath, Palmgren, & Liljedahl, 2019)

Case Study

- In depth understanding of a phenomena through observation of a single, or a few, cases
  - This could be an individual, an event, an organization
  - Trying to understand this case (not all cases)



Ethnography

- Trying to understand a specific culture or subculture through observation and immersion
- Ethnographer immerses themselves, becomes an active participant
- Takes extensive field notes
- Cornerstone of anthropology

Phenomenology

- Describing the world from the participant's point of view (e.g., individuals subjective or lived experiences; what meaning is ascribed to phenomenon)
  - What is it like to have this experience?
  - What is the essence of this experience?
- Bracketing- the researcher must put oneself aside to experience the phenomenon

(Don't just name drop!)

Grounded Theory (Glaser & Strauss, 1967)

- Inductive theory development derived from observation, grounded in the social environment under study
- Researcher compares his/her memo interpretations against the data; "constant comparative method"
- Concept and themes emerge without use of prior literature
- Code as you go along rather than a predetermined codebook ("open coding")

Analysis Key Terms

- **Coding**: Labeling data to organize and simplify data so themes can be ascertained
- **Codebook**: a dictionary of codes, their definitions, and exemplary quotes; used to standardize meaning in a research team
- **Open coding**: early stage coding where codes are created an applied to the data
  - In vivo coding- using the participant's own words to form the code
- **Focused coding**: later stage coding in the iterative process, applying most frequent/significant codes to the data

"*He went out and sat in the car, in the passenger seat and put on a seatbelt and I went out and asked him why he was there and he couldn't respond and I asked him to come to bed and he didn't respond so he sat there for an hour and a half in the dark with the seatbelt on and I could feel my heart rate getting faster, and I do have atrial fibrillation so I decided I would go to bed... I think my response was more or less to ignore it as much as possible*" (ID 126)

Codes: withdraw, resigned, pull back into lived experience

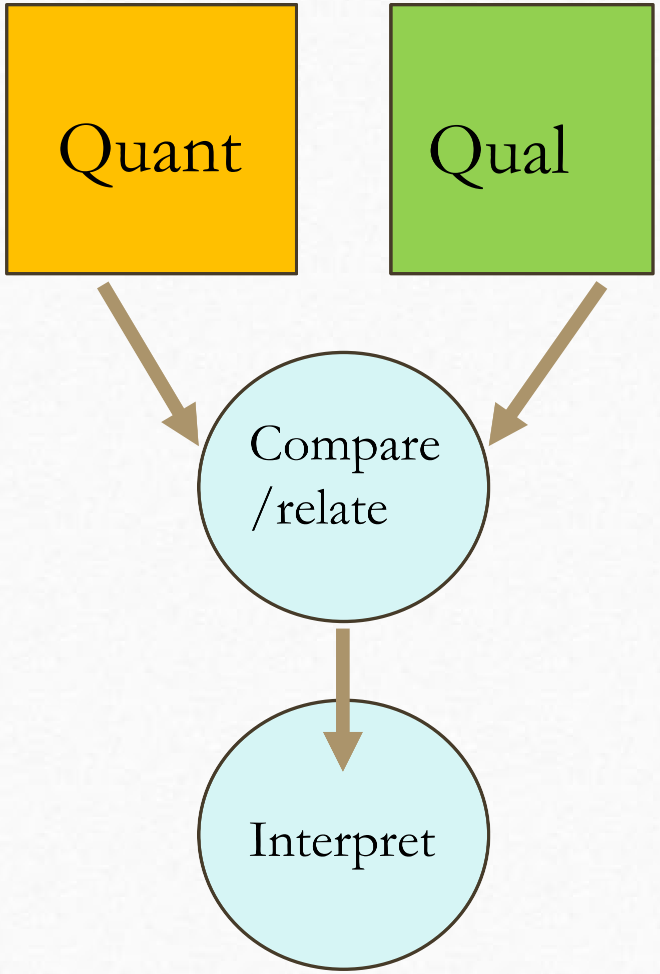
Exploring Mixed Methods

Mixed Methods Designs

- Combines QUAN and QUAL data in the context of a single study
- Simultaneous:
  - QUAL + quan (help to better describe the sample analyzed qualitatively)
  - QUAN + qual (help describe something that couldn’t be quantified)
- Sequential
  - QUAL → quan (help test an emerging hypothesis or quantify frequency in population)
  - QUAN → qual (help decipher unexpected results)

(Morse, 1991)

Convergent parallel



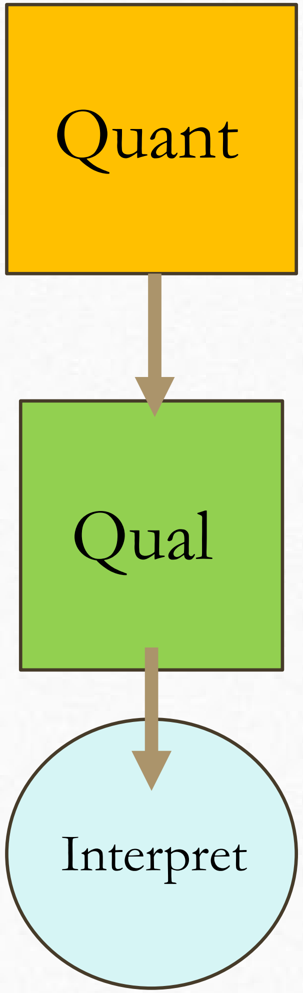
Quant

Qual

Compare /relate

Interpret

Explanatory Sequential

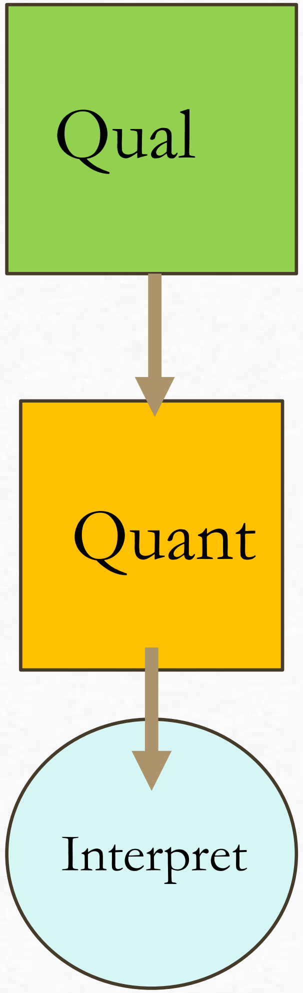


Quant

Qual

Interpret

Exploratory Sequential

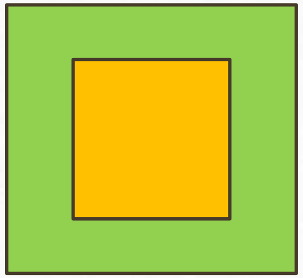


Qual

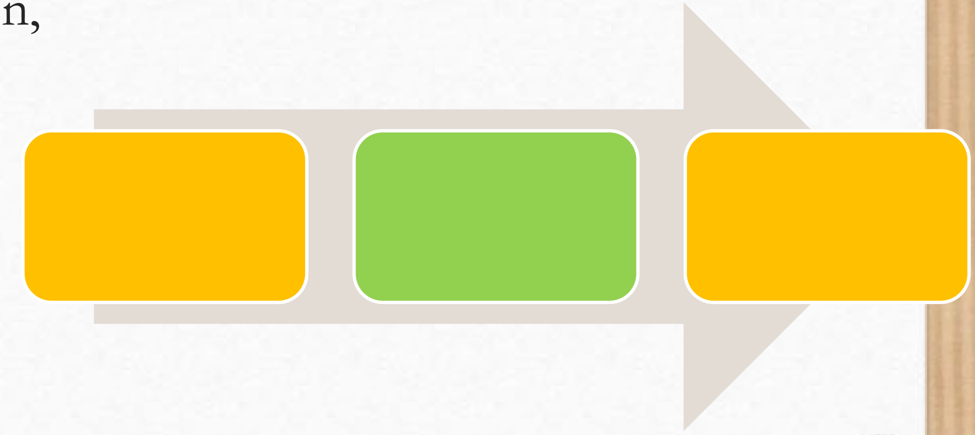
Quant

Interpret

Additional designs



- **Embedded design-** quant or qual is imbedded within the predominantly qual or quant design; primary design is emphasized
    - E.g., examine reactions to participation in an intervention, examine the intervention process
- **Multiphase design-** a series of quant and qual studies that are iterative and can address emerging questions

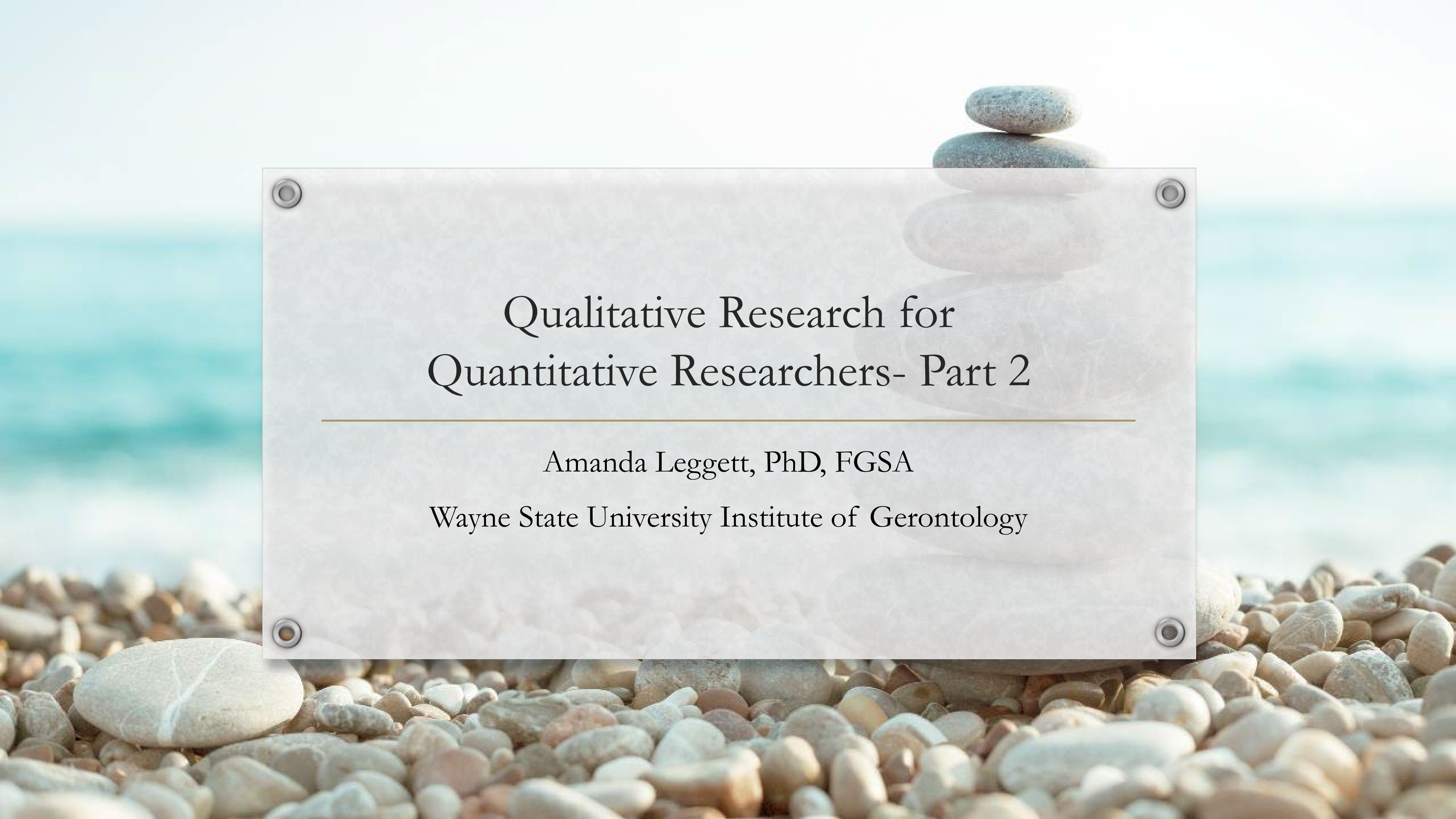


Reporting Qualitative Data

Trustworthiness of data

- Validity → **Credibility**: consistency in explanation, grounded in narrative data, richness of data supports findings
- Reliability → **Dependability**: is the research process carried out according to methodological conventions
- Objectivity→ **Confirmability/reflexivity**: acknowledging one's assumptions, biases, and reactions in how they may have influenced interpretation of data
- Generalizability→ **Transferability**: degree to which results may be applied to other contexts under similar conditions

(Banyard & Miller, 1998; Miles & Huberman, 1994;
Ryan & Bernard, 2000; Ulin et al., 2005; Watkins, 2012)



Qualitative Research for Quantitative Researchers- Part 2

Amanda Leggett, PhD, FGSA

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What we discussed before

- What is a qualitative research question?
- Why collect qualitative data?
- Designs and orientations
- Mixed-methods designs

Watkins’ 2017 RADaR Technique

International Journal of Qualitative Methods
Volume 16, Issue 1, December 2017

https://doi.org/10.1177/1609406917712131

Article

Rapid and Rigorous Qualitative Data Analysis: The “RADaR” Technique for Applied Research

Daphne C. Watkins

1

- All transcripts should be in the same format

2

- Create “all-inclusive” or phase 1 data table from transcripts

3

- Create phase 2 table that only includes text relevant to the specific research question

4

- Research team/coders work from individual tables

5

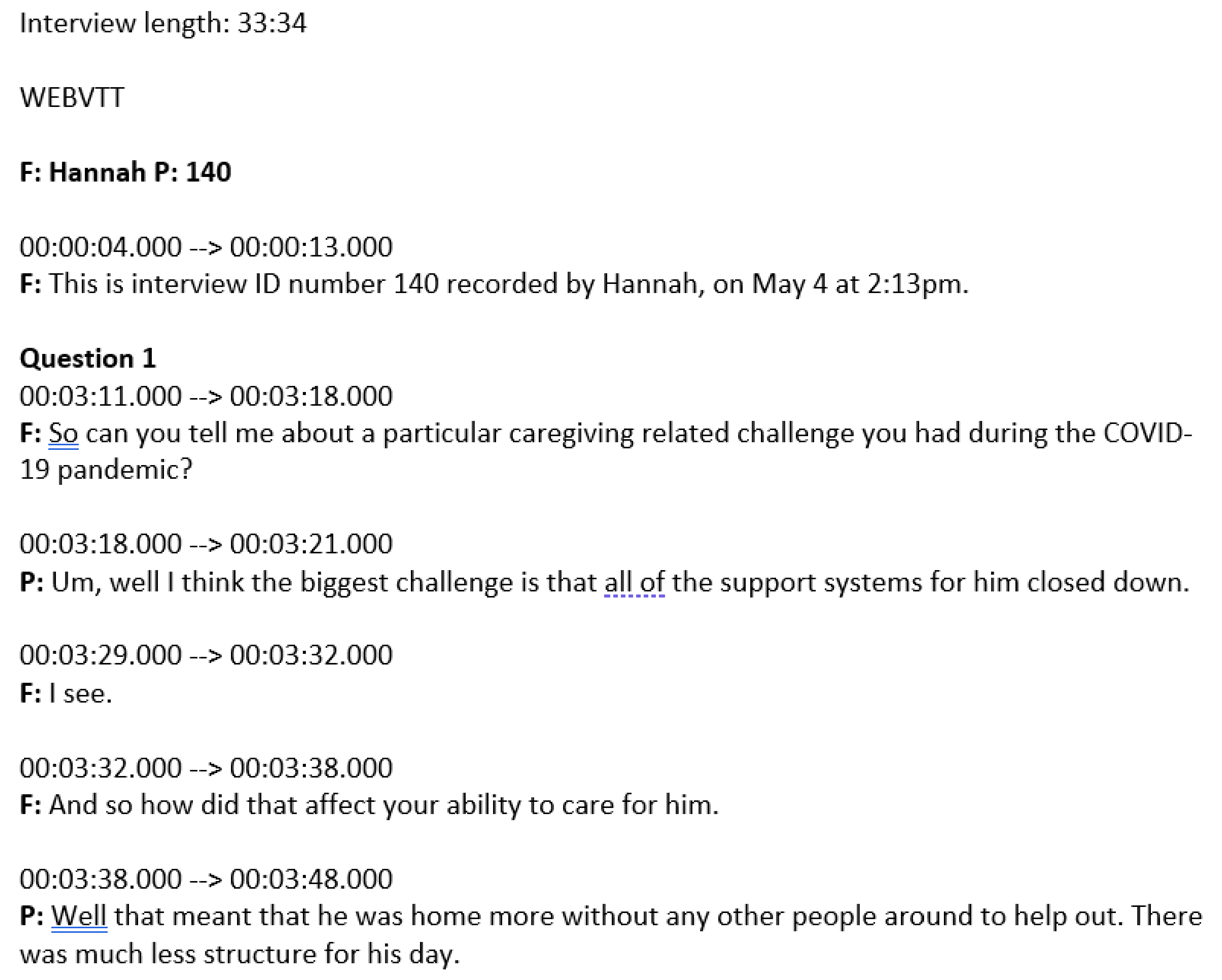
- Draft project deliverables from final table

(Watkins, 2017)

Applying RADaR

- COVID STYLE Study Qualitative Interview:
  - Managing care challenges during COVID
  - Changes to routines and services during COVID
  - Healthcare during COVID
  - Social Support during COVID
  - Barriers and facilitators to care during COVID
- Research Question: **How dementia family/friend caregivers experience of using community-based and health care services for the overall benefit of the care dyad impacted their caregiving practice during COVID-19 (since March 2020)?**

Step 1



Interview length: 33:34

WEBVTT

F: Hannah P: 140

00:00:04.000 --> 00:00:13.000
F: This is interview ID number 140 recorded by Hannah, on May 4 at 2:13pm.

Question 1
00:03:11.000 --> 00:03:18.000
F: So can you tell me about a particular caregiving related challenge you had during the COVID-19 pandemic?

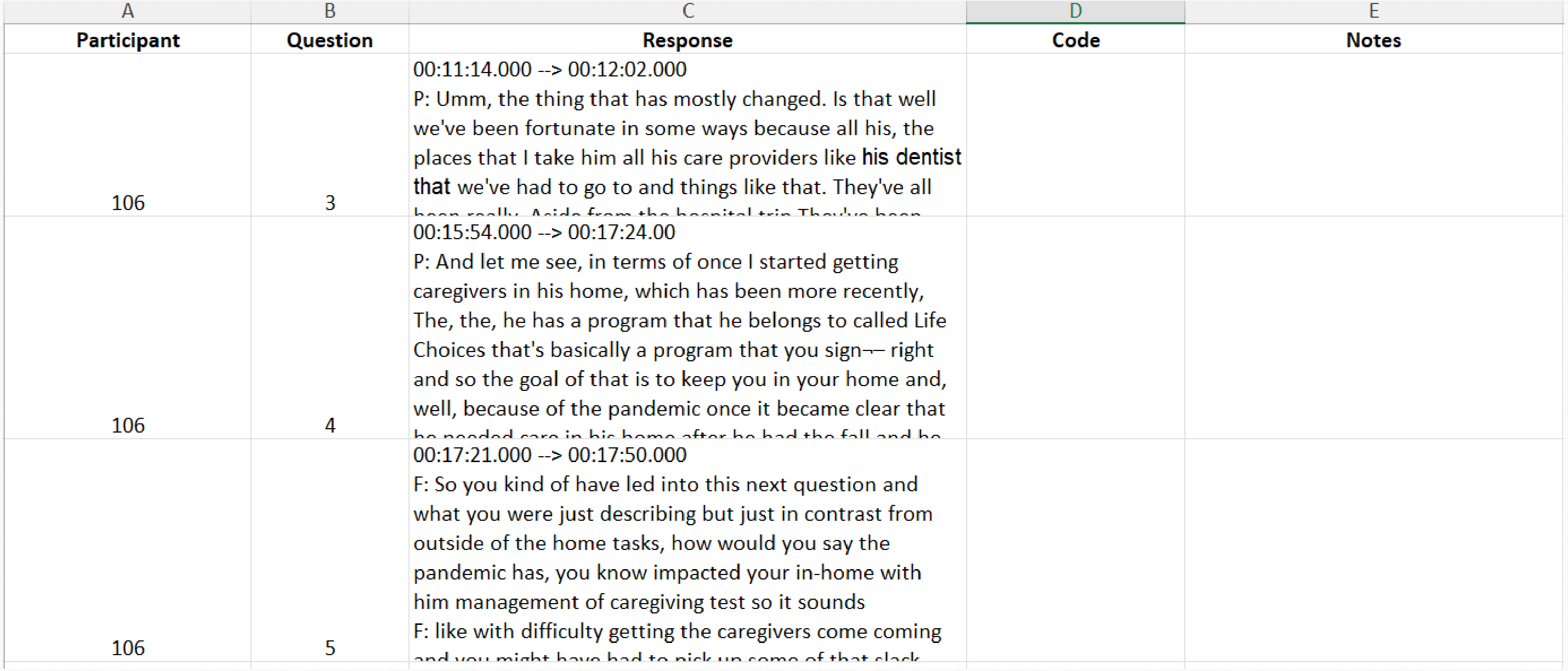
00:03:18.000 --> 00:03:21.000
P: Um, well I think the biggest challenge is that all of the support systems for him closed down.

00:03:29.000 --> 00:03:32.000
F: I see.

00:03:32.000 --> 00:03:38.000
F: And so how did that affect your ability to care for him.

00:03:38.000 --> 00:03:48.000
P: Well that meant that he was home more without any other people around to help out. There was much less structure for his day.

Step 2



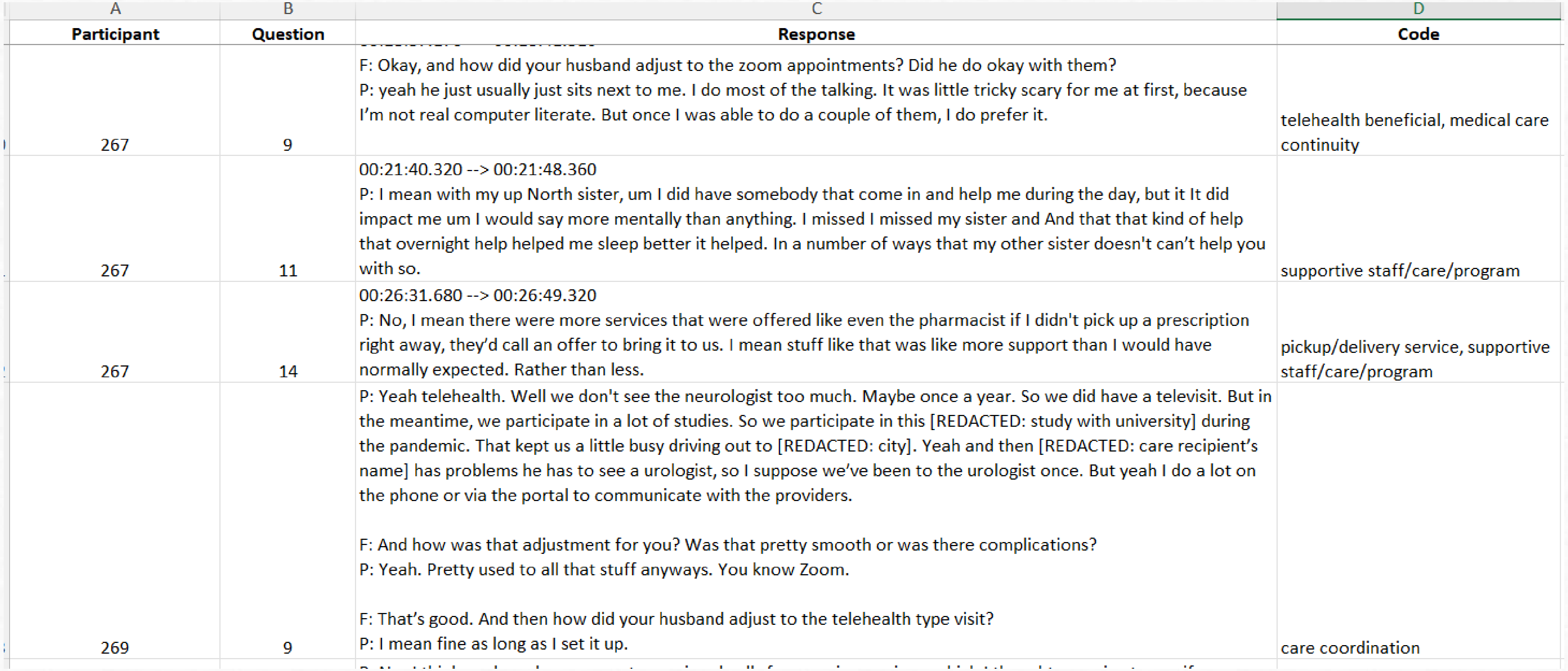
A	B	C	D	E
Participant	**Question**	**Response**	**Code**	**Notes**
106	3	00:11:14.000 --> 00:12:02.000 P: Umm, the thing that has mostly changed. Is that well we've been fortunate in some ways because all his, the places that I take him all his care providers like **his dentist that** we've had to go to and things like that. They've all been really. Aside from the hospital trip They've been		
106	4	00:15:54.000 --> 00:17:24.00 P: And let me see, in terms of once I started getting caregivers in his home, which has been more recently, The, the, he has a program that he belongs to called Life Choices that's basically a program that you sign¬– right and so the goal of that is to keep you in your home and, well, because of the pandemic once it became clear that he needed care in his home after he had the fall and he		
106	5	00:17:21.000 --> 00:17:50.000 F: So you kind of have led into this next question and what you were just describing but just in contrast from outside of the home tasks, how would you say the pandemic has, you know impacted your in-home with him management of caregiving test so it sounds F: like with difficulty getting the caregivers come coming and you might have had to pick up some of that slack		

Step 3

- Highlight relevant text
- Don’t highlight non-relevant text
- → Move relevant text to a new, condensed spreadsheet

Step 4

Individual Coding Spreadsheets



Participant	Question	Response	Code
267	9	F: Okay, and how did your husband adjust to the zoom appointments? Did he do okay with them? P: yeah he just usually just sits next to me. I do most of the talking. It was little tricky scary for me at first, because I'm not real computer literate. But once I was able to do a couple of them, I do prefer it.	telehealth beneficial, medical care continuity
267	11	00:21:40.320 --> 00:21:48.360 P: I mean with my up North sister, um I did have somebody that come in and help me during the day, but it It did impact me um I would say more mentally than anything. I missed I missed my sister and And that that kind of help that overnight help helped me sleep better it helped. In a number of ways that my other sister doesn't can't help you with so.	supportive staff/care/program
267	14	00:26:31.680 --> 00:26:49.320 P: No, I mean there were more services that were offered like even the pharmacist if I didn't pick up a prescription right away, they'd call an offer to bring it to us. I mean stuff like that was like more support than I would have normally expected. Rather than less.	pickup/delivery service, supportive staff/care/program
269	9	P: Yeah telehealth. Well we don't see the neurologist too much. Maybe once a year. So we did have a televisit. But in the meantime, we participate in a lot of studies. So we participate in this [REDACTED: study with university] during the pandemic. That kept us a little busy driving out to [REDACTED: city]. Yeah and then [REDACTED: care recipient's name] has problems he has to see a urologist, so I suppose we've been to the urologist once. But yeah I do a lot on the phone or via the portal to communicate with the providers. F: And how was that adjustment for you? Was that pretty smooth or was there complications? P: Yeah. Pretty used to all that stuff anyways. You know Zoom. F: That's good. And then how did your husband adjust to the telehealth type visit? P: I mean fine as long as I set it up.	care coordination

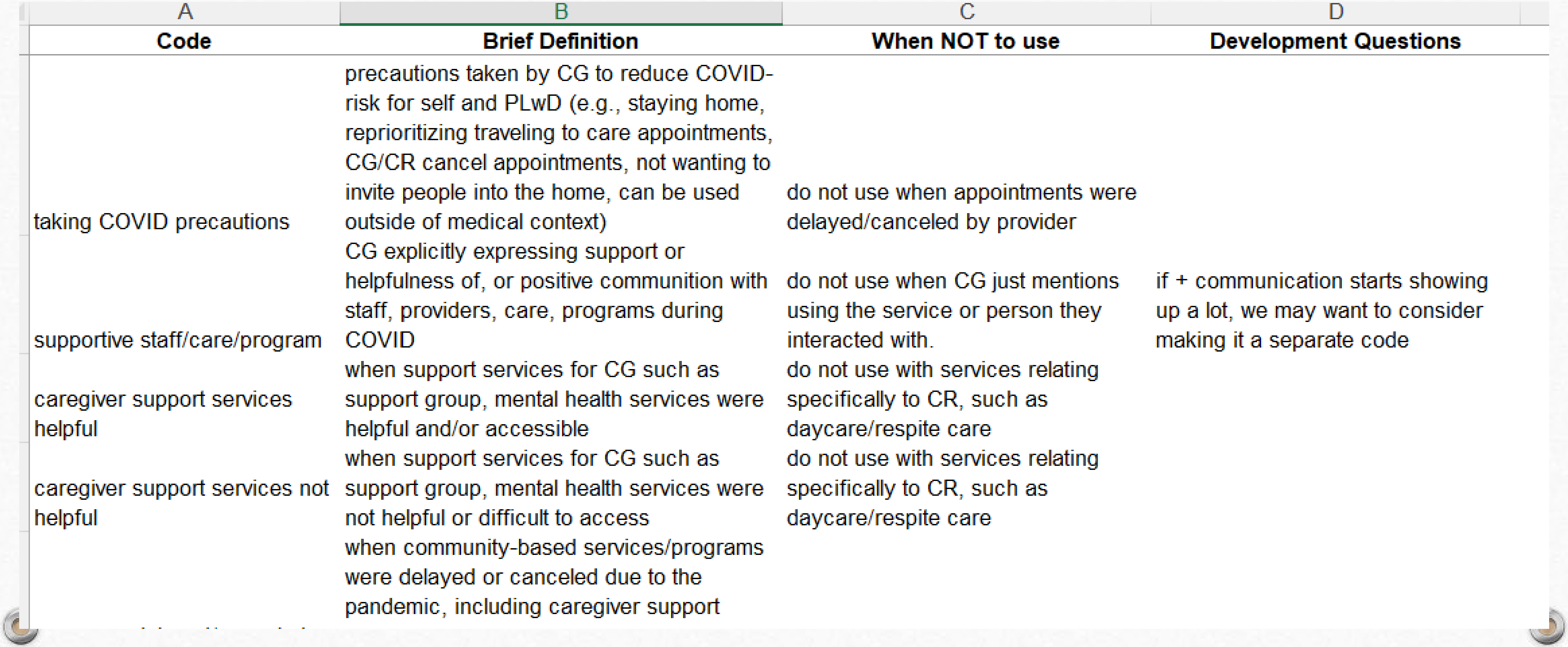
Open Coding

- Breaking text into discrete, meaningful parts to which the researchers apply codes
- “In vivo”
- Broad, exploratory

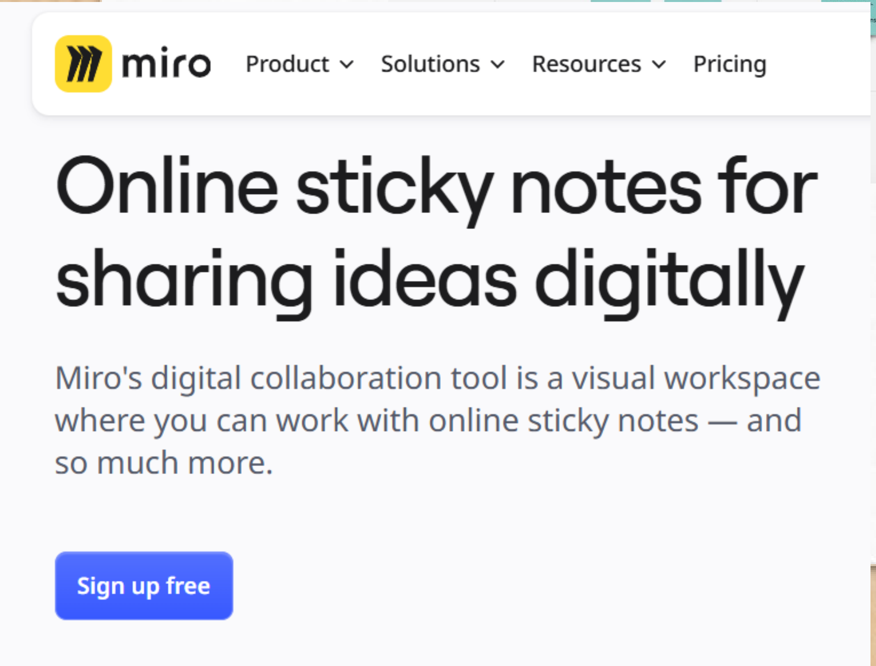
Focused Coding

- Refining and focusing the open codes
- May merge codes together or eliminate codes
- Selective, focused
- Begins to help you organize into themes, broader categories

Codebook

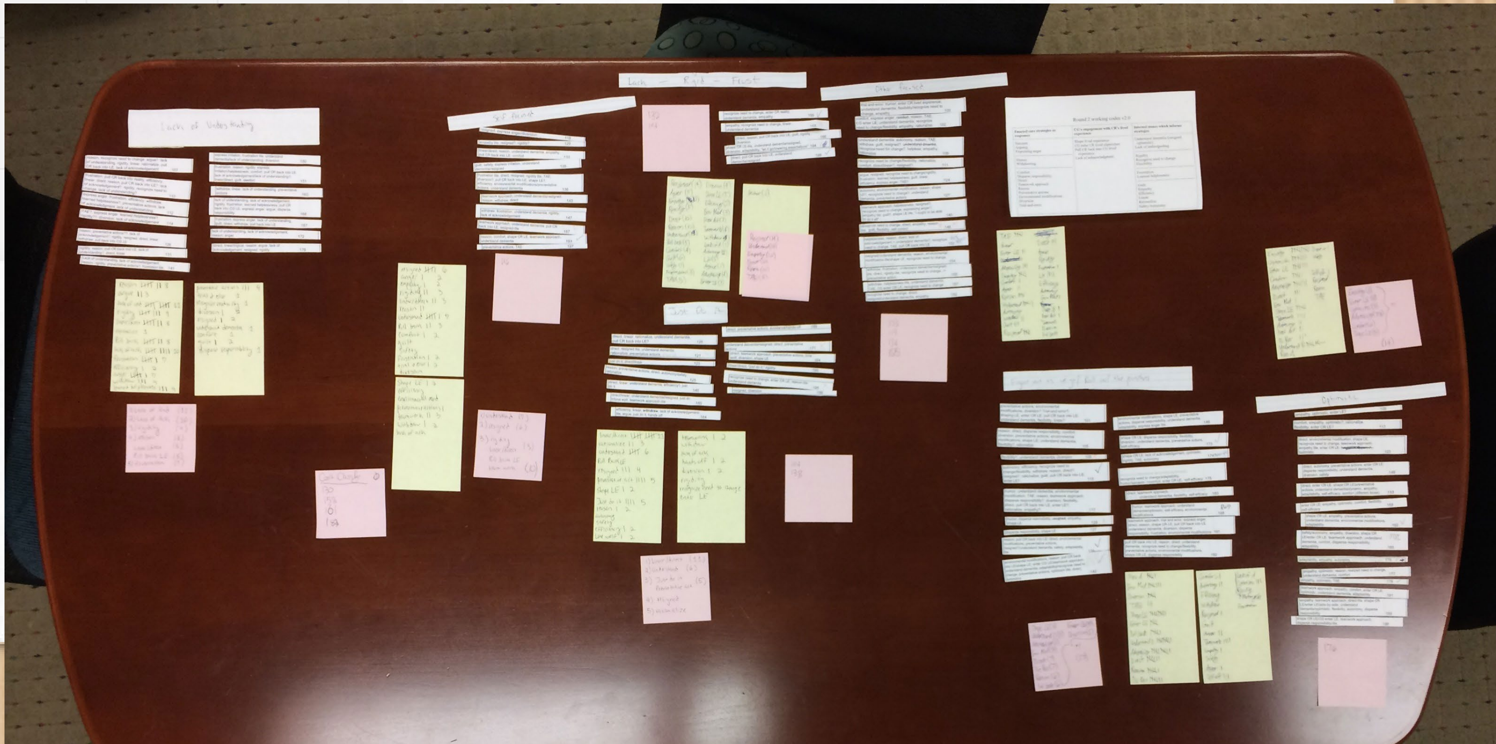


Code	Brief Definition	When NOT to use	Development Questions
taking COVID precautions	precautions taken by CG to reduce COVID-risk for self and PLwD (e.g., staying home, reprioritizing traveling to care appointments, CG/CR cancel appointments, not wanting to invite people into the home, can be used outside of medical context)	do not use when appointments were delayed/canceled by provider	
supportive staff/care/program	CG explicitly expressing support or helpfulness of, or positive communition with staff, providers, care, programs during COVID	do not use when CG just mentions using the service or person they interacted with.	if + communication starts showing up a lot, we may want to consider making it a separate code
caregiver support services helpful	when support services for CG such as support group, mental health services were helpful and/or accessible	do not use with services relating specifically to CR, such as daycare/respite care	
caregiver support services not helpful	when support services for CG such as support group, mental health services were not helpful or difficult to access	do not use with services relating specifically to CR, such as daycare/respite care	
	when community-based services/programs were delayed or canceled due to the pandemic, including caregiver support		



Online sticky notes for sharing ideas digitally

Miro's digital collaboration tool is a visual workspace where you can work with online sticky notes — and so much more.



Dementia Family Caregivers Experiences Using Community-based and Health Care Services During COVID-19

Amanda Leggett, PhD, FGSA, Elaina Baker, BS, Hannah Lee, BS, Anna Webber, Sarah Wallace, Tyson Fang, & Florence Johnson, RN

INTRO

- Family caregivers are key medical decision makers for persons living with dementia (PLwD) and play a critical role in interfacing with community-based services and the health care system.
- The COVID-19 pandemic, however, had dramatic impact on service utilization, with many suspended, delayed, or moved to telehealth and fewer resources attributed to non-COVID medical conditions (Le Couteur, Anderson, & Newman, 2020; Rimmer, 2020).
- Emerging data suggests the pandemic posed challenges to service use for family caregivers, yet how this impacted caregiver's care practice is unknown.
- Research question: How caregivers experience of using or accessing community-based and health care services for the overall benefit of the care dyad impacted their caregiving practice during COVID-19 (since March 2020)?

METHODS

- An in-depth qualitative interview was conducted in 2021 on care management during the COVID-19 pandemic with 100 primary family caregivers for persons with a doctor's diagnosis of an age-related dementia.
- Qualitative interviews were approximately 45 minutes in length, conducted over Zoom, and participants were compensated for their time.
- Watkins' (2017) rigorous and accelerated data reduction technique was used to analyze qualitative data and identify themes specific to family caregiver's access to and use of community-based and health care services.

1. Interviews were recorded, transcribed, and redacted of identifiable information for analysis.
2. Thematic qualitative analysis was conducted through the iterative process of note taking, coding (open and focused), and consensus meetings undertaken by a team of six coders including the lead author.
3. Conventional content analysis was employed to see which codes were most frequent across the themes.

Characteristics	Mean or N (SD or %)
Age	63.29 (14.92)
Female	75 (75.0)
Race	
White	83 (83)
Black	9 (9)
Other	8 (8)
Education	
Less than College	33 (33)
College	42 (42)
Graduate School	25 (25)
Relationship status	
Spouse	61 (61)
Child	26 (26)
Other	13 (13)
Dementia diagnosis	
Alzheimer's	37 (37.0)
LBD	10 (10.0)
Early onset Alzheimer's	10 (10.0)
Other	43 (43.0)
Months of care	72.61 (101.03)

Care Experience

Supportive Staff/Program: "I was one of the lucky ones that we had the support from the Alzheimer's [Association]. I could call Dr [Name] with any of my questions. Zoom, honestly saved my life in being something to look forward to." (ID 182)

Care Partner Restrictions: "[He had a] grand mal seizure… and so… I went to the hospital, followed the ambulance, and they wouldn't let me in…And I said "I've been married 56 years and I'm not going to let the man die alone". And of course they had just come down with the closures. So the doctor came out and… she talked to me about what he had said..so I thought okay he's all right, I, you know I won't make a spectacle and say I have to go to see him." (ID 174)

Access

Accessibility challenge: "[Counseling] was hard to schedule… I craved seeing [someone] more than every five weeks." (ID 111)

Medical care continuity: "He sees a heart doctor, a neurologist, a psychiatrist… and he sees his regular family care doctor. So of those doctors, he was able to see all of them." (ID 174)

Instrumental Support

Pickup/delivery service: "You know the delivery services have become available. Like Shipt- that's a free service for seniors so that was probably the biggest assistant… So it was a wonderful service and very helpful." (ID 156)

Technology

Telehealth challenges: "When you're seeing the doctor for her cognitive difficulties, I think it's just kind of hard to do that on a Zoom call. And one of the things is that she doesn't understand technology. So I really have to do most of the talking for her, which is fine, but I don't think it's optimal in terms of the doctor being able to get a good sense of how she's doing." (ID 214)

Non-telehealth technology beneficial: "I joined those caregiving workshops and really that's given me a lot of support… I never could go to any of the caregiver workshops or caregiver events that were here in the area, because I couldn't leave him alone… the fact that all of these events have gone virtual has [been] amazing to me." (ID 188)

Caregiving Roles/ Responsibilities

Taking COVID precautions: "Prioritizing what needs to be done today. Like what doctor's appointment absolutely needs to be done today, and what can wait until things get better." (ID 209)

Increased responsibility/burden: "The real kicker was because of the pandemic they don't even have caregivers that could even provide three half days a week… it left the family kind of filling in a lot more. Instead of me just stopping over and visiting for a bit and feeling like he had care, it was me staying with him and making a breakfast and making sure we ate lunch and calling every evening at six o'clock to make sure that he remembered how to heat up his dinner and so it just seemed like it was more because of the pandemic. " (ID 106)

Assertive/Advocate: "It was a battle for me to convince them that I need to be with him at all times. He cannot go into an appointment alone. And I won." (ID 155)

Caregivers experienced both disruptions and continuity in accessing care, relied on care in new modalities, served as advocates for desired care, and adjusted their own responsibilities to meet the needs of their care partner during the pandemic.

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RESULTS

- 5 themes of health and community-based service use during the pandemic were identified including (frequency of code use across transcripts):
- Access
  - Accessibility challenge (68), Care reopening (19)
  - Medical Care Access
    - Medical care continuity (75) vs. delayed/canceled (40), In-home health care continuity (40) vs. delayed/ cancelled (28), Emergency services use (47), Vaccine access (11)
  - Community-based programs access
    - Programs continuity (13) vs. delayed/cancelled (42), Caregiver support services helpful (33) vs. not helpful (11), Lack of stimulation/socialization (28)
- Care experience
  - Supportive staff/care/program (67), Care partner restrictions (48), Accommodating (26), Unsatisfactory care (20), Poor communication with staff/providers (18), Insufficient care (8)
- Caregiving roles/responsibilities
  - Taking COVID precautions (60), Increased responsibility/burden (58), Care-coordination (51), Assertive/advocate (23)
- Technology
  - Non-telehealth technology beneficial (10) vs. challenges (11), Telehealth beneficial (28) vs. challenges (41)
- Instrumental support
  - Pickup/delivery service (41), Instrumental support (7)

DISCUSSION

- Caregivers showed great resilience during the pandemic, in filling in the care gaps when services were interrupted or advocating for the continuation or quality of services.
- There were a variety of positive outcomes for caregivers during the pandemic including supportive staff and programs, telehealth and meal delivery services offering support while allowing care dyads to stay home, and increased access to services through virtual modalities.
- On the other hand, services often needed better plans for incorporating caregivers while maintaining health and safety.

FINANCIAL DISCLOSURE

- This work was funded by the National Institute on Aging (K01AG056557, 3K01AG056557-04S1; P30AG053760)

MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

DEPARTMENT OF PSYCHIATRY

Some Mixed-Methods Case Examples

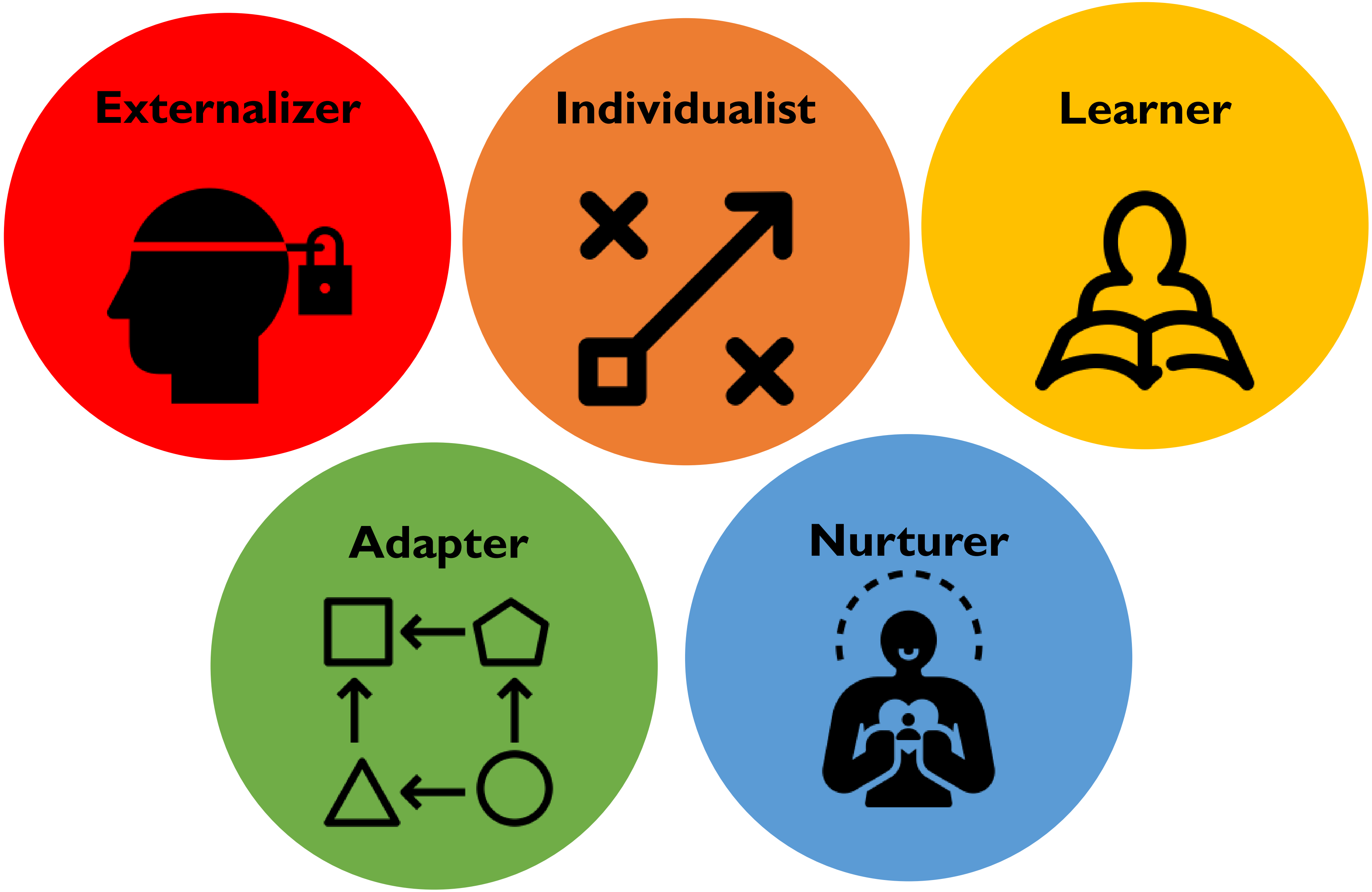
Qualitative Care Challenges	Primary	Secondary
	Freq, % of Total	**Freq, % of Total**
BPSD	**51, 44%**	**16, 21%**
Agitation	25	9
Delusions	6	1
Perseveration	5	1
Other	15	5
Cognitive decline	**22, 19%**	**26, 33%**
Executive dysfunction	10	11
Memory	9	14
Other	3	1
ADL (ex. eating)	**17, 15%**	**16, 21%**
IADL (ex. shopping)	**0**	**6, 8%**
Other (ex. care coordination)	**24, 21%**	**14, 17%**
No challenge	**1**	**--**
Total care challenges	**115**	**78**

Care Challenge	Qualitative Care Management Codes	Quantitative Care Management
ADLs/ IADL	**Straightforward management** (n=15): "direct" instructions, "just doing it" (e.g. "*I just glove up and do what has to be done*") "**Shaping the lived experience**" (n=12): preventative actions and environmental modifications; e.g. ID 101: "*Pretending that we did her hair, that works really well too – just like blowing some like hot air on her hair, she falls for that one almost all the time.*"	• **Active management** was significantly correlated with the overall CAFU score (r=.35, p<.01). • CGs who helped with finances had significantly higher **encouragement scores** • **Criticism** was not associated with help with ADL/IADLs

Care Challenge	Qualitative Care Management Codes	Quantitative Care Management
BPSD	**Lack of adjustment** (n=14): "hands-off", "rigid" in approach, appearing "stuck" without knowing how to manage, or "withdrawing" from the situation/PWD; e.g. ID 107: *"Everybody's told me 'don't argue, just go on to whatever' and again, I go back to my part that you know I just don't like letting it go."* **Criticism** (n=11): arguing, criticizing, expressing irritation and frustration, or pleading with the PWD; e.g. ID 167: *"Mom, you've asked me that 10 times now and I'm getting frustrated with answering 10 times!"*	• **Criticism** was significantly associated with the overall NPI score (r=.34, p<.01). • CGs whose PWD had symptoms of irritability, hallucinations, and aggression **used more criticism** • CGs who cared for a PWD with hallucinations had significantly **higher active management scores** • **Encouragement** was not associated with any BPSD

Care Challenge	Qualitative Care Management Codes	Quantitative Care Management
Agitation	**Criticism** (n=17) **Engaging with the different lived experience of the PWD** (n=11) (specifically by shaping the environment or pulling the PWD back into the CGs' lived experience) **Explaining** (n=9) through reasoning or giving verbal and visual instructions; e.g. ID 151, *"Mom you've been in the hospital 4 times already in the last 2 years, you really need to think about that this might be a good thing to do."*	Agitation was significantly associated with **greater criticism** among CGs (t=-3.44, p<.001), but not encouragement or active management.

Care Challenge	Qualitative Care Management Codes	Quantitative Care Management
Cognitive Decline	**Straightforward management** (n=16) **Shaping the lived experience** (n=13) **Reasoning or a "tell and show"** approach to explain something to compensate for the cognitive decline (n=9); e.g. ID 122, *"every day I would have…a legal pad and I'd say today, here's what we're doing."*	• Significantly associated with **active management** (r=.30, p<.01). • Orientation to place impairment was also associated with significantly less use of **encouragement**



Externalizer

Individualist

Learner

Adapter

Nurturer

Leggett, A.N., Bugajski, B.C., Gitlin, L.N., & Kales, H.C. (2021). “What face should I have on?”: Characterizing dementia caregiving styles. *Dementia.* doi: 10.1177/1471301220988233 PMID: 33517792

The Externalizer (N=14)

"I'll say, 'if you think you're punishing me, you're only punishing yourself'" (ID 172)

Superficial understanding of dementia

Rigid, inflexible approach to care

Focuses on stress to self rather then impact to CR

Helpless, frustrated
Respond with anger

Attempts to pull the CR back into the CGs lived experience

“Sometimes if I say no, no that didn’t happen –everybody’s told me ‘don’t argue’, … [but] I just don’t like letting it go... we get home and **I don’t know if she tries to lie about it or what… she’ll act like that never even happened**.”

(ID 107)

The Nurturer (N=15)

"I value making the most of what is present rather than what is lost" **(ID 170)**

Focuses on impact on CR more than stress to self

Positive affect toward care and the disease

Understanding of dementia, mastery, natural adaptability

Enters into CRs lived experience to address challenge

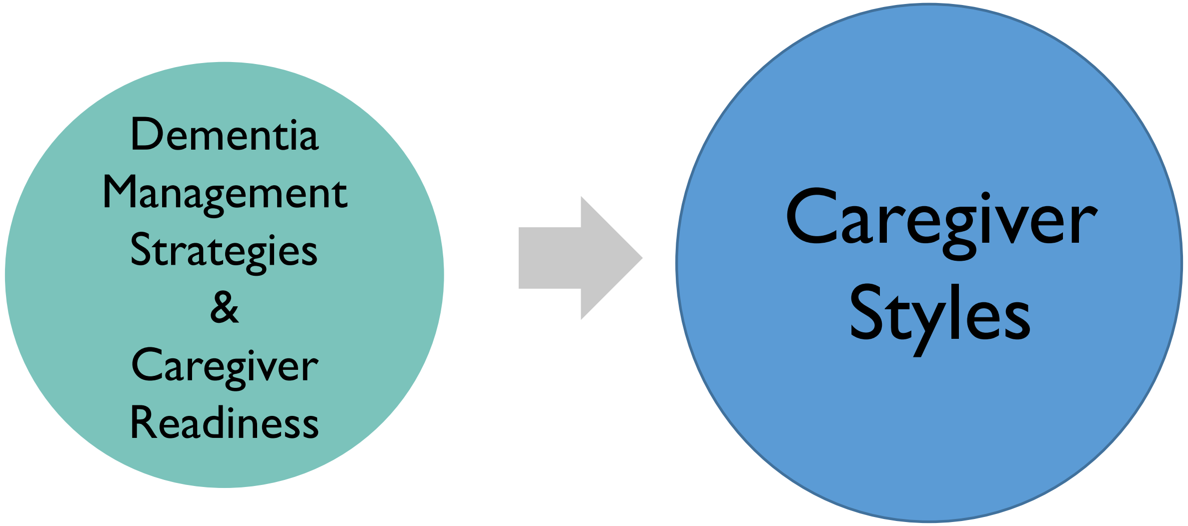
Comforts CR, teamwork

“**I value her** as a person, I value her life, …**I try to make her life still be useful to her and fulfilling**, I’ve got her painting pictures… they aren’t masterpieces but she seems to be enjoying it and we’ll put on music, **she likes** Barbara Streisand... because **I think she wants** to be alive and she wants to be present so I’m trying to do what I can to help her there.”

ID 109

Domains of Caregiving Style	Externalizer	Individualist	Learner	Adapter	Nurturer
Understanding of dementia	Superficial (very low)	Superficial (low)	Still learning (moderate)	Understand (high)	Understand (very high)
Adaptability	Rigid (very low)	Straightforward and direct (low)	Stuck/unsure how to change approach (moderate)	Readily adapt, accrued efficacy (very high)	Reflect natural mastery (high)
Positive emotional approach	Helpless, frustration (very low)	Emotionally removed (moderate)	Emotionally turbulent (moderate)	Regulate emotions (high)	Positive affect, empathy (very high)
Other-focused orientation of care	Self-focused (very low)	In-between (low)	In-between (moderate)	PLwD-focused (high)	PLwD-focused (very high)
Positive behavioral management	Anger, reason, blaming (very low)	Provide care by going it alone (low)	Trial-and-error approaches (moderate)	Arsenal of acquired approaches (very high)	Comfort, teamwork (high)

Mixed Methods- Quantitative Method and Data Integration



Dementia Management Strategies & Caregiver Readiness

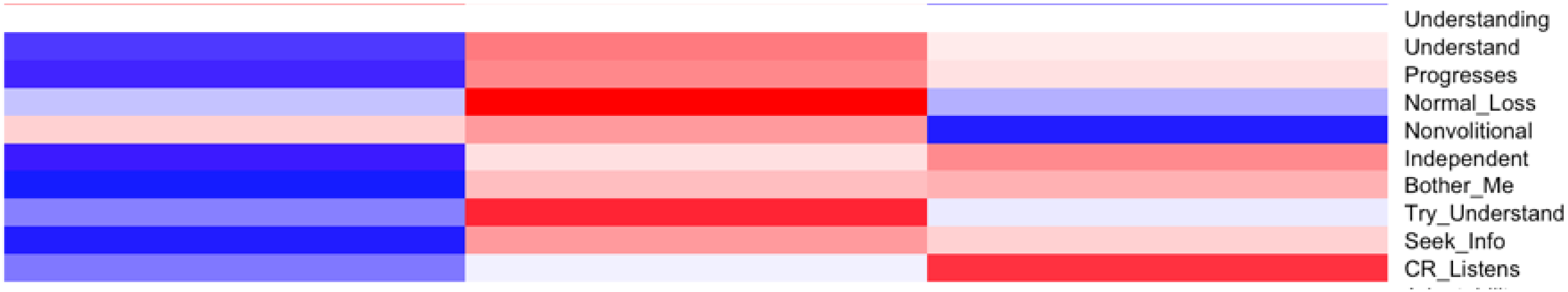
Caregiver Styles

(Hinrichsen & Niederehe, 1994; Gitlin & Rose, 2013)

- K Modes- a nonparametric and frequency-based machine learning cluster analysis method
- Algorithms comparing 2 to 6 cluster models were compared to determine closeness of observations within each group
- 3 clusters were identified as the best fit via the elbow method

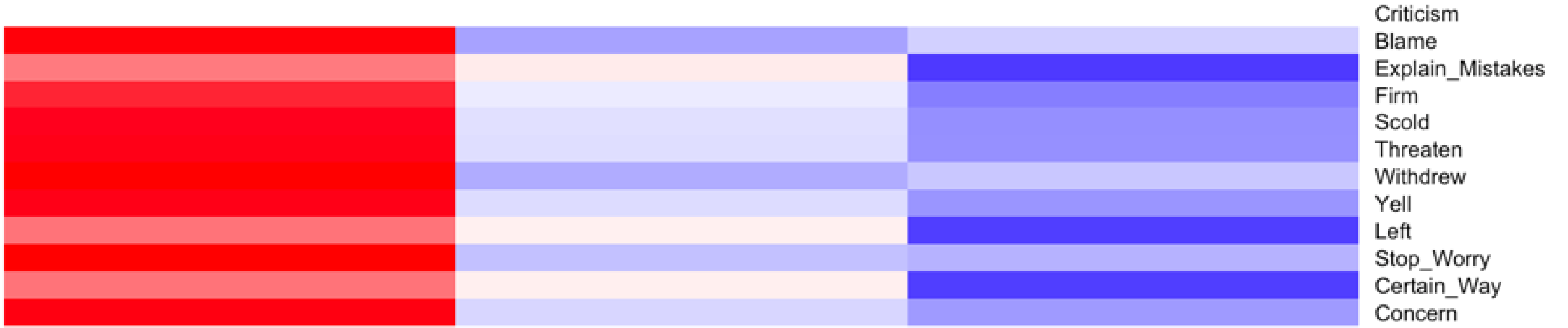
Managers Adapters Avoiders

Understanding



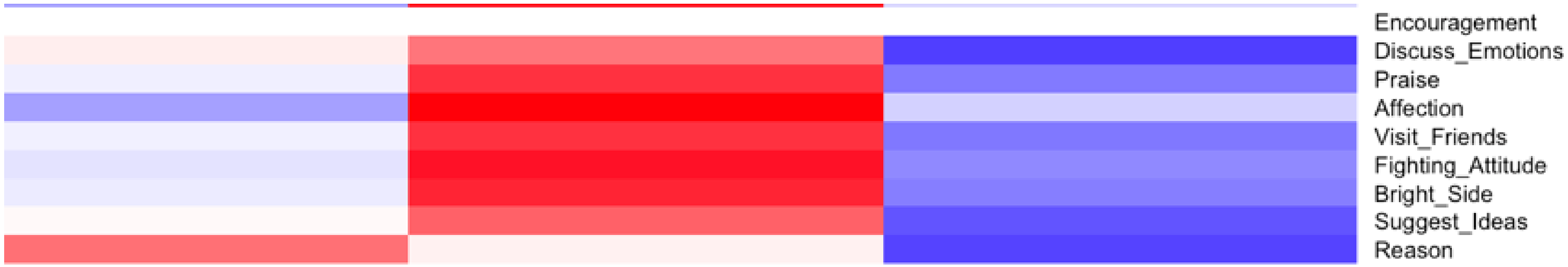
Adaptability

Criticism



Active Management

Encouragement



Iterative refinement: Developing items to build an assessment of dementia caregivers' caregiving style

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INTRO

- While Stress Process Models of family caregiving have been examined extensively, little focus has been placed on caregiver's actual management of care of persons living with dementia (PLwD).
- Prior mixed-methods research by this team has classified 5 distinct dementia caregiving style profiles based on how caregivers vary across 5 domains (Leggett et al., 2021):
  - understanding of dementia
  - adaptability
  - orientation towards oneself vs. the care recipient
  - emotional expression
  - behavioral management
- Style profiles have been associated with important care outcomes, yet for this construct to be useful, it must be measurable.
- We **aim** to develop the first comprehensive assessment of caregiver cognitive-behavioral styles for clinical/service utility or self-assessment. This study presents the iterative item pool development process prior to field testing for validity and reliability.

METHODS

Item Development:

- Full details are provided on the middle green panel.
- Items were developed on a 5-point Likert scale (almost never, rarely, sometimes, usually, almost always) and 6-point Likert scale (strongly disagree, disagree, somewhat disagree, somewhat agree, agree, strongly agree).

Cognitive interview:

- All interviews were conducted by the Principal Investigator and took place over Zoom so the items could be screen shared with participants.
- Participants were told to expect repetition and similarity in items testing each domain set.
- Participants read each item and provided their response using the Likert scale.
- After each item, participants were asked:
  - How did you come up with your answer?
  - Can you think of a better way to word this item?
- After each domain set, participants were asked:
  - Were you comfortable with the questions?
  - After seeing all of the questions, how would you categorize this set of items?
  - Thinking about this one topic area specifically, are there any other questions we should ask?
  - Is there anything else you would like to suggest that would help us improve these items for future use?
- Each item was reviewed by 5 caregivers and each caregiver reviewed one or more complete set of items by domain.

Table 1. Caregiving Styles and Five Component Dimensions

Domains of Style	Externalizer	Individualist	Learner	Adapter	Nurturer
Understanding of Dementia	Superficial understanding	Superficial understanding	Still learning	Understand	Understand
Adaptability	Rigid	Direct and straightforward	Stuck, need to change approach	Readily adapt, accrued efficacy	Reflect natural mastery
Emotional Approach	Emotionally stressed and helpless	Emotionally removed	Emotionally turbulent	Regulate emotions	Positive affect, empathy
Orientation to Self vs. Other	Self-oriented	Self-oriented	Shows both self and other orientation	Other-oriented	Other-oriented
Behavioral Management	Anger, reason, frustration	Provide care by going it alone	Trial-and-error strategies	Arsenal of acquired management strategies	Comfort, teamwork

1) 188 items developed based on prior mixed-methods research

2) **Literacy review** was conducted to ensure items do not exceed a 5th grade reading level (all items kept)

3) **Expert review** (2 content experts and 1 measurement development expert, with 63 items modified and 66 deleted)
   1) E.g., modified what the person I care for "can do" to "is able to do"

4) **Cognitive interviews** with 7 caregivers (caregivers reviewed each domain's item set and provided interview feedback on the items, with 4 items modified and 18 deleted)
   1) E.g., Caregivers preferred positively worded items over negatively worded items

5) **Translatability review** for Spanish (review of wording that could impede translation to other languages, with 28 modified and 4 deleted)
   1) E.g., The phrase "things go wrong" was flagged as vague and changed to "when there are problems"

6) This process resulted in 99 items for field testing

Table 2. Sample Items for Each Caregiving Style Domain

Understanding of Dementia (10 items)	Adaptability (32 items)	Emotional Approach (25 items)	Orientation to Self vs. Other (12 items)	Behavioral Management (20 items)
I understand the progression of dementia	I make adjustments to the way I provide care	I feel frustrated with the person I care for	I encourage the person I care for to do what they enjoy	I argue with the person I care for
I understand why the person I care for acts the way they do	I have learned how to change my approach to caregiving	I feel like my emotions interfere with my caregiving	I have difficulty making personal sacrifices for the person I care for	The person I care for and I work well together
I understand a lot about dementia	I try other care strategies with the person I care for when needed	I have a positive attitude towards my caregiving	I try to make the life of the person I care for fulfilling	I try to distract the person I care for when they are frustrated
I am able to recognize dementia-related declines in the person I care for	When needed, I change the way I interact with the person I care for	I keep an even temper while caregiving	It bothers me when caregiving interferes with my plans	I use trial and error when facing caregiving difficulties
I recognize when the person I care for needs help	I am flexible in handling the challenging behaviors of the person I care for	I hold back my emotions with the person I care for	I have difficulty focusing on what is best for the person I care for	I try to have the patience to let the person I care for do things themselves
I know what the person I care for is capable of doing	I find new ways to do things when providing care	I feel overwhelmed by caregiving	The well-being of the person I care for is more important to me than my own well-being	I use humor to calm the person I care for

Currently we are field testing our 99 items in 200 caregivers through an online survey alongside other validated measures to identify the best performing items (for retention in the final measure) and establish preliminary reliability and validity. Ultimately, we aim for the final assessment measure to include approximately 20 items .

Sample:

- Cognitive interview participants included 7 adult family or friend caregivers for a person living with dementia (excluding mild cognitive impairment).
- Caregivers could not be providing care for:
  - a person living in a nursing home/assisted living
  - a person with a life expectancy of ≤ 6 months
  - a person who was bedbound

Table 3. Sample Characteristics

Variable	M, Range / %
Caregiver age	57.0, 24-78
Caregiver gender (female)	86%
Care Recipient age	78.3, 61-86
Non-white	43%
Latinx	14%
Care duration in years	6.9, 1-11
Hours of care provided in a typical week	21.6, 16-30
Co-residence	71%
Relationship to the care recipient	2 wives 1 husband 1 daughter 1 daughter in law 1 niece 1 granddaughter
Care recipient diagnosis	3 Alzheimer's disease 3 Early onset 1 Not otherwise specified

DISCUSSION

- Our iterative item development process ensures that our newly developed assessment measure will be person-centered, clear, translatable, and relevant to empirical evidence.
- The developed items are now being field tested among 200 family and friend dementia caregivers.
- This measure is vital to the development of more effective and individualized treatment to enhance caregivers' ability to support the PLwD, improve outcomes, and reduce the downstream burden of illness and healthcare costs.

FUNDING

- This study is funded by the Alzheimer's Association & LINC-AD's Advancing Research on Care and Outcome Measurement Program (ARCOM-22-876659). Pilot data for this project was funded by the National Institute on Aging (Leggett, K01AG056557). Dr. Leggett is also funded by the Michigan Alzheimer's Disease Research Center (P30 AG053760).

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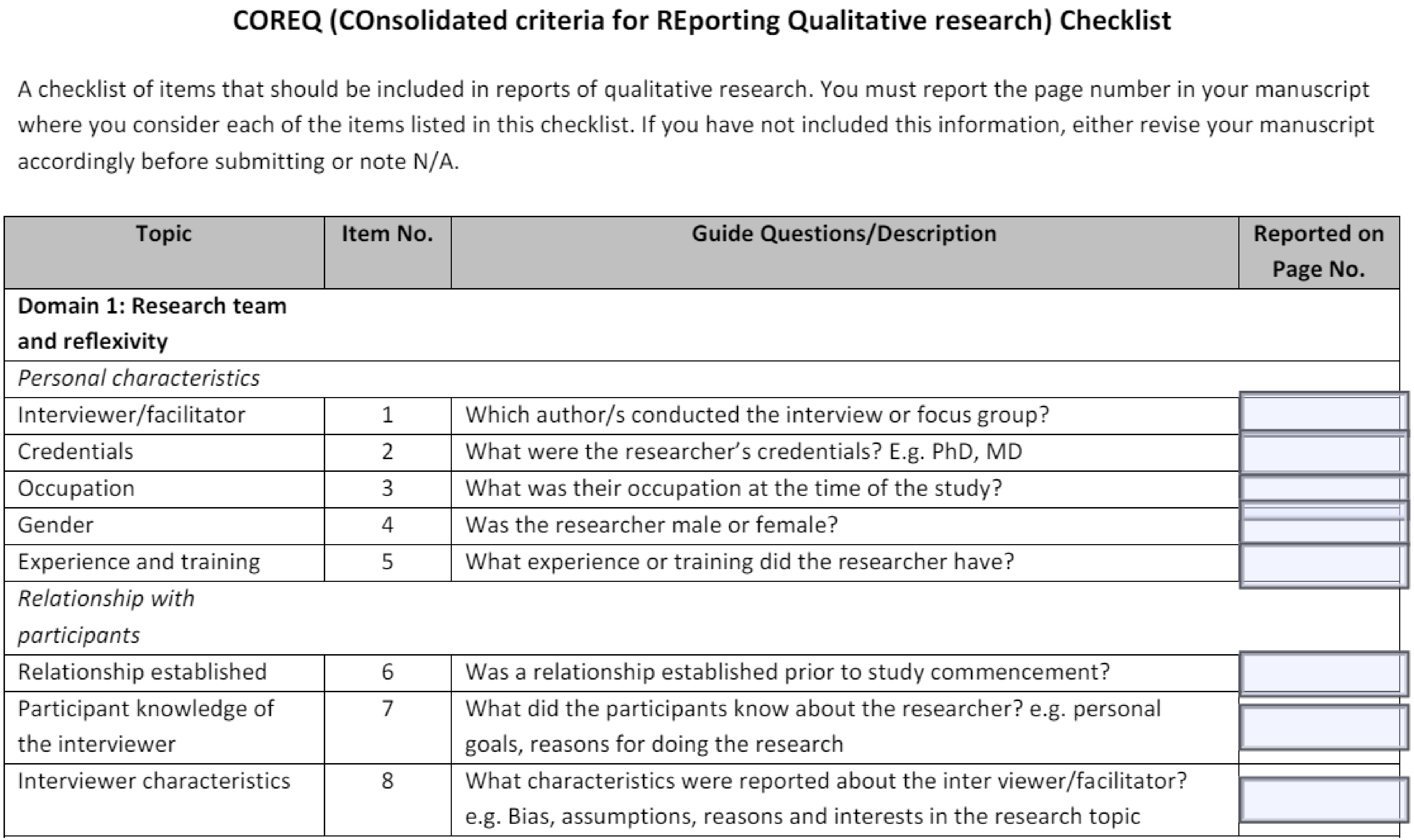
COREQ Checklist



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	

Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Recommended Resources

- Online certificate in Mixed Methods Research: https://ssw.umich.edu/offices/continuing-education/certificate-courses/mixed-methods-research
  - This type of coursework could be part of a K award training plan!

- Watkins 2017 Rapid and Rigorous Qualitative Data Analysis (RADaR) https://journals.sagepub.com/doi/epub/10.1177/1609406917712131