

# Qualitative Research Methodology

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# Disclosure

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I have no personal or financial interests to declare in this presentation.

# Outline

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## **Morning sessions**

- Philosophical perspectives to research
- Qualitative research and qualitative researchers
- Sampling, sample size and saturation
- Qualitative data collection methods

## **Afternoon sessions**

- Qualitative data analysis: Thematic Analysis
- Reporting qualitative research including trustworthiness



Philosophical  
perspectives

# Ontological vs. Epistemological

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## Ontology

the study of being: state or nature of the world (reality)

## Epistemology

a theory of knowledge about the reality

how to obtain and produce the knowledge

what counts a valid or accepted knowledge

# Ontological

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## Ontology

the study of being: state or nature of the world (reality)



# Ontological positions



## Realism

A pre-social reality exists that we can access through research

What we observe is assumed to mirror truthfully what is there

## Critical realism

A pre-social reality exists but we can only ever partially know it



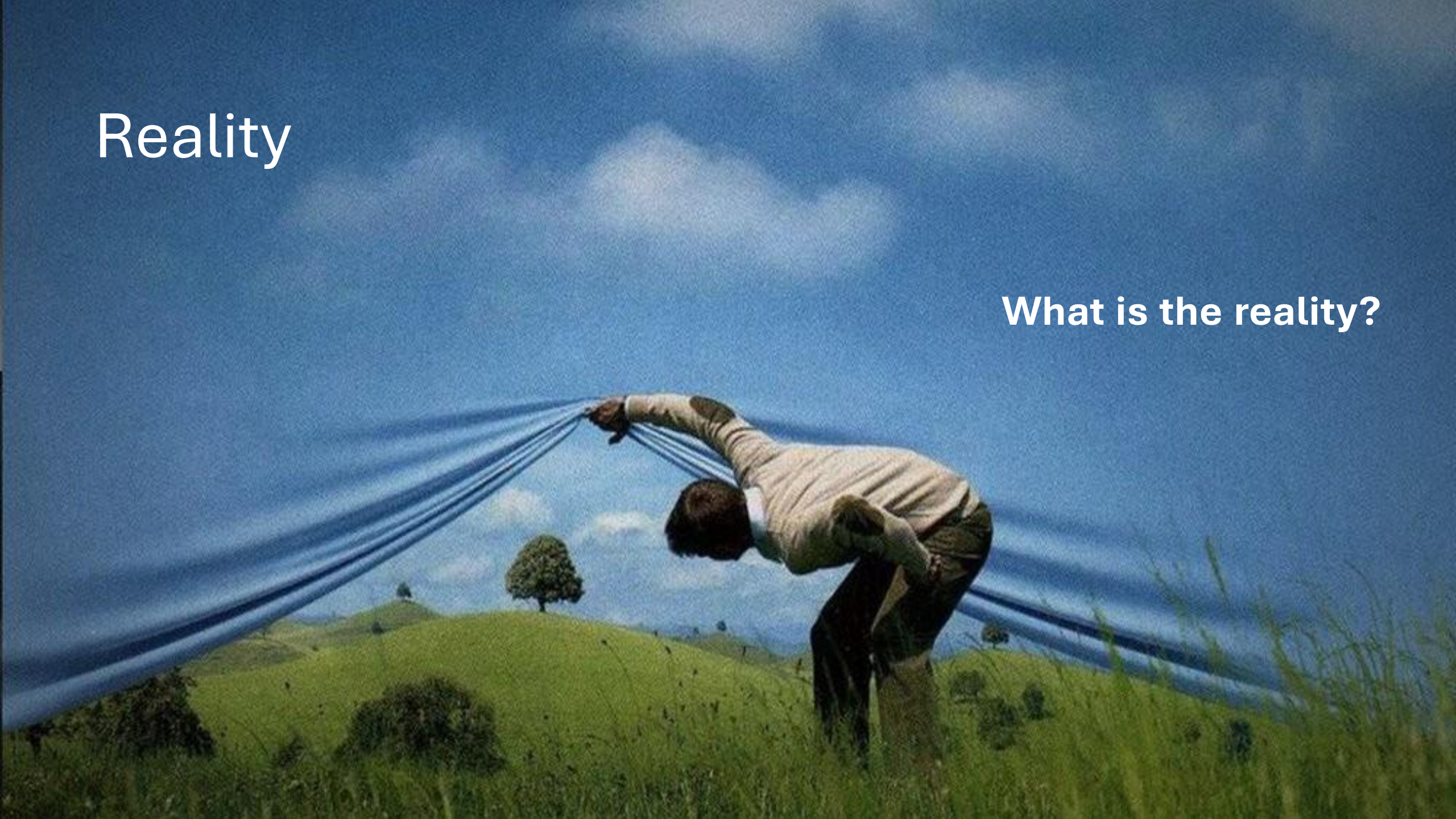
## Relativism

Reality is dependent on the ways we come to know it

There are multiple constructed realities, and we never get beyond these constructs

Reality

What is the reality?





# Epistemological

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## Epistemology

a theory of knowledge about the reality

how to obtain and produce the knowledge

what counts a valid or accepted knowledge

# Epistemological perspectives



## Positivism

Seek for objective  
(unbiased) knowledge (data)  
Discover a singular truth



## Contextualism

There is 'reality', but not a  
single one  
True (valid) in certain contexts  
with certain methods

## Constructivism

Multiple *knowledges* are  
constructed through various  
discourses and systems of meaning  
No one truth



Approach to (or co-create) *knowledge* about the reality



Research

# Epistemological perspectives



## Positivism

Seek for objective  
(unbiased) knowledge (data)  
Discover a singular truth



## Contextualism

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No one truth





# Quantitative vs Qualitative research



**Singular and Unbiased** knowledge

vs

**Multiple and Contextual** knowledge

Well or Not well yet

# Quantitative vs Qualitative research

Prevalence, causes and effects – measurable data – **Numbers**

Meaning, process, interaction – subjective but grounded on data – **Words**

Perceived practical preparedness	
Very	82 (57%)
Somewhat	38 (27%)
Not at all	12 (8%)
Not sure/declined to answer	11 (8%)
Perceived emotional preparedness	
Very	41 (29%)
Somewhat	56 (39%)
Not at all	24 (17%)
Not sure/declined to answer	22 (15%)

## *Uncertainty in dementia progression*

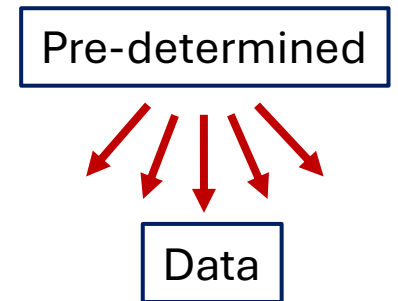
Carers described the uncertain prognosis as a barrier to planning, and were unsure how, or if it were possible, to plan for different possible contingencies.

“I have thought about [writing an advance care plan] but it is just impossible to do. There are so many ifs, you can’t specify all the conditions which might come up. It might be easier to do in cancer where the prognosis might be clearer. I don’t think anything is as difficult to deal with as dementia.” ID124-SI (male, caring for wife with mild dementia)

# Deductive vs Inductive

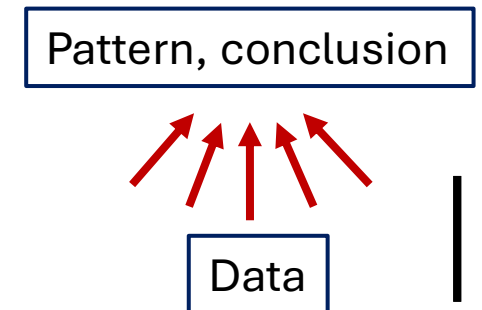
## **Deductive approach** – theory laden

- not begin from the observation, but from theory, to make observations intelligible
- test the theory/hypotheses - falsification or creation of as yet unfalsified law
- e.g. models, questionnaires, measurements



## **Inductive approach**

- seek to find the internal logic of the participant
- culturally derived and historically situated interpretations
- observer (researcher) as a party to what is being observed



# Deductive vs Inductive

## Depression? PHQ-9?

เบื่อ ทำอะไร ๆ ก็ไม่เพลิดเพลิน

ไม่สบายใจ ซึมเศร้า หรือท้อแท้

หลับยาก หรือหลับ ๆ ตื่น ๆ หรือหลับมากเกินไป

เหนื่อยง่าย หรือไม่ค่อยมีแรง

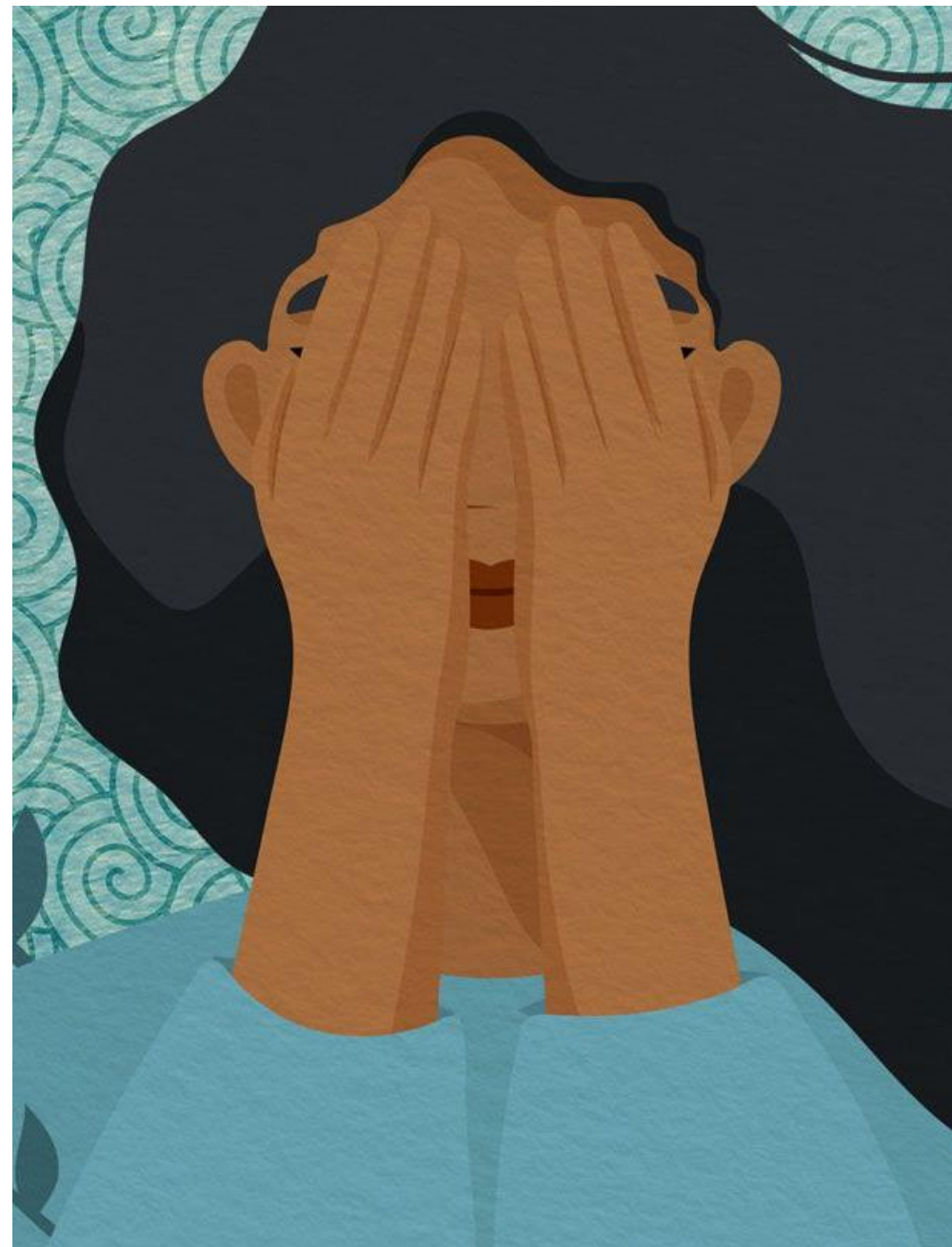
เบื่ออาหาร หรือกินมากเกินไป

รู้สึกไม่ดีกับตัวเอง คิดว่าตัวเองล้มเหลว หรือทำให้ตัวเอง หรือครอบครัวผิดหวัง

สมาธิไม่ดีเวลาทำอะไร เช่น ดูโทรทัศน์ ฟังวิทยุ หรือทำงานที่ต้องใช้ความตั้งใจ

พูดหรือทำอะไรซ้ำจนคนอื่นมองเห็น หรือกระสับกระส่ายอยู่ไม่นิ่งเหมือนเคย

คิดทำร้ายตนเอง หรือคิดว่าถ้าตาย ๆ ไปเสียคงจะดี





# Quantitative vs Qualitative research

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Theoretical perspectives

Deductive vs Inductive

## **Research questions**

Study objectives

Methodology and methods

Research  
question



# Research question

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- Possible (or desirable) to try to measure an objective ‘truth’
- Want to generalize to a larger population

**OR**

- Want to seek thick descriptions
- Too complex to be reduced to a set of observable laws

*(or both)*

$$3\ 3\ 8\ 9\ 7\ 5\ 8\ 7\ 9\ 3 = 6.2$$



Research  
question





# Research methodology vs Methods

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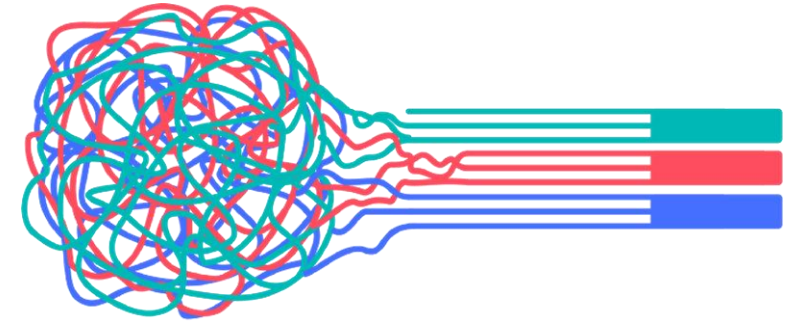
## Methodology

a theory of how: a (broader) **framework** for making a series of decisions  
selecting participants, appropriate method, role of researchers...

## Method

a (specific) tool or **technique** for collecting or analysing data

# Qualitative research

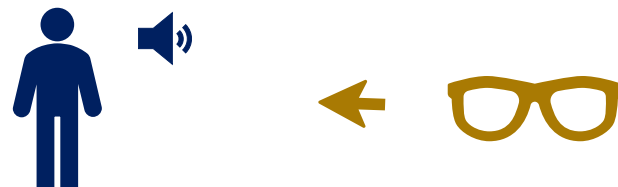


It captures the **complexity, mess** and **contradiction** that characterises the real world, yet allows us to make sense of **patterns of meaning**

Not a single approach, but **diverse** as quantitative methods

**Experiential:** participants' interpretations – organised, interpretative framework

**Critical:** representation, language practice – interrogative stance



# Research methodology and methods

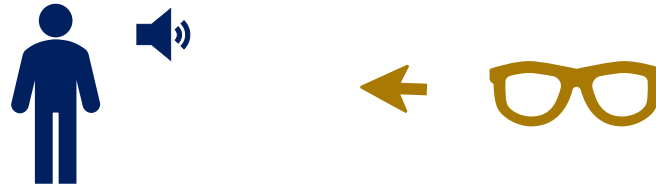
Mixed

Epistemology	Theoretical perspectives	Methodology	Methods
Positivism	Positivism	Experimental research	Sampling
Contextualism	Interpretivism	Survey research	Statistical analysis
Constructivism	• Symbolic interactionism	Ethnography	Questionnaire
	• Phenomenology	Phenomenological research	Observation
	• Realism, including critical	Grounded theory	Interview
	Critical inquiry	Heuristic inquiry	Focus group
	Feminism	Action research	Document analysis
	Postmodernism	Discourse analysis	Content analysis
	etc.	etc.	etc.

# Qualitative research

**Experiential:** participants' interpretations – organised, interpretative framework

**Critical:** representation, language practice – interrogative stance





# Qualitative researcher

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Interest in **process** and **meaning** rather than cause and effect (no hypotheses)

Critical and questioning approach, not face value but its 'why and how'

focus on not only the content of what they said but also analytic ideas

**Bracketing** shared values and assumptions

Good interactional skills, but **not really extroverted**

# Subjectivity and reflexivity

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Co-construct the knowledge: **subjectivity** as a strengths, rather than a weakness

## Reflexivity

a process of critically reflecting on the knowledge and its production

functional (selected methods) **vs** personal (assumption, insider/outsider)

diary or journal

# Qualitative research methodology (and methods)

**Grounded theory (GT)** – a systemic method for data collection and analysis to construct **a theory**, grounded in data

Original concept of ‘saturation’

 **Research Papers in Education** >  
Volume 28, 2013 - Issue 3

[Submit an article](#) [Journal homepage](#)

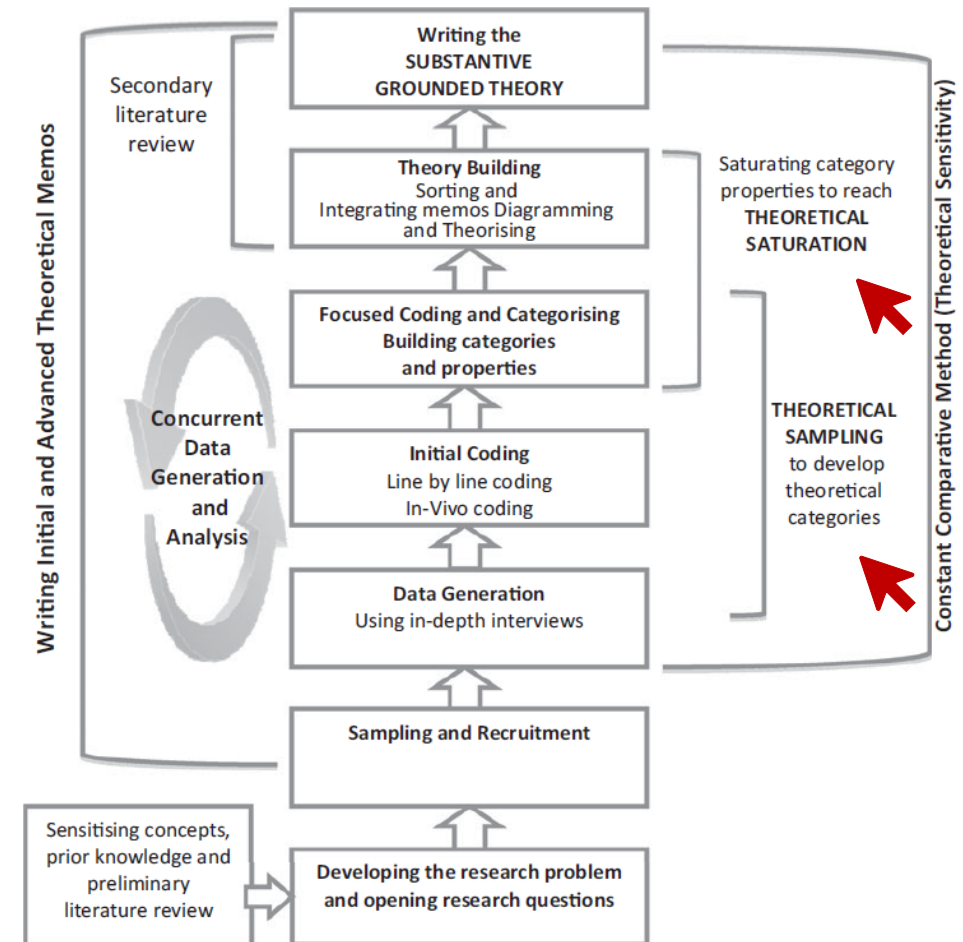
Articles

## Victimising of school bullying: a grounded theory

Robert Thornberg ✉, Karolina Halldin, Natalie Bolmsjö & Annelie Petersson

Pages 309-329 | Received 17 Jun 2011, Accepted 15 Nov 2011, Published online: 12 Dec 2011

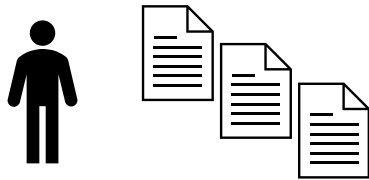
Download citation <https://doi.org/10.1080/02671522.2011.641999>



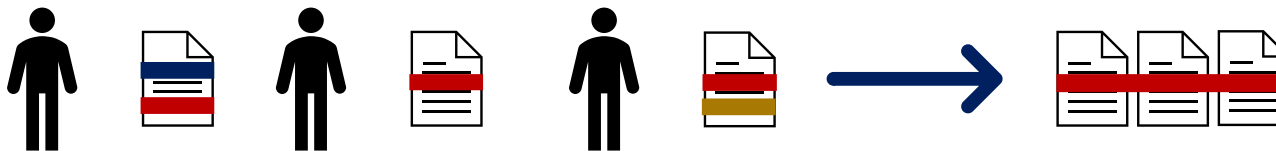
Charmaz 2021, Giles 2016

# Qualitative research methodology (and methods)

**Interpretative Phenomenological Analysis (IPA)** - detailed exploration of personal lived experience, examined on its own terms and with a focus on participants' meaning making



**Thematic analysis (TA)** – a flexible method for identifying, analysing and reporting patterns (themes) within data



# IPA

## Focus on the individual's experiences and meaning

A balance between commonality and individuality  
(Convergence vs Divergence)

Nizza 2021, Dwyer 2019

This subordinate theme illustrates the participant's sense of not belonging in the nursing home environment, which was "not natural for a young person" (Sean, 2403). They described this setting as a place for older adults who are dying and often suffering from dementia, resulting in a *"fear of ending up like them"* (Conor, 656). The nursing home was *"for people who are older than me and people who are behaving like children"* (Liam, 1754–1756). This shared misplacement was vividly captured by Sarah.

*It is terrible. It is terrible. It is just degrading really. It is not for me, not for a young person. Young people shouldn't have to live in a place like this. It is grand and all that but it is not for young people, it is for old people and it is for old people to end their day, you know... Just, I don't think I am old. I am, you know, I know I have disabilities but I am not old. I am still young, I am not senile, I don't have dementia. (Sarah, 1200–1212)*

Although Sarah describes the nursing home itself as a fine for the purpose of caring for older people, her repeated use of "I" asserts her own identity within an aged population she does not identify with. Besides the linkage to ageing and dementia, the participants also saw the nursing home as being a place to die. All participants with the exception of Jack spoke of elderly residents continually dying within the nursing homes, including David and Sean, who had moved on to alternative accommodation. Sean referred to his nursing home experience as living in *"God's waiting room"* (2528). The repetition of death instigated a questioning of their own mortality and heightened their death anxiety. The impact of death and dying in the nursing home dominated Liam's transcript, as he repeatedly conveyed the toll it was taking on him.

*In the company of so many people dying it is just too much like. Really, really too much... If somebody dies there is no movement in them [the older residents]. Whereas it really blows me when somebody dies like you know. Like, so many people have died there, I'm in their company and helping people here and there and next thing you know they are after dying. (Liam, 178–189)*

Like the other participants, Liam depicts feeling overwhelmed surrounded by prolific death. His reference to *"no movement in them"* draws a comparison between himself and the elderly residents, who don't appear fazed by the frequent losses that leave him feeling knocked. This may be interpreted as a consequence of his life stage, in which death is not the norm. There is also a sense of suddenness in *"next thing you know"*, capturing the persistent abrupt and startling nature of the deaths in spite of their frequency.



# Qualitative research methodology (and methods)

**Discourse analysis (DA)** – the study of talk (verbal and nonverbal interactions) and text (language creates meaning)



More **critical approach**

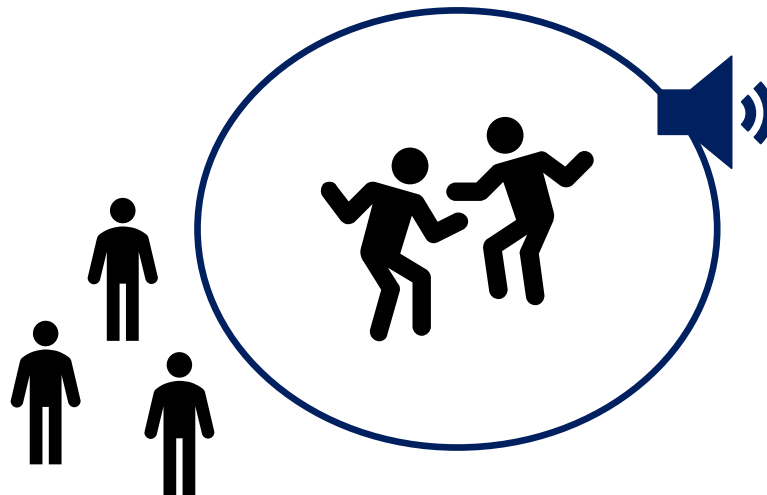
**Conversation analysis (CA)** – analysis to describe the orderliness, structure and sequential patterns of interaction

(?Content analysis – qualitative data are coded and analysed numerically)

# Sampling and sample size

**Purposive sampling** – participants who are able to provide ‘**information-rich**’

Marked difference to quantitative: not concerning bias or seeking generalisation



Talk about your  
dinner last night

# Sampling and sample size

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## Sampling strategies/techniques

Maximum variation (or heterogeneity) sampling

Snowballing

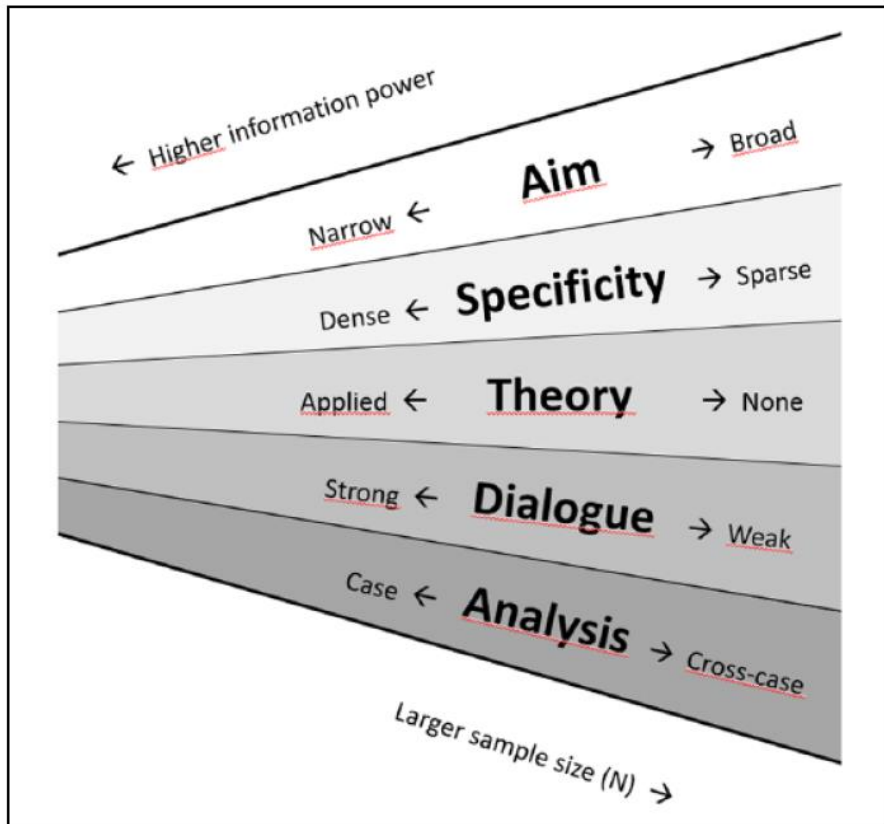
Theoretical sampling (for Grounded Theory)

Experiences of people living  
with poor controlled DM

Needs of sex workers in  
preventing STDs

A model of behavioural engagement  
in medical classrooms

# Sample size and Saturation



**Figure 1.** Information power—Items and dimensions.

Saturation – debate! (notion of completeness)

originated from the grounded theory approach

**Information power** approach

one additional interview – not suddenly rich or insightful (but richer or more insightful)

Too many – preclude deep, complex engagement with data

15-30 interviews – common in research aiming to identify patterns (average 9-17)

4-8 focus ‘groups’ (3-8 participants each generally generate a rich discussion)



# Break



# Qualitative data collection methods

Individual interview

Focus group

Observation

Textual data including secondary sources



Data sources: interview, meeting, informal conversation, transcript, fieldnote, qualitative survey, diaries, magazine, blogs, policy documents, video etc.



# Data collection method: Individual interview

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Ideal for sensitive issues (face-to-face, telephone, virtual, email)

Semi-structured interviews (most common)

- topic guide (interview schedule) contains probing questions

- focus on the research questions but open to **unanticipated topics** – build rapport

- maybe accompanied by **scenarios** for controversial issues (as third person)

Audio-recorded (with permission)

Participant information sheet (PIS), consent form, demographic data form

# Demographic data

Participant characteristics

Context of the study

Anantapong 2021

**Table 2.** Participant characteristics ( $N = 19$ )

Characteristics	$N$ (%)
Age (years)	
Mean (SD)	76.7 (8.0)
Median	79
Range (Min, Max)	57,88
Gender	
Female	9 (47.4)
Male	10 (52.6)
Marital status	
Married or in a civil partnership	11 (57.9)
Widowed	3 (15.8)
Divorced	3 (15.8)
Separated	1 (5.3)
Single	1 (5.3)
Ethnicity	
British, Irish or White other	14 (73.7)
Indian/Asian	3 (15.8)
African/Caribbean	1 (5.3)
Other ethnic group	1 (5.3)
Education completed	
<15 years	3 (15.8)
15–16 years	5 (26.3)
17–20 years	3 (15.8)
21+ years	8 (42.1)
Dementia subtype	
Alzheimer's disease	8 (42.1)
Vascular dementia	3 (15.8)
Frontal lobe dementia	2 (10.5)
Lewy Body Dementia	1 (5.3)
Parkinson's Dementia	1 (5.3)
Mixed dementia	3 (15.8)
Unsure	1 (5.3)
Time from diagnosis (years), mean (SD)	2.1 (1.8)

# Topic guide (semi-structured interview)

Research questions are *not* interview questions

Opening (introducing) and closing (clean-up) question

Start with less probing, sensitive and direct questions – flow logically and clustered

Clear questions – but flexible in the precise wording and order

Trying out questions on someone else – difficulty and tone – rework

Practising and anticipating any difficulties

more confident when **listening** to participants

mentally **ticking off** questions

**Focused but flexible**

# Topic guide (semi-structured interview)

## Questions

### Part A) Experiences of eating, drinking, swallowing

- 1) What is your understanding of dementia?
- 2) What do you know about the later stages of dementia? How might develop over time?
  - a. Probe around the difficulties of eating and drinking/swallowing – Would you expect any difficulties with eating and drinking?
    - i. If yes, which ones?
  - b. What conversations have you had about this topic? (if any)
- 3) Tell me about your experiences of eating and drinking.
  - a. Have you noticed any changes since you were diagnosed?
    - i. If yes, which ones?

### Part B) Scenarios

We have some specific scenarios which we would like to discuss with you which you may not have mentioned. Please let me know if you would not like to continue at any point.

We wanted to understand how you would want your family or care team to approach some of these scenarios at home. *[Participants given each case study on a separate sheet to read and interviewer asks the questions below]*

**Scenario A** – Mrs S is 86 and has vascular dementia. She lives at home with her daughter and her family. Mrs S has recently started to eat less and less and no longer seems to find pleasure in foods she once really enjoyed. She often leaves food at the end of her meal and finds it more and more difficult to feed herself. At times Mrs S refuses to eat. Her daughter does not know what is the right thing to do and if she should encourage her mum to eat or not.

- 1) Would you want to be encouraged to eat?

# Successful interviews

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Keep your eyes on the **recording equipment** (plus carrying spare batteries)

Give participants a clear ideas of **how long** the interview would last (plus pre-/post-)

Not recommend doing more than **one interview in a day** – mix your mind

**Location** – participants feel comfortable and you feel safe, no distraction (and pets!)

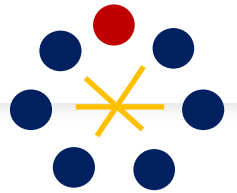
Appropriate **self-disclosure** (with relaxed but professional looks)

Participants as the **experts on their experiences**

**Transcribe** each interview as soon as possible – adjust the next interview

**Field notes** – how you think the interview went, ideas for analysis, subsequent interview

# Data collection method: Focus group



Data collected from multiple participants at the same time

**Unstructured but guided** discussion focuses around the research topic

Using a guide – test out, rework and practise (with scenarios, print image, film clip)

**Among themselves**, participants discussing points raised by the modulator

Mimic real life conversations, real vocabularies – not talking to a researcher

Access the views of **underrepresented** or **marginalised** groups (less intimidating)

Empowered, not isolated – some feel less uncomfortable discussing sensitive topics

Dominant, shy (quiet), bored (restless) participants



# Data collection method: Focus group

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**Heterogenous** or **homogenous** focus group – think about research topics

**Acquaintances** or **strangers** – either facilitate interactions or inhibit free discussion

Confidentiality and participant **withdrawal** – **data management** in PIS, consent form

## Limitations

**Broader** socio-cultural or personal meanings (not able to elicit detailed personal narratives)

Busy professionals or geographically dispersed - **logistically challenging**

Topics raising strongly (emotive) conflicting views may not be suitable e.g. abortion

# Data collection method: Observation

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Often associated with **ethnographic** methodology, which can also use other methods

Systemic viewing of people's **actions**

the recording, analysis and interpretation of their behaviours

Fieldnotes, observational schedules (checklists)

written up **immediately** following the observation – fail to recall at a later date

what did they look like, what did they say, how did you feel about them etc.

**Overt** vs **Covert** observation – modifying behaviours, ethical issues





Ageing & Society (2020), 40, 2771–2772

## REVIEW

### Rituals of Care: Karmic Politics in an Aging Thailand

Felicity Aulino, Cornell University Press, Ithaca, NY, 2019, 210 pp., pbk US \$22.95, ISBN 13: 9781501739736

Kanthee Anantapong 

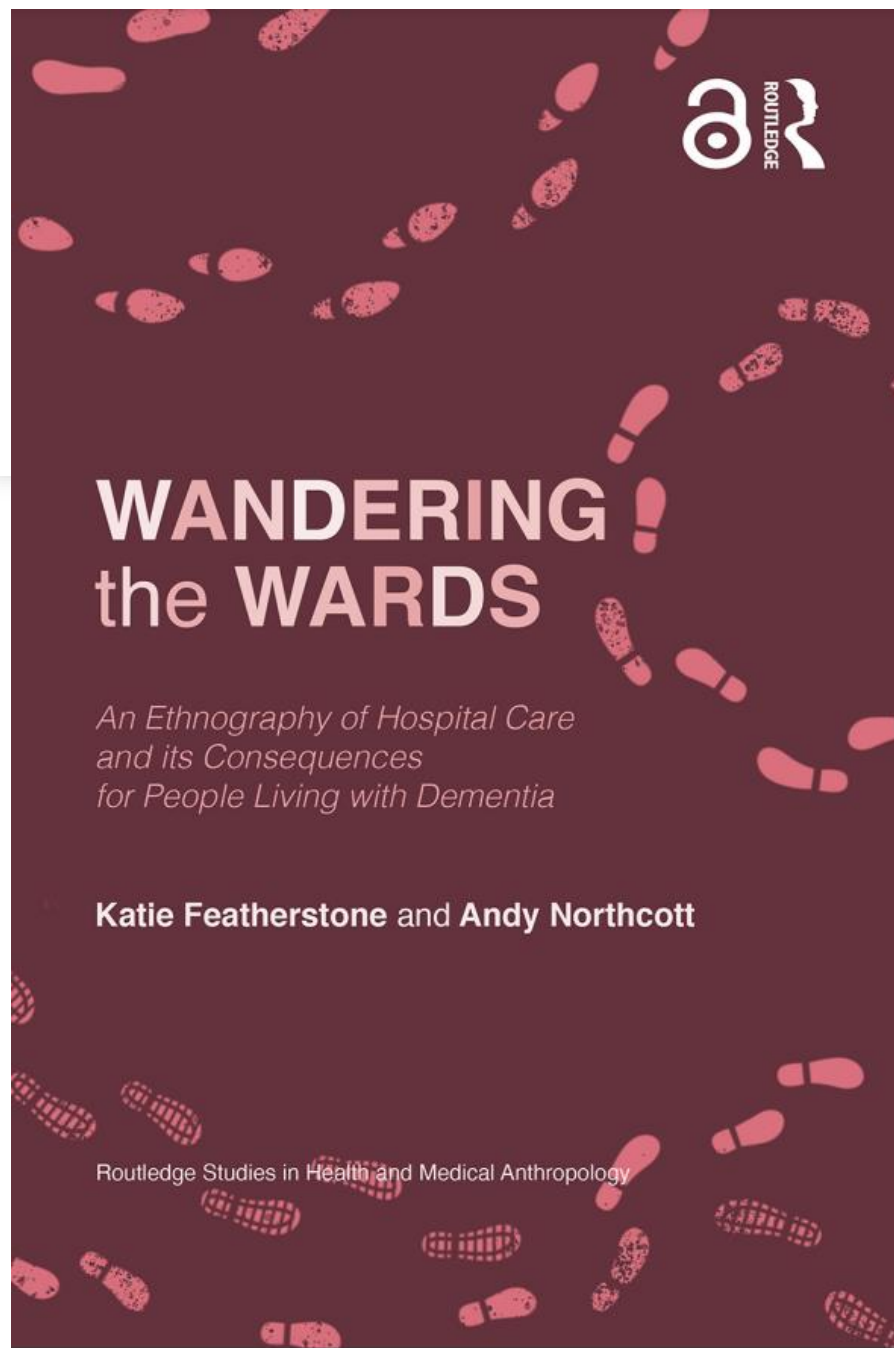
Faculty of Medicine, Prince of Songkla University, Songkhla, Thailand and Marie Curie Palliative Care Research Department, University College London, UK



Image 1: Hair Wash, Chiang Mai, Thailand, 2009. Photo by author.



Image 4: Entrance. Chiang Mai, Thailand, 2008. Photo by author.



Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

## International Journal of Nursing Studies

journal homepage: [www.elsevier.com/ijns](http://www.elsevier.com/ijns)

### Routines of resistance: An ethnography of the care of people living with dementia in acute hospital wards and its consequences

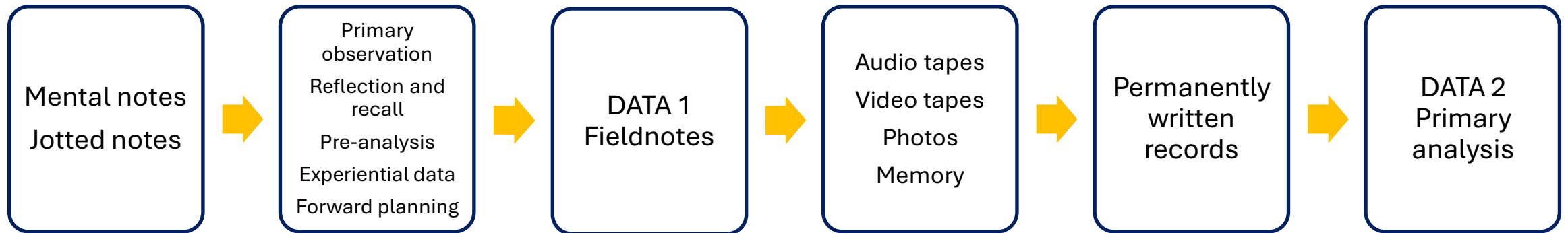
Katie Featherstone<sup>a,\*</sup>, Andy Northcott<sup>b</sup>, Jackie Bridges<sup>c</sup>

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# Data collection method: Observation



**The data gathering process using fieldnotes**



# Data collection method: Textual data

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Data primarily produced in a written form – in writing or typing

A. **Participant-generated** textual data

qualitative surveys, researcher-directed diaries , story-completion task:

participants record views or their experiences in relation to a series of  
**questions or prompts**

B. Pre-existing textual data (**secondary** sources)

official documents, online forums, transcripts of TV programmes

# Data collection method: Textual data

Davey and Emily have to make a decision about their three “left over” embryos following successful in vitro fertilisation (IVF) treatment. One option is to donate them to someone else trying to have a child...

Tom and Lisa have been seeing one another for a while. After having sex one night, Tom realises that Lisa has not had an orgasm...

David has decided to start removing his body hair...

What happens next? (Please spend at least 10 minutes writing your story)

## Story-completion task

- Deliberately ambiguous
- Explore participants' assumptions



L u n c h

T i m e

See you in the afternoon session...



# Qualitative Data Analysis: Thematic Analysis (TA)

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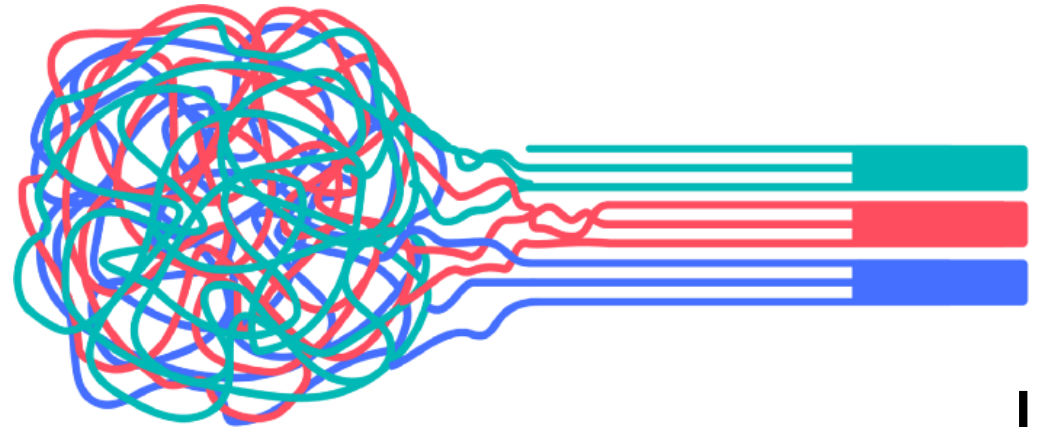
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ResearchGate: <https://www.researchgate.net/profile/Kanthee-Anantapong>

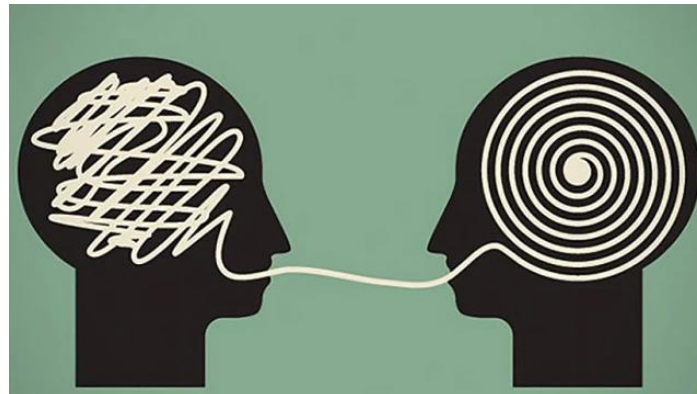


# Qualitative data need analysis & interpretation

Participant quotes should not be left to speak for themselves but require further analysis on the part of the researcher to explore their significance

Analytic reading of the **participant's words**

**Subjectivity** of qualitative research - meaning, process, interaction



# Data analysis method

**Transcription** – verbatim, maybe by a professional transcriber



Pseudo-anonymisation, pseudonyms (still debate)

Focus group – self-introduction helps gain familiarity of their voices

Cross-language: inconsistent guidelines – stay with the original language as long as possible

Then follow the standard procedures for each methodology/method: GT, IPA, DA, CA, TA



# Thematic analysis (TA)

A flexible method for identifying, analysing and reporting patterns (themes) within data

## **Variations:**

- coding reliability TA (more deductive)

- codebook TA

- reflexive TA (more inductive)

Researchers cannot enter a **theoretical vacuum** when doing any TA (some interpretation)

# Thematic analysis (TA)

**Code:** the most basic segment of the raw data that can be assessed in a meaningful way regarding the phenomenon: usually one observation and one facet

**Theme**\*: patterns of shared meaning, united by a central concept or idea: multiple observation and multi-faceted (can contain divergent and disparate responses)

\*usually confused with topics (esp. in coding reliability and codebook TA)

Braun & Clarke 2006, 2021



(Stages can be blended)

# Example of (reflexive) TA

Family carers and hospital staff caring for people with severe dementia in acute hospitals

Specific **research questions**:

1. How do family carers and hospital staff initiate and have conversations about *nutrition and hydration* for people with severe dementia during acute hospital admissions?
2. How do **hospital staff communicate with family carers when planning care** for nutrition and hydration for people with severe dementia in acute hospitals and after discharge?
3. What are the potential strategies to improve communication about nutrition and hydration for people with severe dementia in acute hospitals?

...So our HCAs are like they're excellent. I would be able to manage this ward without our HCAs. What we tend to do is, every Thursday, we have a meeting with our HCAs, the therapists, the [00:27:54] ward manager, nurses, everyone, and each one of us tells our role in it. So I may just simply say, "This man came in with a UTI, has been treated with antibiotics and is medically-optimised. His bloods are fine." And the therapists will say their side, the HCAs will say, "Listen, we noticed that he was really, really confused and delirious to start off with and now he's much more settled." Because they're the ones who actually give us a pattern [00:28:24] about brain fog or what happens in the evening as to how quickly he becomes fatigued. And simple tiny, tiny things that I wouldn't be able to pick up because I don't sit and stare at the patient for like full 8 hours, 12 hours of my shift.

Whereas they are there for – like one is to eight ratio or something like that. But it's not all people with dementia. So the people who are capable, we just leave them by themselves and [00:28:54] help out if need be, but people with dementia, they tend to have a more one-on-one nursing role...

(Physician)

## TA: Data coding process (one facet)



Initiate the discussion

Multidisciplinary team (MDT) work

Staff and time resources  
(in acute hospitals)

Always think of your **research questions!**

# TA: Data coding process (one facet)

PWD = people with dementia

Example quotes	Codes
<p>“...things are delayed in hospital, then you’d get someone come in, a <b>doctor then came in and talked</b> about a feeding tube with me, and I said “no, you’re not reading notes and you’re <b>not talking to the nursing staff</b> correctly. You’re just making an <b>assumption</b> on what you’ve read, and actually you need to see what’s happening here...” (family carer of PWD)</p>	<p>Use of feeding tube in hospital Attitudes towards ANH for PWD <b>Shared decision-making</b> <b>Consult with carers about PWD’ eating</b> <b>Assumption of eating ability</b></p>
<p>“...obviously weekends there is skeleton staff because a lot of people, consultants, everyone is <b>off at weekends</b> so you have not the full capacity of staffing on weekends as you do on week days but... I think in terms of <b>recording</b>... what the patient is eating and not eating that would help other staff who come in...” (family carer of PWD)</p>	<p><b>Involve MDT in assessing and planning</b> Noticing eating and drinking problems Ward policy and culture <b>Keep carers updated</b> <b>Using medical notes and written docs</b></p>
<p>“...it’s very, very important to <b>involve the carer and the family</b>, but in my opinion, I’ve seen it times where I’ve felt that...we’re sort of over-medicalising things when actually that isn’t in that <b>patient’s best interests</b>... the <b>family will really want</b> the patient to be treated like IV antibiotics, IV fluids, putting a – put in a <b>PEG</b>... is this actually what that patient or this <b>person wants</b>?...” (hospital staff)</p>	<p><b>Shared decision-making</b> <b>Balance intervention vs best interest</b> <b>Knowing and respecting the person</b> <b>Family preferences</b> Attitudes towards ANH for PWD Rethink about the conflicting decisions</p>

# TA: Developing themes (multiple facets)

Codes can be...

combined, linked, changed, removed  
promoted to (initial) themes



Patterns across the data

Jot down thoughts: qualitative analysis as part of **writing up**



Using reflexive thematic analysis...

themes were developed **from data**, during the 'coding process'

think about **your research question(s)**: How do hospital staff communicate with family carers when planning care for nutrition and hydration for people with severe dementia in acute hospitals and after discharge?



# TA: Developing themes (multiple facets)

During the coding process... I repeatedly saw 'shared decision-making', 'best-interest', 'consult carers', 'involve MDT', 'over-assumption', 'using medical notes'....

Writing up (**multiple facets**): 'The communication needs all of these to meet everyone's needs and preferences, but it can be fragmented across the MDT and people may not consider the best-interest of the person... so on...'

**Initial theme:** *Keep everyone in the equation* (but this's still one facet, not reflecting the pattern)

**Refining** and naming: **working with your team** (regular meeting, presentation and discussion of themes)

Finalised Theme 2: **Communication** aiming to develop **agreed** care plans

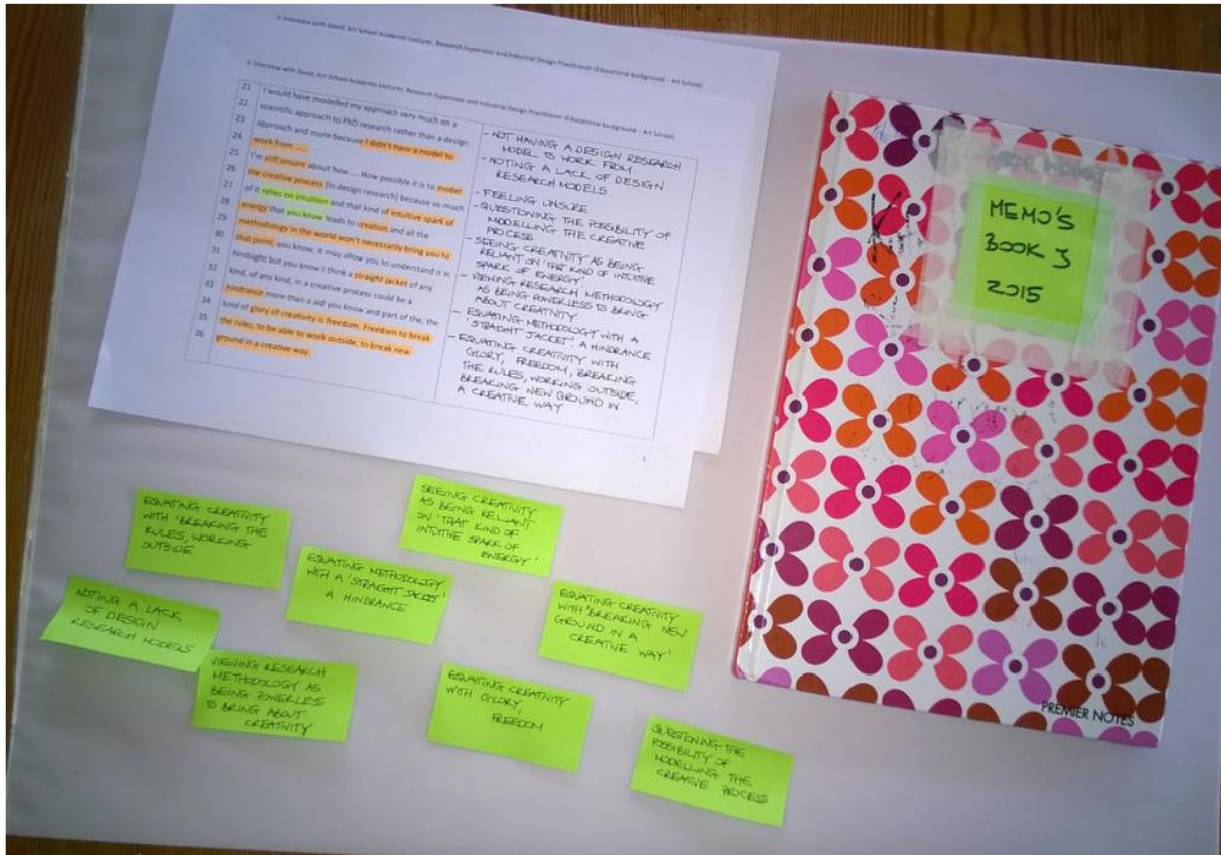
# TA: Developing themes (multiple facets)

(Anantapong 2022)

Then themes were **finalised**... and we had four themes\*...

1. Prerequisites to initiating communication about eating and drinking
2. Communication aiming to develop agreed care plans
3. Difficulty discussing palliative and end-of-life care
4. Needs of information and plans about future eating and drinking difficulties

\*Not simply a **topic** like 'initiation of conversation,' 'communication about eating and drinking,' 'discussion about end-of-life care,' or 'information about eating'



# Traditional methods

Paper, coloured pens, sticky notes,  
large format display boards

MS Word and Excel

# ประสบการณ์และรูปแบบการพัฒนาคุณภาพชีวิตโอริงอัสลี อำเภอจะแนะ จังหวัดนราธิวาส

ผู้วิจัย: รศ.ดร.จุฑารัตน์ สติรปัญญา คุณประเวศ หมีนเสน

## วัตถุประสงค์การวิจัย

- เพื่อศึกษาประสบการณ์และรูปแบบการพัฒนาคุณภาพชีวิตโอริงอัสลีของผู้เกี่ยวข้อง
- เพื่อศึกษาคุณภาพชีวิตของโอริงอัสลี หลังจากเปลี่ยนสถานะ

## กลุ่มผู้ให้ข้อมูลหลัก วิธีการ สันทนากลุ่ม

- เจ้าหน้าที่ภาครัฐฝ่ายปกครอง ผู้นำชุมชนโอริง ผู้สูงอายุ นายจ้าง ครู กศน.

## ประเด็นคำถาม

- ในการพัฒนาคุณภาพชีวิตของกลุ่มนี้ มีการดำเนินการอย่างไร
- หลังจากได้รับความเป็นพลเมืองไทย ได้รับบัตรแล้วคุณภาพชีวิตเขาเป็นอย่างไร

A2 : เราไปพูดคุยขอคำปรึกษากับ [ชื่อ] [ตำแหน่ง] หัวหน้ากลุ่มงานทะเบียน พบว่าเขาใช้วิธีการตาม  
ข้อกฎหมาย ปลัดเล่าว่าตอน ปี 2563 แกลได้รับหน้าที่ให้แก้ไขปัญหาสถานะ โอรังของอำเภอเบตง ซึ่งมี 2 กลุ่ม  
คือ กลุ่มนากอ ไปที่ทับ พบว่ามี 54 คน หลังจากนั้น หนังสือสั่งการที่กรมการปกครองส่งมาให้ได้ย้อนไปดู 3  
ฉบับ 29 กรกฎาคม 2553 แนวทางเดินตามหนังสือสั่งการ การจัดการปัญหาสถานะให้ชาโก หรือมานิ ศอ.บต.  
จัดศึกษาดูงานที่มะนัง ละงู และดูการเพิ่มชื่อสำเร็จที่รัตภูมิ เพื่อให้การแก้ไขสถานะของบุคคล...ถูกต้อง โดย  
การเพิ่มชื่อในทะเบียนราษฎร เขาเป็นบุคคลบุคคลที่ไม่ได้แจ้งเกิด ในขณะเดียวกันก็ไม่มีเอกสารใดๆ การ  
ดำเนินการก็จะทำโดยการสอบสวนพยานบุคคล

A1: ที่นากอ เราใช้การลงไปพูดคุย ที่นั่นมีผู้สูงอายุที่ทำสวนฮาลา ยืนยันได้ว่าเขาอาศัยอยู่จริง ปกษา  
นิติกร กรม (กป.14) เพื่อจะคำนวณอายุ วันเดือนปีเกิด ใช้วิธีเทียบเคียงกับคนในพื้นที่ เช่น เกิดไล่ๆ กับลูกใคร  
ตอนที่เราเห็นเขากระต๊อๆ ใส่ผ้า สะพายหลัง

A2 : เอกสารที่เคยเข้าประชุม.....สำเร็จเมื่อ ก่อนปีใหม่ ทำบัตรประชาชน 54 ราย ตอนนี้ 61 คน เด็ก  
เกิดใหม่ แจ้งเกิดปกติ มีชื่อ ตามระบบทะเบียนราษฎร

A4 : ทีมเราลงไปไม่รู้กี่ครั้ง ไม่ใช่ว่าครั้งแรก ครั้งสองครั้งจะได้เลย โห...ผมว่า ไม่ใช่เรื่องง่าย กว่าจะคุ  
ยกันเข้าใจ บางกลุ่ม คุยกัน 2-3 ครั้ง บอกว่า ทำเลย พออยู่ไปสักพัก ไปได้ยินอะไรมา บอกว่า ไม่ทำแล้ว

B1: “ตอนแรกก็จะไม่ไป เพราะกลัว ไม่เคยเข้าโรงพยาบาล หมอบอกว่า ถ้าไม่ไปก็จะเดินไม่ได้ เพราะ  
กระดูกสะโพก และกลัวจะไปโดนเอดด้วย...(ชี้ที่สะโพก) ไปโรงพยาบาล เจ้าหน้าที่โรงบาลเล็ก (รพ.สต.) กับ  
ศอ.บต. พาไป ตอนแรกกลัว ไม่เคยรู้จักโรงพยาบาล เดินไม่ถูก สว่างไปหมด กลัว ยิ่งเขาบอกว่าจะผ่าตัดยิง  
กลัว กลัวว่าเขาจะเอาเนื้อเราไปหมด.....”

B2: “กลัวมากกับโรงบาล ผ่าแล้ว ในพุงมันจะหายไปหมด แล้วถ้าผมตาย ลูกเมียผมจะกินอะไร จะอยู่กับ  
ใครอะ”

B2: “เมื่อก่อนกลัว.....เพราะไม่เคยเห็น.... กลัวคนไทยทำร้ายเรา .....ตอนนี้ไม่กลัวแล้ว  
“ตอนมาคุยกับเพื่อนๆ ในกลุ่ม ให้เขามาทำบัตร ผมก็ไปคุยกับกลุ่มอื่นด้วย เมื่อก่อนอีกกลุ่มจะไม่เอา  
ผมบอกว่า ผมเอา”

Theme	Code
รูปแบบการพัฒนาคุณภาพชีวิตโอรังอัสลี	
วางแผนดำเนินการโดยยึดการปฏิบัติตามข้อ กฎหมาย และการมีสิทธิเป็นพลเมืองไทย แต่ ไม่ได้แจ้งเกิด ไม่มีเอกสาร	สี่เทา การปฏิบัติโดยยึดข้อกฎหมายตามหนังสือสั่งการ ของกรมการปกครอง เรื่องการจัดการปัญหาสถานะและสิทธิของบุคคล กลุ่มชาติพันธุ์มานิ ชา โก จัดการสถานะบุคคลและการจัดทำทะเบียนราษฎร เพื่อแก้ไขปัญห าสถานะบุคคลของกลุ่ม
เรียนรู้ ขอคำปรึกษา จากพื้นที่ตัวอย่างที่ ดำเนินการสำเร็จ คือพื้นที่ชุมชนนากอ ตำบลอัยเวง อำเภอจังหวัดยะลา	สี่เหลือง ต้นแบบ นากอ ปลัดอำเภอเบตงเป็นบุคคลต้นแบบในการทำงาน พื้นที่ต้นแบบมีประสบการณ์จากพื้นที่อื่นๆ ได้แก่ สตูล รัตภูมิ ขอคำปรึกษา วิธีดำเนินการจากต้นแบบ ทำอย่างไร
มีขั้นตอนการดำเนินการชัดเจน - ค้นหากลุ่มที่เข้าเงื่อนไขสำคัญ คือ มีที่อยู่ เป็นหลักแหล่ง อยู่ในพื้นที่ประเทศไทย สมัครใจ ที่จะเปลี่ยนสถานะ - ลงพื้นที่ สืบสารทำความเข้าใจในสิทธิ หน้าที่ของพลเมืองไทย - จัดทำข้อมูลรายบุคคล เครือญาติ โดยการ สอบสวนข้อมูลจากคนรอบข้าง คนในพื้นที่ ใช้ ข้อมูลจากการบอกเล่า หลักฐานการเทียบเคียง	สี่ฟ้า ลงพื้นที่ หาข้อมูลจากผู้สูงอายุที่ทำสวนฮาลา ผู้นำชุมชน นายจ้าง เพื่อ ยืนยันการอาศัยอยู่จริง เทียบเคียงเพื่อคำนวณอายุ วันเดือนปีเกิด จนท.ปกครอง ท้องที่ ลงไปพบหัวหน้าเผ่าและแกนนำ สืบสารทำความเข้าใจ ในสิทธิ หน้าที่ของพลเมืองไทย หลังทำบัตรประชาชน จะได้รับ อะไร และมีหน้าที่อย่างไร จัดทำผังเครือญาติ อำเภอเคลื่อนที่ บริการทำบัตร
ปัญหาอุปสรรค ลักษณะทางภูมิศาสตร์ สถานการณ์ การรับรู้ การสื่อสารในพื้นที่	สี่แดง การเดินทาง สถานการณ์ความไม่สงบ การสื่อสารไม่ชัดเจน ความกลัว ความเข้าใจเรื่องการนับถือศาสนา



# **Practice 1:** Muslim parents' beliefs and factors influencing complete immunization of children aged 0-5 years in a Thai rural community: a qualitative study

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**Investigators:** Taqwa Jinarong, Rattanaporn Chootong, Polathep Vichitkunakorn, Praneed Songwathana

**Objectives:** To investigate Muslim parents' beliefs and factors influencing them to complete immunization of children aged 0-5 years in Yala province, Thailand

**Participants:** Muslim parents, community/religious leaders

**Data collection method:** Three homogenous groups of complete vaccination, incomplete vaccination, or community/religious leaders

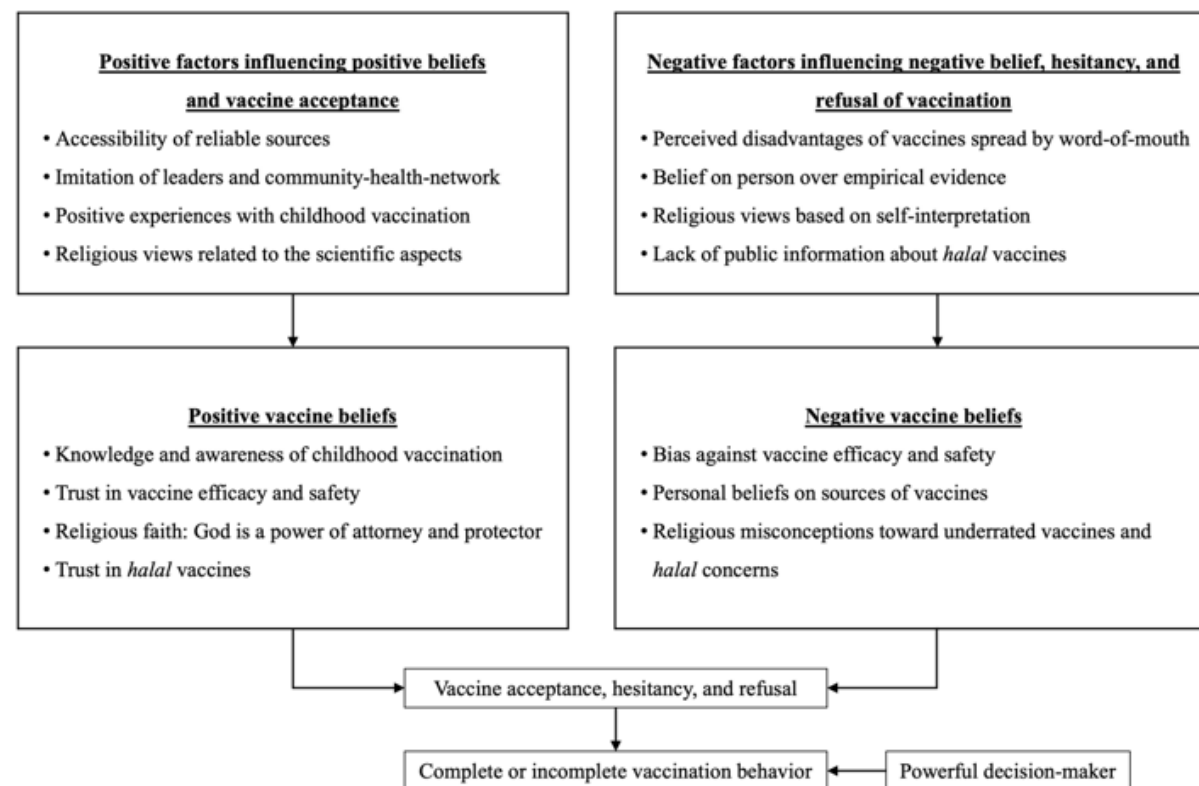
Parent 1	97	สามีเป็นคนปฏิเสธตั้งแต่แรก เราเองที่พยายามจะศึกษาข้อมูลก่อน ครั้งแรกเราก็พาไปฉีดนะคะ แต่พอฉีดแล้วมีไข้สามีเลยยังปฏิเสธเข้าไปใหญ่เลยคะ ทั้งที่เขาก็มีเหตุผลของเขาแต่เราก็ไม่สามารถที่จะถามเยอะได้ว่าเพราะอะไร	อำนาจการตัดสินใจอยู่ที่สามีเพราะเป็นผู้นำครอบครัว
Modulator	98	แล้วเขาเคยแฉง ๆ บอกไหมว่าเพราะอะไรคะ?	ภรรยาต้องเชื่อฟังสามี แม้ว่าไม่ทราบเหตุผลเชิงลึก
Parent 1	99	เหมือนที่กล่าวไปข้างต้นว่าไม่มั่นใจในตัววัคซีน	
Modulator	100	ก็คือว่าเห็นผลข้างเคียงชัด ๆ เลย แต่ไม่รู้ว่าได้ประโยชน์จากวัคซีนจริงไหม แบบนี้ไหมคะ?	
Parent 1	101	ใช่ค่ะ	ภรรยาต้องเชื่อฟังสามี แม้ว่าภรรยาจะเห็นต่าง
Modulator	102	หมอขอถามอีกนิดนึงคะ ถ้าวัคซีนที่ได้เป็นของดีจริง มีประสิทธิภาพในการป้องกันโรคได้จริง [ชื่อ] จะฉีดไหมคะ?	
Parent 1	103	มีเกณฑ์อะไรที่คิดว่าดีจริงมีประสิทธิภาพจริงคะ?	
Modulator	104	จากงานวิจัยบอกว่ามีประสิทธิภาพในการป้องกันโรค 99% แบบนี้มีคำแนะนำเชื่อถือไหมคะ?	
Parent 1	105	ตัว [ชื่อ] เองไม่ค่อยมีปัญหาเท่าไร แต่จะไปกระทบกับตัวสามีอีกที่	
Modulator	106	หมายถึงเราก็ต้องฟังเหตุผลของสามีด้วยใช่ไหมคะ?	
Parent 1	107	ใช่ค่ะ เขาเป็นผู้นำครอบครัว	
Modulator	108	สามีกังวลเรื่องอื่นอีกไหมคะ? นอกจากผลข้างเคียง	
Parent 1	109	เมื่อเขาก็กังวลถามแถมอยู่เลยว่าเพราะอะไรถึงปฏิเสธวัคซีน แกก็บอกว่าไม่มั่นใจในตัววัคซีน ขนาดว่าวัคซีนช่วยสร้างภูมิต้านทานเพื่อป้องกันโรค แต่เด็กที่ฉีดก็ยังเป็นอยู่อีก แต่คนที่ไม่ฉีดกลับไม่ได้เป็นอะไร แกว่าแบบนี้อะคะ	
			เชื่อว่าวัคซีนที่ได้รับในปัจจุบันไม่มีคุณภาพ และไม่ปลอดภัย  เห็นตัวอย่างเด็กได้รับวัคซีนครบแต่ป่วยบ่อย จึงเชื่อว่าวัคซีนไม่ดี

1. ความรู้ความเข้าใจเรื่องโรคและวัคซีน		
Main-theme	Sub-theme	รหัส (code)
1.1 อาการและความรุนแรงของโรคติดต่อที่ป้องกันได้ด้วยวัคซีน	“ตระหนักรู้ เมื่อยามลูกป่วย”	เรียนรู้ลักษณะอาการจากประสบการณ์ตรงที่ลูกป่วยเป็นโรคหัด
		เข้าใจอาการและความรุนแรงของโรคหัดตั้งแต่ระดับเล็กน้อยไปจนถึงเสียชีวิต รับรู้ว่าการเจ็บป่วยด้วยโรคติดต่อฯ ส่งผลกระทบต่อทั้งทางกายและจิตใจของเด็กและผู้ปกครอง
1.2 ประโยชน์ของวัคซีน	“วัคซีนเป็นสิ่งสำคัญ เพราะช่วยป้องกันโรค ดีกว่ารักษาภายหลัง”	เห็นความสำคัญของวัคซีนเพราะมีประโยชน์ในการป้องกันโรค ซึ่งดีกว่ารักษาทีหลัง
		เชื่อว่าวัคซีนช่วยเสริมภูมิคุ้มกัน
		เชื่อว่าวัคซีนช่วยป้องกันโรค
		เชื่อว่าวัคซีนทำให้เด็กสุขภาพแข็งแรง
		เชื่อว่าวัคซีนช่วยลดความรุนแรงของโรคได้
1.3 ความรู้ความเข้าใจเรื่องผลข้างเคียงของวัคซีน	“การสร้างภูมิคุ้มกัน จำเพาะตามวัย ผิดนัดวัคซีนคือการเสียโอกาส”	จะเกิดความรู้สึกเสียใจหากลูกป่วยด้วยโรคติดต่อฯ เพราะไม่ได้รับวัคซีน
		ใส่ใจเรื่องรับวัคซีนให้ตรงนัด เพราะเชื่อว่าจะเสียโอกาสสร้างภูมิคุ้มกันที่เหมาะสมเฉพาะวัย
	“ผลข้างเคียงของวัคซีนที่มากกว่าใช้ คือกังวลไปเอง”	กังวลว่าหากรับวัคซีนล่าช้าจะส่งผลเสียต่อพัฒนาการลูก
		ปัจจุบันไม่กล้าพาลูกออกนอกบ้านไปรับวัคซีน เพราะกลัวความเสี่ยงติดเชื้อโควิด
		ผู้ปกครองที่มีประสบการณ์สูงจะเข้าใจเรื่องการชะลอรับวัคซีนเมื่อมีไข้หรือยามจำเป็น และสามารถปรับเวลานัดวัคซีนได้เองตามความเหมาะสม
		ยอมรับผลข้างเคียงระดับเล็กน้อยเพราะเชื่อว่าเป็นภาวะปกติหลังรับวัคซีน
		เชื่อว่าวัคซีนแต่ละชนิดมีผลข้างเคียงแตกต่างกัน แต่ส่วนมากมีอาการไม่รุนแรง
		ผู้ปกครองบางส่วนมักเกิดความกังวลว่าจะมีผลข้างเคียงรุนแรง
		เชื่อว่าเกิดผลข้างเคียงรุนแรงหลังรับวัคซีนตามที่ได้รับข่าวมา
		มีความกังวลล่วงหน้าเรื่องภาวะพิการหลังรับวัคซีน
		พ่อแม่เมื่อใหม่ประสบการณ์น้อย มีความกังวลล่วงหน้าว่าลูกจะมีผลข้างเคียงหลังรับวัคซีน
		ประสบการณ์แพทย์รุนแรงทำให้เกิดความกลัวล่วงหน้าว่าจะแพ้วัคซีน

6. ความเชื่อส่วนบุคคล ศาสนา และวัฒนธรรม

Main-theme	Sub-theme	รหัส (code)
6.1 มุมมองเชิงศาสนา กับการป้องกันโรค	“การมอบหมายต่อพระเจ้า: น้อมรับทดสอบเรื่องการ เจ็บป่วย ศรัทธาว่าโรคต่าง ๆ จะถูก กำหนดมาพร้อมการรักษา”	เชื่อว่าศาสนาอิสลามส่งเสริมให้รับวัคซีน เพราะมีบทบัญญัติเรื่องการป้องกันและรักษาโรค
		การมอบหมายต่อพระเจ้าที่แท้จริง คือการยอมรับความเจ็บป่วยคือบททดสอบจากพระเจ้าที่ถูกกำหนดมาพร้อมวิธีการรักษา แล้วพยายามป้องกันรักษาโรคให้ดีที่สุด
		ศรัทธาเรื่องการมอบหมายต่อพระเจ้าในการป้องกันและรักษาโรคผ่านวัคซีน
		ศรัทธาเรื่องการมอบหมายต่อพระเจ้าในการยอมรับผลข้างเคียงวัคซีน
		ศาสนาอิสลามมีคำสอนเรื่องการดูแลสุขภาพจิต ควรพูดคุยให้กำลังใจผู้ปกครองเพื่อคลายความกังวลเรื่องวัคซีน
	“วัคซีนคือ ‘ฮิกมะห์’ ต้องเรียนรู้และปฏิบัติ”	เชื่อว่าพระเจ้าสร้างความเจ็บป่วยมาพร้อมกับวิทย์ปัญญาในการรักษาโรค
		เชื่อว่าวัคซีนคือวิทย์ปัญญาหรือวิธีการรักษาโรคอย่างหนึ่งจากพระเจ้าที่เป็นข้อบังคับต้องเรียนรู้และปฏิบัติ
	“ค้อยคำเรื่องการป้องกัน: ไม่เท่าการรักษาโรค ด้วยเงื่อนไขวัคซีนต้องดีจริง”	เชื่อว่าศาสนาอิสลามส่งเสริมให้รับวัคซีน แต่ต้องเป็นวัคซีนที่ดีเท่านั้น เชื่อว่าวัคซีนในปัจจุบันยังไม่ดีพอ
	“ตีความศาสนาต่างออกไป ปฏิเสธวัคซีนคือ การมอบหมายต่อพระเจ้าแล้ว”	เชื่อว่าการไม่รับวัคซีนคือการมอบหมายต่อพระเจ้าในเรื่องความเจ็บป่วย

Map of themes and sub-themes



## **Practice 2:** Attitudes and perceptions towards advance care planning in elderly patients with cancer and their caregivers

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**Investigators:** Supakorn Sripaew, Sawitri Assanangkornchai, Polathep Vichitkunakorn, Rungarun Kittichet

**Objectives:** To describe attitudes and perceptions towards advance care planning in elderly patients with cancer and their caregivers

**Participants:** Elderly patients with cancer and their caregivers

**Data collection method:** Individual semi-structured interviews

I บางทีคุณหมอจะต้องรักษาอย่างไร เช่นต้องผ่า ต้องใส่ท่อ ต้องทำหลายๆ อย่าง แต่ว่าโอกาสที่จะดีขึ้นน้อย หากลองทำหมอก็ไม่รู้ว่าจะคุ้มรึปล่าว อีกทางนึง เราไม่ลอง แล้วเราก็รักษาอาการ ...	Trust in physicians Poor prognosis Risks vs benefits
P น้อง ถ้าว่า พี่ขอน้ำ ใส่ท่อ พี่ขอ เพราะว่าแม่เสียกับใส่ท่อ	Perception about aggressive treatments Death of close family
I สำหรับคุณ (ชื่อ) เรื่องท่อช่วยหายใจ คุณ (ชื่อ) รู้สึกว่า ...	
P รับไม่ได้ ใส่ท่อ	Perception about aggressive treatments
I เป็นเพราะอะไรครับ	
P ซื้อมาได้	
I คำว่า "ซื้อมา" คุณ (ชื่อ) เห็นว่ามันเป็นอย่างไรครับ	
P แม่ แม่ไม่ใช่ถึงกับอาการที่หนักแล้วนะ หมอยังช่วยได้ แต่ไปถึงรพ. (ชื่อรพ. อำเภอ) เคาะไปไม่ทัน เคาะก็ใส่ท่อ ถึงพอไปรพ. (จังหวัด) แม่ไปวันที่ 30 ถึงแผนพามาแม่กลับวันที่ 2 ถึงแม่บอกว่าแกทำมือแหละนะ ว่าพาแกกลับบ้านแหละหนา แกหลงไม่ได้ หลานแกเป็นนางพยาบาลอยู่รพ. (ชื่อจังหวัด) พอเครื่องมือกลับมาถอดที่บ้าน เคาะบอกว่า " แม่ตายผ่านหรือเคาะไม่รับผิตชอบนะ" ถึงเราว่า "ลูก 9 คน ไม่เอาความผิดกับหมอ เพราะว่าแม่นั้นอยากกลับบ้าน" หมอว่า อยู่กับแม่ 14 วัน วันที่แม่มาใส่ท่อ แม่เสียพัน	(Methods to) communicate with the dying <u>person</u> Respect the wishes of the dying <u>person</u> Fear of legal consequences Perception about aggressive treatments
I คุณ (ชื่อ) คิดว่าเรื่องใส่ท่อ ทำให้ คุณแม่ อาการหนักมากขึ้น	Treatments fastening the <u>death</u>
P ไม่บางคนอะนะน้อง บางคนนะ บางคนนั้นใส่ท่อช่วยรอดได้ โอนนั้นนั้นเรียกว่าแบบช็อคนั้น คือแม่ไม่ถึงกับสาหัส แต่พอแม่ใส่ท่อเข้าไป พอถึงว่า คนแก่อะนะ	Death of close family Age of the dying person

P ถูกต้อง เอ้อ! บางทีคนไข้เขียนไว้ให้กับคุณหมอ หรือว่าคนไข้เขียนไว้ให้กับญาติ ว่า ถ้าว่าหมอใส่อะไรผ่านหรือ สมมติว่า ขอโทษนะผมใช้คำหยาบ สมมติว่า หือ ผมเขียนไว้แล้ว คนไข้เขียนไว้แล้ว เหมือนหมอมว่า ถ้าเราถอดได้แล้วจะทำหรือ ถึงว่า สมมติว่า คนไข้หลงไม่ได้ เคาะเขียนก็เท่ากับว่าเคาะก็เขียนไว้ก่อนหน้านี้เพื่อว่า เค้านั้นหลงไม่ได้ ถ้าเคาะหลงได้ก็ไม่ต้องเขียนก็ได้ เคาะเขียนตักไว้ก่อนว่าเพื่อว่า รักษาไปๆ หมอถามไม่ได้ คือเขียนไว้ ความคิดคนไข้คือเขียนไว้ว่า ถ้าเคาะ ยกตัวอย่างว่าหมอ ใส่สายอะไรต่ออะไรก็แล้วแต่ ใส่ไว้แล้ว ใส่ไว้ก่อนแล้ว ก็ว่าผ่านหรือ ให้ถอด หรือว่า ไม่ต้องใส่	Documentation of advance decisions Respect the wishes of the dying <u>person</u> Treatment withdrawal decisions Trust in physicians
I ครับถูกต้องเลย	
P ครับ คือว่าถ้าผ่านหรือคือว่าไม่ต้องใส่ แล้วผ่านนั้น คือนั้นหลงว่าคนไข้หลงไม่ได้ แล้วผ่านนั้น หมอว่าหรือก็ว่า วิสัยนั้น มีสายนั้นมีสายนี้ สายคนไข้ เขียนไว้แล้วว่าไม่ต้องใส่ก็ไม่ต้องใส่	

**Objectives:** To describe attitudes and perceptions towards advance care planning in elderly patients with cancer and their caregivers

## Initial theme development (Examples 2.1 and 2.2)

- Open and honest discussion with family members but may not with older persons.
- Strong influence of family members in making the decisions – although they would respect the wishes of the person, they sometimes override the person's decisions.
- Trust with the physicians, but they might be hiding something to avoid creating unnecessary anxiety in patients and their family.
- Poor awareness and understanding about advance care planning



# Qualitative data analysis software

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MAXQDA, Nvivo, ATLAS.ti ... and so on

Unfortunately, not analysing the data for you

... you still need to code the data and develop themes

But will help...

store and organise the data (e.g. transcripts, fieldnotes)

facilitate coding process and organise codes

visualise and identify patterns (and themes): divergent and disparate data

retrieve illustrative data

File

Home

Import

Create

Explore

Share

Document

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Zoom

Annotations

Quick Coding

Layout

See Also Links

See Also Links

Relationships

Coding Stripes

Highlight

Code

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New Annotation

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Query This Document

Query

Find

Edit

Links

Quick Access

Data

Cases

Notes

Search

Maps

Output

Files

Memos

Nodes

Files

File Classifications

Externals

Nodes

Relationships

Relationship Types

Files

Search Project

Name	Codes	References
Anonymised_C01_04.12.20	57	116
Anonymised_C02_16.02.21	66	144
Anonymised_C03_22.01.21_part12	59	144
Anonymised_C04_28.01.21	76	249
Anonymised_C05_09.02.21	74	210
Anonymised_C06_23.02.21	70	169
Anonymised_C07_05.03.21	75	182
Anonymised_C08_09.03.21	82	236
Anonymised_C09_15.03.21	80	203
Anonymised_C10_23.03.21	72	206
Anonymised_C11_24.03.21	74	244
Anonymised_C12_25_03.21	77	216
Anonymised_Pf01_25.02.21	57	173
Anonymised_Pf02_02.03.21	68	216
Anonymised_Pf03_23.03.21	75	220
Anonymised_Pf04_16.03.21	78	293
Anonymised_Pf05_05.03.21	84	317
Anonymised_Pf06_18.03.21	84	296
Anonymised_Pf07_18.03.21	74	208
Anonymised_Pf08_28.04.21	70	247
Anonymised_Pf09_18.03.21	70	221
Anonymised_Pf10_07.05.21	69	246
Anonymised_Pf11_05.05.21	75	269
Anonymised_Pf12_12.05.21	58	163
Anonymised_Pf13_12.05.21	77	325
Anonymised_Pf14_19.05.21	72	246
Anonymised_Pf15_20.05.21	81	280
Anonymised_Pf16_26.05.21	72	235
Anonymised_Pf17_26.05.21	78	260

Anonymised\_C01\_04.12.20

Click to edit

So she [00:07:30] was in hospital for a total of six weeks during that time –

Interviewer: Wow, so long.

Respondent: [00:07:34] – and I kept saying that I needed her to come home, that it wasn't good for her. She had type 2 diabetes but she was controlling it with taking pills. Is it Metformin? I've forgotten the name. I think it is.

Interviewer: Yes, it might be Metformin.

Respondent: [00:07:50] Yes. But during the time that she was in this rehabilitation hospital, very [00:08:00] soon her diabetes became [00:08:00] worse and she needed to start to have insulin. And also she developed bedsores which she never had had before.

And also during that time, they said that she was having problems swallowing, and she'd never had any problems at all before that.

Interviewer: Oh, that's the time that she had in hospital, right?

Respondent: [00:08:26] Yes. It was really strange, it wasn't obvious to me that she couldn't eat food, but they were saying she couldn't. Well, they were saying, the therapist, what's the therapist who looks after what you eat and drink called? Um...

Interviewer: So you do have \_\_\_ to discuss about that eating and drinking problem?

Respondent: [00:08:53] Yes. What's the name of the, is it occupationa- Who's the type of therapist who –

Interviewer: Yes, occupational therapist maybe.

Respondent: [00:09:00] Is that the person who gives you a sip of syrup to see if you can swallow it and then a sip of water to see if you can swallow it? Anyway, they did that in the hospital and they said someone would come around to the flat after she was discharged but that we should think about only giving her pureed food.

I was a bit discouraged by all these developments. In fact, they didn't want me

Coding Density

Shared decision-making approach to eating drinking decisions

Eating and drinking at home before admission

3.1 Difficulty adapting to hospital meals and timetable

Keep carers updated about PLWD eating and drinking in hospital

Social and environmental factors in hospital care

Wellbeing and QoL of PLWD would determine eating and drinking treatments

Checking capacity of the person with dementia

Links between acute illness and eating problems

Need support for eating at home or care home

Considering the prognosis of dementia and/or acute illness

Having a carer or someone to support eating at hospital

Want to know expected outcomes of interventions for PLWD

Noticing and investigating eating problems in hospital

Support for eating drinking difficulties at the EoL in hospital

Attitudes towards ANH for PLWD

Knowing the person and respecting their decisions and autonomy

Want to listen to professionals' opinions or recommendations

Any discussions for general dementia care including community services

Cultural, social or personal beliefs of eating and drinking

General attitudes of the carers regarding eating and drinking PLWD

3.1 xOther physical conditions including constipation and incontinence

Hospital environment and familiar surroundings

Modified consistency or enhancement

Involve PLWD by helping communicate what the person wants or feels

Hospital dementia care in general

Initiate conversations about eating and drinking

Understanding of the causes and consequences of eating problems related to dementia

In

Nodes

Code At

Enter node name (CTRL+Q)

KA

29 Items

Codes: 57 References: 116

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Uncode

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Annotations

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Query

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Node

Carer and Staff\_interviews\_NutriDemH\_17.08.21.nvp - NVivo 12 Pro

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Memos

Nodes

Data

Files

File Classifications

Externals

Codes

Nodes

Relationships

Relationship Types

Cases

Notes

Search

Maps

Output

Nodes

Search Project

Name	Files	Referenc
1. Baseline eating and drinking at home	0	0
Advance care planning	0	0
Advance discussions or care plan but ignori	25	71
General advance planning	16	26
Eating and drinking at home before admission	1	1
Medication management at home	3	3
Need support for eating at home or care h	20	35
General attitudes of the carers regarding eatin	9	16
2. Difficulties in sharing information about eating	2	2
Bridging medication management between ho	9	18
On admission assessment about baseline dem	26	112
3. (Under)recognising eating and drinking difficulti	0	0
3.1 Chewing, holding and false teeth problems	11	22
3.1 Difficulty adapting to hospital meals and ti	25	59
3.1 Distraction causing eating drinking proble	6	8
3.1 Eat and drink less or not wanting to eat	21	53
3.1 Swallowing difficulties and choking in hospi	22	66
3.1 Unable to eat food or drink water properly	19	59
3.1 xOther physical conditions including consti	25	56
Dementia not considered during treating acute	13	24
Focus more on the acute illness than eating pr	20	46
Hospital staff cant see PLWD as individuals	20	51
Links between acute illness and eating proble	23	77
Noticing and investigating eating problems in	26	88
Over-assumption eating and drinking ability in	16	26
Short hospital stay nobody looks at eating	13	20
4. Conversation patterns around eating at hospital	0	0
Carers feelings re eating drinking difficulties an	28	125
Checking capacity of the person with dementia	24	73
Closely observe and listen what the person wa	25	91
Consult carers for what food PLWD like and ho	28	116

Try offering food and drinks at I

Use of feeding tube during hosp

Timelines and trials of using the

Shared decision-making approach

Involvement MDT team in assessing

Reference 4 - 1.85% Coverage

Sometimes, you know, I – it's very, very important to involve the carer and the family, but in my opinion, I've seen it times where I've felt that we've – [00:33:29] we're sort of over-medicalising things when actually that isn't in that patient's best interests. And I feel like the family will really want the patient to be treated like IV antibiotics, IV fluids, putting a – put in a peg, when I'm looking at this patient, thinking, 'like, is this actually what that patient or this person wants? And is it the right thing for them?' And sometimes – [00:33:59] I don't know – sometimes I'm not sure. Sometimes I think sometimes we sort of – I think it's sort like a – in the medical world, we try – like try and do everything for patients. But sometimes it is really the right thing. And I think it does depend on how pushy families and carers are [00:34:29]. I do think that has an impact, and what that consultant's view on-on sort of things are, and I think there is quite a bit of variation in patient outcomes, depending on those factors.

Reference 5 - 1.35% Coverage

And I think it can empower the carer as well, which I think is really great, because I think that's really important. Because a nurse is only gonna be looking after that patient for their admission. The majority of the time it's gonna be the carer who's supporting their nutrition and hydration, so they should be the ones with the most knowledge. And, you know, they've probably got the most experience because they're looking after that person all the time, that they should be the ones to feel [00:49:35] quite empowered. And I think that is a problem, just not around nutrition and hydration, but more full-term with carers and families that are looking after their loved one with dementia. You know, they don't – they don't have an understanding or knowledge.

Reference 6 - 1.42% Coverage

I think – I think that [01:01:28] probably – yeah, putting a – putting a peg back in wouldn't really be an appropriate option and explaining why that would be – you know, she's been pull-pulling at the peg. It's obviously causing her quite a lot of distress. Is that what you kind of want – would really want for your mum or dad? And explaining the, you know, sort of comfort eating, what that involves, you know, what the [01:01:58] potential risks of that are as well. And, you know, explain – I think – I think just – I think putting the peg in – I mean, I would be quite against – I think that wouldn't be the

Coding Density

Involvement MDT team in assessing and planning

Finding balance how much intervention to do and best interest

Who should be involved in the decisions and discussion

Want to listen to profession?

Summary

Reference

Text

On admission assessment about baseline dementia and eating problems

Decision support - suggested process

Preparedness to eating and drinking decision or conversation

Checking capacity of the person with dementia

Formal discussion around eating drinking in hospital

Time pressure on decisions in hospital

Timelines and trials of using the interventions

Involvement PLWD by helping communicate what the person wants or feels

Attitudes towards ANH for PLWD

Use of feeding tube during hospital

Goals of care consistent to overall progression of dementia

Want hospital staff let carers ask questions and listen to them

Carers feelings re eating drinking difficulties and decisions

Approach or preferences to eating and drinking decisions at the EoL

Cultural, social or personal beliefs of eating and drinking

Knowing the person and respecting their decisions and autonomy

Professional background approaching in different ways

xReflecting about the conflicting decisions or ineffective support

Consult carers for what food PLWD like and how it should be provided

Understanding of the causes and consequences of eating problems related to der

Comfort hand for risk level

KA

115 Items

Files: 27

References: 124

Unfiltered

100%

# Reporting qualitative research

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Writing up and publication – Journal's scope, interest and word limits

Well-organised patterns and coherent stories (vs random and chaotic)

Use different **language**

Co-construct: generate, develop (avoid using 'reveal, discover, uncover, emerge')

Direct quotes: participants said..., reported..., perceived...

Themes and illustrative data: excerpts from transcripts (quotes) and fieldnotes, photos etc.

|

Organisational policies – such as protected mealtimes, restricted visiting hours and infection control – could further limit opportunities for families to undertake care-giving roles:

*Fieldnotes Site 2: (Daughter talking to her father) 'No one will come tomorrow. It's cleaning day, so they won't let us in tomorrow.'*

Participants generally discussed dementia symptoms and overall progression in relation to memory problems and decreasing levels of awareness. Eating and drinking problems were not yet considered relevant by some who had not experienced them (see illustrative quote 'Theme number 1 Quote number 1' (T1Q1) in Table 3). Many participants focused on the present and hoped that they would die before developing such problems (T1Q2). A few felt the whole subject was irrelevant to them and avoided discussing it.

Anantapong 2021, Kelley 2019

# Illustrative data: Quotes



**Table 3.** Illustrative quotes from people with mild dementia

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Theme 1: Awareness of eating and drinking problems

T1Q1	The bigger problem to me is thinking and not being able to remember things. Forgetting people's names and really think around in your mind and never get it, and suddenly out of the blue, 2 min later, it comes into your mind. To me, that's the area of problem, nothing to do with eating or anything. (P12, male, 81–85 years old)
T1Q2	But to be honest, I don't think that we will arrive there (having eating and drinking problems). I will die before. I am 7X. (P16, male, 76–80 years old)
T1Q3	It's later. I mean call me in a years' time, and my life might have changed. And then we can talk more, if I can still talk. And probably you would involve my wife because she would be the carer. (being asked about a discussion on eating and drinking problems) (P02, male, 76–80 years old)
T1Q4	If they understand. . .that everything's going to be degraded at. . .the end stage. Then these questions would not be so troubling for them and so they could be handled in advance. (being asked about advance discussions on eating and drinking problems) (P17, male, 81–85 years old)

Theme 2: Food and drink representing an individual's identity and agency


T2Q1	I don't know if it's good to say, but I think this illness has changed me completely. That's why I have this faith that I'm going to be better, because I'm doing all the right things and it is that has changed me to live the way I am. (referring to eating healthy food) (P15, female, 71–75 years old)
T2Q2	I'm sorry that my difficulties with swallowing bar me from joining in the food eating in company because I feel that's a shame that I'm missing out on that, but I just can't bear to be where people are shovelling. . . I just didn't want to be there when all I could eat was grapes. (P09, female, 71–75 years old)
T2Q3	They'd be changing, reversing it round. I'm the mother of them and then it would turn around and they'd be the mother of me almost, and I wouldn't like that. (P03, female, 76–80 years old)
T2Q4	But if the person is in really advanced dementia, I'm not sure how much they'll notice that and if they do notice it wouldn't really be a problem to them. They're not active. I don't imagine they're active; do they get up and walk around? (being asked about gastrostomy and intravenous hydration) (P17, male, 81–85 years old)



# Illustrative data: Quotes

## *Difficulty discussing palliative and end-of-life care*

At the end of life, staff felt the conversations were particularly difficult because they 'can't just jump in and start talking about nutrition and hydration and [feeding and] swallowing at the end of life' (Nurse, PF10). There could be 'a lot of questions about how long someone is [going to] live and if they're [going to] starve to death or die of thirst' (Therapy staff, PF06). Staff needed to understand overall dementia progression, have some indication of prognosis and be sure that the family was ready to discuss end-of-life care.



*'[Families] can see the patient's deteriorating, [feeding and] swallowing's getting more difficult, appetite's deteriorating. They know this conversation has to happen, and maybe for many different reasons a family is resistant to that conversation. They're fearful of what's coming, fearful of the motives of staff, fearful that this means death is more imminent, any combination of those things.'*  
(Nurse, PF10)

# Trustworthiness

Trustworthiness	In preference to*...
Credibility	Internal validity
Transferability	External validity/ generalisability
Dependability	Reliability
Confirmability	Objectivity

\*Counterproductive if using dominant perspectives of quantitative research

# Trustworthiness

Shenton 2004

Trustworthiness	Examples of strategies
Credibility	Adoption of appropriate, well-recognised <b>research methods</b> ; <b>triangulation</b> via use of different methods, different types of informants and different sites; iterative questioning; negative case analysis; <b>debriefing sessions</b> between researcher and superiors; reflective commentary; description of <b>background, qualifications and experience</b> of the researcher, <b>member checks</b> of data collected and interpretations/theories formed; <b>thick description of phenomenon</b> under scrutiny; examination of previous research to frame findings
Transferability	Provision of background data to establish context of study and detailed description of phenomenon in question to allow comparisons to be made
Dependability	Employment of overlapping methods, <b>in-depth methodological description</b> to allow study to be repeated
Confirmability	Triangulation, admission of researcher's beliefs and assumptions, in-depth methodological description to allow integrity of research results to be scrutinised, use of diagrams to demonstrate "audit trail"

# Trustworthiness

We conducted semi-structured individual qualitative interviews with family carers and hospital staff in England and adopted the ontological assumption of critical realism and the epistemological approach of contextualism, which assumes that some authentic reality exists to produce knowledge, but the knowledge is influenced by social factors, so we can only partially assess the reality.<sup>19</sup>

Anantapong 2023

Context and subjectivity (reflexivity)  
**a strength!**

Anantapong et al. *Age and Ageing*\*, 2021  
Anantapong et al. *Age and Ageing*\*, 2022

\*IF: 12.782, No. 1 in Geriatrics and Gerontology (WoS, 2022)  
(all free to download)

## Reflexivity

The research team consisted of psychologists, old age psychiatrists, general practitioners, social care researchers, and speech and language therapists working with people with dementia and carers and with experience of family dementia care. Our research focuses on dementia care at the end of life, and we share a general view that eating and drinking at this stage should focus on quality of life and comfort rather than maintenance of nutritional status. This might have influenced the research. We reflected on our views throughout the research and considered their impact. We also included PPI members to help us design the study and interpret the data to strengthen our approach.

# Quality assessment (checklist?)

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Be explicit about your **theoretical position** (cite it in your paper)

Universal criteria – not particularly useful but may guide the overall structure e.g. COREQ

**‘the tail (the checklist) is wagging the dog (the qualitative research)’**

Flexibility and adaptable – theoretical congruence

See *‘Introduction to Special Issue Quality in Qualitative Approaches: Celebrating Heterogeneity’*

(Lester & O’Reilly 2021) – a series of guidelines or checklists for specific position including TA



# A tool for evaluating TA (20 questions)

Braun & Clarke 2021

**Table 1.** A tool for evaluating thematic analysis (TA) manuscripts for publication: Twenty questions to guide assessment of TA research quality.

These questions are designed to be used either independently, or alongside our methodological writing on TA, and especially the current paper, if further clarification is needed.

*Adequate choice and explanation of methods and methodology*

1. Do the authors explain why they are using TA, even if only briefly?
2. Do the authors clearly specify and justify which type of TA they are using?
3. Is the use and justification of the specific type of TA consistent with the research questions or aims?
4. Is there a good 'fit' between the theoretical and conceptual underpinnings of the research and the specific type of TA (i.e. is there conceptual coherence)?
5. Is there a good 'fit' between the methods of data collection and the specific type of TA?
6. Is the specified type of TA consistently enacted throughout the paper?
7. Is there evidence of problematic assumptions about, and practices around, TA? These commonly include:
  - Treating TA as one, homogenous, entity, with one set of – widely agreed on – procedures.
  - Combining philosophically and procedurally incompatible approaches to TA without any acknowledgement or explanation.
  - Confusing summaries of data topics with thematic patterns of shared meaning, underpinned by a core concept.
  - Assuming grounded theory concepts and procedures (e.g. saturation, constant comparative analysis, line-by-line coding) apply to TA without any explanation or justification.
  - Assuming TA is essentialist or realist, or atheoretical.
  - Assuming TA is only a data reduction or descriptive approach and therefore must be supplemented with other methods and procedures to achieve other ends.
8. Are any supplementary procedures or methods justified, and necessary, or could the same results have been achieved simply by using TA more effectively?
9. Are the theoretical underpinnings of the use of TA clearly specified (e.g. ontological, epistemological assumptions, guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?
10. Do the researchers strive to 'own their perspectives' (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.)
11. Are the analytic procedures used clearly outlined, and described in terms of what the authors actually did

# Wrap-up

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Theoretical **perspectives** and **research questions** are important when designing a study

Data collection and analysis **methods** should be in line with methodological perspectives

Decisions about **sampling** and sample size are aimed to gain rich and complex data

**Thematic analysis** is a flexible and accessible approach and may be used in Medicine

Reporting qualitative research requires specific practices, including for **quality** assessment

Subjectivity and **reflexivity** are a strength of qualitative research, rather than a weakness



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# Any questions or final thoughts?

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**Areas of interest:** dementia, frailty and palliative care for older adults; qualitative research; codesign research; mixed method

**Thank you**