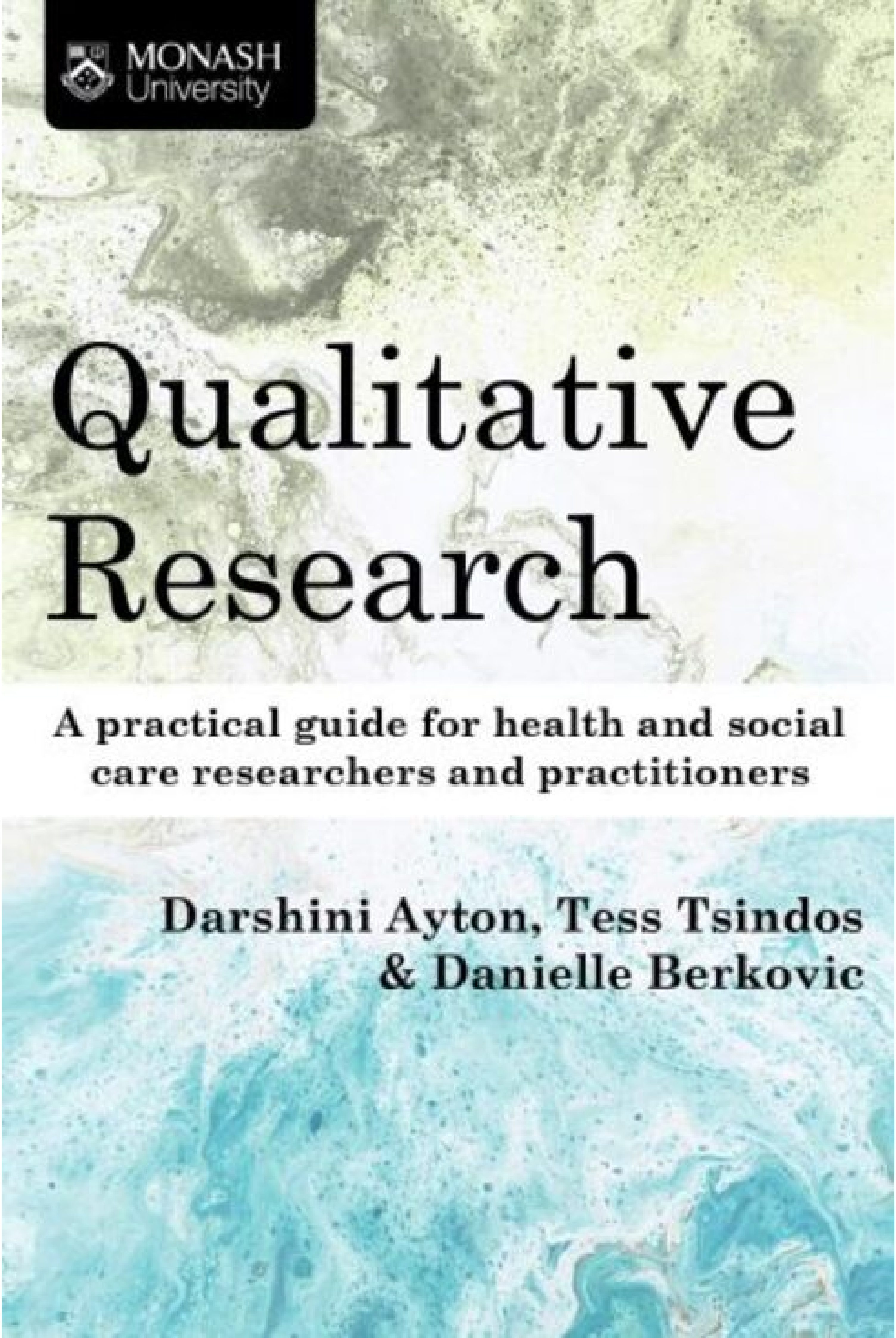

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Qualitative Research

A practical guide for health and social care researchers and practitioners

Darshini Ayton, Tess Tsindos
& Danielle Berkovic

TITLE PAGE

Qualitative Research – a practical guide for health and social care researchers and practitioners

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Qualitative Research – a practical guide for health and social care researchers and practitioners

QUALITATIVE RESEARCH – A PRACTICAL GUIDE FOR HEALTH AND SOCIAL CARE RESEARCHERS AND PRACTITIONERS

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Melbourne, Australia

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The authors gratefully acknowledge the traditional owners of the lands on which we live, learn, teach, research, and write from today – the Wurundjeri people of the Kulin Nation. We pay our respects to elders past and present and future, and recognise that Aboriginal and Torres Strait Islander Peoples are Australia's first storytellers, artists, communities and creators of culture. We recognise their continuing connection to the land and waters and acknowledge that they never ceded sovereignty.

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PREFACE

I discovered qualitative research as a doctoral student in a predominantly quantitative research environment.

As someone trained in biomedical science and quantitative public health research, qualitative research was a new frontier for me.

I taught myself the qualitative research paradigms and designs, methods, and analysis approaches.

I remember being surrounded by qualitative textbooks and feeling lost and confused.

In 2014, the year after finishing my PhD, I designed and launched a three-day short course on qualitative research for public health.

I wanted to provide researchers, clinicians, practitioners, and students with an introduction to the key concepts of qualitative research.

I wanted people to leave the course knowing what to google and read!

I wanted to provide guidance and excitement about what qualitative research is, and what can be achieved through these methods.

This book is the content of the course and more. We draw on our teaching and research experience with examples throughout.

We hope you find this book helpful and wish you all the best on your qualitative research journey.

~Darsh Ayton on behalf of the authorship team

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INTRODUCTION TO RESEARCH

CHAPTER 1: THE WHY OF QUALITATIVE RESEARCH IN HEALTH AND SOCIAL CARE

Darshini Ayton

Learning outcomes

Upon completion of this chapter you should be able to:

- Understand the role of qualitative research in health and social care.
- Describe the differences between quantitative and qualitative research.
- Recognise and understand the words used in qualitative research questions.

Health and social care is complex

Practitioners and researchers in health and social care work across different specialisations in the health system (primary care, tertiary care) and in different settings, including community and residential settings, disability support, aged care, early childhood and other educational settings, health and social service settings, preventive services and supportive services settings. Health and social care encompasses a broad range of disciplines, from medicine, nursing and allied health (e.g. physiotherapy, podiatry, dentistry, occupational therapists) to social work, health promotion, public health and many others.[1]

The word 'care' is at the heart of health and social care— a system of care professions that are relevant across the life span, socio-economic boundaries and social settings. Practitioners and researchers recognise that individuals seeking to access supportive services, such as disability services, are the same individuals who are attending hospitals for treatment and management. While to a great extent the health and social care systems operate in silos, the people for whom the systems seek to care are accessing many components of the system.

Hence, health and social care practices are inherently complex, and so is researching these practices. Health and social care systems are dynamic, unpredictable, non-linear and 'messy'. The people working in these services and those who access them add greater levels of complexity.[2] It is important to measure and understand the experiences of those who provide and access services; to explore multiple perspectives (e.g. of people receiving care and delivering care) and, in doing so, to recognise that truth is socially constructed and subjective; to understand what drives behaviours and why interventions are effective, partially effective or not effective at all.[3-5] As the fields of health care and social care work to innovate, implement and evaluate programs and practices to identify an evidence base for care, we need to measure what we previously thought was not measurable. ***We need a way to explore and understand experience – this is qualitative research.***

Quantitative research has dominated research in health and social care

Quantitative research has dominated approaches to research in health care and social care. This is possibly due to the sector's familiarity with the research designs and the ease of accessing numerical data through health system medical records and processes which in turn are due to preferencing of the scientific method and medicine. Health and medical research, in particular, have tended to preference the generalisability and 'objectivity' of quantitative research as fact and truth. The curricula of health and social care courses are dominated by data and information derived through quantitative research methods, with limited attention given to teaching qualitative research methods and evidence in medical and biomedical degrees. However, the vast array of health and social care phenomena is not amenable to rigorous experimental research design or objective measurement. The complexity inherent in the systems of health care, behavioural aspects of interventions (clinician behaviour, patient behaviour, organisational change) and knowledge of why interventions do or do not work, need a different approach – a qualitative approach. Numbers cannot provide the data needed to understand these aspects of health care and social care. The knowledge required can be acquired through experiential and subjective means, thereby recognising that experiences differ and truth in evidence is socially constructed.

What is qualitative research?

Qualitative research designs are appropriate when we do not know much about the phenomenon (concept) under investigation, and when we may not even know what we are trying to find out.[5,6] Qualitative research is suitable for seeking to understand a phenomenon from the perspectives of the persons experiencing it – for example, the phenomenon of presenting to a hospital's emergency department can be explored from the perspectives of patients, caregivers and staff. The phenomenon of living in out-of-home care can be explored from the perspective of the person living in care as well as that of the care workers.

Quantitative research is objective, hypothesis-testing and deductive; it seeks to assess, make associations, examine causation, relationships and effects; and seeks to answer questions of 'what?' (prevalence/incidence) and 'do/does?' (effectiveness). In contrast, qualitative research is subjective, hypothesis-generating and inductive; it seeks to describe, understand, explore, discover, generate and examine; and to answer questions of 'why', 'how' and what (experience).[5-8]

Qualitative research is often given 'lip service'

Qualitative research is often framed as a toolbox of interviews, focus groups and observations that are devoid of philosophical, methodological or theoretical underpinnings. This perception of qualitative research can lead practitioners and researchers to describe their qualitative study as an 'interview study' or a 'focus group study'. However, clinical and health service research journals are increasingly requesting that researchers undertaking qualitative research complete the 32-item Consolidated Criteria for Reporting Qualitative Studies (COREQ)[9] or the Standards for Reporting Qualitative Research (SRQR).[10] Both of these have items asking specifically about the methodological approach and the research paradigm. The rationale for justifying the research approach (or theoretical framework in the COREQ) is so that 'readers can understand how the researchers explored their research questions and aims' and to provide 'readers the opportunity to evaluate the fidelity of the research approach to the research question(s) and consider the rationale for modifications and deviations from the selected approach'.[9,10]

Many researchers unfamiliar with or new to qualitative research do not know what qualitative research questions to ask. These questions are not about the interview or focus group questions but rather the fundamental question of – what do you want to find out through this research? When researchers and practitioners know which qualitative research paradigms and designs underpin a given study:

1. The scope of research questions is more likely to be broad.
2. They are better equipped to choose the appropriate qualitative methods that strengthen the rigour of health care and social care research.

Numerous problems in health care and social care need a qualitative lens to explore and understand the complexity of experiences and perspectives. The answers to these questions help in identifying the core issues or problems and provide insights into possible solutions. For instance, in the examples of research questions from out-of-home care ('What are the barriers and enablers to implementing a trauma-informed model of care?')[11]; intensive care ('What are the important aspects to care and recovery?' 'What was the patient experience of ICU?')[12]; post-partum care ('How do women diagnosed with depression experience their body image in the post-partum period?')[13]; in-hospital falls prevention programs ('What are the perceived barriers to the implementation of the 6-PACK nurse-led falls prevention program?').[14]

In Table 1.1 we compare and contrast quantitative research with qualitative research, to demonstrate the philosophies, methodologies and paradigms underpinning the different research approaches and the typical words used in the corresponding aims and research questions.

Table 1.1. Comparing quantitative and qualitative

research

Research element	**Quantitative research**	**Qualitative research**
Research designs – the plan for how you will answer your research question	Observational studies Descriptive: case reports, case series, case studies, cross-sectional studies Analytical: cross-sectional studies, case-control studies, cohort studies Experimental studies Non-randomised controlled studies Randomised controlled trials	Descriptive Phenomenological Action research Case study Ethnography Grounded theory
Philosophy	Objective	Subjective
Research paradigm – an agreed disciplinary perspective or set of ideas; a way of looking at something. The research paradigm influences how research problems are understood and solved.	Positivist – a single objective reality can be observed through the scientific method Post-positivist – a single objective reality exists, but scientific observations can be flawed so reality can only be known imperfectly	Interpretivist/constructivist – multiple subjective realities are socially constructed by and between humans Critical theory – multiple subjective realities influenced and shaped by power dynamics (social, political, cultural, economic, ethnic, gender) Post-positivist (some case study research)
Inquiry strategies	Deductive – hypothesis-testing	Inductive – hypothesis-generating
Research methods – the strategy for implementing the research design, including data gathering, data collection and data analysis.	Structured data collection Experiments (laboratory, clinical, drug development and drug trials), behavioural interventions and trials Surveys and questionnaires	Interviews Focus groups Observations Document analysis/review Arts based methods such as photo elicitation, drawing, river of life Social media
Wording in research aim/questions	Effect, association, causation, relationship, examine	Describe, explore, understand, discover, examine

This book aims to provide an introduction to the why and how of qualitative research for health and social care researchers, students and practitioners. Resources and links to open-access sources are provided throughout for further information.

Section 1 is an introduction to qualitative research including brief explanations of research paradigms, theories and frameworks.

Section 2 is an overview of the six key qualitative research designs, mixed methods research and evaluation approaches in health and social care. A table summarising the key elements of each of the six qualitative research designs with prompting questions is provided as a guide to choosing a study design.

Section 3 covers data collection methods including traditional qualitative methods of interviews and focus groups and more recent methods of arts-based methods.

Section 4 is a summary of key analysis processes and techniques and includes a summary table as a guide for approaching the different analysis approaches.

Section 5 explains rigour in qualitative research including researcher positionality, triangulation and reflexivity.

Section 6 is an overview of ethics including practical tips and lessons from our experiences.

Section 7 the final section, is a guide on how to write qualitative research for publication.

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CHAPTER 2: FOUNDATIONS OF QUALITATIVE RESEARCH - PARADIGMS, PHILOSOPHICAL UNDERPINNINGS

Darshini Ayton and Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Recognise and understand the four main paradigms that underpin research.
- Understand how paradigms differ between qualitative and quantitative research.
- Describe the differences between approaches in inductive and deductive research.

What is a paradigm?

All research takes place within a paradigm. A paradigm is a worldview – a framework of beliefs, values and methods. For researchers, the paradigm or worldview framing their research informs the meaning they interpret from the data. Each researcher works within their own, unique paradigm; this includes the techniques they choose for collecting and analysing data.[1] There are four main research paradigms in social science (see Table 2.1.):

- positivist, or scientific, paradigm
- interpretivist, or constructivist, paradigm (also known as the naturalistic paradigm)
- radical, or critical, paradigm
- post–structuralist paradigm.[2,3]

These paradigms reflect the researcher's beliefs about what is reality (ontology), knowledge (epistemology), the means to obtaining knowledge (methodology) and the values of the researcher (axiology).[3] We might think of ontology as 'what is true' and epistemology as 'how do we know those truths?'. The positivist paradigm is suited to quantitative research because it is grounded in the notion of cause and effect. The remaining three paradigms are suited to qualitative research because they are grounded in exploration and understanding.[3]

Qualitative research is embedded in the interpretivist, or constructivist paradigm. The understandings and beliefs of interpretivism or constructivism can be considered in terms of:

- Assumptions and values: The research seeks to understand what it is to be human, and the significance and meanings people ascribe to life events. It aims to identify what is important and what is evidence.[4]
- Researcher–participant relationship: The relationship is 'intersubjective' – that is, the researcher is the listener and interpreter of the data obtained from the participant. The researcher discovers the truth of a situation through thinking and analysis, rather than sensory observation. Interpretation is required.[4]
- Methodology (the research approach): Qualitative research includes study designs such as descriptive, phenomenology, action research, case study, grounded theory and ethnography.[4] These are covered in section 2 of this textbook.
- Ontology (the nature of reality): The researcher recognises that there are multiple subjective realities, and that these are socially constructed in the interactions between research participants and between the researcher and participants.[5]
- Epistemology (the theory of knowledge, or how knowledge is created): Knowledge is derived from the everyday. The researcher creates meaning from the data through their thinking and analysis of the data informed by their encounters with participants.[3]
- Axiology (the value and ethics of the research): The research will reflect the values of the researcher who aims to present a balanced interpretation of the results.[5]

A good example of the interpretivist or constructivist paradigm is a study exploring physical and bodily pain. We humans each experience pain differently, due to many factors, including how we were socialised to respond to pain in our family and communities, our individual pain threshold, our past experiences of pain and the context of our current pain – what else is happening in that moment of pain. Thus, it is reasonable to say that pain is socially constructed. In health care, pain is measured on a numerical scale, but it is the person's perception of the pain that determines the number assigned to their pain (self-report). We may therefore question whether there is an objective, scientific method for measuring pain. A common facilitator for pain relief – paracetamol – reduces pain for some people and not for others. Consider why this is the case. (It is the person's perception of what is working to relieve their perceived pain.) Positivists do not rely on subjective experiences, only facts and a singular truth: objectivity. Constructionists and intepretivists contend that subjective and social experiences *create* reality, and that there are many truths.

Although it is not one of the four main paradigms, post-positivism is another paradigm that appears in the literature. Post-positivism asserts that there are multiple and competing views of science, and multiple truths. Therefore, researchers cannot be completely objective, unbiased and value-free, as the positivist paradigm asserts.[4] This shift in perspective from positivism to post-positivism has led to the incorporation of qualitative methods into the post-positivist paradigm, to enable the research to explore participants' experiences of the phenomenon under study. This paradigm is included in Table 2.1. since its basic ontology is similar to the positivist paradigm.[6]

Table 2.1. Research paradigms in social science

Paradigm	**Positivist/scientific**	**Interpretivist / constructivist**	**Radical/critical**	**Post-structuralist**
Assumptions and values	Objectivity, systematic and detailed observation. Seeks to explore cause and effect. Problem-solving. Stems from science and mathematics.	Seeks to understand what it is to be human, and the significance and meanings people ascribe to life events. Aims to identify what is important and what is evidence.	The desire to change the world and not to just describe it. The world is unjust and inequalities stem from the social lines of gender identity, ethnicity, class, age, sexuality etc. Action is required and it is possible to change these injustices.	No one can stand outside the traditions or discourses of their time.
Researcher/ participant relationship	The researcher is the 'expert' and is expected to be objective. The participant is the object of the research.	'Intersubjective' – the researcher is the listener and interpreter of the data obtained from the participant. The researcher discovers the truth of a situation through thinking and analysis, rather than sensory observation. Requires interpretation.	The researcher takes a normative stance and has views or beliefs about what social structures are powerful and what should be done to change them. The relationship is characterised as co-research, reciprocal, participative, empowering and power-sharing.	The researcher analyses participants as subjects of discourse, in which the researcher is also embedded.
Methodologies and methods	Quantitative experimental, or non-experimental. Hypothesis-driven, statistical-testing, evidence-based practice.	Qualitative – interviews, grounded theory methodology, hermeneutics, phenomenological research.	Emancipatory action research, participatory research, collaborative research, critical ethnography, critical or radical hermeneutics, critical policy analysis.	Research focused on texts – written, spoken and visual. Methodologies allow for complexity and contradiction in data. Discourse analysis, feminist post-structuralism and queer research are examples.
Ontology	Social reality is stable and ordered, and made up of discrete and observed events.	Reality is subjective and socially constructed.	Social change must begin at the roots of social reality.	Power is always part of social practices and in the construction of different forms of knowledge.

Paradigm	**Positivist/scientific**	**Interpretivist / constructivist**	**Radical/critical**	**Post-structuralist**
Epistemology	Knowledge is derived from sensory observations by an objective researcher. Knowledge is sought so that people (health workers, policy makers, and professionals), can explain, predict, or control events. Knowledge is gained through testing an hypothesis.	Knowledge is derived from everyday observations.	Knowledge is socially constructed, communal, contextual and subjective; however, it is also rational and emancipative.	Knowledge is social in nature.
Axiology	The researcher is removed and distanced from the research to ensure that their beliefs and values do not influence the research or research interpretations.	The researcher is part of the research. The 'what' and 'how' of the research will reflect the values of the researcher. The researcher aims to present a balanced interpretation of the results based on their own understanding and the data.	The researcher seeks to change the world through their research by drawing on the experiences of marginalised and disempowered groups in society. The researcher values participation and power sharing.	The researcher is embedded in the same discourses as the research participants and aims to understand how power works through the constructed discourses of participants.

In Table 2.2. an article is provided to highlight the different components of the research paradigms. Note: The aims are reproduced verbatim from the papers (word for word).

Table 2.2. Examples of paradigms within published research

Paradigm	**Positivist**	**Constructivist**	**Radical/critical**	**Post structuralist**
Title	Medical masks versus N95 respirators for preventing COVID-19 among health care workers - a randomized trial[7]	Experiences of home health care workers in New York City during the Coronavirus Disease 2019 Pandemic: a qualitative analysis[8]	Hearing the voices of Australian healthcare workers during the COVID-19 pandemic[9]	A Foucauldian discourse analysis of media reporting on the nurse-as-hero during COVID-19[10]
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Paradigm	**Positivist**	**Constructivist**	**Radical/critical**	**Post structuralist**
Aim	'To determine whether medical masks are non-inferior to N95 respirators to prevent COVID-19 in healthcare workers providing routine care.'[abstract]	'To understand the experiences of home health care workers caring for patients in New York City during the COVID-19 pandemic.'[abstract]	'To better understand the challenges Australian healthcare workers have faced during the COVID-19 pandemic.'[abstract]	'To explore media reporting on the role of nurses as being consistently positioned as 'heroes' during COVID-19.'[abstract]
Epistemology	Knowledge is objectively measured. In this paper, the primary outcome was confirmed COVID-19 infection on a reverse transcriptase polymerase chain reaction test (RT-PCR). Sera from participants were also tested for IgG antibodies. These are objective scientific measurements.	Knowledge is created from the experiences and perspectives of the 33 home health care workers in New York City.	Knowledge is created in the form of advocacy and critical voices of the current state of play.	Knowledge is created through the analysis of discourse to understand social norms and assumptions which influence behaviour and expectations.
Methodology	Pragmatic, randomised, open-label, multicentre trial	Qualitative grounded theory study	Qualitative analysis of responses to an open letter to the Australian government, advocating for better respiratory protection for healthcare workers	Foucauldian discourse analysis of media reports

Paradigm	**Positivist**	**Constructivist**	**Radical/critical**	**Post structuralist**
Ontology	COVID testing via RT-PCR was administered via nasopharyngeal swabs and was administered at baseline and the end of follow-up (10 weeks post-baseline). Other measures such as serologic evidence of infection via IgG antibodies, respiratory illness/ infection, work-related absenteeism, and for those who were positive for COVID – intensive care admission, mechanical ventilation or death. Participants received a text message twice a week asking about signs and symptoms of COVID which triggered a PCR test if symptoms were present. These measures are examples of discrete and objectively measurable observations.	The interview guides canvassed the everyday experiences of healthcare workers during COVID with questions on "1) What workers knew about COVID; 2) how COVID affected their work and 3) the challenges they experienced during COVID".(p1454) These questions create the opportunity for participants to share their stories which is an example of social construction.	The data collection was a social change activity. An open letter was written to the federal government, calling for better access to respiratory protection, infection-control guidelines and transparent reporting of healthcare worker infections. It garnered 3500+ signatures. Healthcare workers were invited to share their concerns and experiences, which led to 569 free-text contributions. These contributions are an example of a call for social change and action based on social reality.	Three Canadian newspapers were searched over three months for articles related to nurses and COVID-19, leading to 559 articles being identified. These were screened for relevance, and 50 articles were included in the analysis. The articles were analysed through a process called 'making strange', in an attempt to remove assumptions and read the stories as an outsider. Articles were read multiple times over weeks to identify discourses about nurses in the context of COVID-19. with particular attention given to the discourse of caring and disciplinary power. These newspaper articles are an example of how sensemaking of a social phenomenon (COVID-19) in the context of a particular role (nurse) creates hierarchies and power dynamics in society.

Paradigm	Positivist	Constructivist	Radical/critical	Post structuralist
Axiology	This study had 29 healthcare facilities, and healthcare workers were randomly allocated to either medical masks or N95 respirators. A total of 1009 healthcare workers were enrolled (the calculated required sample size was 875 people). The randomisation and large participant numbers were to ensure generalisability and objective ability to detect a difference between COVID-19 infections in participants wearing a medical mask versus those wearing a respirator. This approach aims to reduce bias.	Three of the researchers were experienced in how to conduct qualitative interviews. They conducted the interviews and were guided by a semi-structured interview guide, which was developed based on prior research by the team, other studies and conversations with agency leaders. Hence, data collection was informed by subjective experiences and research literature. Data analysis involved three researchers in the coding process, through an analysis process called the constant comparative approach, which is a common approach in grounded theory analysis. This approach is systematic, with much interaction across time and between researchers. Because researchers are involved in the data analysis and interpretation of data, their values and experiences as individuals will shape the analysis process.	This study is fundamentally a call to action and is underpinned by the value of social justice. Some of the authors were actively involved in national advocacy campaigns, leading to strong engagement with healthcare workers for this open letter. The signatories demanded change due to what they perceived to be unfair and unjust circumstances for healthcare workers. The free-text responses provided specific examples of injustice, which were then themed to provide an overall narrative.	Fifty articles were analysed to determine how the discourses of 'nurses as heroes' and 'nurses as carers' and 'nurses as sacrifice' created a reality in which nurses were afraid of speaking up to advocate for their protection at work and hence compromised their own safety.

Approaches in qualitative methods

Approaches are how a researcher intends to carry out their research. In qualitative research, there are two main approaches:

- Inductive: Driven by the participants and their data

An inductive approach employs a 'whole world' view and includes the wider social and historical context. It considers the layers that surround the individual – temporal, spatial, ideational, institutional and structural, and focuses on meanings, ideas and experiences. The inductive approach is concerned with participants' subjective views. When examining what participants have said in an interview, the researcher searches for themes, setting aside preconceived notions.[6] (Review the example in Chapter 3 of exploring seniors' perceptions of health and loneliness. The theoretical drive of the research is inductive because it is describing and exploring the perceptions of seniors.) An inductive research approach is hypothesis–generating – this means the researchers do not have preconceived ideas of what they will find in their research and data, and hypotheses will be generated in the process of analysing the data.[6]

- Deductive: Driven by a pre-existing theory, framework or series of questions

A deductive approach can employ a theory or framework to guide the research, and responses are usually categorised into pre-determined labels (most often called 'codes'). This is usually how questionnaires or structured interviews are interpreted. The pre-determined codes are based on the questions asked in interviews or focus groups. A deductive approach, particularly in the positivist paradigm, is hypothesis-testing – the researchers are looking for evidence of specific ideas, concepts and relationships in the research and data.[5]

All research takes place within a paradigm, consciously or subconsciously; that is, regardless of whether this is understood by the researcher. To interpret the data well, qualitative researchers must explore and acknowledge their own framework of beliefs, values and methods informing the meaning of their data. Qualitative research is embedded in the interpretivist paradigm. Four main paradigms have been explored and explained in this chapter.

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CHAPTER 3: THEORY IN QUALITATIVE RESEARCH

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Define theory.
- Describe foundational qualitative theories.
- Examine theories for qualitative research.
- Explain why theories are used in qualitative research.
- Identify various theories used in qualitative research.

What is a theory?

In essence, 'a theory is a big idea that organises many other ideas with a high degree of explanatory power'.1(p2) Theory has also been defined as 'an organised, coherent, and systematic articulation of a set of issues that are communicated as a meaningful whole'.2(p633) Consider the various theories in you may have encountered. These might include scientific theories, philosophical theories, systems theories, psychological theories, conspiracy theories and many more. Each one of these theories enables the person who embodies that theory to 'explain' their worldview. Qualitative theories are no different, in that the theory that is adopted in qualitative research enables the researcher to organise their ideas and explain their results. Qualitative theories are usually concerned with explaining the 'why' of the complex social world. This is noticeable when examining the locus of control theory, which informs the research question(s), data collection and interpretation. Results from researchers who adhere to this theory are presented within this meaningful whole that revolves around having control over the outcomes of one's life in some form.

Qualitative theories

This chapter investigates the foundational theories that have come to be associated with qualitative research methods. In Chapter 2, paradigms and, in particular, the interpretivist/constructivist paradigm, were discussed. The interpretivist paradigm is a worldview that uses participants' perceptions and experiences of the phenomenon that is being investigated to be analysed. It also acknowledges the researcher's own experiences and background, in terms of how these influence their interpretations and meanings of data.

Reeves and colleagues[2] discuss how theory can be used to describe how societies work, how organisations operate and why people interact in certain ways. They state that 'theories give researchers different 'lenses' through which to look at complicated problems and social issues, focusing their attention on different aspects of the data and providing a framework within which to conduct their analysis'.[2(p631)] Below we describe

There are three levels of theory.

1. Grand theories are broad universal and societal level theories that include many different domains and concepts.[3] There are many grand theories and many theorists. Examples include Karl Marx, Friedrich Engels, Max Weber, Emily Durkheim and Michel Foucault. Sylvia IV applied Foucault's theory of biopolitics to analyse how governments managed populations via technology to enforce social distancing measures to prevent the spread of COVID-19.[4]
2. Middle-range theories are narrower in scope when compared to grand theories, have fewer concepts and are applied at a local level.[3] In healthcare improvement, two examples of middle-range theories include diffusions of innovation,[5] how an idea or product gains momentum and spreads through a system, and normalisation process theory, how a practice or program becomes embedded within a context.[3,6] McEvoy and colleagues applied normalisation process theory to analyse the 'levers and barriers to the implementation of community participation in primary health care in Ireland.'[7(para10)] They conducted an instrumental case study (read more about case studies in Chapter 8) which consisted of two qualitative studies incorporating semi-structured interviews (n=44), focus groups (total number of participants across focus groups was 27) and document analysis (17 documents).[7]
3. Micro-level theories are at the individual level and look at relationships and interactions.[2] Phenomenology is an example of a micro-level theory as the focus is on the individual lifeworld (see Chapter 5). For example, symbolic interactionism explores how social groups and social interactions explain larger social meanings and norms.[8] The social care article by Basic (2022)[9(p1)] applies symbolic interactionism in their study which aims 'to identify and analyse power relations that contribute to the shaping of young people's identities and repertoires of action via stigmatisations and social comparisons with different reference groups'. The research demonstrates that 'narratives about war, escaping war, and post-war life in Sweden, constructing and reconstructing an image of a series of interactive rituals that are both influenced by and influence the power dynamic between the actors'.[9(p1)]

Below, three different theories are applied to a qualitative research topic to provide an example of how these different theories can inform the exploration of experiences in qualitative research.

Exploring loneliness and health status of Chinese and Anglo-Australian Manningham Seniors[10] through three different theories

Phenomenology A researcher using a phenomenological approach would study older persons' perceptions of loneliness by exploring how individuals make sense of their personal and health experiences. The researcher would seek to understand, describe and interpret human behaviour and the meanings the older persons make of their experiences. The approach would be to understand what is being experienced and how it was experienced. This would be done by examining participants' own statements in the interviews. For example, what is the experience of loneliness and the impact of that experience on an older person's health? And, what does it mean for older persons to be lonely? The goal is to understand the meanings that the older persons attached to their experiences of loneliness and health.

Interactionism A researcher using interactionist theory would approach the study of older persons' perceptions of loneliness and health by seeking to understand how the meanings that daily interactions produced. The goal would be to identify and explore the different interactions that contributed to the understanding of loneliness and health in older persons' daily lives. Thus, the researcher might examine the differences between participants' experiences (interactions) with family and with friends. Is there a difference and how is that difference manifested?

Critical theory A researcher using critical theory would approach the study of older persons' interactions by examining power and its relationship to the older persons' characteristics, such as cultural background or gender identity. For example, critical race theory[11] states that institutions such as health systems have laws or procedures that are inherently racist because they lead to different outcomes based on racial factors. The researcher would proceed along the specific critical theoretical lens selected to help them understand how social conceptions of race and ethnicity operate through older persons' interactions with the health system. Is there a difference between how Chinese and Anglo-Australian seniors are treated within health systems and are these differences due to factors such as ageism or cultural background?

Many theories inform qualitative research, and those presented in this chapter are limited examples. Theories have been developed and modified over many years and have influenced each other's changes over time. The theories mentioned in this chapter are those that you are likely to encounter in the health domain. Other important theories in the social sciences and humanities, are also used in health-related research, and include (but are not limited to) Marxism and its descendants, feminism, hermeneutics and the post-modernist family of theories.

Willis and colleagues explore theories in their paper *The essential role of social theory in qualitative public health research*.[8] They posit that social theory assists researchers to generalise results beyond their particular research group, and that 'theories provide structured interpretations or models for investigating and understanding a problem'.[8(p439)] *Table 1: Types of social theory* [8(p439)] provides excellent examples of theorists such as Marx, Durkheim, Foucault and de Beauvoir, along with their key concepts. To provide clarity around the types of social theories, we have included links below to examples of readings that use the social theory type discussed in Willis' table.

Conflict theory – Campbell B. Social justice and sociological theory. *Society*. 2021:58:355-364. doi:10.1007/s12115-021-00625-4[12]

Structural functionalism – Adhikari SR. Manu Smriti as the protection of female in Hindu philosophy: in the dimension of structural-functionalism. *Philosophy Study*. 2020;10(11):706-712. doi:10.17265/2159-5313/2020.11.005[13]

Symbolic interactionism – Basic G. Symbolic interaction, power, and war: narratives of unaccompanied young refugees with war experiences in institutional care in Sweden. *Societies*. 2022;12(3):90. doi:10.3390/soc12030090[9]

Sociology of knowledge – Messina CB. 2022. Breaking the silence on femicide: how women challenge epistemic injustice and male violence. *Br J Sociol*. 2022;73(4):859-884. doi:10.1111/1468-4446.12968[15]

Feminist theory – Lazarus S, Button M, Kapend R. Exploring the value of feminist theory in understanding digital crimes: gender and cybercrime types. *The Howard Journal of Crime and Justice*. 2022; 61(3) 381-398. doi:10.1111/hojo.12485[16]

This chapter has presented examples of studies using phenomenology, interactionism and critical theory. However, there are many other theories used in qualitative research in health, including queer, intersectionality and colonialism theories. Dr Brene Brown is a grounded theory researcher (more about grounded theory in chapter 10) who writes and presents about how she engages with theory in her work. In the video entitled *The anatomy of trust* she talks about how her research starts from personal experience with a story about trust, then she investigates the research data she has collected for ideas about trust and engages with theory from John Gottman, who has worked on trust and betrayal. This process is described from about minutes 7–20. The entire presentation illustrates the interplay between research data and theory.

It is important to remember that qualitative research is not an absolute science and that there is no right or wrong theory or framework to guide research. Every researcher has a different worldview and a different perspective to explore; however, all research needs to be guided by a paradigm, theory and/or framework, to ensure full exploration of the experiences of participants.

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CHAPTER 4: THEORETICAL FRAMEWORKS FOR QUALITATIVE RESEARCH

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe qualitative frameworks.
- Explain why frameworks are used in qualitative research.
- Identify various frameworks used in qualitative research.

What is a Framework?

A framework is a set of broad concepts or principles used to guide research. As described by Varpio and colleagues[1], a framework is a logically developed and connected set of concepts and premises – developed from one or more theories – that a researcher uses as a scaffold for their study. The researcher must define any concepts and theories that will provide the grounding for the research and link them through logical connections, and must relate these concepts to the study that is being carried out. In using a particular theory to guide their study, the researcher needs to ensure that the theoretical framework is reflected in the work in which they are engaged.

It is important to acknowledge that the terms 'theories' (see Chapter 3), 'frameworks' and 'paradigms' are sometimes used interchangeably. However, there are differences between these concepts. To complicate matters further, theoretical frameworks and conceptual frameworks are also used. In addition, quantitative and qualitative researchers usually start from different standpoints in terms of theories and frameworks.

A diagram by Varpio and colleagues demonstrates the similarities and differences between theories and frameworks, and how they influence research approaches.[1(p991)] The diagram displays the objectivist or deductive approach to research on the left-hand side. Note how the conceptual framework is first finalised before any research is commenced, and it involves the articulation of hypotheses that are to be tested using the data collected. This is often referred to as a *top-down approach* and/or a general (theory or framework) to a specific (data) approach.

The diagram displays the subjectivist or inductive approach to research on the right-hand side. Note how data is collected first, and through data analysis, a tentative framework is proposed. The framework is then firmed up as new insights are gained from the data analysis. This is referred to as a *specific (data) to general (theory and framework) approach*.

Why do we use frameworks?

A framework helps guide the questions used to elicit your data collection. A framework is not prescriptive, but it needs to be suitable for the research question(s), setting and participants. Therefore, the researcher might use different frameworks to guide different research studies.

A framework informs the study's recruitment and sampling, and informs, guides or structures how data is collected and analysed. For example, a framework concerned with health systems will assist the researcher to analyse the data in a certain way, while a framework concerned with psychological development will have very different ways of approaching the analysis of data. This is due to the differences underpinning the concepts and premises concerned with investigating health systems, compared to the study of psychological development. The framework adopted also guides emerging interpretations of the data and helps in comparing and contrasting data across participants, cases and studies.

Some examples of foundational frameworks used to guide qualitative research in health services and public health:

- The Behaviour Change Wheel[2]
- Consolidated Framework for Implementation Research (CFIR)[3]
- Theoretical framework of acceptability[4]
- Normalization Process Theory[5]
- Candidacy Framework[6]
- Aboriginal social determinants of health[7(p8)]
- Social determinants of health[8]
- Social model of health[9,10]
- Systems theory[11]
- Biopsychosocial model[12]
- Discipline-specific models
- Disease-specific frameworks

Examples of frameworks

In Table 4.1, citations of published papers are included to demonstrate how the particular framework helps to 'frame' the research question and the interpretation of results.

Table 4.1. Frameworks and references

Framework	**Relevant foundational information**	**Studies using the frameworks**	**How the framework is presented**
The Behaviour Change Wheel – also known as the COM-B framework Suits research exploring: • Changing behaviours within health contexts to address patient and carer practices • Changing behaviours regarding environmental concerns • Barriers and enablers to behaviour/ practice/ implementation • Intervention planning and implementation • Post-evaluation • Promoting physical activity	The behaviour change wheel: a new method for characterising and designing behaviour change interventions[2]	A cross-sectional survey assessing the influence of theoretically informed behavioural factors on hand hygiene across seven countries during the COVID-19 pandemic[13]	This study examined how the COM-B model could be used to increase children's hand-washing and improve disinfecting surfaces in seven countries. Each country had a different result based on capability, opportunity and/or motivation.
		Understanding public attitudes to death talk and advance care planning in Northern Ireland using health behaviour change theory: a qualitative study[14]	This study examined the barriers and facilitators to talking about death and dying among the general population in Northern Ireland. The findings were mapped across the COM-B behaviour change model and the theoretical domains framework.
		Empowerment for behaviour change through social connections: a qualitative exploration of women's preferences in preconception health promotion in the state of Victoria, Australia[15]	This study explored women's understanding of health and health behaviours and the supports that were important to promote behavioural change in the preconception period. Coding took place and a deductive process identified themes mapped to the COM-B framework.
		Barriers and enablers to the implementation of the 6-PACK falls prevention program: a pre-implementation study in hospitals participating in a cluster randomised controlled trial[16]	Identified perceived barriers and enablers of the implementation of a falls-prevention program to inform the implementation in a randomised controlled trial. Strategies to optimise the successful implementation of the program were also sought. Results were mapped against the COM-B framework.

Framework	**Relevant foundational information**	**Studies using the frameworks**	**How the framework is presented**
Consolidated Framework for Implementation Research (CFIR) Great for: • Evaluation • Intervention and implementation planning	Consolidated Framework for Implementation Research (CFIR)[3]	The implementation of a smoking cessation and alcohol abstinence intervention for people experiencing homelessness.[17]	Explored participants' experiences with the program (ceasing smoking) to inform future implementation efforts of combined smoking cessation and alcohol abstinence interventions, guided by the CFIR. Key findings from the interviews are presented in relation to overarching CFIR domains.
		Protocol for the process evaluation of a counselling intervention designed to educate cancer patients on complementary and integrative health care and promote interprofessional collaboration in this area (the CCC-Integrativ study).[18]	This mixed-methods study drew upon the CFIR combined with the concept of 'intervention fidelity' to evaluate the quality of the interprofessional counselling sessions, to explore the perspective of, directly and indirectly, involved healthcare staff, as well as to analyse the perceptions and experiences of the patients.
		Factors influencing implementation of health-promoting interventions at workplaces: Protocol for a scoping review[19]	This is a protocol for a scoping study to identify the topics in need of study and areas for future research on barriers to and facilitators of the implementation of workplace health-promoting interventions. Data analysis was aligned to the CFIR.
		Evaluation of a school-based participatory intervention to improve school environments using the Consolidated Framework for Implementation Research[20]	This study examined the utility of the CFIR in identifying and comparing barriers and facilitators influencing the implementation of participatory research trials, by employing an adaptation of the CFIR to assess the implementation of a multi-component, urban public school-based participatory health intervention. Adapted CFIR constructs guided the largely deductive approach to thematic data analysis.

Framework	Relevant foundational information	Studies using the frameworks	How the framework is presented
Theoretical Framework of Acceptability (TFA) Good for: • Pre-implementation, implementation and post-implementation studies • Feasibility studies • Intervention development	Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework[4]	Application of the Theoretical Framework of Acceptability to assess a telephone-facilitated health coaching intervention for the prevention and management of type 2 diabetes[21]	This study aimed to develop and assess the psychometric properties of a measurement scale for acceptance of a telephone-facilitated health coaching intervention, based on the TFA; and to determine the acceptability of the intervention among participants living with diabetes or having a high risk of diabetes in socio-economically disadvantaged areas in Stockholm. A questionnaire using TFA was employed.
		Understanding factors that could influence patient acceptability of the use of the PINCER intervention in primary care: A qualitative exploration using the Theoretical Framework of Acceptability[22]	This paper reported patients' perceived acceptability of the use of PINCER in primary care and proposes suggestions on how delivery of PINCER-related care could be delivered in a way that is acceptable and not unnecessarily burdensome.
		Acceptability, reach and implementation of a training to enhance teachers' skills in physical activity promotion[23]	This study describes the nationwide implementation of a program targeting physical activity and sedentary behaviour in vocational schools (Lets's Move It; LMI). Results showed high levels of acceptability and reach of training.
		A qualitative study of the acceptability of remote electronic bednet use monitoring in Uganda[24]	This study drew on established models such TFA to assess the acceptability of SmartNet in Ugandan households. Results showed the monitor needs to continue to be optimised to make it more acceptable to users and to accurately reflect standard insecticide-treated nets use to improve understanding of prevention behaviours in malaria-endemic settings.

Framework	Relevant foundational information	Studies using the frameworks	How the framework is presented
Normalization Process Theory (NPT) Good for: • Implementation • Evaluation	Normalization Process Theory[25]	Ready for prime time? Using Normalization Process Theory to evaluate implementation success of personal health records designed for decision making [26]	This pre-implementation evaluation of an integrated, shared decision-making personal health record system (e-PHR) was underpinned by NPT. The theory provides a framework to analyse cognitive and behavioural mechanisms known to influence implementation success. It was extremely valuable for informing the future implementation of e-PHR, including perceived benefits and barriers.
		Impact of a health literacy intervention combining general practitioner training and a consumer facing intervention to improve colorectal cancer screening in underserved areas: protocol for a multicentric cluster randomized controlled trial[27]	This study assessed the impact of an intervention combining health literacy colorectal cancer-screening (CRC) training for GPs, using a pictorial brochure and video targeting eligible patients, to increase screening and other secondary outcomes, after 1 year, in several underserved geographic areas in France. They propose to evaluate health literacy among underserved populations to address health inequalities and improve CRC screening uptake and other outcomes.
		Acceptability of a cessation intervention for pregnant smokers: a qualitative study guided by Normalization Process Theory[28]	This study aimed to ascertain acceptability among pregnant smokers receiving the intervention. Interview schedules were informed by NPT and theoretical domains framework; interviews were analysed thematically, using the framework method and NPT. Findings are grouped according to the four NPT concepts.
		“Primary care is primary care”: use of Normalization Process Theory to explore the implementation of primary care services	The study sought to understand how the implementation of primary care services for transgender individuals compares across various models of primary care delivery in Ontario, Canada. Using the NPT framework to guide analysis, key themes emerged about the successful implementation of primary care services for transgender individuals.

Framework	Relevant foundational information	Studies using the frameworks	How the framework is presented
		for transgender individuals in Ontario[29]	

Framework	**Relevant foundational information**	**Studies using the frameworks**	**How the framework is presented**
Candidacy Framework Good for: • Patient experiences • Evaluation of health services • Evaluation	Is 'Candidacy' a Useful Concept for Understanding Journeys through Public Services? A Critical Interpretive Literature Synthesis[30]	Using the candidacy framework to understand how doctor-patient interactions influence perceived eligibility to seek help for cancer alarm symptoms: a qualitative interview study[6]	The study used the candidacy framework to explore how the doctor–patient relationship can influence perceived eligibility to visit their GP among people experiencing cancer alarm symptoms. A valuable theoretical framework for understanding the interactional factors of the doctor–patient relationship which influence perceived eligibility to seek help for possible cancer alarm symptoms.
		Exploring people's candidacy for mobile health–supported HIV testing and care services in rural KwaZulu-Natal, South Africa: qualitative study[31]	The study aimed to understand ways in which a mHealth intervention could be developed to overcome barriers to existing HIV testing and care services and promote HIV self-testing and linkage to prevention and care in a poor, HIV hyperendemic community in rural KwaZulu-Natal, South Africa. Themes were identified from the interview transcripts, manually coded, and thematically analysed informed by the candidacy framework.
		What is the 'problem' that outreach work seeks to address and how might it be tackled? Seeking theory in a primary health prevention programme[32]	This study explored the perceived problems of non-engagement that outreach aims to address and specific mechanisms of outreach hypothesised to tackle these. Analysis was thematically guided by the concept of 'candidacy', which theorises the dynamic process through which services and individuals negotiate appropriate service use.
		Qualitative study of candidacy and access to secondary mental health services during the COVID-19 pandemic[33]	This was a theoretically informed examination of experiences of access to secondary mental health services during the first wave of the COVID-19 pandemic in England. Findings affirm the value of the construct of candidacy for explaining access to mental health care, but also enable deepened understanding of the specific features of candidacy.

Framework	**Relevant foundational information**	**Studies using the frameworks**	**How the framework is presented**
Aboriginal Social Determinants of Health Good for: • Examining how social injustice affects health of Aboriginal and Torres Strait Islander peoples from a non-medical model • Examining how inequalities in illness and mortality rates result from personal context within communities characterised by social, economic and political inequality, factors	Aboriginal health in Aboriginal hands[7(p8)]	Aboriginal community controlled health organisations address health equity through action on the social determinants of health of Aboriginal and Torres Strait Islander peoples in Australia[34] Revisiting the ability of Australian primary healthcare services to respond to health inequity[35] Towards a National Primary Health Care Strategy: Fulfilling Aboriginal Peoples Aspirations to Close the Gap[36] Culture and health[37]	Culture had a strong presence in program delivery and building social cohesion, and social capital emerged as themes. As a primary health care provider, the ACCHO sector addresses the social determinants of health and health inequity experienced by Indigenous communities. The community-controlled service increased their breadth of strategies used to address primary health care indicates the need for greater understanding of the benefits of this model, as well as advocacy to safeguard it from measures that may undermine its equity performance. The primary health care delivered by ACCHOs is culturally appropriate because they are incorporated Aboriginal organisations, initiated by local Aboriginal communities and based in local Aboriginal communities, governed by Aboriginal bodies elected by the local Aboriginal community, delivering a holistic and culturally appropriate health service to the community that controls it. After investigation, the authors state that failure to recognise the intersection of culture with other structural and societal factors creates and compounds poor health outcomes, thereby multiplying financial, intellectual and humanitarian cost. They review health and health practices as they relate to culture.

Framework	Relevant foundational information	Studies using the frameworks	How the framework is presented
Social Determinants of Health Good for: • Understanding the non-medical factors that influence health and social outcomes	Social Determinants of Health[8]	COVID-19 and the Social Determinants of Health and Health Equity: Evidence Brief[38]	The study identifies and describes the social determinants of health.
		Social determinants of health in Canada: Are healthy living initiatives there yet? A policy analysis[39]	This study examines a socio-ecological approach to healthy eating and active living, a model of health that recognises the interaction between individuals and their greater environment and its impact on health.
		The Mitigating Toxic Stress study design: approaches to developmental evaluation of pediatric health care innovations addressing social determinants of health and toxic stress[40]	The study considers the healthcare screening and referral of families to resources that are critical roles for pediatric healthcare practices to consider as part of addressing social determinants of health.
		Social determinants of sex differences in disability among older adults: a multi-country decomposition analysis using the World Health Survey[41]	This study examines how (apart from age) social and economic factors contribute to disability differences between older men and women.

Framework	**Relevant foundational information**	**Studies using the frameworks**	**How the framework is presented**
Social model of health Good for: • Examining all the factors that contribute to health, such as social, cultural, political and environmental factors	Social Determinants of Health: The Solid Facts[9]	Social ecological factors affecting substance abuse in Ghana (West Africa) using photovoice[42]	Participants provided narratives of the pictures, using pre-identified themes and the different levels of the social-ecological model.
		Recursive path model for health literacy: the effect of social support and geographical residence[43]	The study tested a socioecological model of the determinants of health literacy with a special focus on geographical differences in Europe.
		Family support and transport cost: understanding health service among older people from the perspective of social-ecological model[44]	This study investigated the interaction of family support, transport cost (ex-post) and disabilities on health service-seeking behaviour among older people, from the perspective of the social ecological model.
		A Communicative Model of Mothers' Lifestyles During Pregnancy with low birth weight based on social determinants of health: a path analysis[45]	The study examined the factors that contributed to low birth weight in babies, including age, gestational age, birth spacing, age at marriage, history of having a low birth weight infant, miscarriage and stillbirth, mean weight before pregnancy, body mass index, hemoglobin and hematocrit, educational level, family size, number of pregnancies, husband's support during pregnancy and husband's occupation.

Framework	**Relevant foundational information**	**Studies using the frameworks**	**How the framework is presented**
Systems Theory Good for: • Using a new way of thinking to understand the whole rather than individual parts	General System Theory: Foundations, Development, Applications[10]	A systems theory of mental health in recreational sport[46]	The study outlines a systems theory of mental health care and promotion that is specific to needs of the recreational sport system, so that context-specific, effective policies, interventions and models of care can be articulated and tested.
		The wellness of airline cabin attendants: a systems theory perspective[47]	This study uses a systems-thinking approach to consider the person–environment transaction and to focus on the underlying processes and patterns of human behaviour of flight attendants.
		The role of formal theory in social work research: formalizing family systems theory[48]	The study examines the family as a system and proposes that family systems theory is a formal theory that can be used to guide family practice and research.
		"A new hope" for positive psychology: a dynamic systems reconceptualization of hope theory[49]	The authors examine the meta-theoretical, theoretical and methodological foundations of the literature base of hope. They examine the intersection of positive psychology with systems thinking.

Framework	Relevant foundational information	Studies using the frameworks	How the framework is presented
Biopsychosocial model Good for: • Understanding the many factors that affect health, including biological, psychological and social factors	The need for a new medical model: a challenge for biomedicine[50] The biopsychosocial model of illness: a model whose time has come[51]	3 Dimensions for Long Term Conditions - creating a sustainable bio-psycho-social approach to healthcare[52] A Matter of Life and Death: Explaining the Wider Determinants of Health in the UK[53] Health-related quality of life and associated factors among patients with stroke at tertiary level hospitals in Ethiopia[54] Meeting unmet needs following minor stroke: the SUN randomised controlled trial protocol[55]	The biopsychosocial model was used to guide the entire research study: background, question, tools and analysis. The biopsychosocial model was used to guide the researchers' understanding of 'health' and the many factors that affect it, including the wider determinants of health in the discussion. The biopsychosocial model is not specifically mentioned; however, factors such as depression, age, social support, income, co-morbidities including diabetes and hypertension, and sex were measured and analysed. The study uses the Survey of Unmet Needs for data collection, which determines needs across impairment, activities of daily living, occupational activities, psychological needs, and community access. Data was analysed across the full spectrum of needs.

As discussed in Chapter 3, qualitative research is not an absolute science. While not all research may need a framework or theory (particularly descriptive studies, outlined in Chapter 5), the use of a framework or theory can help to position the research questions, research processes and conclusions and implications within the relevant research paradigm. Theories and frameworks also help to bring to focus areas of the research problem that may not have been considered.

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RESEARCH DESIGN

CHAPTER 5: QUALITATIVE DESCRIPTIVE RESEARCH

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Identify the key terms and concepts used in qualitative descriptive research.
- Discuss the advantages and disadvantages of qualitative descriptive research.

What is a qualitative descriptive study?

The key concept of the qualitative descriptive study is *description*.

Qualitative descriptive studies (also known as 'exploratory studies' and 'qualitative description approaches') are relatively new in the qualitative research landscape. They emerged predominantly in the field of nursing and midwifery over the past two decades.[1] The design of qualitative descriptive studies evolved as a means to define aspects of qualitative research that did not resemble qualitative research designs to date, despite including elements of those other study designs.[2]

Qualitative descriptive studies *describe* phenomena rather than explain them. Phenomenological studies, ethnographic studies and those using grounded theory seek to *explain* a phenomenon. Qualitative descriptive studies aim to provide a comprehensive summary of events. The approach to this study design is journalistic, with the aim being to answer the questions who, what, where and how.[3]

A qualitative descriptive study is an important and appropriate design for research questions that are focused on gaining insights about a poorly understood research area, rather than on a specific phenomenon. Since qualitative descriptive study design seeks to describe rather than explain, explanatory frameworks and theories are not required to explain or 'ground' a study and its results.[4] The researcher may decide that a framework or theory adds value to their interpretations, and in that case, it is perfectly acceptable to use them. However, the hallmark of genuine curiosity (naturalistic enquiry) is that the researcher does not know in advance what they will be observing or describing.[4] Because a phenomenon is being described, the qualitative descriptive analysis is more categorical and less conceptual than other methods. Qualitative content analysis is usually the main approach to data analysis in qualitative descriptive studies.[4] This has led to criticism of descriptive research being less sophisticated because less interpretation is required than with other qualitative study designs in which interpretation and explanation are key characteristics (e.g. phenomenology, grounded theory, case studies).

Diverse approaches to data collection can be utilised in qualitative description studies. However, most qualitative descriptive studies use semi-structured interviews (see Chapter 13) because they provide a reliable way to collect data.[3] The technique applied to data analysis is generally categorical and less conceptual when compared to other qualitative research designs (see Section 4).[2,3] Hence, this study design is well suited to research by practitioners, student researchers and policymakers. Its straightforward approach enables these studies to be conducted in shorter timeframes than other study designs.[3] Descriptive studies are common as the qualitative component in mixed-methods research (see Chapter 11) and evaluations (see Chapter 12),[1] because qualitative descriptive studies can provide information to help develop and refine questionnaires or interventions.

For example, in our research to develop a patient-reported outcome measure for people who had undergone a percutaneous coronary intervention (PCI), which is a common cardiac procedure to treat heart disease, we started by conducting a qualitative descriptive study.[5] This project was a large, mixed-methods study funded by a private health insurer. The entire research process needed to be straightforward and achievable within a year, as we had engaged an undergraduate student to undertake the research tasks. The aim of the qualitative component of the mixed-methods study was to identify and explore patients' perceptions following PCI. We used inductive approaches to collect and analyse the data. The study was guided by the following domains for the development of patient-reported outcomes, according to US Food and Drug Administration (FDA) guidelines, which included:

- Feeling: How the patient feels physically and psychologically after medical intervention
- Function: The patient's mobility and ability to maintain their regular routine
- Evaluation: The patient's overall perception of the success or failure of their procedure and their perception of what contributed to it.[5(p458)]

We conducted focus groups and interviews, and asked participants three questions related to the FDA outcome domains:

- From your perspective, what would be considered a successful outcome of the procedure?

Probing questions: Did the procedure meet your expectations? How do you define whether the procedure was successful?

- How did you feel after the procedure?

Probing question: How did you feel one week after and how does that compare with how you feel now?

- After your procedure, tell me about your ability to do your daily activities?

Prompt for activities including gardening, housework, personal care, work-related and family-related tasks.

Probing questions: Did you attend cardiac rehabilitation? Can you tell us about your experience of cardiac rehabilitation? What impact has medication had on your recovery?

- What, if any, lifestyle changes have you made since your procedure?[5(p459)]

Data collection was conducted with 32 participants. The themes were mapped to the FDA patient-reported outcome domains, with the results confirming previous research and also highlighting new areas for exploration in the development of a new patient-reported outcome measure. For example, participants reported a lack of confidence following PCI and the importance of patient and doctor communication. Women, in particular, reported that they wanted doctors to recognise how their experiences of cardiac symptoms were different to those of men.

The study described phenomena and resulted in the development of a patient-reported outcome measure that was tested and refined using a discrete-choice experiment survey,[6] a pilot of the measure in the Victorian Cardiac Outcomes Registry and a Rasch analysis to validate the measurement's properties.[7]

Advantages and disadvantages of qualitative descriptive studies

A qualitative descriptive study is an effective design for research by practitioners, policymakers and students, due to their relatively short timeframes and low costs. The researchers can remain close to the data and the events described, and this can enable the process of analysis to be relatively simple. Qualitative descriptive studies are also useful in mixed-methods research studies. Some of the advantages of qualitative descriptive studies have led to criticism of the design approach, due to a lack of engagement with theory and the lack of interpretation and explanation of the data.[2]

Table 5.1. Examples of qualitative descriptive studies

Title	**Coping and support-seeking in out-of-home care: qualitative study of the views of young people in care in England**[8]	**Engaging patients and informal caregivers to improve safety and facilitate person-and family centred care during transitions from hospital to home – a qualitative descriptive study**[9]
First author and year	Hiller, 2021	Backman, 2019
CC Licence	CC BY 4.0	CC BY NC 3.0
Aim	'To explore the experiences of these young people within the care system, particularly in relation to support-seeking and coping with emotional needs, to better understand feasible and acceptable ways to improve outcomes for these young people.' [abstract]	'To describe patients' and informal caregivers' perspectives on how to improve and monitor care during transitions from hospital to home in Ottawa Canada' [abstract]
Research question	'1) where do young people in care seek support for emotional difficulties, both in terms of social support and professional services? (2) what do they view as barriers to seeking help? and (3) what coping strategies do they use when experiencing emotional difficulties?'(p2)	Not stated
Why a qualitative descriptive study was implemented	Young people in out-of-home care represent an under-researched group. A qualitative descriptive approach enabled exploration of their views, coping and wellbeing to inform approaches to improve formal and informal support.	Part of a larger study that aimed to prioritise components that most influence the development of successful interventions in care transition.
Study setting and country	Two local authorities in England	Canada
Data collection, sampling and participants	Opportunity sampling was used used to invite participants from a large quantitative study to participate in an interview. Semi-structured interviews with 25 young people.	Semi-structured telephone interviews with 8 participants (2 patients; 6 family members) recruited by convenience sampling. Interviews ranged from 45–60 minutes were audio recorded.
Analysis	Reflexive thematic analysis	Thematic analysis

Title	Coping and support-seeking in out-of-home care: qualitative study of the views of young people in care in England[8]	Engaging patients and informal caregivers to improve safety and facilitate person-and family centred care during transitions from hospital to home – a qualitative descriptive study[9]
Key themes	Broader experience of being in care Centrality of social support to wellbeing, and mixed views on professional help Use of both adaptive and maladaptive day-to-day coping strategies	Need for effective communication between providers and patients or informal caregivers Need for improving key aspects of the discharge process Increasing patient and family involvement Suggestions on how to best monitor care transitions

Summary

Qualitative descriptive studies are gaining popularity in health and social care due to their utility, from a resource and time perspective, for research by practitioners, policymakers and researchers. Descriptive studies can be conducted as stand-alone studies or as part of larger, mixed-methods studies.

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CHAPTER 6: PHENOMENOLOGY

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Identify the key terms, concepts and approaches used in phenomenology.
- Explain the data collection methods and analysis for phenomenology.
- Discuss the advantages and disadvantages of phenomenological research.

What is phenomenology?

The key concept in phenomenological studies is *the individual*.

Phenomenology is a method and a philosophical approach, influenced by different paradigms and disciplines.[1]

Phenomenology is the everyday world from the viewpoint of the person. In this viewpoint, the emphasis is on how the individual constructs their lifeworld and seeks to understand the 'taken for granted-ness' of life and experiences.[2,3] Phenomenology is a practice that seeks to understand, describe and interpret human behaviour and the meaning individuals make of their experiences; it focuses on *what* was experienced and *how* it was experienced.[4] Phenomenology deals with perceptions or meanings, attitudes and beliefs, as well as feelings and emotions. The emphasis is on the lived experience and the sense an individual makes of those experiences. Since the primary source of data is the experience of the individual being studied, in-depth interviews are the most common means of data collection (see Chapter 13). Depending on the aim and research questions of the study, the method of analysis is either thematic or interpretive phenomenological analysis (Section 4).

Types of phenomenology

Descriptive phenomenology (also known as 'transcendental phenomenology') was founded by Edmund Husserl (1859–1938). It focuses on phenomena as perceived by the individual.[4] When reflecting on the recent phenomenon of the COVID-19 pandemic, it is clear that there is a collective experience of the pandemic and an individual experience, in which each person's experience is influenced by their life circumstances, such as their living situation, employment, education, prior experiences with infectious diseases and health status. In addition, an individual's life circumstances, personality, coping skills, culture, family of origin, where they live in the world and the politics of their society also influence their experience of the pandemic. Hence, the objectiveness of the pandemic is intertwined with the subjectiveness of the individual living in the pandemic.

Husserl states that descriptive phenomenological inquiry should be free of assumption and theory, to enable phenomenological reduction (or phenomenological intuiting).[1] Phenomenological reduction means putting aside all judgements or beliefs about the external world and taking nothing for granted in everyday reality.[5] This concept gave rise to a practice called 'bracketing' — a method of acknowledging the researcher's preconceptions, assumptions, experiences and 'knowing' of a phenomenon. Bracketing is an attempt by the researcher to encounter the phenomenon in as 'free and as unprejudiced way as possible so that it can be precisely described and understood'.[1(p132)] While there is not much guidance on *how* to bracket, the advice provided to researchers is to record in detail the process undertaken, to provide transparency for others. Bracketing starts with reflection: a helpful practice is for the researcher to ask the following questions and write their answers as they occur, without overthinking their responses (see Box 1). This is a practice that ideally should be done multiple times during the research process: at the conception of the research idea and during design, data collection, analysis and reporting.

Box 6.1 Examples of bracketing prompts

How does my education, family background (culture), religion, politics and job relate to this topic or phenomenon?

What is my previous experience of this topic or phenomenon? Do I have negative and/or positive reactions to this topic or phenomenon? What has led to this reaction?

What have I read or understood about this topic or phenomenon?

What are my beliefs and attitudes about this topic or phenomenon? What assumptions am I making?

Interpretive or hermeneutic phenomenology was founded by Martin Heidegger (1889–1976), a junior colleague of Husserl. It focuses on the nature of being and the relationship between an individual and their lifeworld. While Heidegger's initial work and thinking aligned with Husserl's, he later challenged several elements of descriptive phenomenology, leading to a philosophical separation in ideas. Husserl's descriptive phenomenology takes an epistemological (knowledge) focus while Heidegger's interest was in ontology[4] (the nature of reality), with the key phrase 'being-in-the-world' referencing how humans exist, act or participate in the world.[1] In descriptive phenomenology, the practice of bracketing is endorsed and experience is stripped from context to examine and understand it.

Interpretive or hermeneutic phenomenology embraces the intertwining of an individual's subjective experience with their social, cultural and political contexts, regardless of whether they are conscious of this influence.[4] Interpretive or hermeneutic phenomenology moves beyond description to the interpretation of the phenomenon and the study of meanings through the lifeworld of the individual. While the researcher's knowledge, experience, assumptions and beliefs are valued, they do need to be acknowledged as part of the process of analysis.[4]

For example, Singh and colleagues wanted to understand the experiences of managers involved in the implementation of quality improvement projects in an assisted living facility, and thus they conducted a hermeneutic phenomenology study.[6] The objective was to 'understand how managers define the quality of patient care and administrative processes', alongside an exploration of the participant's perspectives of leadership and challenges to the implementation of quality improvement strategies.(p3) Semi-structured interviews (60–75 minutes in duration) were conducted with six managers and data was analysed using inductive thematic techniques.

New phenomenology, or American phenomenology, has initiated a transition in the focus of phenomenology from the nature and understanding of the phenomenon to the lived experience of individuals experiencing the phenomenon. This transition may seem subtle but fundamentally is related to a shift away from the philosophical approaches of Husserl and Heidegger to an applied approach to research.[1] New phenomenology does not undergo the phenomenological reductionist approach outlined by Husserl to examine and understand the essence of the phenomenon. Dowling[1] emphasises that this phenomenological reduction, which leads to an attempt to disengage the researcher from the participant, is not desired or practical in applied research such as in nursing studies. Hence, new phenomenology is aligned with interpretive phenomenology, embracing the intersubjectivity (shared subjective experiences between two or more people) of the research approach.[1]

Another feature of new phenomenology is the positioning of culture in the analysis of an individual's experience. This is not the case for the traditional phenomenological approaches[1]; hence, philosophical approaches by European philosophers Husserl and Heidegger can be used if the objective is to explore or understand the phenomenon itself or the object of the participant's experience. The methods of new phenomenology, or American phenomenology, should be applied if the researcher seeks to understand a person's experience(s) of the phenomenon.[1]

See Table 6.1. for two different examples of phenomenological research.

Advantages and disadvantages of phenomenological research

Phenomenology has many advantages, including that it can present authentic accounts of complex phenomena; it is a humanistic style of research that demonstrates respect for the whole individual; and the descriptions of experiences can tell an interesting story about the phenomenon and the individuals experiencing it.[7] Criticisms of phenomenology tend to focus on the individuality of the results, which makes them non-generalisable, considered too subjective and therefore invalid. However, the reason a researcher may choose a phenomenological approach is to understand the individual, subjective experiences of an individual; thus, as with many qualitative research designs, the findings will not be generalisable to a larger population.[7,8]

Table 6.1. Examples of phenomenological studies

Title	**Investigating the lived experiences of abused mothers: a phenomenological study** [9]	**A phenomenological study of nurses experience about their palliative care approach and their use of mobile palliative care teams in medical and surgical units in France**[10]
First author and year	Abbaspour, 2021	Engberink, 2020
CC Licence	CC BY 4.0	CC BY 4.0
Aim	'To investigate the lived experiences of mothers abused by their adolescent children' [abstract] and to determine the ultimate structure of maternal abuse as the phenomenon under study. To explore the way the abused mothers describe the experience of being abused by their children.' (p109)	'To understand the Palliative Approach (PA) of the nurses in the medical and surgical care units of 3 hospitals in the south of France and the circumstances and impact of the use of Mobile Palliative Care Teams' [abstract] (MPCTs), using a phenomenological approach focused on the lived experience.

Title	**Investigating the lived experiences of abused mothers: a phenomenological study** [9]	**A phenomenological study of nurses experience about their palliative care approach and their use of mobile palliative care teams in medical and surgical units in France**[10]
Research questions or objectives	Not stated	Why do nurses encounter reluctance to the implementation of palliative care despite its effectiveness? Are these difficulties psychological, organizational, and/or managerial? How can MPCTs help them?
Why a phenomenology study was implemented	Focuses on the lived experience of the participants, acknowledging the dynamic nature of their experiences. Does not require the researchers to analyse and extract the point of view of the participants and focuses on the perspectives of the participants. (p109)	Focus on the lived experience
Study setting	Khuzestan province, Iran	South of France – medical and surgical care units in 3 hospitals
Data collection, sampling and participants	Purposive sampling was employed, with counsellors reporting to researchers if they knew of mothers meeting inclusion criteria for the study (being abused by an adolescent child (12–18 years of age) and willing and cognitively able to participate in the study and share experiences with researchers). In-depth interviews with 12 mothers. Interviews lasted 50–90 minutes	Purposive sampling with data saturation was applied. Interviews followed by focus groups 11 individual interviews lasting between 35-90 minutes. Focus group with 7 registered nurses lasting 1 hour and 45 minutes
Analysis	Descriptive phenomenological analysis	Semio-pragmatic phenomenology – a descriptive method for categorising lived experience; constant comparison approach

Title	**Investigating the lived experiences of abused mothers: a phenomenological study** [9]	**A phenomenological study of nurses experience about their palliative care approach and their use of mobile palliative care teams in medical and surgical units in France**[10]
Key themes	11 elements of abuse were identified based on the participants' experiences	The RN role as a witness to patient experiences served as a watchful eye for physicians, which in turn, helped in anticipating and clarifying the steps leading to a patient-centred palliative approach. The physician's position regarding the role of the RN influenced the implementation of a palliative approach and the behaviour of professional caregivers. The palliative approach as a reflective process, which is ethical and anticipated, calls for 'rethinking care within a team setting, in which time is set aside for this patient-centred approach. The MPCT is seen as the intermediary that facilitates the physician–nurse 'balance' and helps nurses reclaim their professional and ethical values within the environment of shared care.

Summary

Phenomenology focuses on understanding a phenomenon from the perspective of individual experience (descriptive and interpretive phenomenology) or from the lived experience of the phenomenon by individuals (new phenomenology). This individualised focus lends itself to in-depth interviews and small scale research projects.

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CHAPTER 7: ACTION RESEARCH

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Explain the purpose of an action research approach.
- Explain the action research cycle.
- Describe action research characteristics.

What is action research?

The key concept in action research is *change or action*.

Action research (also known as 'participatory action research') aligns well with the practice of health and social care because researchers and practitioners in this discipline work with people and communities in holistic and relational ways to understand the history, culture and context of the setting. Action research aims to understand the setting and improve it through change or action.[1] This method has its roots in activism and advocacy and is focused on solutions. It is practical and deals with real-world problems and issues. Action research often undergoes phases in seeking to understand the problem, plan a solution, implement the solution and then reflect on or evaluate the solution, cyclically and iteratively. Action research is used in the practice of health and social care because it has two fundamental aims: to improve and to involve. This chapter outlines how this is evident, using examples from the research literature (see Table 7.1.).

Action research as involvement

Action research is a collaborative process between researchers and community members. This process is a core component of action research and represents a significant shift from typical research methods. Through action research, those who are being researched become the researchers, with close consideration given to power dynamics. The research participants become partners in the research and are involved in identifying and prioritising the research area, designing and undertaking data collection, conducting data analysis, and interpreting and disseminating the results.[1] The research partners may be provided with support and training to enable them to undertake these activities and to promote empowerment and capacity building (see examples following). Patient and public involvement in research and healthcare improvement (known in Australia as 'consumer and community involvement'), has led to action research gaining popularity as a research design that captures the 'living knowledge' with, for and by people and communities throughout the research journey.

As an example, in the project *Relationships Matter for Youth 'Aging Out' of Care,*[2] Doucet and colleagues aimed to examine relationships that matter to young people in care and how these relationships can be nurtured and supported over time. The project is a collaborative participatory action research study incorporating photovoice (see Chapter 17 for more information on photovoice). Eight young people, formerly in care and from diverse backgrounds, were recruited to the study. The lead researcher highlighted their own lived experience of the child welfare system and a consciousness of the power dynamics at play. The lead researcher created processes within the project to ensure the youth co-researchers were empowered to share their experiences and that the research team members were working *with* the youth co-researchers and not *for* them. These processes included three months of weekly facilitated group discussions, shared meals before project commencement and group outings and community engagement during the project to encourage connection, bonding and trust. The youth co-researchers were provided with photography training and digital cameras. Data collection included the youth co-researchers submitting 6–7 photographs with responses to the following questions for photo contextualisation:

1. What does this photograph mean to you? Why is this photo, in particular, most significant to you?
2. How do you see this photo as a reflection of the issue of supportive long-term relationships – and one that is relevant to you as a former youth in care in your community?
3. What is the relationship between the content of the photo and how you perceive the community or the world around you? What recommendation for change in your community is associated with this photo?[2(para22)]

The photographs were showcased at an exhibition that was open to the community; those in attendance included policymakers, advocates and community representatives. The change documented through this project was one of social transformation for the community and self-transformation and healing for the individuals.

Action research as improvement

Action research can be practitioner-led, whereby the study investigates problems identified by the practitioner with the goal of understanding and improving practice over time. Improvement can be both social improvement and healthcare improvement. Healthcare improvement, in particular quality (of healthcare) improvement, has been the focus of clinical practice, research, education and advocacy for more than 30 years. The two main frameworks guiding healthcare and quality improvement efforts are the Plan, Do, Study, Act (PDSA) cycle and Learning Health Systems.[3] Both of these frameworks lend themselves to action research. For example, the PDSA cycle is guided by three overarching questions:

- What are we trying to accomplish?
- How will we know that a change is an improvement?
- What change can we make that will result in improvement?[4(Figure1)]

Learning Health Systems is another approach to quality improvement that has gained popularity over the past decade. Data collected by health services (e.g. patient data, health records, laboratory results) are used for knowledge creation in continuous and rapid cycles of study, feedback and practice change.[5] A Learning Health Systems framework incorporates systems science, data science, research methods for real-world contexts, implementation science, participatory research and quality improvement approaches.

Van Heerden and colleagues adopted an action research study to transform the practice and environment of neonatal care in the maternity section of a district hospital in South Africa. The study *Strategies to sustain a quality improvement initiative in neonatal resuscitation*[6] was conducted in three cycles. Cycle 1 was a situation analysis that explored and described the existing practices and factors influencing neonatal resuscitation and mortality in the hospital through administering questionnaires with nurses (n=69); a focus group with nine doctors; and an analysis of hospital records. A nominal group discussion (structured group discussion including prioritisation) was conducted with 10 managers and staff, followed by a reflective meeting with the project's steering committee. Cycle 2 developed and implemented strategies to sustain a quality improvement initiative. The strategies addressed training, equipment and stock, staff attitudes, staff shortages, transport transfer for critically ill neonates, and protocols. Cycle 3 was an evaluation of change and sustainability after the implementation of strategies (Cycle 2) and involved the analysis of hospital record data, repeat questionnaire with nurses (n=40), focus group discussion with 10 doctors, steering committee and management members, followed by reflective meetings with the steering committee. Qualitative data was analysed through open coding, and quantitative data was analysed descriptively. The neonatal mortality rate declined (yet still needed to improve) and the implementation strategies facilitated change that led to improvement and practice transformation.

Action research as a methodology or an approach

There is debate as to whether action research is a methodology or an approach, since several different research methods and methodologies can be used. For example, multiple forms of data collection can be utilized, including quantitative data from surveys or medical records, to inform the identification and understanding of the problem and evaluation of the solution. Action research can also draw on descriptive qualitative research, quantitative cross-sectional studies, case studies (see Chapter 8), ethnography

(Chapter 9) and grounded theory (Chapter 10). Action research can therefore take a purely qualitative approach, or can take a mixed-methods approach. See Table 7.1. for examples of action research studies.

Advantages and disadvantages of action research

Action research addresses practical problems, drawing on principles of empowerment, capacity-building and participation. The research problem to be addressed is typically identified by the community, and the solutions are for the community. The research participants are collaborators in the research process. The examples presented in this chapter demonstrate how the research collaborators and co-researchers received training and support to lead elements of the project. Another advantage of action research is that it is a continuous cycle of development. Hence, the approach is iterative and the full solution can take multiple cycles and iterations to develop and sustain.[7,8]

Since action research is fundamentally about relationships and integrating research into the real world, studies can take years to result in a solution. It is important to be able to adapt and be flexible in response to community and stakeholder needs and contexts. The research can therefore be constrained by what is practical and also ethical within the setting. This may limit the scope and scale of the research and compromise its rigour. Action research can also create unanticipated work for community members and participants because they are not usually involved in research in this way, and thus training may be required, as well as remuneration for time and experience.[7,8]

Table 7.1. Action research study examples **Title** Critically examining a community-based participatory action research project with forced migrant youth[9] Implementing solutions to improve and expand telehealth adoption: participatory action research in four community healthcare settings[3] **First year and author** Middleton, 2021 Taylor, 2015 **CC Licence** CC BY NC ND 4.0 CC BY 4.0 **Aim** 'To provide a critical analysis of the continuous process required to engender a collaborative effort towards developing socially just community sports programs.' 'To identify the factors affecting telehealth adoption, and to test solutions to address prioritised areas for improvement and expansion.' **Why an action research study was implemented** This project was initiated by staff at the YMCA. Hence, it was community initiated and led. The YMCA team wanted to improve the sports program for forced migrant young people resettled in their community. The young people were provided with a one-year free membership; however many families did not renew this after the free period. The research team believed that an action research approach in which they worked alongside forced migrant young people would extend to the young people's family members also benefiting from sports involvement. The YMCA team had a staff member with lived experience of being an asylum seeker and the manager knew about YMCA programs that could benefit from an action research approach. To improve the adoption of telehealth aligned with the principles of plan do study act (PDSA) quality improvement process.

Phase 1: Qualitative in-depth case study

Phase 2: Action research – researchers worked in partnership with participants at each site to plan, test and evaluate solutions to telehealth adoption. **Study setting** YMCA in Northeastern Ontario, Canada Four community nursing settings using telehealth to monitor the symptoms of patients with Chronic Obstructive Pulmonary Disease (COPD) and Chronic Health Failure, United Kingdom **Data collection, sampling and participants** Relationships between the research team, YMCA team and young people were developed through meetings, shared meals, community encounters, Facebook group and visits to the homes of the young people.

33 forced migrant young people from 15 families became collaborators in the study. The average age was 13 years.

Get-to-know-you interviews were conducted, incorporating art and interviewing techniques – 'draw any images and/or symbols that meaningfully depicted personal stories related to playing sport in Canada', which was followed by interpreting events. The team then co-developed creative non-fiction polyphonic vignettes – these were shared with the young people and families and the YMCA and research teams for feedback. Recruitment via site collaborators and local telehealth champions. All case study participants were invited to take part in the action research component if interested. 57 staff (community matrons, nurse specialists, frontline clinical and support staff, clinical leads and service managers, and other managers) and 1 patient. Total participants: 58.

Phase 2: Action research component.

Workshop 1 – develop an implementation plan (plan component of the PDSA cycle). Phase 1 case study findings presented. 3–6 actions were identified.

An Action Inquiry Group (AIG) was established for each action with members responsible for implementation (DO) and review of progress and learning (STUDY).

Workshop 2 – review and reflect on work and extend, refine or discontinue the plan. (ACT) **Analysis** Reflexive thematic analysis Thematic analysis using framework analysis **Key themes** Themes are not presented in this article as it focuses on the process of the action research project. Seven main action areas were identified (see subheadings in the article)

Summary

Action research is a research design in which researchers and community members work together to identify problems, design and implement solutions and evaluate the impact of these solutions. Change or action is a core component of this research design.

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CHAPTER 8: CASE STUDY

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Identify the key terms and concepts used in qualitative case study research.
- Discuss the advantages and disadvantages of qualitative case study research.

What is a case study?

The key concept in a case study is *context*.

In qualitative research, case studies provide in-depth accounts of events, relationships, experiences or processes. Stemming from the fields of evaluation, political science and law, the aim of a qualitative case study is to explore a phenomenon within the context of the case[1] and to answer how and why research questions.[2] The contextual conditions are relevant to the phenomenon under study and the contextual factors tend to lie with the case.[1] From the outset it is important (a) to determine who or what is your case – this can be a person, program, organisation or group, or a process – and (b) to articulate the phenomenon of interest.

An example of why context is important in understanding the phenomenon of interest is a study of health promotion action by local churches in Victoria, Australia.[3] The phenomenon under study was health promotion action, with 10 churches comprising the cases, which were mapped across the framework of health promotion approaches.[4] The contextual factors included church denomination (Baptist, Church of Christ, Uniting, Anglican, Catholic and Salvation Army), size (small, medium and large), location (rural and metropolitan), partnerships with external organisations (government, local schools and social welfare organisations) and theological orientation (traditional, modern or postmodern), to understand the phenomenon of health promotion action. Data collection took 12 months and involved interviews with 37 church leaders, 10 focus groups with volunteers, 17 instances of participant observation of church activities, including church services, youth events, food banks and community meals, and 12 documentary analyses of church websites, newsletters and annual reports. The case studies identified and illustrated how and why three different expressions of church – traditional, new modern and emerging – led to different levels and types of health promotion activities.

Three prominent qualitative case study methodologists, Robert Stake, Robert Yin and Sharan Merriams, have articulated different approaches to case studies and their underpinning philosophical and paradigmatic assumptions. Table 8 outlines these approaches, based on work by Yazan,[5] whose expanded table covers characteristics of case studies, data collection and analysis.

Table 8.1. Comparison of case study terms used by three key methodologists

Book Title	**The Art of Case Study Research**[6]	**Case Study Research: Design and Methods.**[7]	**Qualitative Research and Case Study Applications in Education.**[8]
First author and year	Stake, 1995	Yin, 2002	Merriam, 1998
Definition of qualitative case study	study of the particularity and complexity of a single case, coming to understand its activity within important circumstances'(pxi)	empirical inquiry that investigates a contemporary phenomenon within its real-life context...relies on multiple sources of evidence'(p13)	'an intensive, holistic description and analysis of a bounded phenomenon such as a program, an institution, a person, a process, or a social unit'(pxiii)
Paradigm	Constructivism	Positivism	Constructivism
Definition of a case	'a specific, a complex, functioning thing, more specifically an integrated system' which 'has a boundary and working parts' and purposive (in social sciences and human services)(p2)	'a contemporary phenomenon within its real life context, especially when the boundaries between a phenomenon and context are not clear and the researcher has little control over the phenomenon and context'(p13)	'a thing, a single entity, a unit around which there are boundaries'(p27) It can 'be a person... a program, a group...a specific policy, and so on'(p27)

Table 8.1 is derived from 'Three Approaches to Case Study Methods in Education: Yin, Merriam, and Stake ' by Bedrettin Yazan, licensed under CC BY-NC-SA 4.0.[5]

There are several forms of qualitative case studies.[1,2]

Discovery-led case studies, which:

- describe what is happening in the setting
- explore the key issues affecting people within the setting
- compare settings, to learn from the similarities and differences between them.

Theory-led case studies, which:

- explain the causes of events, processes or relationships within a setting
- illustrate how a particular theory applies to a real-life setting
- experiment with changes in the setting to test specific factors or variables.

Single and collective case studies, where:[2, 9]

- the researcher wants to understand a unique phenomenon in detail– known as an intrinsic case study
- the researcher is seeking insight and understanding of a particular situation or phenomenon, known as an illustrative case study or instrumental case study.

In both intrinsic, instrumental and illustrative case studies, the exploration might take place within a single case. In contrast, a collective case study includes multiple individual cases, and the exploration occurs both within and between cases. Collective case studies may include comparative cases, whereby cases are sampled to provide points of comparison for either context or the phenomenon. Embedded case studies are increasingly common within multi-site, randomised controlled trials, where each of the study sites is considered a case.

Multiple forms of data collection and methods of analysis (e.g. thematic, content, framework and constant comparative analyses) can be employed, since case studies are characterised by the depth of knowledge they provide and their nuanced approaches to understanding phenomena within context.[2,5] This approach enables triangulation between data sources (interviews, focus groups, participant observations), researchers and theory. Refer to Chapter 19 for information about triangulation.

Advantages and disadvantages of qualitative case studies

Advantages of using a case study approach include the ability to explore the subtleties and intricacies of complex social situations, and the use of multiple data collection methods and data from multiple sources within the case, which enables rigour through triangulation. Collective case studies enable comparison and contrasting within and across cases.

However, it can be challenging to define the boundaries of the case and to gain appropriate access to the case for the ‘deep dive’ form of analysis. Participant observation, which is a common form of data collection, can lead to observer bias. Data collection can take a long time and may require lengthy times, resources and funding to conduct the study.[9]

Table 8.2 provides an example of a single case study and of a collective case study.

Table 8.2. Examples of qualitative case studies

Title	**The lived experiences of a male survivor of intimate partner violence: a qualitative case study**[10]	**Implementing infection prevention practices across European hospitals: an in-depth qualitative assessment**[11]
First author and year	Nayback-Beebe, 2012	Clack, 2018
CC License		CC BY NC 4.0
Aim	'The purpose of this phenomenological qualitative case study… was to gain a holistic understanding of the lived-experience of a male victim of intimate partner violence and the real-life context in which the violence emerged.'(p89)	'in-depth investigation of the main barriers, facilitators and contextual factors relevant to successfully implementing these strategies in European acute care hospitals'(p771)
Research question	'What is the lived experience of living in and leaving an abusive intimate relationship for a white middle class male?'(p90)	'(1) what are the main barriers and facilitators to successfully implementing CRBSI prevention procedures?; and (2) what role do contextual factors play?'(p771)
Why a qualitative case study was conducted	A single, intrinsic qualitative research study. Following Yin's case study approach, the authors wished to uncover the contextual conditions relevant to the phenomenon under study – living in and leaving an abusive intimate relationship as a white, middle-class male. The researchers wanted to understand and explore the contextual conditions related to female-to-male perpetrated intimate partner violence.	A qualitative comparative case study of 6 of the 14 hospitals participating in the Prevention of Hospital Infections by Intervention and Training (PROHIBIT) randomised controlled study on the prevention of catheter-related bloodstream infection prevention. The case study examined contextual factors that affect the implementation of an intervention, particularly across culturally, politically and economically diverse hospital settings in Europe.
Study setting and country	United States of America, insights from a case study to provide nurses with an understanding that intimate partner violence occurs in the lives of men and women, and to be aware of this in the inpatient and outpatient settings.	European acute-care hospitals that were participating in the PROHIBIT randomised controlled trial.

Title	**The lived experiences of a male survivor of intimate partner violence: a qualitative case study**[10]	**Implementing infection prevention practices across European hospitals: an in-depth qualitative assessment**[11]
Data collection, sampling and participants	Three in-depth interviews conducted for one month. The participant was a 44-year-old man who met the following inclusion criteria: • self-reported survivor of physical, emotional, verbal abuse, harassment and/or humiliation by a current or former partner • the violence occurred in the context of a heterosexual relationship • was in the process of leaving or had left the relationship	Data collection before and after the implementation of an intervention and included 129 interviews (133 hours) with hospital administration, IPC and ICU leadership and staff, telephone interviews with onsite investigators alongside 41 hours of direct observations
Analysis	Existential phenomenology following Colaizzi's method for data analysis.	Thematic analysis was inductive (first site visit) and deductive (second site visit), with cross-case analysis using a stacking technique; cases were grouped according to common characteristics and differences, and similarities were examined.
Key themes	Theme 1. Living in the relationship – confrontation from within Theme 2. Living in the relationship – confrontation from without Theme 3. Leaving the relationship – realisation and relinquishment Overarching theme: Living with a knot in your stomach	Three meta themes were identified • implementation agendas • resourcing • boundary spanning

Summary

Qualitative case studies provide a study design with diverse methods to examine the contextual factors relevant to understanding the why and how of a phenomenon within a case. The design incorporates single case studies and collective cases, which can also be embedded within randomised controlled trials as a form of process evaluation.

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CHAPTER 9: ETHNOGRAPHY

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Identify the key terms and concepts used in ethnography.
- Discuss the advantages and disadvantages of ethnography.

What is ethnography?

The key concept in ethnography is *culture*.

Ethnography studies emerged from the discipline of anthropology. They aim to understand the meanings and behaviours associated with the membership of groups, teams, organisations and communities.[1] The focus of ethnographic research is on the lived culture of groups of people; ethnographers have studied systems of belief, religious frameworks, worldviews and structures that form the social world. There are many definitions of culture. In ethnography, culture is defined as the group norms and expectations that allow members of the group to communicate and work together. This includes attributes, beliefs, customs, behaviours, knowledge, capabilities and habits. Examples of cultural groups include people from a particular region or race, religious groups, organisational groups, workplaces and social groups (for example, friendship groups, and mothers groups). Note that culture is dynamic and socially constructed and it is normal for there to be sub-cultures within cultural groups.[2]

Multiple methods can be used in ethnographic research, but participant observation is a hallmark method.[1,3] To explore culture requires a 'triangulation'; that is, the use of multiple methods, such as observations and interviews, to develop a comprehensive understanding of culture through observing people and listening to what they have to say about (or within) the culture.

Several approaches to data analysis lend themselves to ethnography, including the identification, study and analysis of patterns. The process of analysis follows a typically unstructured and iterative path consisting of description (describing data), analysis (examining relationships and linkages) and interpretation (explanations beyond analysis).[4]

There are other key concepts in ethnographic research, which are outlined below.

Additional key concepts in ethnographic research

- **Fieldwork and field notes** – the time spent engaging in primary data collection, which is predominantly participant observation, and the mode of data collection. Fieldwork is the time spent immersed in the culture under study, while field notes are the written reflections, observations and ideas documented during or soon after fieldwork.[5]
- **Participant observation** – the main method of data collection in ethnography involves the researcher participating as a member of the community or culture, to gain first-hand experience of daily life in the research setting.[5]
- **An emic perspective** – ethnography seeks to understand the worldview of the participant; it thus follows that the researcher can have an emic perspective (insider) or an etic perspective (outsider). This is not a binary category. Rather, researchers might be considered on a continuum, from emic to etic[6] (see Chapter 28 for an overview of insider and outsider research), and therefore reflexivity (Chapter 30) and researcher positionality (Chapter 28) are important elements of the research process. *Implementing 'insider' ethnography: lessons from the* Public Conversations about HIV/AIDS *project in rural South Africa* describes an ethnography project involving insider community members and outsider investigators reflecting on the advantages and challenges of this approach.[7]
- **Thick description** – the researcher creates detailed observational field notes with references to the social actions and behaviours of participants. The field notes include anecdotes, observations about the language used and quotes to illustrate the activities of the cultural group being observed. The researcher then integrates theoretical frameworks to help create meaning for the observations.[8]
- **Holism** – ethnography focuses on studying all aspects of a culture, including religious practices, politics, institutions, family structures and cultural traditions. Using the analogy of the structure of the human body, Bronislaw Malinowski, one of the founders of the functionalist school of anthropology, described survey research as the skeleton and ethnography as the flesh and blood.[4]

How long researchers spend conducting observations in the field depends on the research question and context. For example, in research to observe and characterise the behaviours and processes of antimicrobial decision-making in two surgical units of an acute hospital setting, researchers spent *58 hours* in participant observation at three points of care: pre-admission clinic, surgery and on the ward following surgery. These three points of care were chosen as key moments in the patient's experience of surgery. The observations were conducted in an acute hospital where medical practice is process-driven and protocol-driven. Hence, it did not take extensive time to observe the typical process and protocol in this setting. Researchers used an observation audit sheet (see Chapter 15) and informed participants that the study was focused on clinical decision-making, rather than specifically antimicrobial prescribing. This was done to minimise the 'Hawthorne effect', whereby people are said to change their behaviour because they know they are being observed. Following participant observations, six semi-structured interviews were conducted with two surgeons and four anaesthetists to clarify and discuss the findings of the observations. Interview data were analysed thematically, using inductive and deductive coding.[9]

In contrast, an ethnographic study of homecare workers supporting people living with dementia involved 100 hours of participant observations of 16 homecare workers who were supporting 17 people living with dementia. Interviews were conducted with 82 people, including people living with dementia, family carers, homecare managers and support staff, homecare workers, and health and social care professionals.[10]

Advantages and challenges of ethnography

The immersive approach to ethnography enables a nuanced understanding of the cultural group under study. Unlike other research designs, the prolonged engagement with the research setting provides an opportunity to refine and iterate research questions leading to a deeper understanding of the phenomenon. Participant observation provides a first hand of the behaviours and interactions of people within a cultural group which can be triangulated with interviews and documents to increase the rigour of the research.[9]

There are many challenges in conducting ethnographic research. The time required to undertake ethnographic fieldwork can range from short sessions of observations over months or years, to the researcher living in the community for a period of time. The resources and time required may be substantial. When a researcher is embedded within a community, their departure can cause anxiety and distress for both the researcher and the community members. This experience was described by Paolo Franco, who spent 18 months conducting fieldwork in a retirement village, as a volunteer technology supporter for the residents. Franco described how the participants became dependent on his technology service as well as socially and emotionally connected to him as the researcher. To mitigate problems occurring with a researcher withdraws from a research setting, the researcher should let participants know as early as possible about their estimated time in the community, and should have a plan for their exit.[11]

Another key challenge in ethnography is gaining access to 'the field' and enlisting the support of gatekeepers. Careful planning and engagement are required to ensure communication channels are open and positive relationships are established. Managing ethical conduct is another important consideration in ethnography. Researchers need to consider how much they will disclose to participants about the purpose of the research, and whether they will be covert (undercover) or overt (open and transparent) in their approach to fieldwork. For the most part, researchers are overt about their research, hoping that participants will 'forget' that they are being studied and will revert to natural behaviours.[5]

Table 9.1 provides two examples of ethnography from health and social care.

Table 9.1. Ethnographic examples

Title	The costs of care: an ethnography of care work in residential homes for older people[12]	Understanding the perspectives of women who Use intravenous drugs and are experiencing homelessness in an urban centre in Canada: an analysis of ethnographic data[13]
First author and year	Johnson, 2022	Kitson, 2022
CC Licence	CC BY 4.0	CC BY NC 4.0
Aim	Not stated	'To explore the subculture of persons who identify as women who were experiencing homelessness and who use injection drugs (WUID) and to present an understanding of what was meaningful to these women when making healthcare decisions.'[para9]
Research question	1. 'What do residents who pay for high-cost care and those who receive low-cost care, actually get in the homes they live in? Is there a clear link between the price of care and its quality?'	

'What factors contribute to the provision of good and bad quality care? What respective roles are played by management, training, material resources and the normative and symbolic culture of work?

'What moral, emotional and material stresses are experienced by care workers, and how are these stresses negotiated and managed, both by care workers and their employers?'

'What contribution can sociological theory make to our understanding of the practices and experiences of care workers in residential homes today?'(p57)

Why an ethnography study was conducted The author wanted to gain an insider perspective of what life was like in the care homes Critical ethnography was conducted as the authors explored social injustice in the hope of facilitating change to enhance healthcare services for WUID experiencing homelessness
Study setting Two care homes in southern England
Low cost – Millstead
High cost – Shorefield Ottawa, Canada in healthcare settings and a women's-only social program **Data collection, sampling and participants** 800 hours of participant observations conducted over 2 years.

The author took the role of a care worker for 12 months (first at Millstead and then at Shorefield). 104 hours of participant observation across six locations representing healthcare appointments, women's shelters, and women's drop-in programs for those at risk for bloodborne infections and chance encounters. Women were asked to take photographs.
Field notes included descriptions of the waiting areas and hand-drawn a map of the area.
Interviews with WUID **Analysis** A formal analysis approach not followed
The author read and re-read field notes and interview transcripts and created analytical notes.
The analysis consisted of 'identifying, studying and analysing patterns in the data and noting similarities/ differences between observations and interviews with care workers'. Inductive thematic analysis
'Braiding' the data from multiple sources and methods – a form of triangulation that illustrates a thick, nuanced description of the data **Key themes** Daily routines
The content and philosophies of care
Carers, cooks, or cleaners? The care worker's role The results are presented under each of the data collection methods with a description of what was observed, combined with interpretation and quotes, images, and categories from the data.

Summary

Ethnography focuses on understanding culture and the behaviours, experiences and meanings at the group level. The main method of data collection is participant observation, which can be combined with interviews, focus groups and field notes to inform interpretations of the research topic.

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CHAPTER 10: GROUNDED THEORY

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Identify the three approaches to grounded theory research.
- Define the key terms and concepts used in grounded theory research.
- Discuss the advantages and disadvantages of grounded theory research.

What is a grounded theory study?

The key concept of grounded theory is *building theory*.

Grounded theory studies, developed by Barney Glaser and Anselm Strauss, aim to build theory 'from the ground up' – meaning 'from the data'.[1,2] For many people, the idea of developing a theory can be intimidating.[3] However, the theories generated from grounded theory studies are rarely grand theories at the level developed by, for example, philosophers Foucault or Hegel. Rather, the focus is on discovering concepts that explain social processes, actions and interactions from the collected data.[1,2] In health and social care research, this can typically take the form of a framework or typology.

Since Glaser and Strauss initiated the grounded theory approach in the 1960s, multiple competing methods have arisen from different ontological and philosophical foundations, which are outlined in Table 10.1.

Table 10.1. Grounded theory approaches

	Classic Grounded Theory – Glaser and Strauss (1967)	**Straussian Grounded Theory – Strauss and Gorbin (1990)**	**Constructivist grounded theory – Charmaz (2006)**
Philosophical perspective[4]	Positivist realist ontology	Pragmatist and symbolic interactionist	Constructivist stance, relativist ontology, subjective epistemology
Role of the researcher[4,5]	Independent and separate - objective Few to no predetermined thoughts No initial literature review	Active, with an interpretive role The researcher's experience influences the research questions that are asked, the generation of the hypothesis and theoretical sensitivity – it is the researcher that conducts data collection and analysis and hence discovers the relationship between data categories to construct the theory.	Co-construction – the researcher influences the research in the data collection and analysis process through interactions. The researcher's experience is a valued part of the process, hence researcher reflexivity is important (see Chapter 30).
Data and data analysis[4,5]	Open, selective and theoretical coding	Open, axial and selective coding	Line-by-line conceptual coding with focused coding to synthesise large amounts of data. Inductive, deductive and abductive logic – the process of moving back and forth between data and conceptualisation. Abductive logic is the process of exploring different theoretical explanations for what the researcher observes in the data to then arrive and the most likely explanation.

To ensure that the theory is derived from the data, researchers undertaking Classical or Straussian Grounded Theory should have no preconceived theories before starting the research – which means they should not be seeking to test a theory – they should not be constrained by the literature when coding data and they should not impose prior concepts on the data.[3] Grounded theory is therefore inductive – it generates theory – as opposed to deductive – which tests theory.[4] Theories about social processes and actions should be generated systematically through research, and 'discovered' from the data rather than hypothesised and tested against data.[6,2] Hence, grounded theory studies suit research topics in which little is known about the 'how and why' of social processes.[5]

Multiple forms of data collection can be employed in ground theory studies, with data collection and data analysis occurring concurrently to inform theory development.[1] For example, the researcher may conduct 20 interviews, undertake the analysis and begin to form a theory, and then, based on this theory, develop an interview guide that will elicit further theoretical development as more data is collected. This process happens across multiple cycles of data collection; analysis and data collection usually stops when theoretical saturation is reached.[7] Hence, the research is *iterative* and evolves through the collection and analysis of data. *Theoretical saturation* is when all the domains or aspects of the theory have been thoroughly examined.[1] Grounded theory studies can draw on other qualitative designs – for example, a researcher can conduct a grounded theory phenomenology study or a grounded theory case study. The approach to analysis is typically the constant comparative approach.[1,2]

Advantages and disadvantages of grounded theory

The advantages of grounded theory studies include that the researcher is able to be immersed in the data at a detailed level, and this immersion occurs early in the research process, to enable the constant interplay between data collection and analysis. The concept of theoretical saturation ensures that the data accounts for all elements of the theory that is generated. However, the process of theoretical sampling and the iterative nature of going back and forth between data collection and data analysis can take a long time. In creating the theory, the context of the social processes may be lost and the overall theory may lack nuance. Consequently, it can be difficult to scale up the theory to different contexts.[4,8-10] Examples of studies employing grounded theory are shown in Table 10.2.

Table 10.2. Examples of grounded theory studies

Title	**Motivating change: a grounded theory of how to achieve large-scale, sustained change, co-created with improvement organisations across the UK**[11]	**A taxonomy of dignity: a grounded theory study**[12]
First author and year	Breckenridge, 2019	Jacobson, 2009
CC Licence	CC BY NC 4.0	CC BY 2.0
Aim	'sharing knowledge about sustaining large-scale change' [abstract methods]	To 'describe and classify the forms of dignity, the elements that comprise these forms, and the relationships among the elements, thus expanding understanding of the concept and providing an empirical base from which to develop strategies for enhancing human well-being' [last paragraph of background]

Title	**Motivating change: a grounded theory of how to achieve large-scale, sustained change, co-created with improvement organisations across the UK**[11]	**A taxonomy of dignity: a grounded theory study**[12]
Why a grounded theory study was conducted	The authors wanted to develop a theory of 'what works when implementing and sustaining individual initiatives and they did this using a participatory approach so that the theory was co-created and co-owned'	'grounded theory is an excellent methodology to use when investigating concepts like dignity that are simultaneously extremely abstract and strongly rooted in tangible aspects of social life. In addition, because grounded theory "fosters [the integration of] subjective experience with social conditions," it is a valuable tool for social justice research' [second paragraph of methods]
Study setting and country	Scottish Improvement Science Collaborating Centre	Toronto, Canada
Data collection, sampling and participants	Data collection involved 42 staff across 3 organisations: Unicef UK, NHS Highland and Healthcare Improvement Scotland. Three full-day consultations were held with small group discussions in which participants worked in groups to create their theory of 'what works' when implementing and sustaining individual initiatives. Groups compared their different theories and collectively identified similarities and differences and then compared group theories with existing improvement models, theories and frameworks.	64 semi-structured interviews were held with people who were marginalised because of their health or social status, individuals who provide health and social care services and people working in the area of health and human rights. Interview questions and whom to recruit evolved as the analysis was conducted. demonstrating the iterative nature of the research.
Analysis	The authors applied a classic grounded theory analysis approach, consisting of open coding of the core category identified as motivating change. Selective coding was used to expand the core category and related categories and theoretical coding examined relationships and created an integrated theory. According to grounded theory principles, theory development was discussed with a second researcher and relevant literature was reviewed following theory development. The final theory was presented to the three organisations.	'Schatzman's formulation of dimensional analysis, constant comparison of concepts and conditions derived from the data, development of higher order categories to encompass and link these concepts and conditions, and extensive memo writing to track and explore developing ideas.'(para7)
Results	The final theory was presented to the three organisations. The theory of motivating change consists of three main domains: (1) The psychological conditions for sustained large-scale change – internalised motivation (intrinsic and extrinsic motivators for change identified); (2) the social conditions for sustained large-scale change – a flow of trust; and (3) the structural conditions for sustained, large-scale change.(p5-7)	A taxonomy of dignity identifying: – Form of dignity: human dignity and social dignity – Elements of dignity: dignity encounters, dignity violation and dignity promotion – Objects of violation and promotion – The consequences of violating dignity.

Summary

Grounded theory is an appropriate research design to explain a process through a theory. The design incorporates multiple forms of data collection and is iterative in approach, with cycles between data collection and analysis.

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CHOOSE YOUR QUALITATIVE STUDY

Darshini Ayton

Each qualitative research design has a unique focus and will elicit different results. Hence, to facilitate the integration of qualitative research into health and social care, an understanding of these designs and what they can achieve is needed.

Table S2 presents an overview of considerations for each of the six qualitative study designs covered in section 2. The first column, on the far left, is a prompting question based on the key concept for the specific research design, and the answers to this question prompt are mapped to a corresponding research design (the column on the far right of the table).[1,2] The second column indicates the practicalities of data collection, sample size, and time, resources and expertise required. Note that the sample sizes given are not prescriptive; they provide a guide or recommendation as to the likely number of participants required; for example, to inform applications for grants and ethics approval. The final column indicates the appropriate qualitative research design, based on all of these prior considerations. For more detail on each of the study designs, please read the corresponding chapter indicated in the final column.

Table S2. Considerations to inform the selection of a research design

Prompting question based on key concept	**Data collection**	**Sample size**	**Time, resources and expertise**	**Qualitative study design**
Do you want to **describe** a phenomena (situation) – who what, where?	Semi-structured interviews; may require other forms of data collection, such as focus groups and observations.	Small sample size, conveniently and purposively sampled. This will depend on the research question and context. Recommended sample sizes: 3–20 interviews or 1–2 focus groups of 4–6 participants.[3]	Suitable for use by novice and busy researchers; can be embedded within mixed-methods studies.	**Descriptive study.** (Chapter 5)
Do you want to focus on the lived experience of **individuals**?	In-depth interviews; typically does not involve focus groups.	Small sample size, depending on whether the group is heterogeneous or homogenous, research question and context. Recommended sample size of about 20 participants. [4]	Expertise is required due to the complexity of understanding the different philosophical and methodological influences.	**Phenomenology.** (Chapter 6)

Prompting question based on key concept	**Data collection**	**Sample size**	**Time, resources and expertise**	**Qualitative study design**
Do you want to create, implement and evaluate **change or action** in collaboration with members of a community or setting?	Members of the community or setting must be involved in data collection and/or analysis. Multiple forms of data collection are required: interviews, focus groups, surveys, existing data sources.	The sample size needed can be large due to the different cycles of action research; depends on the number of stakeholders and the research context. The sample size required may be similar to that of a case study	Engaging with community members or stakeholders can take time and may require multiple rounds of engagement	**Action research.** (Chapter 7)
Do you want to study phenomena within **context**?	Multiple forms of data collection are required: interviews, focus groups, surveys, existing data sources.	If a multiple case study design – the sample size can be large due to having representatives from different stakeholder groups. Recommended sample size is 30-100. [4]	Multiple case studies can be resource-intensive and time-intensive.	**Case study.** (Chapter 8)
Are you interested in studying group behaviours, attitudes and experiences where **culture** is relevant (e.g. power, hierarchy, social norms, socio-cultural factors)?	Participant observation which incorporates informal conversations, formal interviews, document analysis and direct observations.	Moderate to large, depending on the size of the culture-sharing group. Recommended sample size of between 50-150.[4]	Time-intensive, requiring personnel for observations, interviews and analysis.	**Ethnography.** (Chapter 9)
Do you want to develop an explanation of processes or concepts through **theory** or a **framework**?	Multiple forms of data collection – interviews, focus groups, surveys, existing data sources	Tends to require a large sample size to achieve theoretical saturation, whereby domains of the theory are explored sufficiently across participants. Of 10 grounded theory studies, the mean sample was 59. Studies in health sciences ranged from 20–147 participants. [4]	Time-intensive, not suited to the novice researcher unless supervised by an experienced qualitative researcher	**Grounded theory.** (Chapter 10)

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CHAPTER 11: MIXED-METHODS RESEARCH

Danielle Berkovic

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the definition of mixed-methods research.
- Identify the three main mixed-methods research designs.
- Articulate an answerable mixed-methods research question.

What is a mixed–methods study?

The key concept in mixed-methods research is *combining qualitative and quantitative research designs and data*.

Mixed-methods research requires a purposeful gathering of quantitative and qualitative research methods, including in data collection, data analysis and interpretation of the results. The main word here is 'mixed': there must be an intentional combining of both research methods to address the research question.

Planned integration of quantitative and qualitative methods enables researchers to answer research questions that neither quantitative nor qualitative methods could answer on their own. Mixed-methods research draws on the strengths of both quantitative and qualitative research methods, enabling the exploration of diverse perspectives and relationships within the two different types of data.[1]

How does mixed-methods research fit into a research paradigm?

As described in Chapter 2, a paradigm is a worldview – a framework of beliefs, values and methods.[2] There is some debate about whether research paradigms should be bound to a particular methodology. Paradigm purists argue that it is impossible for quantitative and qualitative methods to achieve compatibility, due to the varying types of research questions that the two methods address.[3] This perspective suggests that a research project should include only quantitative OR only qualitative methods.

However, researchers using mixed methods argue that it is perfectly logical to use different methods within a single project, blending them as needed to address a particular research question. Many mixed-methods researchers also highlight that paradigms are socially constructed, and that there is no plausible reason these constructs cannot exist within mixed-methods research. As such, mixed-methods researchers encourage other research professionals to consider the evolving relationship between paradigms and methods, in an ever-changing world.[4]

Chapter 2 describes the four main research paradigms (positivist or scientific, interpretivist or constructivist, radical or critical, and post-structural). Most mixed-methods research reflect post-positivist assumptions, whereby outcomes are perceived to occur based on a combination of factors that interact with each other, rather than assumed to occur in a linear process of cause and effect between exposure and outcome.[4] The 'post' addition to the positivist paradigm reflects further development from its original concept. Post-positivists maintain the assumption of cause and effect but are willing to identify more complex and non-linear relationships within the data.

The other paradigm (although it is not one of the main four) that primarily exists in the context of mixed-methods research is pragmatism. Pragmatism is oriented towards using multiple research methods but stipulates that the use of these methods should always be guided by existing research problems. Pragmatism values both objective (quantitative) and subjective (qualitative) knowledge to meet research objectives.[4] The main reason for adopting a pragmatist position in research is to enable the researcher to collect and analyse their data through a pluralistic lens in order to best answer the research question.

What are the mixed-methods research designs?

There are three mixed-methods research designs: convergent, explanatory and exploratory.

- A **convergent** mixed-methods study seeks to combine qualitative and quantitative results with the intention of creating a complete understanding of a particular phenomenon. A convergent mixed-methods study may also validate one set of findings against another, such as comparing participants' responses on quantitative scales with responses to open-ended qualitative interview questions.
- An **explanatory** mixed-methods study seeks to explain quantitative results through qualitative inquiry.
- An **exploratory** mixed-methods study seeks to use qualitative results in the development of a quantitative component, which is then tested with study participants.

The terminology used to describe the different mixed-methods designs changes from time to time. When reading an article or textbook written prior to 2021, mixed-methods designs may be referred to as 'triangulation', 'embedded', 'explanatory' or exploratory.[5] Table 11.1. presents a comprehensive review of the three mixed-methods designs.

Table 11.1. Summary of the three mixed-methods designs

	Convergent	**Explanatory**	**Exploratory**
Key idea	Combine	Explain	Develop
Seeks to	• Combine quantitative and qualitative results with the intention of achieving a complete understanding of the phenomena of interest. • Validate one set of quantitative or qualitative findings with another set of quantitative or qualitative findings. • Check whether people provide similar answers on quantitative scales to qualitative open-ended questions.	Explain quantitative results with further qualitative inquiry	Utilise qualitative findings in the development of a quantitative research program, which is subsequently tested or implemented.
Data collection	Data is collected concurrently; the qualitative and quantitative data collection occur at the same time.	Data is collected sequentially: quantitative followed by qualitative.	Data is collected sequentially: qualitative followed by quantitative.
Sample considerations	Data is being collected simultaneously, and therefore participants are recruited from the same sample. Unequal sample sizes may mean that there is insufficient statistical power to interpret the quantitative or qualitative results with complete confidence; at the same time, having equal sample sizes is likely to compromise the rigor of the quantitative research.	Participants in the qualitative study are usually sampled from those who have participated in the quantitative component of the mixed-methods study. The qualitative sample will be smaller than the quantitative sample, which is acceptable.	Participants in the quantitative study should not be recruited from the qualitative phase, in order to avoid confirmatory bias.
Data integration	• Look for similarities and differences in the quantitative and qualitative research individually. • Consider how the individual results confirm or diverge from each other. • Discuss these similarities and differences to complete your understanding of the phenomena of interest.	• Identify the quantitative results that need to be further integrated. • Purposefully explore these results, using qualitative methods. • Discuss how the qualitative results explain your quantitative findings.	• Use your qualitative results to identify and plan a follow-up quantitative study; e.g. trial a patient-reported outcome measure. • Pilot and test the quantitative component with a new sample of participants. • Build on the qualitative findings.

	Convergent	**Explanatory**	**Exploratory**
Suggestions for displaying results*	A table with side-by-side columns highlighting similarities and differences between the quantitative and qualitative studies.	A table with side-by-side columns, with one column displaying a summary of the quantitative results, and the second column displaying qualitative results.	Use arrows to connect the development of the quantitative study with the qualitative results.
Advantages	Intuitive and timely because participants are recruited from the same sample. Facilitates team research, with quantitative and qualitative skills required for the research as a whole. Gives a 'voice' to those who have participated in the quantitative component of the research.	May appeal to quantitative researchers because results that are familiar can be followed up through qualitative research. A good opportunity to explore emergent findings in greater detail.	Useful when further quantitative investigation is warranted but it is not yet clear what form that should take. Able to produce a new instrument, measure, variable or intervention, based on the qualitative phase.
Disadvantages	The different sample size requirements can be challenging to navigate. Merging numerical data with words can be challenging. Expertise is required in explaining the similarities and differences between the datasets.	It can be time-consuming to conduct two phases of research. The qualitative study cannot be planned in advance and so it requires innovation and flexibility.	It can be time-consuming to conduct two phases of research, especially when a new round of participants needs to be recruited. The quantitative study cannot be planned before the qualitative analysis has taken place, so it requires the ability to be innovative and flexible. Requiring two different samples means that each step of the study has its own limitations.

*This can also be created using appropriate imagery.

For example, in Patient-centred innovation for multimorbidity care: a mixed-methods, randomised trial and qualitative study of the patients' experience,[6] both a randomised trial (quantitative) and interviews (qualitative) were conducted to address two research aims: (1) to assess the effectiveness of the intervention in relation to relevant patient-reported outcomes, and (2) to understand what worked and did not work about the intervention for patients. A one-hour case conference intervention was developed for the randomised trial, involving a nurse exploring what was important to patients. A planned and coordinated case conference followed with the patients' healthcare professionals (for example, psychiatrist, social worker and dietitian) based on this feedback. The nurse, the patient and all relevant health professionals then met for over an hour to focus on the patient's goals and to co-create a care plan. Outcomes assessed included self-efficacy in managing chronic disease, health status, quality of life, psychological distress and health behaviour.

For the qualitative component of this project, semi-structured interviews were conducted, with purposively selected patients (e.g. by age, sex and type of patient) as the qualitative component of the research in the trial intervention arm. The researchers analysed the data using thematic analysis.

From a quantitative research perspective, the intervention provided no statistically significant improvement. However, five themes were identified from the interviews: (1) patients valued the team developed as part of the intervention, (2) patients felt more supported, (3) receiving a follow-up plan was helpful, (4) being offered a change in the treatment plan was refreshing, and (5) patients perceived positive outcomes from the intervention.

Without the qualitative evaluation of this intervention, the trial would have been considered unsuccessful. Yet, by seeking participant feedback, it became evident that the trial did in fact improve patients' healthcare-seeking experiences and perceptions, in terms of multimorbidity, in ways not captured through quantitative measures. The researchers now know what works and what does not work about the intervention and can use this data to tailor future trials or implementation.

Table 11.2. provides three more examples of mixed-methods studies across the health and social care sector.

Table 11.2. Examples of mixed-methods research

Title	**The social cure of social prescribing: a mixed-methods study on the benefits of social connectedness on quality and effectiveness of care provision**[7]	**A mixed methods case study exploring the impact of membership of a multi-activity, multicentre community group on social wellbeing of older adults**[8]	**Using an exploratory sequential mixed method design to adapt an Illness Perception Questionnaire for African Americans with diabetes: the mixed data integration process**[9]
First author and year	Kellezi, 2019	Lindsay-Smith, 2018	Shiyanbola, 2021
CC Licence	CC BY NC 4.0	CC BY 4.0	CC BY 4.0
Mixed-methods study type	Convergent	Explanatory	Exploratory

Title	**The social cure of social prescribing: a mixed-methods study on the benefits of social connectedness on quality and effectiveness of care provision**[7]	**A mixed methods case study exploring the impact of membership of a multi-activity, multicentre community group on social wellbeing of older adults**[8]	**Using an exploratory sequential mixed method design to adapt an Illness Perception Questionnaire for African Americans with diabetes: the mixed data integration process**[9]
Aim	• Qualitative methods: To gain a deeper insight into perceptions or understandings of the social factors influencing health and presentation to primary care • Quantitative methods: To evaluate the overall efficacy of the created pathway to healthcare usage	• Quantitative methods: To examine whether loneliness and social support of new members of Life Activities Clubs changes in the year after joining • Qualitative methods: To conduct an in-depth exploration of how social wellbeing changes in new and longer-term members of Life Activities Clubs	• Qualitative methods: To address the sociocultural contexts and assess the perceptions of type 2 diabetes African Americans. • Quantitative methods: To culturally adapt the Illness Perception Questionnaire-Revised (IPQ-R) for African Americans with type 2 diabetes.
Why a mixed-methods study was conducted	Ageing populations and increasing demand for health services are two major challenges facing the National Health Service in the United Kingdom, exacerbated by increasing prevalence of loneliness. This study investigated the degree to which healthcare professionals and patients recognised their experiences with social (dis)connection and was able to measure the impact of group membership on experiences of loneliness.	Social wellbeing factors such as loneliness and social support have a major impact on the health of older adults and can contribute to physical and mental wellbeing. This study combined a survey assessing loneliness, social support and focus group data to further explore the positive and negative impacts of joining community groups in older age.	Mixed-method approaches offer opportunities to study contextual factors such as culture, perceptions and beliefs qualitatively, and to develop quantitative measures. Although this has been done previously to develop and adapt questionnaires, the methods used have not been thoroughly described. This study adapted the IPQ-R to address sociocultural contexts of African Americans with type 2 diabetes, and to evaluate the congruence between qualitative and quantitative data in the mixed-methods approach.
Study setting/ country	• Semi-structured interviews (n=35) • 18-month pathway implementation and survey measurements of belonging, loneliness and health service use	• Quantitative survey collected at 3 time points across a 12-month period, investigating the effects of joining a community group on social wellbeing of older adults (n=28 • Focus group (n=11)	• Qualitative focus groups conducted with 40 participants exploring beliefs about type 2 diabetes. • Quantitative survey of African Americans with type 2 diabetes • Survey items written and adapted based on focus group findings.

Title	The social cure of social prescribing: a mixed-methods study on the benefits of social connectedness on quality and effectiveness of care provision[7]	A mixed methods case study exploring the impact of membership of a multi-activity, multicentre community group on social wellbeing of older adults[8]	Using an exploratory sequential mixed method design to adapt an Illness Perception Questionnaire for African Americans with diabetes: the mixed data integration process[9]
Analysis	• Realistic thematic analysis • Statistics: ANOVA, Bonferroni-corrected t-tests	• Linear mixed models • Thematic analysis	• Deductive content analysis • Descriptive statistics, item mean scores, and item-total correlations.
Key themes	• Qualitative results: (1) GP perspective – social factors and the need for a holistic service; (2) patients' perspective – relationship with healthcare workers and building social connections • Quantitative results: Psychosocial factors are important for predicting reductions in primary care usage (p=0.022).	• Quantitative results: There was a significant reduction in loneliness (p=0.023) and a trend toward an increase in social support (p=0.056) in the first year after joining a community group • Qualitative results: Group membership provided important opportunities for developing new and diverse social connections through shared interest and experience, which was key to feeling supported.	• Qualitative results: timeline perception of diabetes not going away and diabetes goes away if you lose weight, consequences of diabetes, personal control domain, the importance of medications, and understanding diabetes by family members. • The matching of qualitative themes to survey domains included the timeline, consequences, personal control, treatment control, illness coherence, and emotional representations.

Summary

The three types of mixed-methods research can be conducted across health and social care disciplines, with a multidisciplinary team. Each type of mixed-methods study has its own strengths and limitations, but all integrate quantitative and qualitative research methods to develop a thorough picture of the phenomena under investigation.

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CHAPTER 12: EVALUATION APPROACHES

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Identify the key terms, concepts and approaches used in evaluation.
- Explain the methods of data collection and analysis for evaluations.
- Discuss the advantages and disadvantages of different evaluative approaches.

What is evaluation?

There are many definitions of 'evaluation'. Mertens and Wilson[1] quote from Fournier:

Evaluation is an applied inquiry process for collecting and synthesizing evidence that culminates in conclusions about the state of affairs, value, merit, worth, significance, or quality of a program, product, person, policy, proposal, or plan. Conclusions made in evaluations encompass both an empirical aspect (that something is the case) and a normative aspect (judgement about the value of something). (p6)

Hawe and colleagues provide the following definition of (program) evaluation[2]:

> … program evaluation usually involves observing and collecting measures about how a program operates and the effects it appears to be having and comparing this to a preset standard or yardstick. (pp6–7)

A more clearer definition, however, is this one from the *Better Evaluation website* (para1):

> any systematic process to judge merit, worth or significance by combining evidence and values.

Many words are used interchangeably to refer to evaluation, such as 'appraise', 'review', 'assess' and 'interpret'. This is because the definition differs between disciplines and sectors, depending on the aims and outcomes of what is being evaluated. While evaluation is different to research, it is often considered similar because the underlying principles of collecting and assessing research evidence are the same.[3] The differences and similarities between research and evaluation are outlined extensively on the *Better Evaluation website*.

Approaches to evaluation

Given that evaluation is conducted across many sectors, spanning education, agriculture, community services, international development, policing and justice, health, and others, it is unsurprising that a diverse array of evaluation approaches have been developed. Stufflebeam describes 22 program evaluation approaches in his widely cited monograph.[4] These approaches are distinguished by factors such as their purpose, scope, engagement with stakeholders, methods, timing and applications. In this chapter we focus on four approaches that are most often used in health and social care (Table 12.1.).

Objectives-based evaluation

Objectives-based evaluation methods are widely used in the education sector and public health. The focus of this approach is the assessment of whether the program's objectives, which must align with the identified needs of program participants, are achieved. This approach places strong emphasis on valid measurement of program effects. It is also referred to as 'impact evaluation'.

Program and service managers, funding bodies and researchers usually determine the questions that guide these evaluations and the appropriate measures to answer them. While experimental or quasi-experimental methods are not essential to this approach, they are reasonably commonly used in public health to address questions concerning the causal relationships between interventions (independent variables) and the achievement of objectives (dependent variables). The objectives-based approach has been criticised for placing too great an emphasis on a tightly prescribed set of program endpoints, with insufficient attention to the process of implementing a program. However, the collection of process information is compatible with the approach, particularly for determining the association between intervention exposure and outcomes.

Empowerment and participatory evaluation

Empowerment and participatory evaluation is distinguished by the prominent role it gives to program participants in the evaluation process. Participants must determine the evaluation questions, consistent with the interests they have in the program, and make decisions about the appropriate methods to use. Participants may be heavily involved in data collection, analysis and dissemination. The evaluator must respect participants' choices in all aspects of the inquiry and facilitate and build their capacity to control the evaluation in their preferred ways. Including program participants in an evaluation can be time consuming and require additional resources.

The empowerment approach values the rich and diverse insights that participants bring from their lived experiences, and places greater emphasis on relevance than rigour. One perspective is not regarded as more 'true' than others, and the purpose of the evaluation is not to reach ultimately correct conclusions but rather to empower participants (especially people who are disenfranchised) and catalyse social change through raised consciousness.[5] Qualitative methods, and participatory action research (see Chapter 7), are commonly used in empowerment evaluation.

Realist evaluation

The realist evaluation approach has been advanced by Pawson and Tilley. It shares many elements of the theory of change perspective and is founded on the critical realist paradigm.[6] Researchers adopting this approach maintain that interventions are theories concerning how a set of activities will operate in given social contexts to bring about change and the achievement of desired objectives. A key role for evaluators, therefore, is to work with program managers and other stakeholders to ensure the theory of change is inherent and explicit within a program; this is usually represented as a program logic model, which is used to guide the evaluation.

The realist evaluation approach is characterised by the purposive sampling of a wide variety of quantitative and qualitative information to shed light on the generative mechanisms of change that take place in the program, and the contextual factors that determine whether they are activated or not. The focus on learning about how change is achieved (rather than the assessment of program effects), together with its recognition of the critical role of context (defined in the broadest sense) and attention to both intended and unintended consequences, has made this an appealing approach for the evaluation of complex interventions.[6]

Utilisation-focused evaluation

Patton argues that evaluations should be undertaken for specific intended uses.[7] A critical role for the evaluator, therefore, is to undertake an analysis of program stakeholders, to identify the primary users of the program and to determine the needs and associated questions they have concerning the program. Utilisation-focused evaluation has a neutral value base in that the approach acknowledges that evaluation may be undertaken to assess processes, impacts and cost–benefit, to bring about improvement, to generate knowledge, or for other purposes determined by stakeholders.

The utilisation-focused approach may adopt quantitative, qualitative or mixed methods, and these decisions are also guided by the interests of stakeholders (all those involved in a program, including those who develop, deliver and benefit from the program) and their views about the kinds of data that are credible and useful. The evaluator can facilitate this decision-making by presenting a menu of evaluation methods to stakeholders and providing expert advice to enable assessment of the utility, validity and cost-effectiveness of different options. This approach provides a wide ranging set of design options to stakeholders making it more expensive to conduct than applying a single evaluation design option. As Patton states, '… by actively involving primary intended users, the evaluator is training users in use, preparing the groundwork for use, and reinforcing the intended utility of the evaluation every step along the way'.[7(p38)]

No single evaluation approach is better than the other, and multiple approaches can be drawn upon within one evaluation project, depending on the purpose of the evaluation.[8]

Table 12.1. Summary of the four evaluation designs

	Objectives-based (also known as 'impact evaluation')	**Empowerment and participatory**	**Realist**	**Utilisation-focused**
Key idea	**Set and meet objectives**	**Share power**	**Context**	**Useful**
Seeks to	Set clear objectives and achieve them. Measure program effects. Address questions concerning the causal relationships between interventions and the achievement of objectives.	Actively involve program participants, practitioners and community in the design, delivery and analysis of the program and its evaluation. Ensure the community identifies issues, how to address the issues, monitor progress and use information to sustain the program.	Understand and explain 'what works, for whom, under what circumstances, and how' 6(p15) Attempts to explain how outcomes are caused by identifying the underlying reasoning of people – the context makes a difference.	Provide evaluation findings that are worth using and can inform decision-making.
Data collection	Data is collected after the program has been fully implemented. Data collection, methods and tools should be guided by the specific types of data that are needed to answer the evaluation question(s).	Data is collected at any point, with the community defining design, delivery and outcomes. Data collection, methods and tools should be guided by the types of data that are needed to answer the evaluation question(s).	Data is collected once the program has had time to operate and outcomes can be evaluated. Data collection, methods and tools should be guided by the types of data that are needed to answer the evaluation question(s).	Data is collected once the program has had time to operate and outcomes can be evaluated. Data collection, methods and tools should be guided by the types of data that are needed to answer the evaluation question(s).
Sample considerations	Not a consideration. Whether the program achieved its goals is being evaluated.	Sample size is not usually relevant but dependent on program size, participant involvement, and evaluation questions.	Sample size is dependent on program size and evaluation questions.	Sample size is dependent on program size and evaluation questions.

	Objectives-based (also known as 'impact evaluation')	**Empowerment and participatory**	**Realist**	**Utilisation-focused**
Advantages	Identifies where programs can be improved or modified to meet objectives, or discontinued. Attempts to make unbiased, balanced observations about the program's outcomes are based on verifiable data. Can provide clear recommendations based on what has worked.	Shared control in the evaluation to define issues, judge effectiveness, set directions and influence the flow of resources.The insider role is valuable for interpreting findings. Can create continuity between evaluation, planning and action.	Well suited to assess how interventions in complex situations work. Can lead to a shared understanding of the intervention (program) among people involved. Most appropriate for evaluating new programs that work, but why they work is not understood.	Advocates for a participatory approach where key stakeholders assume ownership of the evaluation. an provide solid evidence of program effectiveness. Focusses on real and specific users and uses.
Disadvantages	Evaluators need to remember that their own assumptions will influence the interpretation of findings and recommendations.	Community members may have low levels of objectivity and/or limited ability to contribute to planning and development. Time-consuming and requires additional resources. May raise false expectations about future support for the program.	It is a theory-driven approach than can be difficult to understand. Evaluation scope needs to be clearly set. an be more expensive than a simple evaluation design.	Time-consuming to involve the full range of stakeholders. Not necessarily a linear evaluation process.

Data–collection methods and analysis

The methods of data collection and analysis rely on correct evaluation designs. Evaluation designs describe a set of tasks to systematically examine the effects of a program. A good study design creates confidence that the program caused the observed changes; because there is optimal planning, the best possible measures are used to assess the impacts of the program, no alternative explanations exist for the results and it is possible to identify how the program worked on the target population.[9]

It is not possible to provide an in-depth discussion about evaluation designs here, but they follow the same principles of research designs used in academic research: observational, quasi-experimental and experimental. Observational designs do not use control or comparison groups and usually measurements are taken from one point in time. They include pre-tests and post-tests, time-series designs and case studies.

Quasi-experimental designs are generally more suited to public health than other types of evaluations, and aim to use a comparison group. They do not, however, randomly allocate to the groups. Quasi-experimental designs include reciprocal group design, historical control group design and stepped intervention design. Experimental study designs expose a group of people to an intervention, and this group is then compared to a control group that was not exposed to the intervention. The main types of experimental designs are randomised controlled trials (RCT) and cluster randomised controlled trials (CRCT).[10]

Data collection methods (discussed in Section 3) also depend on the level of evaluation being conducted. The four levels of evaluation are:

- Formative: prior to implementation testing and refinement
- Process: implementation of strategies
- Impact: attainment of objectives
- Outcome: attainment of goals.

Examples of these evaluation levels are outlined in Table 12.2.

Data collection measures rely on the level of evaluation being clearly articulated and planned, with clear objectives and data collection points identified. The appropriate method of data collection will be the one that can gather the information necessary to answer the evaluation questions. For example, quantitative measures and tools are best suited to collecting information about attendance at training programs (surveys and attendance sheets), but qualitative measures and tools (interviews and focus groups) are best suited to collecting information about participants' experiences of the training. The evaluator must become familiar with the program and its goals, so as to choose the most appropriate data-collection methods and tools.

Data analysis follows the same principles as academic data analysis, which are explained in Section 4. For example, numerical data such as cost, attendance numbers and biometric measures are analysed for patterns, correlations, cross-tabulations, frequency tables and more. Textual analysis of spoken or written words can be analysed through content, themes, framework matrices and timelines.

Table 12.2. Examples of evaluation levels

	Formative	**Process**	**Impact**	**Outcome**
Title	Primary care provider perceptions and experiences of implementing hepatitis C virus birth cohort testing: a qualitative formative evaluation[11]	A mixed methods process evaluation of a person-centred falls prevention program[12]	Design of an impact evaluation using a mixed methods model – an explanatory assessment of the effects of results-based financing mechanisms on maternal healthcare services in Malawi[13]	A realist evaluation to identify contexts and mechanisms that enabled and hindered implementation and had an effect on sustainability of a lean intervention in pediatric healthcare[14]
First author and year	Yakovchenko, 2019	Morris, 2019	Brenner, 2014	Flynn, 2019
CC Licence	CC BY 4.0	CC BY 4.0	CC BY 4.0	CC BY 4.0
Aim	'To inform design and implementation of a quality improvement intervention, ...studied primary care provider (PCP) perceptions of and experiences with HCV birth cohort testing.'[abstract]	'to determine whether RESPOND [a falls prevention program] was implemented as planned, and identify implementation barriers and facilitators.'[abstract]	'To provide an example of how qualitative methods can be integrated into commonly used quantitative impact evaluation designs.'[para12]	To use 'the context (C) + mechanism (M) = outcome (O) configurations (CMOcs) heuristic to explain under what contexts, for whom, how and why Lean efforts are sustained or not sustained in pediatric healthcare.'[abstract]

	Formative	**Process**	**Impact**	**Outcome**
Intervention or program	No intervention. Formative evaluation is about testing the intervention in its early stages.	A person-centred falls prevention program for people presenting to the emergency department following a fall. Consists of 4 evidence-based modules: (1) Better strength and balance, (2) better bones, (3) better eyesight and (4) better sleep. Program included telephone coaching, positive health messaging and motivational interviewing for 6 months.	Reduce maternal and neonatal mortality by introducing the RBF4MNH Initiative. The Initiative seeks to upgrade infrastructure, have quality based performance agreements in place and provide women who have delivered babies a monetary compensation.	
Study design	A formative evaluation using interviews	Convergent, parallel mixed methods	Explanatory mixed methods design	A case study realist evaluation using interviews

	Formative	**Process**	**Impact**	**Outcome**
Data collection and participants	Semi-structured interviews with 22 primary care providers guided by the integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) framework.	RESPOND trial intervention participants (n=263) and healthcare professionals involved in delivering the program (n=7). Focus groups and surveys with trial participants, interviews with health professionals, audit of telephone sessions to assess adherence to the trial protocol, data extraction from trial database to assess recruitment, and dose.	Three study components; collection of quantitative data that described quality of care at facilities; quantitative data collection of health care utilisation at community level; a mixture of non-participants observations, in-depth interviews and focus groups.	Interviews with 32 participants from 4 pediatric units and neonatal intensive units.
Analysis	Content analysis with a priori and emergent codes was performed on verbatim interview transcripts.	COM-B framework used to guide analysis. Inductive and deductive coding for thematic analysis. Descriptive statistics for quantitative data analysis	Quantitative consisted of a controlled pre- and post-test design with difference-in-difference analysis. Grounded theory approach for qualitative data. Then triangulation across both elements.	Interviews were analysed using context, mechanism, outcome configurations (CMOc) heuristic.

	Formative	**Process**	**Impact**	**Outcome**
Results	A multi-component intervention for awareness and education, feedback of performance data, clinical reminder updates and leadership support, to address both a significant need and to be deemed acceptable and feasible for primary care providers.	Implementation of the falls prevention program was at a lower dose than planned; however, health professionals delivered the program as planned. Facilitators were positive; health messages and person-centred approach. Complex health and social issues were barriers.	The design is expected to create robust evidence measures of outcomes and generate insights about how and why the intervetions produce intended and unintended effects.	A causal link between implementation and sustainability was demonstrated. Sense-making and engagement were identified as critical mechanisms to sustainability. It provides practical guiding principles that health care leaders may incorporate into planned LEAN implementation.

Summary

Evaluation is a discrete area of research yet shares many similarities with research conducted in the health and social care field. To create well-planned and delivered program evaluations, it is necessary to understand the approaches, levels and study designs.

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DATA COLLECTION

CHAPTER 13: INTERVIEWS

Danielle Berkovic

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand when to use interviews in qualitative research.
- Develop interview questions for an interview guide.
- Understand how to conduct an interview.

What are interviews?

An interviewing method is the most commonly used data collection technique in qualitative research.[1] The purpose of an interview is to explore the experiences, understandings, opinions and motivations of research participants.[2] Interviews are conducted one-on-one with the researcher and the participant. Interviews are most appropriate when seeking to understand a participant's subjective view of an experience and are also considered suitable for the exploration of sensitive topics.

What are the different types of interviews?

There are four main types of interviews:

- **Key stakeholder:** A key stakeholder interview aims to explore one issue in detail with a person of interest or importance concerning the research topic.[3] Key stakeholder interviews seek the views of experts on some cultural, political or health aspects of the community, beyond their personal beliefs or actions. An example of a key stakeholder is the Chief Health Officer of Victoria (Australia's second-most populous state) who oversaw the world's longest lockdowns in response to the COVID-19 pandemic.
- **Dyad:** A dyad interview aims to explore one issue in a level of detail with a dyad (two people). This

form of interviewing is used when one participant of the dyad may need some support or is not wholly able to articulate themselves (e.g. people with cognitive impairment, or children). Independence is acknowledged and the interview is analysed as a unit.[4]
- **Narrative:** A narrative interview helps individuals tell their stories, and prioritises their own perspectives and experiences using the language that they prefer.[5] This type of interview has been widely used in social research but is gaining prominence in health research to better understand person-centred care, for example, negotiating exercise and food abstinence whilst living with Type 2 diabetes.[6,7]
- **Life history:** A life history interview allows the researcher to explore a person's individual and subjective experiences within a history of the time framework.[8] Life history interviews challenge the researcher to understand how people's current attitudes, behaviours and choices are influenced by previous experiences or trauma. Life history interviews have been conducted with Holocaust survivors[9] and youth who have been forcibly recruited to war.[10]

Table 13.4 provides a summary of four studies, each adopting one of these types of interviews.

Interviewing techniques

There are two main interview techniques:

- **Semi-structured:** Semi-structured interviewing aims to explore a few issues in moderate detail, to expand the researcher's knowledge at some level.[11] Semi-structured interviews give the researcher the advantage of remaining reasonably objective while enabling participants to share their perspectives and opinions. The researcher should create an interview guide with targeted open questions to direct the interview. As examples, semi-structured interviews have been used to extend knowledge of why women might gain excess weight during pregnancy,[12] and to update guidelines for statin uptake.[13]
- **In-depth:** In-depth interviewing aims to explore a person's subjective experiences and feelings about a particular topic.[14] In-depth interviews are often used to explore emotive (e.g. end-of-life care)[15] and complex (e.g. adolescent pregnancy) topics.[16] The researcher should create an interview guide with selected open questions to ask of the participant, but the participant should guide the direction of the interview more than in a semi-structured setting. In-depth interviews value participants' lived experiences and are frequently used in phenomenology studies (as described in Chapter 6).

When to use the different types of interviews

The type of interview a researcher uses should be determined by the study design, the research aims and objectives, and participant demographics. For example, if conducting a descriptive study, semi-structured interviews may be the best method of data collection. As explained in Chapter 5, descriptive studies seek to describe phenomena, rather than to explain or interpret the data. A semi-structured interview, which seeks to expand upon some level of existing knowledge, will likely best facilitate this.

Similarly, if conducting a phenomenological study, in-depth interviews may be the best method of data collection. As described in Chapter 6, the key concept of phenomenology is the individual. The emphasis is on the lived experience of that individual and the person's sense-making of those experiences. Therefore, an in-depth interview is likely best placed to elicit that rich data.

While some interview types are better suited to certain study designs, there are no restrictions on the type of interview that may be used. For example, semi-structured interviews provide an excellent accompaniment to trial participation (see Chapter 11 about mixed methods), and key stakeholder interviews, as part of an action research study, can be used to define priorities, barriers and enablers to implementation.

How do I write my interview questions?

An interview aims to explore the experiences, understandings, opinions and motivations of research participants. The general rule is that the interviewee should speak for 80 per cent of the interview, and the interviewer should only be asking questions and clarifying responses, for about 20 per cent of the interview. This percentage may differ depending on the interview type; for example, a semi-structured interview involves the researcher asking more questions than in an in-depth interview. Still, to facilitate free-flowing responses, it is important to use open-ended language to encourage participants to be expansive in their responses. Examples of open-ended terms include questions that start with 'who', 'how' and 'where'.

The researcher should avoid closed-ended questions that can be answered with yes or no, and limit conversation. For example, asking a participant 'Did you have this experience?' can elicit a simple 'yes', whereas asking them to 'Describe your experience', will likely encourage a narrative response. Table 13.1 provides examples of terminology to include and avoid in developing interview questions.

Table 13.1. Interview question formats to use and avoid

Use	Avoid
Tell me about…	Do you think that…
What happened when…	Will you do this…
Why is this important?	Did you believe that…
How did you feel when… How do you…	Were there issues from your perspective…

Use	Avoid
What are the... What does...	

How long should my interview be?

There is no rule about how long an interview should take. Different types of interviews will likely run for different periods of time, but this also depends on the research question/s and the type of participant. For example, given that a semi-structured interview is seeking to expand on some previous knowledge, the interview may need no longer than 30 minutes, or up to one hour. An in-depth interview seeks to explore a topic in a greater level of detail and therefore, at a minimum, would be expected to last an hour. A dyad interview may be as short as 15 minutes (e.g. if the dyad is a person with dementia and a family member or caregiver) or longer, depending on the pairing.

Designing your interview guide

To figure out what questions to ask in an interview guide, the researcher may consult the literature, speak to experts (including people with lived experience) about the research and draw on their current knowledge. The topics and questions should be mapped to the research question/s, and the interview guide should be developed well in advance of commencing data collection. This enables time and opportunity to pilot-test the interview guide. The pilot interview provides an opportunity to explore the language and clarity of questions, the order and flow of the guide and to determine whether the instructions are clear to participants both before and after the interview. It can be beneficial to pilot-test the interview guide with someone who is not familiar with the research topic, to make sure that the language used is easily understood (and will be by participants, too). The study design should be used to determine the number of questions asked and the duration of the interview should guide the extent of the interview guide. The participant type may also determine the extent of the interview guide; for example, clinicians tend to be time-poor and therefore shorter, focused interviews are optimal. An interview guide is also likely to be shorter for a descriptive study than a phenomenological or ethnographic study, given the level of detail required. Chapter 5 outlined a descriptive study in which participants who had undergone percutaneous coronary intervention were interviewed. The interview guide consisted of four main questions and subsequent probing questions, linked to the research questions (see Table 13.2).[17]

Table 13.2. Interview guide for a descriptive study

Research question	Open questions	Probing questions and topics
How does the patient feel, physically and psychologically, after their procedure?	From your perspective, what would be considered a successful outcome of the procedure?	Did the procedure meet your expectations? How do you define whether the procedure was successful?
How did you feel after the procedure?	How did you feel one week after the procedure and how does that compare with how you feel now?	
How does the patient function after their procedure?	After your procedure, tell me about your ability to do your daily activities?	Prompt for activities including gardening, housework, personal care, work-related and family-related tasks. Did you attend cardiac rehabilitation? Can you tell us about your experience of cardiac rehabilitation? What effect has medication had on your recovery?
What are the long-term effects of the procedure?	What, if any, lifestyle changes have you made since your procedure?	

Table 13.3 is an example of a larger and more detailed interview guide, designed for the qualitative component of a mixed-methods study aiming to examine the work and financial effects of living with arthritis as a younger person. The questions are mapped to the World Health Organization's International Classification of Functioning, Disability, and Health, which measures health and disability at individual and population levels.[18]

Table 13.3. Detailed interview guide

Research questions	**Open questions**	**Probing questions**
How do young people experience their arthritis diagnosis?	Tell me about your experience of being diagnosed with arthritis. How did being diagnosed with arthritis make you feel? Tell me about your experience of arthritis flare ups what do they feel like? What impacts arthritis flare ups or feeling like your arthritis is worse? What circumstances lead to these feelings? Based on your experience, what do you think causes symptoms of arthritis to become worse?	When were you diagnosed with arthritis? What type of arthritis were you diagnosed with? Does anyone else in your family have arthritis? What relation are they to you?
What are the work impacts of arthritis on younger people?	What is your field of work, and how long have you been in this role? How frequently do you work (full-time/ part-time/casual)?	How has arthritis affected your work-related demands or career? How so? Has arthritis led you to reconsider your career? How so? Has arthritis affected your usual working hours each week? How so? How have changes to work or career because of your arthritis impacted other areas of life, i.e. mental health or family role?
What are the financial impacts of living with arthritis as a younger person?	Has your arthritis led to any financial concerns?	Financial concerns pertaining to: • Direct costs: rheumatologist, prescribed and non-prescribed medications (as well as supplements), allied health costs (rheumatology, physiotherapy, chiropractic, osteopathy, myotherapy), Pilates, and gym/personal trainer fees, complementary therapies. • Indirect costs: workplace absenteeism, productivity, loss of wages, informal care, cost of different types of insurance: health insurance (joint replacements)

It is important to create an interview guide, for the following reasons:

- The researcher should be familiar with their research questions.
- Using an interview guide will enable the incorporation of feedback from the piloting process.
- It is difficult to predict how participants will respond to interview questions. They may answer in a way that is anticipated or they may provide unanticipated insights that warrant follow-up. An interview guide (a physical or digital copy) enables the researcher to note these answers and follow-up with appropriate inquiry.
- Participants will likely have provided heterogeneous answers to certain questions. The interview guide enables the researcher to note similarities and differences across various interviews, which may be important in data analysis.
- Even experienced qualitative researchers get nervous before an interview! The interview guide provides a safety net if the researcher forgets their questions or needs to anticipate the next question.

Setting up the interview

In the past, most interviews were conducted in person or by telephone. Emerging technologies promote easier access to research participation (e.g. by people living in rural or remote communities, or for people with mobility limitations). Even in metropolitan settings, many interviews are now conducted electronically (e.g. using videoconferencing platforms). Regardless of your interview setting, it is essential that the interview environment is comfortable for the participant. This process can begin as soon as potential participants express interest in your research. Following are some tips from the literature and our own experiences of leading interviews:

- ***Answer questions and set clear expectations.*** Participating in research is not an everyday task. People do not necessarily know what to expect during a research interview, and this can be daunting. Give people as much information as possible, answer their questions about the research and set clear expectations about what the interview will entail and how long it is expected to last. Let them know that the interview will be recorded for transcription and analysis purposes. Consider sending the interview questions a few days before the interview. This gives people time and space to reflect on their experiences, consider their responses to questions and to provide informed consent for their participation.
- ***Consider your setting.*** If conducting the interview in person, consider the location and room in which the interview will be held. For example, if in a participant's home, be mindful of their private space. Ask if you should remove your shoes before entering their home. If they offer refreshments (which in our experience many participants do), accept it with gratitude if possible. These considerations apply beyond the participant's home; if using a room in an office setting, consider privacy and confidentiality, accessibility and potential for disruption. Consider the temperature as well as the furniture in the room, who may be able to overhear conversations and who may walk past. Similarly, if interviewing by phone or online, take time to assess the space, and if in a house or office that is not quiet or private, use headphones as needed.
- ***Build rapport.*** The research topic may be important to participants from a professional

perspective, or they may have deep emotional connections to the topic of interest. Regardless of the nature of the interview, it is important to remember that participants are being asked to open up to an interviewer who is likely to be a stranger. Spend some time with participants before the interview, to make sure that they are comfortable. Engage in some general conversation, and ask if they have any questions before you start. Remember that it is not a normal part of someone's day to participate in research. Make it an enjoyable and/or meaningful experience for them, and it will enhance the data that you collect.

- ***Let participants guide you.*** Oftentimes, the ways in which researchers and participants describe the same phenomena are different. In the interview, reflect the participant's language. Make sure they feel heard and that they are willing and comfortable to speak openly about their experiences. For example, our research involves talking to older adults about their experience of falls. We noticed early in this research that participants did not use the word 'fall' but would rather use terms such as 'trip', 'went over' and 'stumbled'. As interviewers we adopted the participant's language into our questions.
- ***Listen consistently and express interest.*** An interview is more complex than a simple question-and-answer format. The best interview data comes from participants feeling comfortable and confident to share their stories. By the time you are completing the 20th interview, it can be difficult to maintain the same level of concentration as with the first interview. Try to stay engaged: nod along with your participants, maintain eye contact, murmur in agreement and sympathise where warranted.
- ***The interviewer is both the data collector and the data collection instrument.*** The data received is only as good as the questions asked. In qualitative research, the researcher influences how participants answer questions. It is important to remain reflexive and aware of how your language, body language and attitude might influence the interview. Being rested and prepared will enhance the quality of the questions asked and hence the data collected.
- ***Avoid excessive use of 'why'.*** It can be challenging for participants to recall why they felt a certain way or acted in a particular manner. Try to avoid asking 'why' questions too often, and instead adopt some of the open language described earlier in the chapter.

After your interview

When you have completed your interview, thank the participant and let them know they can contact you if they have any questions or follow-up information they would like to provide. If the interview has covered sensitive topics or the participant has become distressed throughout the interview, make sure that appropriate referrals and follow-up are provided (see section 6).

Download the recording from your device and make sure it is saved in a secure location that can only be accessed by people on the approved research team (see Chapters 35 and 36).

It is important to know what to do immediately after each interview is completed. Interviews should be transcribed – that is, reproduced verbatim for data analysis. Transcribing data is an important step in the process of analysis, but it is very time-consuming; transcribing a 60-minute interview can take up to 8 hours. Data analysis is discussed in Section 4.

Table 13.4. Examples of the four types of interviews

Title	**Current and emerging disaster risks perceptions in Oceania: key stakeholders recommendations for disaster management and resilience building**[19]	**Thematic analysis of dyadic coping in couples with young-onset dementia**[20]	**Living with psychosis without mental health services: a narrative interview study**[21]	**Life histories and lifelines: a methodological symbiosis for the study of female genital mutilation**[22]
CC Licence	CC BY 4.0	CC BY	CC BY 4.0	CC BY-NC 4.0
First author and year	Cuthbertson, 2019	Bannon, 2021	McGranahan, 2020	Gutierrez-Garcia, 2021
Interview type	Key stakeholder	Dyad	Narrative	Life history
Interview guide	Appendix A	eAppendix Supplement	Not provided, but the text states that 'qualitative semi-structured narrative interviews' were conducted.' [methods]	Not provided, but the text states that 'an open and semi-structured question guide was designed for use.' [methods]
Study design	Convergent mixed-methods study	Qualitative dyadic study	Narrative interview study	Life history and lifeline techniques
Number of participants	30 Key stakeholders were emergency management or disaster healthcare practitioners, academics specialising in disaster management in the Oceania region, and policy managers.	23 dyads	28	7

Title	**Current and emerging disaster risks perceptions in Oceania: key stakeholders recommendations for disaster management and resilience building**[19]	**Thematic analysis of dyadic coping in couples with young-onset dementia**[20]	**Living with psychosis without mental health services: a narrative interview study**[21]	**Life histories and lifelines: a methodological symbiosis for the study of female genital mutilation**[22]
Aim	'To investigate threats to the health and well-being of societies associated with disaster impact in Oceania.' [abstract]	'To explore the lived experiences of couples managing young-onset dementia using an integrated dyadic coping model.'[abstract]	'To explore the experiences and views of people with psychotic experiences who have not received any treatment or other support from mental health services for the past 5 years.' [abstract]	'To analyse the use of life histories and lifelines in the study of female genital mutilation in the context of cross-cultural research in participants with different languages.' [abstract]
Country	Australia, Fiji, Indonesia, Aotearoa New Zealand, Timor Leste and Tonga	United States	England	Spain
Length of interview	45–60 minutes	60 minutes	40-120 minutes	3 sessions Session 1: life history interview Session 2: Lifeline activity where participants used drawings to complement or enhance their interview Session 3: The researchers and participants worked together to finalise the lifeline. The life history interviews ran for 40 – 60 minutes. The timing for sessions 2 and 3 is not provided.

Title	**Current and emerging disaster risks perceptions in Oceania: key stakeholders recommendations for disaster management and resilience building**[19]	**Thematic analysis of dyadic coping in couples with young-onset dementia**[20]	**Living with psychosis without mental health services: a narrative interview study**[21]	**Life histories and lifelines: a methodological symbiosis for the study of female genital mutilation**[22]
Sample of interview questions from interview guide	1. What do you believe are the top five disaster risks or threats in the Oceania region today? 2. What disaster risks do you believe are emerging in the Oceania region over the next decade? 3. Why do you think these are risks? 4. What are the drivers of these risks? 5. Do you have any suggestions on how we can improve disaster risk assessment? 6. Are the current disaster risk plans and practices suited to the future disaster risks? If not, why? If not, what do you think needs to be done to improve them? 7. What are the key areas of disaster practice that can enhance future community resilience to disaster risk? 8. What are the barriers or inhibitors to facilitating this practice? 9. What are the solutions or facilitators to enhancing community resilience? [Appendix A]	1. We like to start by learning more about what you each first noticed that prompted the evaluations you went through to get to the diagnosis. • Can you each tell me about the earliest symptoms you noticed? 2. What are the most noticeable or troubling symptoms that you have experienced since the time of diagnosis? • How have your changes in functioning impacted you? • Emotionally, how do you feel about your symptoms and the changes in functioning you are experiencing? 3. Are you open with your friends and family about the diagnosis? • Have you experienced any stigma related to your diagnosis? 4. What is your understanding of the diagnosis?	Not provided.	Not provided.

Title	**Current and emerging disaster risks perceptions in Oceania: key stakeholders recommendations for disaster management and resilience building**[19]	**Thematic analysis of dyadic coping in couples with young-onset dementia**[20]	**Living with psychosis without mental health services: a narrative interview study**[21]	**Life histories and lifelines: a methodological symbiosis for the study of female genital mutilation**[22]
		• What is your understanding about the how this condition will affect you both in the future? How are you getting information about this diagnosis? [eAppendix Supplement]		
Analysis	Thematic analysis guided by The Hazard and Peril Glossary for describing and categorising disasters applied by the Centre for Research on the Epidemiology of Disasters Emergency Events Database	Thematic analysis guided by the Dyadic Coping Theoretical Framework	Inductive thematic analysis outlined by Braun and Clarke.	Phenomenological method proposed by Giorgi (sense of the whole): 1. Reading the entire description to obtain a general sense of the discourse 2. The researcher goes back to the beginning and reads the text again, with the aim of distinguishing the meaning units by separating the perspective of the phenomenon of interest 3. The researcher expresses the contents of the units of meaning more clearly by creating categories 4. The researcher synthesises the units and categories of meaning into a consistent statement that takes into account the participant's experience and language.

Title	**Current and emerging disaster risks perceptions in Oceania: key stakeholders recommendations for disaster management and resilience building**[19]	**Thematic analysis of dyadic coping in couples with young-onset dementia**[20]	**Living with psychosis without mental health services: a narrative interview study**[21]	**Life histories and lifelines: a methodological symbiosis for the study of female genital mutilation**[22]
Main themes	1. Climate change is observed as a contemporary and emerging disaster risk 2. Risk is contextual to the different countries, communities and individuals in Oceania. 3. Human development trajectories and their impact, along with perceptions of a changing world, are viewed as drivers of current and emerging risks. 4. Current disaster risk plans and practices are not suited to future disaster risks. 5. Increased education and education of risk and risk assessment at a local level to empower community risk ownership. [Results, Box 1]	1. Stress communication 2. Positive individual dyadic coping 3. Positive conjoint dyadic coping 4. Negative individual dyadic coping 5. Negative conjoint dyadic coping [Abstract]	1. Perceiving psychosis as positive 2. Making sense of psychotic experiences 3. Finding sources of strength 4. Negative past experiences of mental health services 5. Positive past experiences with individual clinicians [Abstract]	1. Important moments and their relationship with female genital mutilation 2. The ritual knife: how sharp or blunt it is at different stages, where and how women are subsequently held as a result 3. Changing relationships with family: how being subject to female genital mutilation changed relationships with mothers 4. Female genital mutilation increases the risk of future childbirth complications which change relationships with family and healthcare systems 5. Managing experiences with early exposure to physical and sexual violence across the lifespan.

Summary

Interviews are the most common data collection technique in qualitative research. There are four main types of interviews; the one you choose will depend on your research question, aims and objectives. It is important to formulate open-ended interview questions that are understandable and easy for participants to answer. Key considerations in setting up the interview will enhance the quality of the data obtained and the experience of the interview for the participant and the researcher.

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CHAPTER 14: FOCUS GROUPS

Tess Tsindos

Learning Outcomes

Upon completion of this chapter, you should be able to:

- Assess when to use focus groups in qualitative research.
- Develop questions for a focus group guide.
- Understand how to conduct a focus group.

What are focus groups?

Focus groups are convened to discuss an issue of mutual concern. The purpose of a focus group is to explore the experiences, understandings, opinions or motivations of research participants.[1] While individual interviews explore the experiences of (usually) one participant (see Chapter 13), focus groups are conducted with three or more people who share an experience or concern. The conversation between participants in a focus group is mediated and facilitated by the researcher. Focus groups can be used when little is known about the participants or a topic (an exploratory process), when testing new ideas (e.g. acceptability of a program or intervention) or when undertaking an evaluation of a service or product.

The focus of the discussion is on the interaction between participants in the group; some participants may have similar experiences or views, while others have different experiences. The group dynamic is important and therefore it is important that participants lead the discussion and are encouraged to talk through their similarities and differences, so that the researcher might gain a well-rounded perspective and account of the topic. A group might be homogeneous, get along well and share similar experiences. Or the group might be heterogeneous and have differing opinions and experiences. Participants might know each other because they have been recruited from the same program or community, or they could be total strangers. All these elements contribute to the focus of discussion, and to the group dynamic; that is, the interactivity of the focus group.

How many focus group members should there be?

Ideally, a focus group should include 6–10 participants[2] and the conversation should be moderated by the researcher, using a focus group discussion guide. However, the number of participants may vary according to the topic and the number of participants able to be recruited. The data collected from focus groups tends to differ from interview data because people respond and compare their own experiences with those of others in the group. Therefore, the number and composition of group members influence the data gathered.

Having too many people in a group means that discussion can become chaotic and it is unlikely that everyone in the group will have a say. Having too few people means that there may not be sufficient interaction to enable to capture a group perspective. Focus groups have been conducted with as few as two people: in a focus group conducted by one of the authors of this chapter, several participants had been invited, but only two attended. Since participants were difficult to recruit from the target population, it was not feasible to cancel the focus group. The topic was recovery after percutaneous coronary intervention (a cardiac procedure). The focus group discussion developed into an intimate conversation between two older men about their challenges in physical recovery and the psychological effects of not being able to fulfil a traditional male role. The small group size was serendipitous, in that the researcher may not have been able to collect such rich data had the group been larger.[3]

The researcher(s)

It is common to have two researchers present in a focus group. One facilitates the group, while the other observes and records the session, and takes notes about who said what, body language and other observable information that contributes to the context of the data being collected. The observer should be as unobtrusive as possible and not participate in the group discussion. Similar to interviews, focus groups are audio-recorded so the conversation can be transcribed for analysis. The researcher is encouraged to build rapport with focus group participants, which is aided by having a friendly and approachable manner. The focus group method enables the facilitator to probe ideas as they arise and to check their understanding of participants' responses. This active facilitation enhances the robustness of the data collected. The quality of the data collected will depend greatly on how effective the researcher is at facilitating the group, and thus good interpersonal skills are essential. Conducting effective focus group discussions comes with practice and experience.

How long should a focus group be?

There are no strict rules about how long a focus group should be. Different groups will likely run for different amounts of time because this depends on the research question/s and the types of group members. For example, a group of people who know each other and have a common experience may need no longer than 45 minutes, whereas a group of strangers with different experiences may need up to 2 hours. Additionally, the number of people in the focus group will affect the amount of time needed. A focus group discussion with 6 participants may likely be shorter than a focus group with 12 participants.

Designing the focus group guide

Before the commencement of a focus group, the researchers need to develop a focus group discussion guide, which is similar to an interview guide. Both aim to explore the experiences, understandings, opinions and motivations of participants. If the study's research methods include interviews and focus groups, the questions will be very similar. The difference is that the focus group discussion guide does not typically ask questions to elicit individual storytelling, but rather to ask questions to invite discussion of shared experiences, in which participants confirm or contrast each others' views. If focus groups are the sole data collection method, the researcher may consult existing literature, speak to experts, including people with lived experience about the focus of the research, and draw on their knowledge so that the topics and questions can be mapped to the research question/s.

The focus group guide should be developed well in advance of commencing data collection. This provides time for the facilitator and the observer to explore together the language and clarity of questions, the order and flow of the guide, and whether the instructions for participants are clear and comprehensive. To facilitate free-flowing responses, it is important to use open-ended questions that encourage participants to be expansive in their responses. Examples of open-ended question formats include those that start with 'who', 'how' 'tell me more about' and 'where'.

Pilot interview/s enable the researchers to test the interview guide. However, they are often not conducted because it can be difficult to recruit enough relevant participants. Instead, focus group questions might be reviewed by other members of the research team for clarity and comprehensiveness. The study design will determine the number of questions asked and the extent of the focus group guide. The target population may also determine the extent of the focus group guide; for example, clinicians who are time-poor may need shorter focus groups while patient populations may be interested in exploring their experiences in detail and at length.

Following is a template that can be adapted for the introduction of a focus group. Table 14.1 offers example questions for a focus group discussion guide.

Focus group introduction

> 'Hi everyone. My name is [insert name] and I'm from [insert organisation]. I am conducting [describe study]. Thank you for agreeing to be part of this focus group today. You were invited to participate in this focus group because [include reason]. Today we would like to discuss [outline topics]. We anticipate that the session will go for approximately [insert expected time].

Before we get started, I'd like to explain how we would like to structure the discussion.

1. We would like to hear from everyone present. This may mean that I will call on you by name to respond to a question. I may also indicate to you when it's time to wrap up your thoughts so we can move on to another person or topic.

2. Feel free to respond directly to each other. I'm here to facilitate the discussion, but you are encouraged to respond to the other participants in this group.

3. We are recording the session today. This will ensure that we capture everything discussed. Your names will not be used in the reporting of this data and we will be using pseudonyms or codes instead when writing up results.

4. Please be respectful of what other participants share. Due to the nature of focus groups, we cannot ensure confidentiality, but we do ask that you do not repeat what is discussed in this group to people who were not present. You should feel free to not answer a question if you don't feel comfortable answering.

Do you have any questions before we begin?"

Table 14.1. Focus group guide: Example questions for a descriptive study

Question	**Probing questions**
In your experience, how prevalent is plagiarism?	Over the time you have taught at university, do you think the rates of plagiarism have increased, decreased or remained the same – why do you think that is?
What do you think students understand plagiarism to be?	What do you think influences a student's understanding of plagiarism? (e.g. cultural conceptions, high school curriculum)
What do you think are the factors that contribute to students plagiarising without intention to do so?	

Question	**Probing questions**
What barriers to plagiarism are you aware of?	How effective do you think these barriers are?
What process do you use to identify plagiarism?	What are the barriers to you investigating further? How much time do you spend following up cases of suspected plagiarism?
How could you be supported to help identify and follow up on cases of suspected plagiarism?	
How have students responded when you have discussed suspected plagiarism in their work?	
In your opinion, how does plagiarism affect student wellbeing?	
How does the process of identifying plagiarism affect your wellbeing?	

An earlier variation of this table has appeared in the Supplementary material for the article *Why do students plagiarise? Informing higher education teaching and learning policy and practice.*[4]

Setting up the focus group

In the past, most focus groups were conducted in person. Emerging technologies have enabled the conduct of focus groups online, using teleconferencing and videoconferencing platforms. While it is more challenging to conduct a focus group online – primarily because participants' body language is often not seen – it can be a very useful method of collecting data. The benefits include low cost, greater access to participants in different locations and time efficiencies.[5] Participants who are less inclined to participate verbally are able to use ‘chat’ functions to contribute their comments. Whether the focus group is face-to-face or online, the facilitator will need to help participants feel as comfortable as possible and encourage discussion.

Focus group activities

Focus groups may incorporate activities in addition to, or to aid discussion; for example, sorting and ranking activities to prioritise topics for discussion in the focus group; or a River of Life[6] activity (see Chapter 18).

Considerations for the conduct of focus groups

Confidentiality should be addressed explicitly; for example, using the Chatham House rule, which sets out expectations about repeating what is said in a meeting without revealing the identities of who said it or other participants.[7] It is advisable to provide each participant with an explanatory statement to read, which states that confidentiality is essential to the focus group discussions.

Expectations need to be communicated in advance. Many of the tips for interviews in Chapter 13 apply also to focus groups, but it is important to communicate the researchers’ and the group’s expectations upfront. Some, but not all, of the expectations of focus groups are included in Table 14.2. The facilitator should explain these expectations before the focus group starts. Table 14.3 provides examples of studies using focus groups for data collection.

Table 14.2. Dos and don’ts of conducting focus groups

Do	**Don’t**
Ideas are encouraged; all ideas are valid.	React to perspectives, experiences or ideas that are different to your own.
Ensure the group is a judgement-free space.	Vocalise judgements about statements made.
Engage in healthy discussion.	Disrespect group members.

Do	**Don't**
Each group member needs to be included – individuals may need to be called on to provide their responses.	Allow the loudest group member too much talking time; loud group members could be asked not to answer a question.
Facilitate free-flowing discussion.	Let group members talk over each other.

Power imbalances. When setting up a focus group, the facilitator should pay strict attention to how homogenous the group needs to be concerning the topic, and how possible power imbalances might affect the data collection. For example, if the research question seeks to understand why drug administration errors occur in hospitals, it would not be a good idea to have doctors, nurses and pharmacists in the same group. Why? Because they might not feel comfortable expressing views in front of the very people they have seen make errors. Instead, you could run three separate groups: one with doctors, one with nurses and another with pharmacists. Conducting separate group discussions helps to avoid the chance that a powerful group might dominate the discussion and enables each group member to express their views openly.

Participant identity. The facilitator should invite participants to introduce themselves to other group members, to encourage familiarity; name tags can help participants remember each other's names. The researchers will need to maintain a list of participants and any necessary demographic details.

Risk. The possibility of distress or harm occurring must always be considered in a focus group. Participants may become distressed because sensitive topics are being discussed, and there is always a risk that some participants might overshare their experiences. The facilitator will need to judge when to stop the discussion if it becomes clear that one or more participants are distressed.[8] Researchers should have a clear protocol developed that provides advice about how to handle distress.

After the focus group

Once the discussion is concluded, participants should be thanked for their time and contributions. Explain how participants might contact the researcher if they have any questions or would like to provide the facilitator with follow-up information. If the focus group has covered sensitive topics or any participants have become distressed during the discussion, make sure that you spend some time privately with the participant to provide appropriate referrals and follow-up (see Section 6). Referrals and follow-up are usually described in the protocol addressing distress.

Data analysis is discussed in Section 4, but it is important to know what to do immediately after each focus group is completed. Download (or upload) the recording from the audio-recording device to ensure it is saved in a secure location that can only be accessed by people on the research team (see Chapter 34). The recording should be transcribed; that is, reproduced verbatim, for data coding and analysis. The transcription of data is an important step in the analysis process, and it is important to note that this is a highly time-consuming task. Transcribing a 60-minute focus group discussion can take up to 10 hours.

Table 14.3. Examples of focus groups

Title	**Meaning making in cancer survivors: a focus group study**[9]	**Patients' experiences and wellbeing after injury: a focus group study**[10]	**Communicating about overdiagnosis: learning from community focus groups on osteoporosis**[11]	**Traditional male circumcision in Uganda: a qualitative focus group discussion analysis**[12]
CC Licence	CC BY 4.0	CC BY 4.0	CC BY 4.0	CC BY 4.0
First author and year	van der Spek, 2013	Visser, 2021	Moynihan, 2017	Sabet Sarvestani, 2012
Aim	To describe: 1. the meaning-making themes that play a role in cancer survivors, 2. the experienced changes in meaning making after cancer treatment, and 3. the perceived needs for help in this particular area	To explore, using focus groups, patients' experiences and wellbeing after injury, and which factors impede or facilitate patients' wellbeing	To explore community awareness of the overdiagnosis of osteoporosis and related controversies surrounding the condition, including the definition of osteoporosis, whether it is best understood as a "disease" or a "risk factor", and the perceived value of the most common medications, as well as responses to potentially new information about these issues	To characterise traditional male circumcision (TMC) practices in Uganda and the cultural implications, using a comprehensive focus group discussion and qualitative analysis
Study design	Descriptive	Phenomenology	Phenomenology	Descriptive (culture)
Country	The Netherlands	The Netherlands	Australia	Uganda
Orientation	Existential distress and meaning making	Experiences and consequences of injury	Community understanding of overdiagnosis	Understanding cultural implications

Title	**Meaning making in cancer survivors: a focus group study**[9]	**Patients' experiences and wellbeing after injury: a focus group study**[10]	**Communicating about overdiagnosis: learning from community focus groups on osteoporosis**[11]	**Traditional male circumcision in Uganda: a qualitative focus group discussion analysis**[12]
Number of focus groups and participants	4 focus groups 3 groups of 6 and 1 group of 5	6 focus groups 3–7 in each group (total of 28)	5 focus groups 7–9 in each group (total 41)	26 focus groups 6–12 in each group (total 208)
Duration of focus groups	120 minutes	60–90 minutes	135 minutes	60 minutes

Title	**Meaning making in cancer survivors: a focus group study**[9]	**Patients' experiences and wellbeing after injury: a focus group study**[10]	**Communicating about overdiagnosis: learning from community focus groups on osteoporosis**[11]	**Traditional male circumcision in Uganda: a qualitative focus group discussion analysis**[12]
A sample of open focus group questions from each guide	1. What is meaningful in your life at the moment? 2. Did meaning in your life change after you were diagnosed with cancer? And if so, how did it change? 3. Have you ever had the feeling that you couldn't find meaning? And how did you deal with that? 4. What helps you to find meaning, despite possible problems in your life? 5. Are there aspects of meaning making that you wish you received help with? And if so, what kind of help would you like to receive? [Table 2](p3)	1. Which experiences after injury impressed you the most? 2. Can you describe the consequences of injury on your life? 3. Could you describe your feelings after injury, hospitalisation, and rehabilitation? 4. Does someone (i.e. another participant) recognise these experiences, consequences or feelings? 5. In what way do you experience changes in wellbeing? [In-text (data collection)](pp3,4)	1. What is osteoporosis? 2. Apart from bone density, are there other things increasing fracture risk? 3. How well do common medications for osteoporosis work? 4. Among people diagnosed, how many will never have a fracture? [Supporting information files S2 text]	1. What are the traditions, customs and rituals associated with male circumcision in your ethnic group? (p3) 2. What are the reasons parents decide to circumcise their sons traditionally?(p3) 3. What are the techniques used for traditional circumcision cuts in your ethnic group? Is there any variation among cutters' methods? How much foreskin is cut?(p6) 4. Have you ever heard of a circumcision that has resulted in an adverse event? If yes, what was the reason? Who is to blame if an adverse event happens? 5. Have the traditions, customs, and rituals associated with circumcision in this region changed over time? If yes, how? Why?(p7) 6. Would you support changes in TMC practice to make it safer?

Title	**Meaning making in cancer survivors: a focus group study**[9]	**Patients' experiences and wellbeing after injury: a focus group study**[10]	**Communicating about overdiagnosis: learning from community focus groups on osteoporosis**[11]	**Traditional male circumcision in Uganda: a qualitative focus group discussion analysis**[12]
				What type of changes would you consider?(p7)
Analysis	Thematic analysis within the framework approach. Under three topics: 1. Meaning making 2. Changes in meaning making 3. Need for help with meaning making	Analysis using a phenomenological approach. Data analysis proceeded stepwise using the open, axial and selective coding techniques.	Thematic analysis was based on framework analysis, as described by Ritchie and colleagues	Predetermined themes with codebook developed

Title	**Meaning making in cancer survivors: a focus group study**[9]	**Patients' experiences and wellbeing after injury: a focus group study**[10]	**Communicating about overdiagnosis: learning from community focus groups on osteoporosis**[11]	**Traditional male circumcision in Uganda: a qualitative focus group discussion analysis**[12]
Main themes	1. Sources of meaning: relationships, experiences, creativity, work 2. Enhanced meaning through relationships, experiences, resilience, goal orientation, leaving a legacy 3. Loss of meaning through experiences, social roles, relationships, uncertainty about the future 4. Searching for meaning 5. Meaninglessness: isolation, threats to identity, physical limitations, confrontation with death, fear of passing cancer to offspring, loss of freedom	1. Impact on relatives 2. Dependent of care 3. Social support 4. Communication health care provider to patient 5. Take self-initiative to receive medical care 6. Communication: health care providers to relatives, between medical staff, hospital to GP and to authorities, authorities to patient 7. Media attention 8. Practical problems	1. Risk factor' versus 'disease': preference for risk factor 2. The dilemma of diagnosis: awareness of downsides, belief in early diagnosis 3. Medications and prevention: underwhelmed by drugs, interest in other strategies 4. Overdiagnosis: complexities in communicating counter-intuitive concept 5. Overdiagnosis in osteoporosis: changing perceptions after new information 6. Questioning the definition of osteoporosis: unease over young women's bones defined as normal	Predetermined themes, such as TMC's cultural importance, logistics of the practice, cutters' training procedures and tools used during TMC were selected prior to holding the focus groups

Summary

Focus groups and (individual interviews) are the most common data collection techniques in qualitative research. The success of a focus group depends on the group composition and the effectiveness of the facilitator. It is important to formulate open-ended focus group questions that are understandable and easy for participants to engage with. Setting up the focus group discussion guide, rules and other considerations will enhance the experience of the focus group for the participant and the researchers, as well as the quality of the data collected.

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CHAPTER 15: PARTICIPANT OBSERVATION

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Know when to use participant observation in qualitative research.
- Create a participant observation guide.
- Understand how to conduct participant observations.

What is participant observation?

Participant observation is the hallmark data-collection method in ethnography (see Chapter 9).[1,2] A major feature of this method is that the researcher is embedded in the context of the research to conduct fieldwork, and takes part in the daily life of the group. As an observer, the researcher studies the activities, events, rituals and interactions of the group or community, or its culture.[2] According to Bernard, '[p]articipant observation… puts you where the action is and lets you collect data… any kind of data that you want, narratives or numbers'.[3(p343)]

Participant observation is an umbrella term for methods that include observations, formal and informal interviewing and the collection of documentary data such as photographs and diaries.[1,2] Participant observation is an appropriate method when the research question seeks to understand group culture, behaviours, attitudes and the overall human experience of a particular context and in the reality of everyday life. It provides a holistic understanding of the phenomena under study.[2] Participant observation is a helpful first phase in data collection, and can be helpful in orienting the researcher to the setting, context, participants and behaviours. Researchers often find that participant observation provides the foundations for the research questions to be asked, and that this, in turn, informs the development of more structured data collection, such as interviews.[4]

In ethnography, participant observation is the main form of data collection and hence it is done intensively (see Chapter 9, Table 9.1). However, participant observation can be used in other forms of qualitative research to complement other forms of data collection. This type of participant observation is less intense.

The key features of participant observation are outlined as follows.

'Insider' viewpoint. The researcher seeks to gain a perspective of the phenomena under study. They might be an 'insider', which gives an emic perspective through shared experiences and membership of the group of people under study, or an 'outsider', which is an etic perspective, or that of a person external to the group. Hence, the researcher needs to participate in the life of the group to observe and experience the meanings and interactions of the group, and to explore the meaning of the lifeworld of the group. Participation by the researcher may be passive or active, depending on their role in the group, which ranges from marginal (etic) to membership (emic) roles.[5]

Unstructured data. The researcher may not know what data they might encounter on any given day. While they may record observations across key dimensions (see Table 15.1), they need to be ready to record insights, ask questions and listen actively as events, activities and interactions occur.[1] When participating in activities or events, the researcher needs to listen and note (mentally or by writing unobtrusively) what is being said, and to prompt conversation where appropriate when further information may be relevant to the research topic.

Field notes. The researcher typically may take short written notes or mental notes while conducting their observations. Once the researcher exits the field they write up their observations, including where possible verbatim quotes, key phrases, the number of people who were present, maps of the space and details of interactions. It is recommended that field notes are written up promptly before details are forgotten.[6] Where appropriate, the researcher might use a device to record their observations and transcribe them at a later stage.

How to undertake participant observation

Know when the phenomenon happens. Before starting participant observation, it is important to know what and who is to be observed, and when these events, activities, processes and behaviours are likely to occur. Consider whether it is a one-off event or something that happens regularly, and when, where and how things may be occurring. Are multiple locations and times relevant? Often, it is best to start broad if unsure and then to narrow the focus over time as the researcher gains familiarity with the setting, people and phenomena.[4]

Gaining access to the setting. How the researcher gains access to the setting of participant observation can vary. If the researcher is known to the people in the setting, this may be easy to navigate through letters of permission and consent from leaders. However, if the researcher is an outsider to the setting, they may need to approach gatekeepers and build relationships with stakeholders before permission may be granted to enter the setting.[6]

Explaining the presence of the researcher. There are three main approaches in terms of explaining what the research is doing in the research setting. The first is to let everyone in the setting know about the presence and intention of the observer–researcher. This is known as 'overt participant observation'[7], which reduces the risk of running into ethical problems. However, connection, trust and rapport with people in the setting may take longer to develop because people know that the researcher is there to observe their behaviours and conversations. In some situations, disclosing to everyone that research is being conducted may not be practical.[4]

The second approach, known as 'semi-covert participant observation'[7] is when the researcher lets some people know about their presence as an observer–researcher. For example, gatekeepers and leaders at the setting may be told while others may not know that observations and research are being undertaken. This poses the risk of people who know about the research disclosing this information to others in the setting, which in turn can lead to mistrust of the researcher. Ethical issues in this approach are trickier to manage, particularly regarding informed consent.[4]

The third approach is when the researcher does not disclose to anyone in the setting that they are undertaking observations and research; this is 'covert participation observation'.[7] This approach poses the highest risk in terms of ethical issues, as people have the reasonable expectation of privacy and confidentiality, and covert observations may compromise their dignity and wellbeing. The extent to which covert participant observation is a concern also depends on how public or private the research setting is. There may also be safety concerns for the researcher, who may be accessing risky settings and may be required to adopt a persona that goes against their natural tendencies. Hence, the risks and benefits of covert participant observations need to be well considered. The benefits of covert participant observation include that the researcher might gain access to a setting that may be off limits for research studies, and the method reduces the risk of people changing or modifying their behaviours and can therefore reveal the true nature of behaviours and the phenomenon under study. The researcher can take part in the everyday life of the setting and experience the phenomenon in the same way as people in the setting.[4]

How to conduct data collection

Systematically observing and recording observations are key elements of the field notes to be documented by a researcher. For the novice researcher, it can be overwhelming to figure out what to observe and how to document these observations. Spradley[8] outlined 9 observational dimensions to consider when undertaking participant observation; these are outlined in Table 15.1.

Table 15.1. Nine observational dimensions and their descriptions

Dimension	**Description**
Space	The physical layout of the setting
Actor	Range of people in the setting
Activity	Description of the activities that take place in the setting
Object	The physical things that are present in the setting
Act	Single actions people do
Event	Activities that people carry out
Time	The schedule of events or activities that happen
Goal	The purpose of activities or events
Feeling	Emotions that are felt and expressed

DeWalt and DeWalt described 3 components of participant observation[2], which are outlined here and are complementary to the 9 dimensions in Table 15.1.

Mapping the scene – mapping the physical and spatial layout and the social scene, including social interactions and where interactions take place in the space.[2]

Counting – recording how many people are in the place in all the situations under observation. Categorise groups of people and record the counts; for example, how many people are facilitating an activity, how many children, how many women and how many attendees? How do the counts change throughout the observation?[2]

Listening to conversations – attending to what is being said, by whom and when. Recording verbatim, as much as possible, the conversations that are taking place. The researcher may also casually facilitate some of these conversations, if appropriate.[2]

It may be helpful to use Table 15.1 to create a data collection sheet with notes being recorded next to each of the dimensions. The unpublished data collection sheet in Figure 15.1 is from a study undertaken in surgical theatres to understand decision-making on antimicrobial prescribing.[9]

PEOPLE IN SPACE

Who	Duration/timing/flow	Comments/key phrases
e.g. Consultant surgery, consultant anaesthetist, resident, registrar, nurse, technical staff (create a row for each staff member)		

SEQUENCE/PROCESS

	Time point	Key phrases	Who
When is the antibiotic administered?			
When is it re-dosed/repeated?			
Who administers the antibiotics?			

CONVERSATIONS

Type	Things to look for (prompts)	Comments
Timeout – who — safety checklist	Who runs TIMEOUT? Who attends TIMEOUT conversation? Have they had antibiotics? (Yes/No/About to administer) Who makes the decision about an antibiotic?	
Hierarchy – particularly between 'tribes' (surgical/anaesthetist)	Who leads the conversations or decisions? How is hierarchy influenced by flow (e.g. people leaving and entering the theatre)?	
Record disagreements and how resolved		
References to guidelines		

PATIENT CHARACTERISTICS – INFLUENCE ON ANTIBIOTIC DECISION-MAKING

Characteristic	**Comments**
Heart rate	-
Blood pressure	-
Allergies	-
Obesity – over 120kg (3g antibiotics)	-
Other medication – contraindications	-
Other	-

NOTES:

Figure 15.1 Example of participant observation data collection sheet[9]

Box 15.1 is an excerpt from field notes from Ayton's PhD research[10], which demonstrates how the 9 dimensions are recorded in narrative form. While this may seem lengthy, it provides a detailed description of the space, the people in the space and their activities. When the researcher re-reads the field notes, a strong and clear picture will be remembered about the community centre.

Box 15.1 Observation excerpt – community centre[10]

The red and blue building of the community centre is modern; the space is open and light. When I enter the building the reception desk is in front and slightly to the left. The receptionist, Nicole, greets everyone who enters and she is always smiling. Cameron, a volunteer, is hovering at the entrance, eager to be helpful to those who enter. He has cerebral palsy; he wears a neck brace and walks with a limp. Despite it being a cold day, Cameron is wearing shorts and a T-shirt. He has a bushy beard and he is difficult to understand, communicating in grunts and energetic arm movements. He seems enthusiastic about his role as a volunteer and does not leave his post the whole day.

To the right are four large, comfortable blue chairs and a very big, comfortable, blue velvet, L-shaped couch. Cushions are scattered over the couch and chairs. There is a red circular carpet and a coffee table with the day's newspapers on it. Next to the couch and against the wall, near the entrance to the computer room, is a bookshelf with some books including a Bible and a range of Christian books including self-help books and books about the Christian faith; none are specific to the Salvation Army. The bookcase also has a shelf of pamphlets about health services, upcoming courses and training opportunities, and a variety of health promotion materials such as booklets on depression and anxiety, and drug and alcohol assistance. On top of the bookshelf is a collection of board games. The atmosphere feels like one of a home, a comfortable place to hang out, a place that is open to everyone. The chairs all face each other so that no one would be sitting on the outer. When I walk to sit on the couch, I feel like I'm entering their circle.

On the other side of the computer training room, there is a table with Fair Trade tea and coffee. There is also a table with two large bowls of fruit. Notice boards are positioned on the main walls and these display newspaper articles about the centre, Salvation Army training college information, biographies of the officers-in-charge, a poster advertising the street soccer program coordinated by the *Big Issue* and a poster advertising a local drum school.

Advantages and disadvantages of participant observation

Participant observation provides a holistic perspective of the research setting and people, and the opportunity for the researcher to experience the everyday life of the group or community. Participant observation provides a foundation for further enquiry as the researcher is embedded in the research context. Hence, the researcher learns the relevant research questions to ask and the potential cultural implications of the 'how' of the research.[4] However, there are many challenges, including navigating the ethical issues of consent and access to the research setting. The time and resources to undertake participation observation is often extensive and may not be easily covered in research budgets or timeframes.[4] Table 15.2 provides two examples of participant observation in qualitative research.

Table 15.2. Examples of participant observation from health and social care research

Title	**Constructions and experiences of motherhood in the context of an early intervention for Aboriginal mothers and their children: mother and healthcare worker perspectives**[11]	**Palliative care in its own discourse: a focused ethnography of professional messaging in palliative care**[12]
CC Licence	CC BY 4.0	CC BY 4.0
First author and year	Ussher, 2016	Reigada, 2020
Aim	To examine healthcare workers and mothers' perspectives on motherhood and the intervention program.	To understand what message is conveyed by PC professionals, explicitly or implicitly, in their daily clinical practice.
Study design	Not stated	Focused ethnography
Why participant observation was conducted	Participant observation facilitates a close and intimate familiarity with a given group of individuals and their practices through an intensive involvement in their cultural environment, usually over an extended period of time.	To allow for a deep understanding of a particular problem in the palliative care context, exploring its cultural aspects, values and beliefs
Access	Overt participant observations	Overt participant observations – all participants knew of the research and consented to the observations
Length of time undertaking participant observation	6 months of weekly mothers' group sessions, facilitated by a trained therapist and support workers	8 months (242 hours)

Title	**Constructions and experiences of motherhood in the context of an early intervention for Aboriginal mothers and their children: mother and healthcare worker perspectives**[11]	**Palliative care in its own discourse: a focused ethnography of professional messaging in palliative care**[12]
Observation process	The researcher conducted the observations as the first phase of the research. They attended the mothers' groups for 6 months to become familiar with the program and the members of the group. Semi-structured interviews were conducted with mothers and the healthcare worker.	Observations were from 9am to 2pm each day, with the palliative care service commencing with a team meeting. Afternoons were spent making notes and reviewing internal documents (admission sheets, protocols). Field notes were recorded initially on mobile phones and then later transcribed and imported into word-processing software. The researcher then conducted informal conversations with professionals to clarify observations. A reflexive diary was maintained throughout the data collection period.
Analysis	Thematic analysis of field notes and interview transcripts	Thematic analysis of field notes, internal documents and informal conversations
Main themes and how data was presented	Vignettes from field notes Constructions of motherhood • The resilient mother: coping with early life trauma and social stress • The good mother: transformation of self through motherhood Perspectives on the intervention • Mothers come to life: transformation through therapy • 'I know I'm a good mum': The need for connections, skills and time for self	Excerpts from field notes **Message 1** – We are a team, focused on your wellbeing • We are a multidisciplinary team • We are experts in symptom control **Message 2**– You matter: we want to meet you • We want to know about you as a person • We want to know about your experience with the disease **Message 3**– family matters: they are also important to us •We are here to relieve the suffering of the family •We want to support the caregivers

Summary

Participant observation is a hallmark of ethnography but can also be used in other qualitative research designs. The aim is to understand group culture and the phenomenon under study. Careful planning is required for participant observation, to ensure ethical considerations are addressed and processes are established for gaining access to the research setting and systems for collecting participant observation data.

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CHAPTER 16: SOCIAL MEDIA RESEARCH

Danielle Berkovic

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the three different typologies of social media research.
- Identify the steps and key considerations in undertaking social media research.
- Articulate the ethical and legal challenges associated with social media research.

What is social media?

Social media are online platforms that allow individuals, communities and organisations to collaborate, connect, interact and build community by enabling them to create, co-create, modify, share and engage with user-generated content that is easily accessible.[1] Examples of social media include Facebook, Twitter (now known as X), Instagram, Pinterest, LinkedIn and Reddit. The global scale and use of social media are huge: 57 per cent of the world's population uses social media (4.48 billion people) and 99 per cent of these users access social media by smartphone.[2] Social media connectivity is growing: from 2020–2021, 520 million more people joined at least one social media platform.[3] Global populations using social media represent a large and as yet mostly untapped source from which researchers can download, analyse and interpret data on some of the world's most pressing research agendas.

Types of social media studies

There are no specific study designs for social media research, but researchers have developed three typologies: extant, elicited and enacted.[4] The three typologies are described in more detail below, and Table 16.1 provides examples of social media research based on each typology.

- **Extant:** Social media research that is extant seeks to use existing data through unobtrusive observation. The key idea is to *observe*, so there is no direct contact between participants and the researcher. Example data types include existing materials such as blog posts, tweets, or Instagram photos.[4]

- **Elicited:** Social media research that is elicited seeks to use data from participants in response to the researcher. The key idea is to *interact*, so there is interaction between >1 consenting participant and the researcher. Example data types include responding to a researcher-initiated blog post, tweet, or Instagram photo.[4]
- **Enacted:** Social media research that is enacted seeks to use data generated with participants during the study. The key idea is to *co-develop*, so there is collaboration between >1 participant and the researcher. Example data types include creative interaction, vignettes, problem-centred or scenario interviews using video or text, chat or messaging features. Of note, enacted studies are more likely to be mixed methods in design.[4]

How to undertake a social media study

Given the variability in social media platforms and the type of data that can be collected and analysed, there are as yet no standard guidelines as to how to conduct a social media study. A mixed-methods framework designed by Andreotta et al[5] enables the collection and analysis of social media data.

Phase 1: Harvest social media and compile a corpus

Researchers can use automated tools to find social media data, extract this data and compile it into a corpus (a collection of written texts). Researchers might search for content posted in a particular time frame, containing specific content or posted by users with certain characteristics. This all depends on the research question and its aims and objectives.

Phase 2: Use data science techniques to compress the corpus along a dimension of relevance

Although researchers may want to examine the entire dataset, it is often more practical to focus on a subset of the data. Researchers can use data science techniques (e.g. algorithms, topic modelling) or manual qualitative methods (e.g. by narrowing the search strategy) to identify a representative subset of data to analyse.

Phase 3: Extract a subset of data from the most relevant spaces of the corpus

Once the data from phase 2 has been identified, researchers can extract the data most relevant for answering the research question. This may include all data in the compressed corpus, but the researcher may choose to randomly sample from the corpus if this is too large to analyse. If the data is perceived to be too narrow, the researcher can revisit phase 2 and adopt a more lenient search strategy.

Phase 4: Perform a qualitative analysis on this corpus of data

The final phase involves performing a qualitative analysis to address the research question, aims and objectives.

What should be considered before conducting social media research?

Franz et al have outlined 5 concepts to consider prior to conducting social media research: [6]

- **Participants:** What kinds of participants, if any, will be included in the study? This generally applies only to the enacted social media typology. The researcher needs to consider the user characteristics of various social media platforms; for example, Facebook users tend to be older than Instagram users.
- **Social media platform:** There is a plethora of social media platforms, and each contains different types of data. Facebook, for example, collects a combination of public and private information about individual users. Twitter's advanced search filters can be used to select desired variables and data about social media users. Many Instagram users have a 'hidden' profile that is inaccessible to researchers who are not 'friends' with them. Some platforms may also prohibit researchers to use their data; the words 'no research' may be indicated. When deciding what data is needed to address the research question, these factors need to be considered.
- **Data analysis:** Depending on the size of the dataset, researchers may prefer a manual versus an automated approach to coding and data analysis. Content, framework and thematic analysis, as described in Chapters 23–25, are methods often used by researchers to analyse social media research data.
- **Data protection:** *ReCODE health*[7] is a US, web-based resource to help navigate ethical issues in social media research, which are outlined in the following section.

Ethical and legal challenges associated with social media research

Several challenges are associated with social media research. To begin with, social media users are generally unaware that their data could be used by researchers without their knowledge, which raises questions of informed consent.[8] Second, the terms and conditions of social media platforms define the relationship between the platform and its users, but these legal agreements are often long and complex. It is questionable as to whether users understand these terms and conditions.[9] At the same time, the terms and conditions of various social media platforms are always changing and will likely also change as the researcher's work is underway. It is essential to constantly check this information to ensure that the research being undertaken does not violate these rules.[10] At a minimum, it is essential for the researcher to apply for ethical approval from their institution's ethics committee to conduct a social media study. Such a committee will require answers to the following questions:

- What action or process has the researcher implemented to ensure that the data used is published by a reliable source?
- Is it possible that social media users are the correct age or gender identity for the proposed study, and have the conditions, experiences or circumstances stated in their profiles?
- How will the data be extracted from the platform? It is important to be mindful when publishing research findings, as it may be possible to reverse-identify individual users.

Advantages and disadvantages of social media research

There are several strengths and limitations in conducting social media research.

Advantages of social media research include the ability to:

- engage with or gain access to populations that are difficult to access through traditional recruitment efforts; for example, highly immunocompromised people, or those living in the most remote communities
- gain easy access to a large volume of data that would otherwise take researchers months or years to collect themselves
- collect data quickly through search functions on various social media platforms; for example, using the advanced search function on Twitter

Disadvantages of social media research include:

- problems in identifying participants – the researcher is never fully able to know who participants are; for example, a social media account may be a bot. At the same time, the researcher is never able to fully de-identify people either
- users' ability to delete or modify their content
- the highly curated nature of social media – posts are often not truly reflective of people's views and perspectives
- the monitoring or prohibition of certain social media platforms in some countries; for example, in China and Iran. This limits data collection from some parts of the world. Governments in Australia are also poised to ban TikTok from devices issued to staff, which means that obtaining data from some populations may also be restricted

Table 16.1. Examples of social media studies

	Extant	**Elicited**	**Enacted**
Article title	Tweets by people with arthritis during the COVID-19 pandemic: content and sentiment analysis[11]	Barriers to managing fertility: findings from the understanding fertility management in contemporary Australia Facebook discussion group[12]	Exploring the relationship between perceptions of social capital and enacted support online[13]
First author, year	Berkovic, 2020	Holton, 2016	Stefanone, 2012
CC Licence	CC BY 4.0	CC BY 2.0	
Aim(s) and objective(s)	'To identify proxy topics of importance for individuals with arthritis during the COVID-19 pandemic, and to explore the emotional context of these tweets by people with arthritis during the early phase of the pandemic.' [Abstract]	'To identify public opinion about sexual and reproductive health in Australia' [Abstract]	'To explore the relationship between perceptions of online relationships and actual, enacted support.'(p455)
Social media platform	Twitter	Facebook	Facebook
Statement on the terms and conditions of the social media platform	'All data were collected and reported according to the terms and conditions of Twitter, which state that content posted by individuals is publicly available to syndicate, broadcast, distribute, retweet, promote or publish, excluding private information (e.g. home addresses and identity documents). Use of tweets by individuals outside of Twitter can be carried out with no compensation paid to the individual tweeter, as use of Twitter is agreed upon as sufficient compensation.' [Methods, Design]	'Facebook allows users to determine how much of their personal information is publicly displayed. Profile security settings can be public (e.g. allowing access to the complete profile by any Facebook user) or private (e.g. limiting access of some or all profile information). Before joining the discussion group, participants were asked to ensure that their Facebook privacy settings were consistent with what they wanted to reveal to the group. Participation in the group was voluntary, and participants could withdraw at any time. A request to join the group was taken as informed consent to participate.' [Methods, Ethics]	Not included.

	Extant	**Elicited**	**Enacted**
Recruitment	No participants were recruited for this study.	English-speaking women and men aged 18 to 50 years who were Facebook users living in Australia were sought and invited to participate in the online discussion group. 'From October through December 2013, an advertisement briefly describing the research and discussion group was placed on the Facebook pages of all users meeting the eligibility criteria… The project page provided further details about the research and the participation involved. Those who chose to participate requested to join the group by clicking on a link on the Facebook project page. The group moderator approved requests and sent participants a 'welcome to the group' message on Facebook, inviting them to participate in the discussion by posting their responses to questions and to comments from other members.' [Methods, Recruitment and Procedures]	Participants were recruited from a communication class at a large US-based university and instructed not to discuss the study with anyone else until the completion of the study (2-week period).

	Extant	**Elicited**	**Enacted**
Data collection	'Tweets were retrospectively extracted from March 20 to April 20, 2020... The desktop version of the Twitter website (versus the mobile app) was used for data collection for ethical purposes, with only publicly available tweets extracted, rather than through a private login. In addition to the tweets themselves, accompanying data fields were extracted from each tweet using a customised template. Extracted data fields included (where possible): Twitter profile blurb, gender identity of tweeter, country of tweeter, number of likes, number of retweets, number of replies, hashtags used, number of hashtags and use of accompanying photos.' [Methods, Data Collection]	'In a closed-group moderated discussion, participants responded to questions about how people in Australia attempt to manage three aspects of fertility: 1. avoiding pregnancy, 2. achieving pregnancy, and 3. difficulties conceiving. Non-identifiable demographic information was sought; no personal accounts of fertility management were requested.' [Abstract]	49 participants sent requests for instrumental help from their Facebook friends to determine the accessibility of networked resources and online social capital. Each participant was instructed to examine their entire Facebook friend network and to think about their 6 strongest and 6 weakest relationships on this site. Then they were required to record the identities and contact information for each of these 12 online friends. Participants completed a brief survey measuring demographic information and their perceptions about a series of relationship characteristics for each of the 12 friends. Finally, they were instructed to send each friend the following message: 'Hey, [First Name] I need your help with a class project I'm working on. I need people to provide labels for a series of online images. I'd really appreciate your help! Please go to [study URL] and take the quick survey and label as many images as you can. Your participation will be a huge help. Thanks!'

	Extant	**Elicited**	**Enacted**
			[Method]
Data analysis	Content and sentiment analysis. Content analysis was used to characterise the textual contents of tweets related to arthritis and COVID-19. Sentiment analysis was employed to assess the emotion associated with the theme of each tweet using Glaser and Strauss's 6 codes for sentiment analysis.	Thematic analysis using the 4 systematic steps appropriate for focus groups: organising, shaping, summarising and explaining	Survey data was analysed using Williams' Internet Social Capital Scale. Frequency of communication was measured with a 7-point scale. Responses to the message were measured using binary outcomes (yes/no response to the message) and the quality of help provided based on participants' perceptions.
Data protection	'To avoid reverse identification of participants based on their tweets (which can be found through internet searches), tweets analysed in this study are not quoted verbatim. Instead, all data are expressed in aggregate form through descriptive statistics and qualitative syntheses.' [Methods]	'Before the group began, researchers made decisions about reasonable expectations for privacy, ownership of any data generated and means of moderating the discussion and removing any offensive posts. These expectations were outlined to potential participants on the project's Facebook page.' [Methods, Recruitment and Procedures]	Not stated.
Main findings	Content analysis revealed 7 themes from the tweets: 1. health care experiences, 2. personal stories, 3. links to or advertisements of relevant blogs, 4. discussion of arthritis-related symptoms, 5. advice sharing, 6. messages of positivity and 7. stay-at-home messaging. Sentiment analysis categorised the 7 themes into 'great', 'swell', 'so-so', 'bad', 'wretched' and 'no sentiment' categories.	Four main themes about fertility management were identified: 1. access,2. geographical location, 3. knowledge and 4. cost. Participants reported that young people and people from rural areas faced barriers accessing contraception and fertility services. Limited knowledge about sex and reproduction, and the cost of fertility services and contraception were also said to impede effective fertility management.	Perceptions of online support are associated with actual, enacted support.

Summary

Social media platforms can provide researchers with access to data that can be downloaded, analysed and interpreted to understand some of the world's most pressing research agendas. There are 3 social media research typologies: extant, elicited and enacted, each involving varying levels of participant involvement. There is no definitive method of conducting social media research, and there are several ethical and legal challenges that researchers need to address.

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CHAPTER 17: PHOTOVOICE

Kostas Hatzikiriakidis

Learning outcomes

Upon completion of this chapter, you should be able to:

- Know when it is most appropriate to use photovoice in qualitative research.
- Understand the steps involved in conducting a photovoice study.
- Create a study protocol for a photovoice project.

What is photovoice?

Photovoice was first conceptualised in the mid-1990s as a community based, participatory action research methodology (see Chapter 7). It is grounded in the use of photographs produced by participants.[1] Photovoice most often seeks to engage individuals and communities who are underrepresented in research. It uses visual imagery to understand the subjective experiences of vulnerable and marginalised people, in order to provide insights into their perspectives and the meanings they make about the world.[1] Engagement in the process of photography encourages photovoice participants to critically reflect on the issues and barriers they are confronted with, both individually and as part of their broader community; the visual image therefore becomes a symbolic representation of their lived experience.[2]

In their article first introducing photovoice, Wang and Burris outlined that the three main goals of photovoice are '(1) to enable people to record and reflect their community's strengths and concerns, (2) to promote critical dialogue and knowledge about important community issues through large and small group discussion of photographs, and (3) to reach policymakers.'[1(p370)] Put simply, photovoice offers an opportunity to promote critical conversations on the problems or barriers experienced by underrepresented communities. In doing this, the overarching objective is to build awareness of their needs, with the intention of advocating for social change at the policy level.

How has photovoice been applied in research?

Early research was primarily conducted within the context of public health and social justice.[3] The first photovoice study sought to explore the reproductive healthcare needs and experiences of women living in Yunnan, China, to inform local healthcare quality improvement in rural communities.[1,4-6] Other early photovoice studies sought to understand the everyday life conditions of homeless people[7], the family and maternal health concerns of community residents[8], and young people's concerns about community safety and neighbourhood violence.[9] Since its conceptualisation by Wang and Burris[1], photovoice has been applied to explore concerns about social justice for underrepresented communities, including research in education[10]; civic engagement[11]; disability and inclusion[12]; neurodiversity[13]; indigenous and First Nations communities[14]; gerontology and ageing[15]; mental health[16]; caregiving[17]; gender-based violence[18]; occupational therapy[19]; sustainability and climate change[20]; and its continued use in public health more broadly.[3] Table 17.3 provides an overview of two photovoice studies.

What are the steps involved in conducting a photovoice study?

Wang outlined nine core steps that are critical in conducting a photovoice study (Table 17.1).[6] Since the first conceptualisation of photovoice, researchers have adapted, condensed and shifted the order of the steps involved in photovoice projects.[21] The importance of continuing consultation with participants and community members at each stage of photovoice should be emphasised, and the protocol should be adapted accordingly to their needs.[22] Participants in photovoice studies are often referred to as 'co-researchers', to reflect their active role in generating knowledge and directing social change.[23]

Table 17.1. Wang's nine steps in conducting a photovoice study

Steps	**Tasks**
1	Select and recruit a target audience of policymakers or community leaders.
2	Recruit a group of photovoice participants.
3	Introduce the photovoice methodology to participants and facilitate a group discussion.
4	Obtain informed consent.
5	Pose an initial theme for taking pictures.

Steps	Tasks
6	Distribute cameras to participants and review how to use them.
7	Provide time for participants to take pictures.
8	Meet to discuss photographs.
9	Plan with participants a format to share photographs and stories with policymakers or community leaders.

Step 1: Identifying policymakers

One of the main goals of photovoice is to communicate the lived experiences of underrepresented communities to policymakers who can mobilise social change.[1] Intentional action planning that extends beyond simple dissemination of research findings is therefore recommended.[24] A first step in influencing social and policy change is to identify a target audience of policymakers who can enact the desired change.[6] Although researchers may initially conceptualise a photovoice project with a predetermined topic, and may also have an existing network of policymakers or a preconceived notion of whom the findings will reach[6], the desired policy change and target audience are best selected and refined with full involvement of participants throughout the project.[25] Examples of policymakers who may be engaged in photovoice research include key stakeholders working across various levels of government, community service organisations, health departments or educational institutions.[24]

Step 2: Recruiting participants

Purposive sampling is recommended as a starting point, to target specific groups who are likely to have the relevant knowledge, insights and experiences that relate to the research topic.[26] It is useful for recruitment to be coordinated by someone who already has a strong relationship with the community and can approach potential participants to gauge their interest.[25] A sample of 7 to 10 participants is often sufficient[6]; however, larger groups may also be recruited.[3]

Steps 3 and 4: Introducing the methodology and obtaining informed consent

Introducing the methodology typically involves an initial group ‘orientation’ meeting with the participants, to provide information about the photovoice methodology.[6] Researchers must ensure that they communicate all aspects of the methodology, with a particular focus on the risks and benefits, intention to inform policy change and unique ethical considerations in photovoice.[27] In communicating these aspects, the researchers are also seeking informed consent. A broader discussion around obtaining informed consent can be found in Chapter 30; however, obtaining informed consent in photovoice research also involves ethical considerations specific to the use of visual imagery, including asking participants to (1) agree to participate in the research project; (2) give permission for the release of photographs (i.e. by signing photograph release forms); and (3) obtain consent from others who may appear in photographs (sought by the participant themselves).[28]

Step 5: Posing an initial theme

In the initial meeting with participants, researchers should facilitate a discussion to brainstorm concepts and pose a specific question (or theme) to guide participants in taking their photographs.[6] The themes that guide photography assignments need to be specific enough that they can be captured and represented in a photograph, yet broad enough that they can capture a diverse range of experiences.[25] In this space, the researcher can also facilitate conversation between participants on what they might want to capture in their photographs. It is imperative that participants' ideas drive this discussion.

Step 6: Photography instruments and training

Appropriate training (as part of a group or one-on-one) is delivered to participants regarding how exactly they are going to be taking their photographs.[6] Researchers need to consider which photography instruments to select, based on factors such as their advantages and disadvantages, available resourcing (i.e. funding) and technological literacy. Participants may be provided with:

- **Disposable cameras** – they are easy to learn and cost-effective; however, photographs cannot be reviewed before being developed.
- **Digital cameras** – these are reusable for future projects and capture higher-quality photographs than disposable cameras, but are more expensive and more complicated to use.
- **Personal smart devices** – there is no cost to researchers and minimal training is required; however, participants from resource-poor communities may not own such devices.

The amount of time spent training participants will vary according to the complexity of the selected instrument and participants' familiarity with the device. The intention is to provide participants with training on only the most basic of camera operations, as priority is given to the meaning of the photograph rather than its quality.

Step 7: Time to take photographs

Once trained, participants are allocated a timeframe to capture their photographs (e.g. 2-3 weeks).[6] This timeframe may be predetermined by the researchers; however, consulting participants to gauge the feasibility of the chosen timeframe is encouraged. It is also important to set expectations about:

- **Checking in** with the participant; that is, whether reminders will be sent, how frequently and in what format (e.g. text, email, phone call); offering additional time as needed; and finding out whether they are experiencing difficulties.
- **Setting a maximum number of photographs** to aim for; participants should be advised that only a limited number of photographs can be discussed and analysed.
- **Sharing photographs** and what methods they will use to do this. Participants may share photographs in real time (by text or email) or during their follow-up discussion.

Step 8: Discussing photographs

The focus of this step is to elicit the meaning that participants have attributed to their photographs and to understand the underlying message that they are intending to convey.[6] In meeting the second primary goal of photovoice, researchers facilitate a discussion that encourages interaction between participants, similar to a focus group (see Chapter 14).[1] For example, the researcher might ask, 'Did anyone else take a similar photograph or has anyone had a similar experience to what was just discussed?'. Separate to group discussion, some participants may prefer semi-structured interviews, but some level of group interaction is recommended, based on the photovoice methodology. The group dynamic contributes to a shared and collective representation of the community's lived experience.[22]

The SHOWeD technique is a commonly adopted line of questioning that researchers use at this stage (see Table 17.2).[29] This technique is applied for each photograph; however, participants may be asked to select only a small sample depending on the feasibility of discussing all photographs. At this stage, researchers are also encouraged to elucidate individual experiences by exploring how participants felt about participating, what they learned about themselves and their wider community, how they have (or will) apply the knowledge they gained and whether they encountered any challenges.[30]

Table 17.2. The SHOWeD technique for eliciting meaning from photographs

SHOWeD	**Question**
S	What do you **see** here?
H	What's really **happening** here?
O	How does this relate to **our** (your) lives?
We	**Why** does this problem, concern, or strength **exist**?

SHOWeD	Question
D	What can we **do** about it?

Step 9: Disseminating findings to policymakers

Researchers work closely with participants to develop recommendations to be communicated to policymakers.[25] The desired outcomes can range from improved efforts for advocacy, capacity-building initiatives, distribution of funding, development of interventions, community resourcing, accessibility of services and the introduction of new policies.[24] Lofton and Grant explored how photovoice studies have intentionally engaged in action planning, and common methods of dissemination have included public forums, exhibitions and galleries open to policymakers and the community; presentations to local organisations; meetings with key stakeholders; presentations at academic conferences; radio or television events; and social media campaigns.[24] It is also important to note that policy change is a time-consuming process that often requires additional data to adequately support the need for change, and continuing collaboration is needed between researchers, policymakers and the community following the conclusion of a project.[8]

Data analysis

The underlying principles of qualitative data analysis (see Section 4) apply similarly to photovoice studies; that is, data are transcribed, immersed, coded and themes generated. Visual data can introduce complexities to the process of analysis, and researchers may use triangulation between photographs, transcripts and other data sources (e.g. photograph titles, captions, journals, biographies, field notes).[31] Capous-Desyllas and Bromfield sought to develop a practical guide for analysing photovoice data; they proposed that analysis involves '(1) a within-case analysis of each participant's transcript, (2) a cross-case analysis comparing all of the participants' transcripts together, and (3) creating visual art to gain a deeper understanding of the transcript data and corresponding photographs'.[31(p4)] Depending on feasibility, resourcing and the target population, researchers may involve participants in codifying the data through analysis workshops.[32]

Summary

Photovoice is a community based, participatory action research methodology that uses visual imagery to understand the subjective, lived experiences of underrepresented communities. The goal of photovoice is to inform social change through policy reform, by drawing attention to the collective needs and challenges faced by marginalised groups of people.

Table 17.3. Characteristics of a select sample of photovoice studies

Title	**The challenges of managing diabetes while homeless: a qualitative study using photovoice methodology**	**Yet we live, strive, and succeed: using photovoice to understand community members' experiences of justice, safety, hope, and racial equity**
First author and year	Campbell, 2021	Wendel, 2019
Copyright	CC BY NC 4.0	CC BY 4.0
Country	Canada	United States
Aim	To explore and understand the challenges of managing diabetes from the perspectives of individuals with lived experience of homelessness	To explore the common experiences and perspectives of community residents, to facilitate collective dialogue and action for social change in West Louisville, Kentucky
Participant characteristics	People with lived experience of both diabetes and homelessness	Community residents with diverse identities
Recruitment methods	Community groups and posters displayed on community boards and in shelters	Through local agencies, community organisers, community centres and civic groups.
Sample size	8	43
Photography instruments	Point-and-shoot digital cameras	Personal cellphones or digital cameras, or supplied disposable cameras
Photography training	Training provided by a professional photographer and additional sessions to discuss ethical considerations	Technical training on how to use a camera and training on ethics and safety
Discussing photographs	• SHOWeD method– participants first considered the questions individually, then reflected as a group • Participants developed narratives for each of their photographs	• Adapted SHOWeD method– group dialogues with participants sharing stories about their photographs • Participants selected or provided a narrative to accompany photographs
Analysis	Inductive thematic analysis (themes discussed and decided with participants)	Content and thematic analysis (participants involved in codifying photographs and reviewing themes)

Title	The challenges of managing diabetes while homeless: a qualitative study using photovoice methodology	Yet we live, strive, and succeed: using photovoice to understand community members' experiences of justice, safety, hope, and racial equity
Themes	1. Effects of homelessness on emotional and mental health and on diabetes self-management 2. Barriers to healthy eating in shelters 3. Benefits and challenges to diabetes management after getting housed 4. Access to diabetes care professionals and prescription medications	1. Systemic inequalities are apparent and oppressive 2. Those who have power in the city do not care 3. Despite the rest of the city's ambivalence, Black lives and Black history matter 4. Collective community action is needed
Dissemination to policymakers	Photographs and narratives presented at a public exhibition held at a research institute, followed by exhibitions at scientific conferences and in public spaces across 8 locations in Canada (participants present to discuss photographs).	Photographs and narratives presented at a 2-year exhibit open to the public (participatory opening event), and incorporation of the exhibit into local community meetings and events.

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CHAPTER 18: RIVER OF LIFE STORYTELLING

Sarah Carmody

Learning outcomes

Upon completion of this chapter, you should be able to:

- Know when to use river of life storytelling in qualitative research.
- Create instructions and questions to guide the river of life technique.
- Understand how to facilitate the river of life storytelling technique

What is river of life storytelling?

River of life storytelling is a qualitative research technique that invites a person to consider how they might represent a particular experience, journey or event, as if it were a river.[1,2] The river is used as a metaphor for the person's journey. It enables them to consider what their river looks like, choose how it twists and turns, and the features along the river.[3,4]

This creative technique has a history of use throughout the not-for-profit sector, including youth work, community development, social care, religious organisations and international development. It is applied as an interactive tool for deep reflection on people's experiences and events.[2-7]

What does a river of life diagram look like?

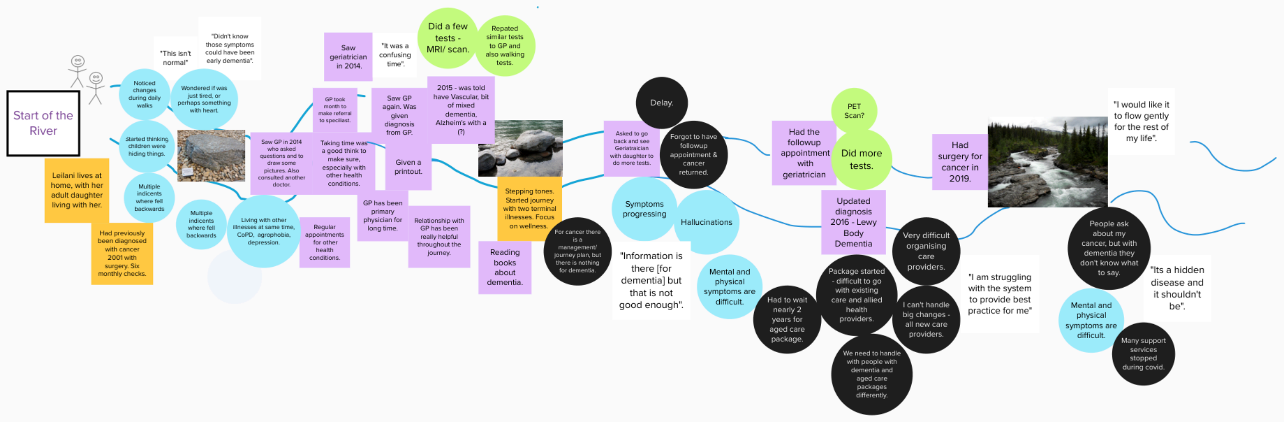
While there is no set format for a river of life diagram, several features will likely be included.[1,7] An illustration of the river itself, whatever shape that takes, is a central feature of the method, along with features, such as rocks, rapids and waterfalls. Figure 18.1 provides an example river of life diagram.

For more detail about the person's story, it is good to include information about the specific people, activities and events that occurred, as outlined in Table 18.1. Depending on the purpose of the activity, it might also be helpful to identify the barriers and enablers they experienced.

The additional features along the river might be presented using drawings, text or images. They can also be colour-coded to identify items: in Figure 18.1 items about family and friends are shown in orange boxes, items about crucial events in blue circles, and barriers in black circles. Colour-coding features can make the diagram easy to read and is helpful for analysis.

Completing a river diagram using an online storyboard program enables the participant or the researcher to include drawings, text and sticky notes in different colours, along with relevant images.

Figure 18.1 An example river of life diagram (click to enlarge)



©Sarah Carmody. Image is not to be reproduced.

How does river of life storytelling work?

The river of life storytelling technique can be used differently, depending on the purpose and audience. The river of life technique has often been conducted in group settings, where each group member draws a river using pens, pencils and paper to represent their journey.[2,3] The technique has been adapted to the research setting and can be used on its own or integrated as part of a qualitative interview.

This chapter examines three ways to facilitate the river of life technique in qualitative research.

In-person group activity

The river activity is conducted in person, in a group setting. The facilitator explains the purpose and process of creating a river of life diagram. The group is provided with pens, pencils and paper to create their diagram.[3]

The group setting enables participants to interact with each other and to share ideas and experiences. The facilitator answers questions, provides prompts and encourages and supports each member of the group to create their river of life diagram, reflecting an experience, journey or event. This type of activity is well suited to people who can more easily attend an in-person venue and who find it comfortable to share with others and design their river in a group setting. For example, a group of women from a local community are invited to explore the effects of the COVID-19 pandemic.[1]

Individual activity

A participant is invited to create a self-directed river of life diagram; they are provided with the instructions and materials needed to develop the diagram independently.

The self-directed river of life may include sending each participant a pack of materials needed to develop the diagram, including pens, pencils and paper, and a way to provide the researcher with a copy.

The individual river of life approach gives high autonomy and control to the participant. Still, it does involve greater responsibility on the part of the participant, to complete the diagram in their own time and return it to the researcher. A follow-up interview may be conducted with the participant about their river of life activity at a later date. This type of activity is suited to people who are comfortable following the instructions and completing their river diagram independently, particularly for participants across different locations. For example, men across Australia may be invited to reflect on their experience of living with prostate cancer.[8]

Facilitated interview activity

Through the facilitated interview activity, the river of life is used more subtly and integrated within a semi-structured interview. This approach is effective when the in-person or individual options are not suitable or feasible. It is also useful when there are additional questions the researcher may like to include. Interviews using this approach can be done in person or by video call or phone.

The facilitated activity is well suited for use with communities who find it difficult to complete the river diagram individually. This may include people who do not have English as not their first language, or people less confident in literacy, or people living with a type of cognitive impairment, such as people living with dementia.[9]

The river of life prompt questions are asked using an interview-style format. The researcher facilitates the river diagram during the interview process or shortly afterwards. For the facilitated interview activity, an online storyboard program can be used to create the diagram based on the guidance and responses discussed during the interview.

The participant is provided with a copy of the river diagram shortly after the interview and asked to check it to ensure that the diagram accurately reflects the conversation and their experience, that they are happy with it and to make any changes or additions.

Conducting river of life storytelling

Once you have decided on the most suitable river of life activity for your purpose, you can begin planning how to conduct your river of life activity.

Design

Begin writing the prompt questions to guide the river of life activity.[1] Writing the prompts is especially important for the facilitated interview, where you will generally include the prompt questions within the broader interview questions.

Prompt questions will also be helpful to refer to during the in-person group activity. The prompt questions can be integrated within the river of life instructions for the individual activity.

Example prompt questions are outlined in Table 18.1.[2, 3, 5]

Next, you need to write up the instructions to provide to participants, including instructions explaining the purpose of the activity and how it works.

Facilitate

Remind participants about the purpose and structure of the river of life activity and ask if they have questions. The activity can be described as a visual way to explore their personal journey, where the river might change, have obstacles and other features.

Start the river of life discussion by exploring the first part of the river, seeking to tease out the different elements and features. Some people will be comfortable discussing and drawing their river without much assistance. Others may need more guidance and prompting. Have the river of life prompts and questions ready to use as needed.

Those completing the activity without a facilitator will rely on having clear instructions and require an easy way to return their completed diagram.

Feedback

Once the river diagram is completed, it is vital to confirm with each person that they are happy with their river and to make any changes they wish to. Seeking feedback is especially important when the researcher creates the river diagram.

Analyse

Content analysis (as described in Chapter 21) can explore key themes within and across the river of life diagrams. They may also inform case studies or triangulate with other methods, including qualitative interviews.

Table 18.1. River of life prompts and questions

Part of the river	**Prompt questions**
The start of the river/ start of the journey	Where does the river start, and what does it look like? Who is at the start of the river?
What does the river look like?	When are there changes in the river (When the situation or perspective changed.) Does the river have any sudden bends or turns? Is your river long and winding? Does the river have a waterfall?
What happens along the river?	Does the river flow fast or slow? Is the river muddy? Is it clear? Are there rocks or boulders along the river? (e.g. obstacles and life-altering moments)
The other end of the river	What does the other end of your river look like?

Table 18.2. Features of the river

Features of the river	**This feature may help represent**
Pebbles, rocks, boulders	Obstacles along the way and the size of the obstacle
Bends in the river	Changes that occurred
Rapids, fast-flowing water and/or whirlpools	Times along the journey that were particularly difficult
Murky water	Confusing and unclear about what was happening
Shallow river	Easier to navigate at this point of the journey
Deep river	More difficult to navigate at this point of the journey

Features of the river	**This feature may help represent**
Calm and/or clear water	Times along the journey that were easier and went well
Waterfall	Major event, moment or change that occurred<
Family, friends and support people	Learning *who* formed the person's support network
Specific activities and events	Exploring *what* happened along their journey
Organisations, services, resources and supports along the river	Examining *what* organisations, services and resources the person had access to throughout their journey
Specific barriers or difficulties	Identifying *what* was hard along their journey
Specific enablers and supports	Identifying *what* was helpful along their journey
Other river features	Anything else the person would like to include

What are the benefits of the river of life storytelling?

The river of life storytelling technique is a creative approach to engage participants in the research process in a meaningful way. It provides many benefits that differ from other qualitative methods, including:

- a creative and interactive structure for a participant to reflect on their journey. The process subtly guides the flow of questions and conversation, beginning at the start of the river (a person's experience) and considering all that happens along the way. Prompt questions enable the person to reflect on their story from start to finish
- enabling deep reflection about how a person felt throughout their experience by representing different emotions as features of the river, such as rocks, rapids and waterfalls[2,10]
- a supportive process to reflect on experiences that may be difficult to revisit[10]

The three types of river of life activities described in this chapter enable the researcher to cater for differing needs, abilities, time availabilities, accessibility and levels of engagement.[1]

How long does the river of life storytelling take?

The time to complete a river of life story depends on how it is conducted.[3] A facilitated river of life interview usually takes about 60 minutes but will vary according to the number of additional questions in the process and the detail the person provides in sharing their story. It is important to consider a suitable duration for the people involved.

Summary

River of life storytelling is an innovative and meaningful technique that engages people in a creative activity to learn about their experiences. Through the storytelling process, the person reflects on their experience as though it were a river, and a river diagram is created to represent their journey. The chapter described three types of river of life storytelling activities, each with strengths and limitations. The type of river of life activity used will vary depending on your topic, community, location and time available. The river of life technique is beneficial for encouraging deep reflection and exploring a person's experiences in detail.

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CHAPTER 19: YARNING

Sue-Anne Hunter

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe the different types of yarning.
- Discuss key considerations when undertaking yarning.
- Describe the advantages of yarning.
- Identify the challenges of yarning.

What is yarning?

Indigenous and non-Indigenous scholars[1] have maintained, for decades now, the need for First Nations representation in the creation of knowledge. Indigenous community viewpoints have historically been misunderstood, misrepresented in many cases ignored altogether. To achieve greater representation of Indigenous peoples' live experiences, epistemologies and ontologies, Indigenous research methodologies are becoming more recognised. Yarning is one of these methodologies. In this chapter, yarning is discussed in the context of its use by Indigenous and Non-Indigenous researchers who are working with Indigenous peoples.

Yarning is an Indigenous cultural form of conversation.[1] Yarning can involve just two people, or in the case of a 'yarning circle', can involve a group of people. Yarning creates a culturally safe space in which Aboriginal and Torres Strait Islander participants have authority and ownership in the process of sharing information and places the researcher in the position of the learner.[2] Yarning as a research method privileges Indigenous ways of knowing, drawing on Indigenous ontologies rather than Western social science ontologies.[2, 3] For this reason, when research involves First Peoples, yarning is an effective alternative to traditionally non-Indigenous formal interview techniques.

> *Yarning in a semi-structured interview is an informal and relaxed discussion through which both the*

> *researcher and participant journey together visiting places and topics of interest relevant to the research study. Yarning is a process that requires the researcher to develop and build relationship that is accountable to Indigenous people participating in the research.*[4(p.38))]

The four types of yarning described by Bessarab and Ng'andu[1] are described here.

Social yarning – an informal and unstructured conversation with the intent of purposeful exchanges to build trust and relationship. Social yarning typically precedes research or topic yarning. While social yarning is led by both the research participant and researcher, it is the responsibility of the researcher to establish connection through authentic and meaningful interest in the participant's life while also sharing information about themselves. Points of connection may stem from sharing of community news, advice and whatever else people feel like sharing that is not related to the topic of the research.[1]

Research or topic yarning – an unstructured or semi-structured conversation with purpose. The goal of research or topic yarning is to gather stories from the participant in relation to the topic while maintaining a relaxed and interactive style of interviewing.[1]

Collaborative yarning – an unstructured or semi-structured conversation with purpose. A method whereby two or more people explore research ideas and explanations of new concepts. The yarn may lead to new understandings and discoveries relevant to the research topic.[1]

Therapeutic yarning – a conversation in which the participant shares a personal story that includes memories of trauma or in some way evokes an emotional reaction. The researcher listens and provides space for the participant to give voice to their story and to make sense of it. Therapeutic yarning is not counselling; rather, it is the participant making meaning from the process of telling their story. Therapeutic yarning requires facilitation by a skilled professional who has both clinical and First Peoples cultural awareness knowledge. Therapeutic yarning can have empowering effects and enable participants to find meaning from the process of sharing their story and feeling heard.[1, 5]

The four types of yarning are inter-connected and can all be part of the one yarning session. See Figure 1 in the article 'Decolonising Qualitative Research with Respectful, Reciprocal, and Responsible Research Practice'.[3]

Yarning is about relational connection with and between and with Indigenous peoples. It is about building and maintaining trusting relationships. Therefore, in the development phase of any research project, yarning in research with the Indigenous people or communities the research relates to, should start early, to ensure that the Indigenous participants are research partners, and have the opportunity to direct the research purpose, providing insights into local expectations and negotiating roles for the research. Yarning is flexible, adaptable and diverse, and hence starting the yarn in the early phases of the research is important in undertaking culturally safe and just research.[4]

Yarning with Indigenous communities with the purpose to establish an inquiry design was recently exampled by The Yoorrook Justice Commission, in Victoria, Australia. The Yoorook Justice Commission inquiry, ongoing at the time of writing this chapter, is the first formal truth-telling Commission inquiry into historical and contemporary systemic injustices committed against Aboriginal and Torres Strait Islander peoples living in Victoria. In the period March to June 2022, in order to establish inquiry approaches, five Commissioners conducted 29 Yarning Circles involving 200 Elders across Victoria. The purpose of the Yarning Circles is described on page 18 of the interim report[6(p18)]:

> *The primary purpose of the Elders' yarning circles was to provide information to Elders about Yoorrook, to build trust in Yoorrook's approach, and to hear from Elders their priorities for the Commission's focus in the next phase of work. Elders also took the opportunity to share parts of their own experiences or stories of their families and ancestors. Many expressed frustrations with, and cynicism towards, prior government efforts and official inquiries, noting that nothing had changed as a result. Many Elders had questions about Yoorrook, such as how it would be different, or expressed concern about how it is distinct from the First Peoples' Assembly of Victoria or government. These meetings were a powerful source of ideas and information that have informed and will continue to guide Yoorrook's work.*

Key considerations in yarning

- All research that concerns or impacts Aboriginal and Torres Strait Islander peoples in any way should align with the principles of the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research.[7]
- Many of the logistics and practicalities of running yarning sessions should be discussed in partnership and collaboration with Traditional Owners and Elders of the community. This includes determining who is appropriate to facilitate the yarning sessions; for example, someone within the community, a First Nations person external to the community or a non-Indigenous person, and the appropriate customs and protocols to follow. Payment for running the yarning sessions and participating in the yarning should also be discussed with Elders and incorporated into the research protocol.
- Before a researcher commences yarning, ways of providing a feedback loop for sharing research findings with the participating community, and especially the individuals who participated in the yarning, should be discussed and planned. When the yarning has finished and the research findings have been generated, this feedback loop should be enacted to ensure that the researchers' interpretations and understandings accord with those of the individual and community participants. This process can mitigate against non-First Nations peoples' worldviews being applied inappropriately to First Nations' ways of knowing and being.
- The use of culturally appropriate and respectful language is essential. There is great diversity across Aboriginal and Torres Strait Islander communities in Australia, and thus there is no single Indigenous identity. Consultation with Traditional Owners, Elders and community members is vital in ensuring that the preferences of the people involved are respected. Researchers should recognise that First Nations languages are firstly oral, and hence when written the language needs to reflect the spellings of local traditional owners, elders and community members. Language needs to be specific

and strengths-based (focus on abilities, knowledge and capacities rather than what is lacking or deficits). If you are not sure, ask; for example, different individuals and communities may prefer to be named as Indigenous, Aboriginal, Aboriginal and Torres Strait Islander, First Peoples or First Nations. The Australian Government's Style Manual[8] provides a good starting point for researchers to orient themselves to culturally appropriate and respectful language when writing with, for or about Aboriginal and Torres Strait Islander peoples; however, it cannot take the place of meaningful consultation.

- When writing up yarning results, the elders and community members should be acknowledged in the report's credits. Researchers should ensure they are quoting yarning participants with appropriate credits, including their names and Country, to demonstrate that the knowledge came from them and not from the researcher. The project report More Than Personal Communication: Templates for Citing Indigenous Elders and Knowledge Keepers provides guidance on how to appropriately acknowledge Indigenous participants.[9]
- Be mindful of the principles of Indigenous data sovereignty – contributions by Indigenous people are not just data, they are stories. The principles can be found on the webpage of Maiam Nayri Wingara Communique.[10] These principles assert that control and accountability of the data rests with First Peoples and as such data should be contextualised and made accessible at an individual and community level. This approach is consistent with principles of self-determination. Culturally informed data management should be considered to be a process of protecting and respecting individual and collective interests. People who participate in one-to-one yarning sessions or yarning circles should be given the opportunity to indicate how they wanted their stories used, whether they wanted to be named and be informed of any other relevant contextual factors. This process will uphold the participants' rights to their stories.
- First Nations peoples worldwide are over-researched, with research done *to* and *on* them rather than *for* and *with* them. Therefore, it is important that researchers work with First Nations communities, and that the research is initiated and led by the participating community, to ensure that it will be relevant and of benefit to the community. Community-Led Research – Walking New Pathways Together, by Rawlings, Flexner and Riley, provides guidance on how to build relationships and collaboration with communities, and the appropriate protocols.[11]

Advantages and challenges of yarning

Yarning fosters connection, establishes trust and enables the researcher to explore the research topic in great detail. Yarning is an Indigenous way of doing things and recognises the importance of relationship, responsibility and accountability, to create cultural safety in partnership with the people who participate in the research.[1, 4] A challenge of yarning is managing time. The unstructured nature of yarning, focus on relationship and rapport-building and the researcher being the listener, can lead to an endless discussion. Negotiating the time expectations for the research or topic yarn with participants through social yarning can help to address this challenge.[1]

Table 19.1 provides two examples of research in which yarning has been used as a data collection method.

Table 19.1. Examples of yarning in research

Title	**A multi-methods yarn about SMART Recovery: first insights from Australian Aboriginal facilitators and group members** [12]	**Yarning about fall prevention: community consultation to discuss falls and appropriate approaches to fall prevention with older Aboriginal and Torres Strait Islander people** [13]
First author and year	Dale, 2021	Lukaszyk, 2018
CC Licence	CC BY-NC-ND 4.0	CC BY 4.0
Aim	To explore 'the cultural utility of SMART Recovery in an Australian Aboriginal context' (abstract introduction)	1. Investigate the impact of falls on the health and wellbeing of older Aboriginal and Torres Strait Islander people; 2. Assess the level of existing knowledge older Aboriginal and Torres Strait Islander people have on fall prevention; and 3. To identify desirable elements of a fall prevention program from the perspective of older Aboriginal and Torres Strait Islander people.'p2
Intervention	SMART Recovery is a support group program for people seeking to recover from addictions to alcohol, illicit drugs or gambling.	Not applicable
Method	An Indigenous lensed, multi-method explorative design< Incorporating yarning and quantitative (survey, program adherence check list) and qualitative (group observation) research methods.	Yarning circles conducted by an Aboriginal facilitator and trained qualitative researcher. Yarning circles started with morning tea to build rapport with participants. Discussions began with the project team and participants introducing themselves and sharing about their family origins.
Participants	Five Aboriginal communities: 3 in New South Wales and 2 in South Australia. Facilitators and group members of the SMART recovery groups	Aboriginal and Torres Strait Islander people aged 45 years and older from New South Wales.

Title	**A multi-methods yarn about SMART Recovery: first insights from Australian Aboriginal facilitators and group members** [12]	**Yarning about fall prevention: community consultation to discuss falls and appropriate approaches to fall prevention with older Aboriginal and Torres Strait Islander people**[13]
Yarning	Research topic yarning and social yarning; An example questions for group members included: 'How could SMART Recovery be better for Aboriginal people?'p1019 An example question for facilitators included: 'How would you describe what it is like to be an Aboriginal person facilitating SMART recovery groups?'p1019 Social yarning occurred before and after the research topic yarning.	The questions for the yarning circle were: 1. Has anyone had a fall recently? Can you talk about what happened? 2. Is it important to find ways to prevent falling? 3. Are you aware of any fall prevention programs in your community? 4. Would you attend an Aboriginal-specific falls prevention program if it was available? 5. Are there any things that would or do stop you from attending a falls prevention program? Do you have any ideas about how these things could be addressed? Laminated cards with pictures representing existing falls prevention programs were distributed. Are there any parts of these programs that you would like to see incorporated into a falls program for Aboriginal people? [Table 1, p3]
Data analysis	Thematic analysis	Conventional content analysis

Title	**A multi-methods yarn about SMART Recovery: first insights from Australian Aboriginal facilitators and group members** [12]	**Yarning about fall prevention: community consultation to discuss falls and appropriate approaches to fall prevention with older Aboriginal and Torres Strait Islander people** [13]
Results	Themes: 1. Integrate Aboriginal perspectives into the facilitator training 2. Create Aboriginal-specific program materials 3. Community engagement, marketing and networking 4. Establish an Aboriginal SMART recovery program [Table 5, p.1024]	Themes and subthemes Impact of falls on older Aboriginal people:$^{p3-5}$ • Physical disability • Loss of emotional wellbeing • Loss of connection to family and community Falls prevention in Aboriginal communities:^{p5} • Use of falls prevention programs • Knowledge about falls prevention • Interest in falls prevention Desired attributes of a falls prevention program for Aboriginal people:$^{p5-6}$ • Type of program • Program delivery • Accessibility of program

Summary

Yarning is a First Nations research method for sharing knowledge and is built on a foundation of relationship and collaboration. Yarning should be initiated and led by the participating community so that the research can be of benefit to Aboriginal and Torres Strait Islander peoples. Working with Traditional Owners and Elders will help to ensure that the process of yarning is culturally appropriate and respectful, and recognises the diversity in Aboriginal and Torres Strait Islander communities in Australia.

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DATA ANALYSIS

CHAPTER 20: CODING APPROACHES

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe coding.
- Describe inductive and deductive qualitative coding.
- Understand how to conduct qualitative coding.

What is coding?

Coding is a process whereby the researcher applies a label to describe the meaning of text and is the first step in qualitative analysis. It is important to be clear about the terminology used in coding and analysis. Erlingsson and Brysiewicz[1] have provided the following succinct definitions, which can help the researcher understand the three different, commonly used terms:

- **Code** – a label, a name (or tag) that describes the meaning of the text, usually in one or two words. It is about the meaning, not only the words in the transcript.
- **Category** – active grouping or organisation of codes that are related to each other through content or context. A category answers questions about who, what, when or where. Category names should be factual and short. Codes can be grouped into subcategories and then moved into broader categories.
- **Theme** – expresses the underlying meaning across categories. A theme is interpreted from the codes, categories and context or meaning of the transcript. It answers the questions why, how, in what way or by what means. Poetic and metaphoric language can be used; a theme is descriptive and uses verbs, adverbs and adjectives. A theme is more a statement than simply a word.

Deductive and inductive coding

There are two primary methods of coding: deductive and inductive.[2] Deductive coding begins with a set of **pre-established codes,** which the researcher applies to the data set (e.g., interview transcripts). Deductive coding is more descriptive than interpretive, and is most often used for content analysis (see Chapter 21). For example, in a study about 'falls', a researcher asked participants for their perceptions and experiences of falls, whether they believed falls were a problem, and to what extent they are a problem. One participant stated:

> Answer: I think they're an unsolved problem. I think they're something that we certainly need to manage better, and that's not unique to [Hospital], it's across the globe. And I don't think that we've paid enough attention to it in the past. And I think we can learn from experiences, for instance, bacteraemia where there's been a focus on prevention that's worked so greatly. And then when we think about where we were 10/15 years ago with that, where we just more or less accepted that there's going to be bacteraemia and people would be sick from them and die from them. And so I think falls is in that bracket now, where we need to put that concentrated effort into it. They should be preventable. We shouldn't have them. We need to implement multiple, I think, projects or processes to prevent them. And I think you're correct, there are many different types of patients, different environments, different type of buildings, different equipment available, that makes it fairly unique in each situation and in each ward even.
>
> (Anonymous participant in unpublished falls study dataset collected by the authors)

The following are some of the deductive codes that could be generated from this answer. Remember that deductive codes come from the interview guide and prompts, and may also be also based on the literature. These are the codes the researcher is actively looking for *in* the data, rather than the codes that the researcher finds *from* the data (inductive).

- Attitudes or perceptions
- Unsolved problem
- Learn from past lessons
- Need to manage
- Preventable
- Ward layout
- Patient characteristics
- Access to resources.

Dacillo et al provided another good example of deductive coding. They examined 'videoconferencing fatigue and its relationship with online student engagement (OSE) during the COVID-19 pandemic'.[3(p1)] The study examined existing concepts or ideas, informed by pre-existing theory – the surface meaning of their data. Dacillo's first objective followed a deductive process because the themes had already been identified from the literature and the scale used (the five domains of videoconferencing).

Inductive coding works the opposite way to deductive coding. Codes are created based on what is revealed in the data set (e.g. interview transcripts). For example, inductive coding explores meanings and issues raised by the participant, such as fear of dying from falling, or the unique nature of each fall across the world. Inductive coding is more interpretive than deductive coding, and often leads to the development of new theories. Inductive coding can be used in thematic analysis and framework analysis (see Chapter 22), and in grounded theory (see Chapter 25) as open, axial and selective coding. For a good example of inductive coding, refer to Wang et al.[4] Wang et al explored 'the effects of initial contact with the clinical learning environment on first-year nursing students' empathy levels and perceptions of professional identity'.[4(p1)] Diary recordings about their clinical learning experiences were collected and a thematic analysis was conducted on the content regarding professional identity in nursing students' diaries. Based on the framework of grounded theory (see Chapter 25), the researchers adopted an inductive thematic analysis approach developed by Braun and Clarke.[3] Wang discovered that first-year nursing students' initial contact with the clinical learning environment helped them to enhance empathy and shape professional identity. Returning to Dacillo et al[3], their second objective followed an inductive process because the themes were formed on the basis of emergent, lower-level concepts gleaned from the narratives.

Nearly everything mentioned in an interview can be coded, including but not limited to:

- setting and context
- definition of situation
- perspectives
- ways of thinking about people and objects
- process
- activities
- actions
- events
- conditions
- consequences
- strategies
- relationship and social structure
- meanings.

How to code

Before commencing coding, the researcher must accept that they are the data analysis tool. Because qualitative data analysis is subjective and inductive, the way the researcher sees the world will influence how data will be collected and interpreted. To ensure accurate coding, the researcher needs to acknowledge their own influences, such as education, gender identity, social class, professional role, preconceptions, ethnicity, and many more.

It is advisable to create a coding guide, which can be developed prior to data analysis, based on a literature review. The coding approach can also evolve through the process of coding. Codes can be factual (content analysis) or interpretive (thematic analysis or grounded theory). The coding guide will have names for codes, categories and themes. These names can come from the researcher, the participants and/or the literature. Most often, the researcher comes up with terms, concepts and categories that reflect what they 'see' in the data.

Coding can vary depending on the approach to data analysis. Coding for content analysis is most often deductive and categorical. Coding for thematic analysis[5] and grounded theory are most often inductive, deductive, matrix and charting, open, axial and selective coding (see chapters 22 and 25). Thematic and grounded theory coding entails examining the text for codes that are discovered in the data. Table 20.1 provides some examples of various types of coding.

Table 20.1. Coding examples from health and social care research

Title	**The language of TV commercials' slogans: a semantic analysis**[6]	**Measuring the patient experience of mental health care: a systematic and critical review of patient-reported experience measures**[7]	**Contexts and mechanisms that promote access to healthcare for populations experiencing homelessness: a realist review**[8]	**Transforming while transferring: an exploratory study of how transferability of skills is key in the transformation of higher education**[9]
CC Licence	CC BY 4.0	CC BY-NC 3.0	CC BY-NC 4.0	CC BY 4.0
First author and year	Noor, 2015	Ferdinand, 2020	Siersbaek, 2020	Bazana, 2018

Title	The language of TV commercials' slogans: a semantic analysis[6]	Measuring the patient experience of mental health care: a systematic and critical review of patient-reported experience measures[7]	Contexts and mechanisms that promote access to healthcare for populations experiencing homelessness: a realist review[8]	Transforming while transferring: an exploratory study of how transferability of skills is key in the transformation of higher education[9]
Aim	To analyse linguistic tools that copywriters of TV commercials use in relation to product specialism; to highlight the semantic property of TV commercial slogans; to pinpoint strategies employed by copywriters to influence viewers (p.11)	To provide an overview of the psychometric properties and the content of available PREMs(p.2156)	To identify and understand the health system contexts and mechanisms that allow for homeless populations to access appropriate health care when needed(p.16)	To highlight issues in terms of institutional culture and race, as well as establish and highlight the problematic issue of skills transferability within higher education between academics(p.13-14)
Study design	Descriptive qualitative	Inductive qualitative	Realist review	Explanatory qualitative
Data collection	Watching TV channels	A comprehensive review of the published peer-reviewed literature was conducted using the MEDLINE bibliographic database	A review of reviews and grey literature.	Interviews
Coding analysis approach	Semantic: explicit content of the data (factual codes), obvious meanings, also known as descriptive codes	Latent: concepts and assumptions underpinning the data, underlying concepts, also known as conceptual codes	Realist: reality is evident in the data; what objectively exists in the data (inductive and deductive coding)	Constructionist: how reality is created in the data

Title	The language of TV commercials' slogans: a semantic analysis[6]	Measuring the patient experience of mental health care: a systematic and critical review of patient-reported experience measures[7]	Contexts and mechanisms that promote access to healthcare for populations experiencing homelessness: a realist review[8]	Transforming while transferring: an exploratory study of how transferability of skills is key in the transformation of higher education[9]
Results	The study unveils the underlying mechanism of encoding and decoding meanings of the discussed slogans of TV commercials.	Provides a description and a critical analysis of the available PREMs for mental health care that can help professionals choose PREMs that best suit their needs.	Access to health care for populations experiencing homelessness depends on adequately resourcing and training providers to meet the needs of patients in a welcoming and attentive setting without stigma and judgement. Services should be closely linked, and staff and providers should be empowered to take responsibility for providing flexible, responsive and opportunistic care in flexible settings. The contexts in which this is possible arise in a respectful, empathetic culture, which is created when managers and leaders value and champion it.	The diversity of cultures does not allow for a one-size-fits-all approach to skills transferability and collaboration, and the diversification and allowed growth of new generation academics will only be realised by the institution once the institutional culture embedded in the policies and procedures of the university for a dynamic response to teaching.

Creswell[10] developed a figure on page 244 of his book to demonstrate the coding process. While Creswell demonstrates these steps as a linear process, in fact they do go back and forth to refine codes, categories and themes. He commences the process by reading the text data and then dividing the text into as many segments of information as possible. Then codes are assigned to the segments, the codes are reduced, and finally codes are collapsed into themes. He presents a linear process that commences with many pages of texts and ends with everything reduced to five to seven themes. Refer to his book for the figure.

It is advisable to create a coding guide that can be developed prior to analysis, based on a literature review. Codes can be factual (content analysis) or interpretive (thematic analysis/grounded theory).

Coding can also be thought of as a simple, 3-step process involving deconstruction and reconstruction of text.

Step 1: Deconstruction, or fragmentation[2]

Deconstruction begins by assigning a code word or phrase that accurately describes the meaning of the text segment. Then line-by-line coding is conducted, first in theoretical research (grounded theory, framework) or segmentation (applied thematic analysis). More general coding involving larger segments of text is adequate for practical research. Deconstruction breaks down data and reconceptualises it, and makes comparisons between events, actions and interactions. Then conceptual labels are applied, and these are grouped into categories. Initial relationships between categories are developed.

Clustering is undertaken as the next action. After coding text, a list of all code words is developed, whereby similar codes are brought together (clustered) and redundant codes are reviewed. The objective of clustering is to reduce the long list of codes to a smaller, more manageable number (perhaps 25–30 codes).

The researcher should be looking for key phrases. Are there phrases that make some sense but are not necessarily describable? People often circle through the same ideas in their answers: are there topics that occur and recur? Are there local or common terms that are used in unfamiliar ways (e.g. 'women's troubles', 'bad blood', or 'difficulties')? Are metaphors or idioms used (e.g. 'rock-solid marriage' or 'cooking with gas')? If yes, what do they represent?

Step 2: Reconstruction

Reconstruction involves specifying more rigorous codes than in the first step. Data is combined (put back together) to demonstrate new ways of making connections between a category and subcategories. Table 20.2 demonstrates the code-to-category reconstruction.

Table 20.2. Interconnecting the data

Deconstruction: code	**Reconstruction: category**
Attitudes or perceptions • Ward layout • Patient characteristics • Access to resources	Barriers or challenges to falls prevention

Step 3: Grouping

Grouping brings categories into a core category that is built from a core code. This is a point of theoretical integration, used in selective or theoretical coding with grounded theory. The story is built from categories.

After you have created codes and categorised them, you have come to the end of the coding process. After this process, you move on to creating and naming themes, and then describe the approach to the analysis (see chapters 21–25).

Summary

Coding is a process of assigning labels to text. Coding can be inductive or deductive. Each coding approach has its own techniques but should be chosen on the basis of the researchers' approach to analysing their data.

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CHAPTER 21: CONTENT ANALYSIS

Danielle Berkovic

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe the three types of qualitative content analysis.
- Understand how to conduct the three types of qualitative content analysis.
- Identify the strengths and limitations of each type of qualitative content analysis.

What is content analysis?

Content analysis is a widely used qualitative research technique to systematically classify codes and identify themes or patterns within the data.[1] Content analysis goes beyond counting words; it can be used to examine data and to organise large amounts of text into an efficient number of categories that represent similar meanings.[2] This textual data can be derived from the transcripts of interviews or focus groups, from the researcher's notes taken during participant observation, from documents such as medical or policy guidelines, or from free-text responses to open-ended survey questions. There are three types of content analysis, which are explored in this chapter[1]:

- Conventional – the inductive creation of descriptive categories (i.e. categories are not predefined)
- Directed – the deductive creation of descriptive categories using a structured approach (i.e. categories may be predefined if analysing data within an existing framework)
- Summative – the identification and quantification of words or content in the text, which aims to understand the contextual use of words or content, and to explore their usage.

Conventional content analysis

Conventional content analysis is used when existing theory or research literature on a phenomenon is limited.[1] Researchers should avoid using preconceived codes, instead allowing the codes and names for codes to inductively arise from the data through the following steps:

- The researcher should be immersed in the data, to enable new insights to emerge. This might include reading all interview and/or focus group transcripts, or the field notes from a participant observation project. This enables the researcher to obtain a sense of the whole dataset. Notes can be made on the transcripts at this time.
- Once the researcher has read the dataset as a whole, the data should be read closely, sentence by sentence, to inductively capture key thoughts or initial concepts.
- The researcher should approach each of these sentences by making notes of their first impressions, thoughts and initial direction for analysis.
- As this process continues, potential categories should emerge that are reflective of more than one thought. These should be present directly within the text and become the initial coding scheme.
- Codes should be sorted into categories, based on how the categories are related and linked. Depending on the relationships between categories, researchers can choose to combine categories or organise them into a smaller number of subcategories.
- Definitions for each category, subcategory, and code should be developed.
- To prepare for reporting the findings, example quotes for each of the codes and category definitions should be identified from the data.
- Depending on the study's aims and objectives, researchers might decide to explore further relationships between categories.
- Before writing up results, the researcher should check the alignment of codes, categories and quotes.

Example of conventional content analysis

Heydari et al[3] used conventional content analysis to better understand home-based palliative care for people with terminal cancer. The researchers collected data through 17 semi-structured interviews and one focus group with 8 participants. They describe reading the transcripts several times, extracting initial codes and merging codes to form categories based on their similarities, before attributing quotes to the categories. Two main categories (challenges and opportunities) and 10 subcategories were identified.

Directed content analysis

Sometimes, existing theory or prior research exists about a phenomenon that is incomplete or would benefit from further description.[4] In this instance, the researcher should choose to conduct a directed content analysis.[5] Directed content analysis is used to validate or extend conceptually a theoretical framework or theory. For example, researchers used Watson's Human Caring Theory to analyse healthcare workers' perspectives on human caring[6], and the Information Motivation Behavioural skills model was used to better understand adherence to antiretroviral therapy.[7] Directed content analysis provides a more structured process for data analysis than the conventional approach, through the following steps:

- Using existing theory or prior research, the researchers begin by identifying key concepts as initial coding categories.
- Next, operational definitions for each category are determined using the theory.
- The researcher reads their data as a whole and highlights all text that on first impression appear to represent an aspect of the theory. This provides some reassurance that the researcher has captured all possible occurrences of a phenomenon.
- The researcher codes the highlighted passages using the predetermined codes from the selected theory.
- Any text that cannot be categorised with the initial coding scheme can be given a new code and used to provide new insight into the original theory or prior research.
- The findings from a directed content analysis offer supporting and non-supporting evidence for a theory. This evidence can be presented by showing codes with example quotes, and by providing descriptive evidence.

Example of directed content analysis

Purkey et al[8] used the Life Course theory to understand and imagine public health and policy responses to the multiple and varied impacts of the COVID-19 pandemic on different groups. Data was collected through participant-offered short stories and key informant interviews. The data was analysed using directed content analysis; transcripts were read and coded according to definitions outlined in the Life Course theory, which was identified as a theory with sufficient complexity to illustrate many of the impacts of COVID-19. The Life Course theory is described by three constructs: (1) timing (related to cohort effect and period effect), (2) trajectories (related to social pathways, transitions and turning points) and (3) broader principles through which any impact can be examined (related to life span development, agency, time and place, timing, and linked lives).

Summative content analysis

Researchers using summative content analysis start by identifying and quantifying certain words or content in the data to understand the contextual use of the words. This quantification is not designed to infer meaning, but rather to explore the usage and frequency of content.[9]

In a summative approach to content analysis, the researchers begin by searching the dataset for occurrences of the identified words (this can be done manually or using assistive software). The word frequency for each identified word is calculated, with the context also noted (e.g. the participant providing that data, or the setting in which it was provided). Counting is used to identify patterns in the data and to contextualise the codes. This enables interpretation of the context associated with the use of the word or phrase.[1]

Example of summative content analysis

Bender et al[10] aimed to characterise the purpose, use and creators of Facebook groups related to breast cancer. The researchers began by analysing the content of the first 100 Facebook groups to develop a coding and classification scheme that could be applied to the entire set. This step led to the identification of four main codes within which to categorise posts: (1) fundraising groups, (2) awareness-raising groups, (3) support groups and (4) promote-a-site groups. The majority of posts related to fundraising (44.7%), followed by awareness (38.1%). Through a summative content analysis, the researchers were able to learn how Facebook is used to promote support for breast cancer.

Advantages and disadvantages of content analysis

Conventional content analysis

Advantages

- The ability to gain information directly from study participants without imposing preconceived categories
- The establishment of data credibility through activities such as triangulation, negative case analysis and member checking

Disadvantages

- There is potential for incomplete understanding of the context of the data, leading to codes that do not accurately represent the data
- This method of analysis can be easily confused with other qualitative methods that share similar analytical approaches

Directed content analysis

Advantage

- Existing theories can be supported and extended.

Disadvantages

- Researchers may approach the data with an informed yet visible bias based on the framework or theory that is being used. As a result, they may be more likely to find evidence that is supportive of, rather than non-supportive, of a particular theory
- An overemphasis on the theory can limit researchers' understanding of contextual aspects of the phenomenon

Summative content analysis

Advantages

- A simple and systematic way to study the phenomenon of interest
- Provides basic insights into how words are used

Disadvantage

- Limited by inattention to the broader meanings present in the data

Summary

Content analysis is a widely used qualitative research technique to systematically classify codes and identify categories or patterns within the data. There are three types of content analysis: conventional, directed and summative. These three types cover the spectrum of content analysis, from inductive (conventional) to deductive (directed and summative) techniques. Each type of content analysis has its own advantages and disadvantages, but should be chosen based on the researchers' aims and objectives.

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CHAPTER 22: THEMATIC ANALYSIS

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe the different approaches to thematic analysis.
- Understand how to conduct the three types of thematic analysis.
- Identify the strengths and limitations of each type of thematic analysis.

What is thematic analysis?

Thematic analysis is a common method used in the analysis of qualitative data to identify, analyse and interpret meaning through a systematic process of generating codes (see Chapter 20) that leads to the development of themes.[1] Thematic analysis requires the active engagement of the researcher with the data, in a process of sorting, categorising and interpretation.[1] Thematic analysis is exploratory analysis whereby codes are not predetermined and are data-derived, usually from primary sources of data (e,g, interviews and focus groups). This is in contrast to themes generated through directed or summative content analysis, which is considered confirmatory hypothesis-driven analysis, with predetermined codes typically generated from a hypothesis (see Chapter 21).[2] There are many forms of thematic analysis. Hence, it is important to treat thematic analysis as one of many methods of analysis, and to justify the approach on the basis of the research question and pragmatic considerations such as resources, time and audience. The three main forms of thematic analysis used in health and social care research, discussed in this chapter, are:

- Applied thematic analysis
- Framework analysis
- Reflexive thematic analysis.

Applied thematic analysis

This involves multiple, inductive analytic techniques designed to identify and examine themes from textual data in a way that is transparent and credible, drawing from a broad range of theoretical and methodological perspectives. It focuses on presenting the stories of participants as accurately and comprehensively as possible. Applied thematic analysis mixes a bit of everything: grounded theory, positivism, interpretivism and phenomenology.[2]

> Applied thematic analysis borrows what we feel are the more useful techniques from each theoretical and methodological camp and adapts them to an applied research context.[2(p16)]

Applied thematic analysis involves five elements:

- **Text segmentation** involves identifying a meaningful segment of text and the boundaries of the segment. Text segmentation is a useful process as a transcript from a 30-minute interview can be many pages long. Hence, segmenting the text provides a manageable section of the data for interrogation of meaning. For example, text segmentation may be a participant's response to an interview question, a keyword or concept in context, or a complete discourse between participants. The segment of text is more than a short phrase and can be both small and large sections of text. Text segments can also overlap, and a smaller segment may be embedded within a larger segment.[3]
- **Creation of the codebook** is a critical element of applied thematic analysis. The codebook is created when the segments of text are systematically coded into categories, types and relationships, and the codes are defined by the observed meaning in the text. The codes and their definitions are descriptive in the beginning, and then evolve into explanatory codes as the researcher examines the commonalities, differences and relationships between the codes. The codebook is an iterative document that the researcher builds and refines as they become more immersed and familiar with the data.[3] Table 22.1 outlines the key components of a codebook.[3]

Table 22.1. Codebook components and an example

Code	**Definition**	**When to use**	**When not to use**	**Example**
Attitudes or perceptions: falls	Attitudes about falls from health professionals	When a health professional describes their thoughts about falls. Look for 'I think' and 'I believe' statements.	When providing definitions about falls	'I think they [falls] are an unsolved problem.'

- **Structural coding** can be useful if a structured interview guide or focus group guide has been used by the researcher and the researcher stays close to the wording of the question and its prompts. The structured question is the structural code in the codebook, and the text segment should include the participant's response and any dialogue following the question. Of course, this form of coding can be used even if the researcher does not follow a structured guide, which is often the reality of qualitative data collection. The relevant text segments are coded for the specific structure, as appropriate.[3]

- **Content coding** is informed by the research question(s) and the questions informing the analysis. The segmented text is grouped in different ways to explore relationships, hierarchies, descriptions and explanations of events, similarities, differences and consequences. The content of the text segment should be read and re-read to identify patterns and meaning, with the generated codes added to the codebook.
- **Themes** vary in scope, yet at the core they are phrases or statements that explain the meaning of the text. Researchers need to be aware that themes are considered a higher conceptual level than codes, and therefore should not be comprised of single words or labels. Typically, multiple codes will lead to a theme. Revisiting the research and analysis questions will assist the researcher to identify themes. Through the coding process, the researcher actively searches the data for themes. Examples of how themes may be identified include the repetition of concepts within and across transcripts, the use of metaphors and analogies, key phrases and common phrases used in an unfamiliar way.[3]

Framework analysis

This method originated in the 1980s in social policy research. Framework analysis is suited to research seeking to answer specific questions about a problem or issue, within a limited time frame and with homogenous data (in topics, concepts and participants); multiple researchers are usually involved in the coding process.[4-6] The process of framework analysis is methodical and suits large data sets, hence is attractive to quantitative researchers and health services researchers. Framework analysis is useful for multidisciplinary teams in which not all members are familiar with qualitative analysis. Framework analysis does not seek to generate theory and is not aligned with any particular epistemological, philosophical or theoretical approach.[5] The output of framework analysis is a matrix with rows (cases), columns (codes) and cells of summarised data that enables researchers to analyse the data case by case and code by code. The case is usually an individual interview, or it can be a defined group or organisation.[5]

The process for conducting framework analysis is as follows[5]:

1. Transcription – usually verbatim transcription of the interview.

2. Familiarisation with the interview – reading the transcript and listening to the audio recording (particularly if the researcher doing the analysis did not conduct the interview) can assist in the interpretation of the data. Notes on analytical observations, thoughts and impressions are made in the margins of the transcript during this stage.

3. Coding – completed in a line-by-line method by at least two researchers from different disciplines (or with a patient or public involvement representative), where possible. Coding can be both deductive – (using a theory or specific topics relevant to the project – or inductive, whereby open coding is applied to elements such as behaviours, incidents, values, attitudes, beliefs, emotions and participant reactions. All data is coded.

4. Developing a working analytical framework – codes are collated and organised into categories, to create a structure for summarising or reducing the data.

5. Applying the analytical framework – indexing the remaining transcripts by using the categories and codes of the analytical framework.

6. Charting data into the framework matrix – summarising the data by category and from each transcript into the framework matrix, which is a spreadsheet with numbered cells in which summarised data are entered by codes (columns) and cases (rows). Charting needs to balance the reduction of data to a manageable few lines and retention of the meaning and 'feel' of the participant. References to illustrative quotes should be included.

7. Interpreting the data – using the framework matrix and notes taken throughout the analysis process to interpret meaning, in collaboration with team members, including lay and clinical members.

Reflexive thematic analysis

This is the thematic analysis approach developed by Braun and Clarke in 2006 and explained in the highly cited article 'Using thematic analysis in psychology'.[7] Reflexive thematic analysis recognises the subjectiveness of the analysis process, and that codes and themes are actively generated by the researcher. Hence, themes and codes are influenced by the researcher's values, skills and experiences.[8] Reflexive thematic analysis 'exists at the intersection of the researcher, the dataset and the various contexts of interpretation'.[9(line 5-6)] In this method, the coding process is less structured and more organic than in applied thematic analysis. Braun and Clarke have been critical of the use of the term 'emerging themes', which many researchers use to indicate that the theme was data-driven, as opposed to a deductive approach:

> This language suggests that meaning is self evident and somehow 'within' the data waiting to be revealed, and that the researcher is a neutral conduit for the revelation of said meaning. In contrast, we conceptualise analysis as a situated and interactive process, reflecting both the data, the positionality of the researcher, and the context of the research itself… it is disingenuous to evoke a process whereby themes simply emerge, instead of being active co-productions on the part of the researcher, the data/participants and context.[10(p15)]

Since 2006, Braun and Clarke have published extensively on reflexive thematic analysis, including a methodological paper comparing reflexive thematic analysis with other approaches to qualitative analysis,[8] and have provided resources on their website to support researchers and students.[9] There are many ways to conduct reflexive thematic analysis, but the six main steps in the method are outlined following.[9] Note that this is not a linear, prescriptive or rule-based process, but rather an approach to guide researchers in systematically and robustly exploring their data.

1. **Familiarisation with data** – involves reading and re-reading transcripts so that the researcher is immersed in the data. The researcher makes notes on their initial observations, interpretations and insights for both the individual transcripts and across all the transcripts or data sources.

2. **Coding** – the process of applying succinct labels (codes) to the data in a way that captures the meaning and characteristics of the data relevant to the research question. The entire data set is coded in numerous rounds; however, unlike line-by-line coding in grounded theory (Chapter 27), or data segmentation in applied thematic analysis, not all sections of data need to be coded.[8] After a few rounds of coding, the codes are collated and relevant data is extracted.

3. **Generating initial themes** – using the collated codes and extracted data, the researcher identifies patterns of meaning (initial or potential themes). The researcher then revisits codes and the data to extract relevant data for the initial themes, to examine the viability of the theme.

4. **Developing and reviewing themes** – checking the initial themes against codes and the entire data set to assess whether it captures the 'story' of the data and addresses the research question. During this step, the themes are often reworked by combining, splitting or discarding. For reflexive thematic analysis, a theme is defined as a 'pattern of shared meaning underpinned by a central concept or idea'.[8(p39)]

5. **Refining, defining and naming themes** – developing the scope and boundaries of the theme, creating the story of the theme and applying an informative name for the theme.

6. **Writing up** – is a key part of the analysis and involves writing the narrative of the themes, embedding the data and providing the contextual basis for the themes in the literature.

Themes versus codes

As described above, themes are informed by codes, and themes are defined at a conceptually higher level than codes. Themes are broader categorisations that tend to describe or explain the topic or concept. Themes need to extend beyond the code and are typically statements that can stand alone to describe and/or explain the data. Fereday and Muir-Cochrane explain this development from code to theme in Table 22.2.[11]

Table 22.2. Corroborating and legitimating coded themes to identify second-order themes

First-order theme	**Clustered themes**	**Second-order themes**
The relationship between the source and recipient is important for feedback credibility, including frequency of contact, respect and trust The source of the feedback must demonstrate an understanding of the situational context surrounding the feedback message. Feedback should be gathered from a variety of sources. Verbal feedback is preferred to formal assessment, due to timing, and the opportunity to discuss issues.	**Theme 1:** Familiarity with a person increases the credibility of the feedback message. **Theme 2:** Feedback requires a situational-context. **Theme 3:** Verbal feedback is preferred over written feedback. **Theme 4:** Trust and respect between the source and recipient of feedback enhances the feedback message. **Theme 5:** Familiarity within relationships is potentially detrimental to the feedback process.	Familiarity When relationships enhance the relevance of feedback

When I [the author] first started publishing qualitative research, many of my themes were at the code level. I then got advice that when the themes are the subheadings of the results section of my paper, they should tell the story of the research. The difference in my theme naming can be seen when comparing a paper from my PhD thesis,[12] which explores the challenges of church-based health promotion, with a more recent paper that I published on antimicrobial stewardship[13] (refer to the theme tables in the publications).

Table 22.3. Examples of thematic analysis

Title	Connection, constraint, and coping: a qualitative study of experiences of loneliness during the COVID-19 lockdown in the UK[14]	'It is this very knowledge that makes us doctors': an applied thematic analysis of how medical students perceive the relevance of biomedical science knowledge to clinical medicine[15]	Misconceptions and the acceptance of evidence-based nonsurgical interventions for knee osteoarthritis. a qualitative study[16]
CC Licence	CC BY 4.0	CC BY 4.0	Public Domain Mark 1.0
First author and year	McKenna-Plumley, 2021	Dickinson, 2020	Bunzli, 2019
Aim/ research question	What are people's experiences of loneliness while practising physical distancing due to a global pandemic? (p3)	'To explore how medical students in their first clerkship year perceive the relevance of biomedical science knowledge to clinical medicine with the goal of providing insights relevant to curricular reform efforts that impact how the biomedical sciences are taught' (p2)	'To investigate the patient-related cognitive factors (beliefs/attitudes toward knee osteoarthritis and its treatment) and health system-related factors (access, referral pathways) known to influence treatment decisions.' 'Exploring why patients may feel that nonsurgical interventions are of little value in the treatment of knee osteoarthritis.' (p1976)

Title	Connection, constraint, and coping: a qualitative study of experiences of loneliness during the COVID-19 lockdown in the UK[14]	'It is this very knowledge that makes us doctors': an applied thematic analysis of how medical students perceive the relevance of biomedical science knowledge to clinical medicine[15]	Misconceptions and the acceptance of evidence-based nonsurgical interventions for knee osteoarthritis. a qualitative study[16]
Data collection	Semi-structured interviews by phone or videoconferencing software. Interview topics covered social isolation, social connection, loneliness and coping. Interview guide (supplementary file 2)[14]	55 student essays in response to the prompt: 'How is biomedical science knowledge relevant to clinical medicine?' A reflective writing assignment based on the principles of Kolb experiential learning model	Face-to-face or phone interviews with 27 patients who were on a waiting list for total knee arthroplasty.
Thematic analysis approach	Reflexive thematic analysis	Applied thematic analysis	Framework analysis

Title	Connection, constraint, and coping: a qualitative study of experiences of loneliness during the COVID-19 lockdown in the UK[14]	'It is this very knowledge that makes us doctors': an applied thematic analysis of how medical students perceive the relevance of biomedical science knowledge to clinical medicine[15]	Misconceptions and the acceptance of evidence-based nonsurgical interventions for knee osteoarthritis. a qualitative study[16]
Results	Table of themes and illustrative quotes: 1. Loss of in-person interaction causing loneliness 2. Constrained freedom 3. Challenging emotions 4. Coping with loneliness	1. Knowledge-to-practice medicine 2. Lifelong learning 3. Physician-patient relationship 4. Learning perception of self	Identity beliefs – knee osteoarthritis is 'bone on bone' Casual belief – 'osteoarthritis is due to excessive loading through the knee' Consequence beliefs – fear of falling and damaging the joint Timeline beliefs – osteoarthritis as a downward trajectory, the urgency to do something and arriving at the end of the road.

Advantages and challenges of thematic analysis

Thematic analysis is flexible and can be used to analyse small and large data sets with homogenous and heterogenous samples. Thematic analysis can be applied to any type of data source, from interviews and focus groups to diary entries and online discussion forums.[1] Applied thematic analysis and framework analysis are accessible approaches for non-qualitative researchers or beginner researchers. However, the flexibility and accessibility of thematic analysis can lead to limitations and challenges when thematic analysis is misapplied or done poorly. Thematic analysis can be more descriptive than interpretive if not properly anchored in a theoretical framework.[1] For framework analysis, the spreadsheet matrix output can lead to quantitative researchers inappropriately quantifying the qualitative data. Therefore, training and support from a qualitative researcher with the appropriate expertise can help to ensure that the interpretation of the data is meaningful.[5]

Summary

Thematic analysis is a family of analysis techniques that are flexible and inductive and involve the generation of codes and themes. There are three main types of thematic analysis: applied thematic analysis, framework analysis and reflexive thematic analysis. These approaches span from structured coding to organic and unstructured coding for theme development. The choice of approach should be guided by the research question, the research design and the available resources and skills of the researcher and team.

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CHAPTER 23: DISCOURSE ANALYSIS

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe discourse analysis.
- Understand how to conduct discourse analysis.
- Identify the strengths and limitations of discourse analysis.

What is discourse analysis?

Discourse analysis is a field of qualitative analysis that has its origins in disciplines such as linguistics, philosophy, psychology, anthropology.[1] It is an interdisciplinary field that deals with 'language' and meaning.[2]

According to Jaworski and Coupland, the purpose of discourse analysis is that it 'offers a means of exposing or deconstructing the social practices that constitute 'social structure' and what we might call the conventional meaning structures of social life. It is a sort of forensic activity'.[3(p5)] There are three domains of discourse analysis: the study of social interaction; the study of minds, selves and sense-making; and the study of culture and social relations.[4(p5)]

Discourse analysis is the study of texts such as transcribed interviews, websites, forums, books, newspapers, government documents (and many more), and the analysis of those texts to understand different accounts and the meanings behind those accounts. Qualitative researchers strive to understand the relationships between text (discourse) and social constructs. As text is analysed, the meaning behind the text is also explored, often as the 'voices' in the text. For example, when a participant is asked about their eating habits and they discuss their joy in eating as well as feelings of guilt from eating high-calorific foods, they may be voicing their parents' disapproval of this eating behaviour. The relationship between text and social constructs can also be seen in alcohol advertising: an advertisement may be promoting alcohol consumption as a fun behaviour, but also cautions listeners to drink 'responsibly', because the advertiser is required to do so by advertising standards authorities. This inherent contradiction in the advertising is part of the meaning-making regarding alcohol consumption. This meaning-making is contextual and differs between countries, such as Australia (a high alcohol consumption culture) and Canada (a lower alcohol consumption culture). Another example of context is in the use of the word 'just' by an interview participant; the term can mean many things, but if the researcher is asking about job title, 'just' may the participant's implication or inference that the title does not reflect an important position (e.g. 'I'm just an editor'). In discourse analysis, texts, meanings and inferences are important.

Following is an example of media articles and two distinct discourses about violence towards women. The first media article, published by *The Guardian* on 15 June 2018,[5] presents a discourse about how it is the responsibility of women to prevent men from being violent towards them. The second article about the same incident, published by *The Age* on 25 May 2019,[6] presents a discourse that it is the responsibility of men not to be violent towards women.

Meanings of texts are particularly important when participants use metaphors. The researcher needs to examine the implications of the metaphor, deliberate or inadvertent. For example, when the researcher asks the participant how they felt about their life and the participant replies, 'life is a highway', the researcher needs to look beyond what was said to understand the participant's meaning.

As an interdisciplinary method, discourse analysis can be complex and intricate. Gee[7] provides 72 tools to assist with various types of discourse analysis, ranging from identifying what is being said and what is not being said, to examining 'how the person is using language, as well as ways of acting, interacting, believing, valuing, dressing, and using various objects, tools, and technologies in certain sorts of environments to enact a specific socially recognizable identity and engage in one or more socially recognizable activities'.[7(p201)] Gee also includes a helpful table (see Table 23.1) populated with his 7 building tasks for researchers to examine their discourses, and provides the answers.[8]

Table 23.1. Seven Building Tasks and associated discourse analysis questions

Gee's building task	**Gee's discourse analysis question**
Significance	How is this piece of language being used to make certain things significant or not, and in what ways?
Practices	What practice or practices is this piece of language being used to enact (i.e. to get others to recognise as going on)?

Gee's building task	**Gee's discourse analysis question**
Identities	What identity or identities is this piece of language being used to enact (i.e. to get others to recognise as operative)? What identity or identities is this piece of language attributing to others, and how does this help the speaker or writer enact his or her own identity?
Relationships	What sort of relationship or relationships is this piece of language seeking to enact with others?
Politics	What perspective on social goods is this piece of language communicating (i.e. what is being communicated as to what is taken to be 'normal,' 'right,' 'good,' 'correct,' 'proper,' 'appropriate,' 'valuable,' 'the ways things are,' 'the way things ought to be,' 'high status or low status,' 'like me or not like me,' and so forth)?
Connections	How does this piece of language connect or disconnect things; how does it make one thing relevant or irrelevant to another?
Sign systems and knowledge	How does this piece of language privilege or deprivilege specific sign systems or different ways of knowing and believing, or claims to knowledge and beliefs?

How to conduct discourse analysis

Discourse analysis, as in all other qualitative methods, is used depending on the research topic and question(s) or aim(s). The following steps are recommended:

Step 1: Have a clearly defined topic and research question, because this informs the types of research materials that will be used.

Step 2: Conduct wide-ranging searches for materials that will inform the research topic.

Step 3: Determine which theory and framework will be used as the underpinning foundation for the analyses (see Section 1 chapters 1–4).

Step 4: Analyse the content of the materials. This analysis is different (but similar) to content analysis, which is a research technique to systematically classify codes and identify themes or patterns within the data. Discourse analysis is concerned with identifying themes and patterns within the texts that relate to the social contexts reflected in the research topic and within the theoretical lens chosen for analyses.

Step 5: Interpret and draw conclusions. Reflect on your work and examine how the various texts use language within the context of the research topic to answer the research question(s).

As an example, Table 23.3 includes a study on girls' experience of competitive dancing.[9] The authors progressed through the steps as follows:

Step 1: The topic is eating disorders and young dancers. The research question is '*How does experience in the world of competitive dance shape the relationship that young girls have with their bodies?*'

Step 2: The author conducted wide–ranging literature searches on eating disorders, ballet dancers, body image, thinness, Western culture, dieting, media influences and many more topics.

Step 3: Feminism was the theoretical underpinning of the textual analysis. As described by the authors, 'a feminist post structural approach was chosen to provide a critical lens to explore the beliefs, values, and practices of young dancers… aimed to provide an understanding of the dominant and competing discourses present in the world of dance and discover how these discourses are constituted, perpetuated, and form ways of knowing in relation to body and body image.'[9(p7)]

Step 4: The transcripts were analysed in 5 steps, following Aston[10] and presented in table 23.2:

Table 23.2. A guide to using feminist poststructuralism informed by discourse analysis

1. Identify important issues	Read the transcript and mark quotations you feel represent an important issue. Name the issue as you see it.
2. Apply beliefs, values and practices	Provide the quotation (cut and paste) and write something about the belief, value and practice within the quotation.
3. Social and institutional discourses	Write about the social and institutional discourses you see informing the issue you identified. Sometimes this is clearly described in the quotation but most often you will need to expand on the implied ideas. You still need to clearly connect to the evidence (words and meaning provided by participant).
4. Respond to relations of power	As you write about the discourses, you need to connect these ideas to the participant. How do the discourses affect the participant? Does he/she agree or disagree with the beliefs, values and practices? Is it an easy or positive fit? Or are there questions, conflicts, tensions etc.? These are the 'relations of power' that the participant is feeling experiencing.
5. Subjectivity and agency	You can also add in the participant's 'subjectivity' (how they are positioned as a nurse, man, woman, teacher etc.) as well as their 'agency' (how they choose to act in each situation by fitting in or challenging).

*Note: This table is from an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0), which permits copy and redistribution of material in any medium or format, remix, transform and build upon the material for any purpose, even commercially provided the original work is properly cited.

Step 5: Results were first interpreted within an 'environmental' context (competitive culture, ideal dancer's body, mirrors, and dance attire and costumes), which was predominately negative due to the competitive culture. The second context was 'parents', which encompassed body monitoring, joking, and parents and support. Although most of the dancers stated that their parents did not influence their relationship with their body, discourse analysis demonstrated that parents did influence them. The third context was 'coaches'. Coaches had a very strong influence on participants' body image. While the dancers believed their coaches were supportive, the discourse demonstrated that most coaches' comments were negative. 'Peers' represented in the final context for analysis. Again, the dancers believed their peers were supportive; however, discourse analysis demonstrated that many peer comments were negative. The conclusions drawn from the research were that 'all participants experienced negative physical, mental, and/or emotional repercussions throughout their competitive dance experience. It was also determined that environment, parents, coaches, and peers largely shaped the dancer's relationship with body and body image in the world of dance. These influences generated and perpetuated the dominant negative body image discourse that dancers were often unable to resist, and consequently their relationship with body and body image suffered.'[9(pp22-23)]

This is a good example of situating a topic (body image) within a context (young women dancing) underpinned by a theoretical framework that explores the dancers' beliefs, values and practices.

Table 23.3. Discourse analysis examples

Title	**The public health turn on violence against women': analysing Swedish healthcare law, public health and gender-equality policies**[11]	**Social representation of palliative care in the Spanish printed media: a qualitative analysis**[12]	**Dancing in a culture of disordered eating: a feminist post structural analysis of body and body image among young girls in the world of dance**[9]
CC Licence	CC BY 4.0	CC BY 4.0	CC BY 4.0
First author and year	Ohman, 2020	Carrasco, 2019	Doria, 2022
Aim/ research question	'To describe and problematise the main content and characteristics of Swedish healthcare law, public health and gender-equality policies representing the public health turn on violence against women.'(p.2)	'To analyse how palliative care is portrayed in Spanish newspapers, as well as the contribution made by the press to its social representation.' (abstract)	'How does experience in the world of competitive dance shape the relationship that young girls have with their bodies'(p.7)

Title	**The public health turn on violence against women': analysing Swedish healthcare law, public health and gender-equality policies**[11]	**Social representation of palliative care in the Spanish printed media: a qualitative analysis**[12]	**Dancing in a culture of disordered eating: a feminist post structural analysis of body and body image among young girls in the world of dance**[9]
Study design	Multidisciplinary, socio-legal	Qualitative	Qualitative
Data collection	National healthcare law and policies	Four Spanish general printed newspapers	One-on-one, semi-structured phone interviews, directed by an open-ended interview guide
Analysis approach	Discourse analysis	Discourse analysis	Discourse analysis
Theoretical approach	Legal documents primarily analysed from a feminist legal point of view; public health actions and interventions analysed from a public health perspective; and general gender-equality policies analysed from a policy angle	Sociological discourse analysis: contextual analysis focusing on the message as a statement; interpretative analysis considering the discourse as a social product	Feminist poststructuralismp

Title	**The public health turn on violence against women': analysing Swedish healthcare law, public health and gender-equality policies**[11]	**Social representation of palliative care in the Spanish printed media: a qualitative analysis**[12]	**Dancing in a culture of disordered eating: a feminist post structural analysis of body and body image among young girls in the world of dance**[9]
Results	In law and public health policies, the problem is primarily articulated as a matter of 'violence within close relationships' The term 'violence within close relationships' is a new approach that deviates from the earlier framings of 'men's violence against women', and is a specific Swedish policy term. This new approach indicates a gender-neutral conceptualisation in which both victim and perpetrator are invisible in terms of gender. Legal obligations and the problems for the healthcare sector are only vaguely defined.	'The discourses identified were characterised by strong ideological and moral content focusing on social debate, strong ties linking palliative care and death and, to a lesser degree, as a healthcare service. The messages transmitted by representatives with direct experience in palliative care (professionals, patients and families) contributed the most to building a positive image of this healthcare practice. Overall, media reflect different interests in framing public understanding about palliative care.' (abstract)	'All participants experienced negative physical, mental, and/or emotional repercussions throughout their competitive dance experience. It was also determined that environment, parents, coaches and peers largely shaped the dancers' relationship with body and body image in the world of dance. These influences generated and perpetuated the dominant negative body image discourse that dancers were often unable to resist, and consequently their relationship with body and body image suffered.' (p.23-24)

Advantages and challenges of discourse analysis

Discourse analysis can be used to analyse small and large data sets with homogenous and heterogenous samples. It can be applied to any type of data source, from interviews and focus groups to diary entries, news reports and online discussion forums. However, interpretation in discourse analysis can lead to limitations and challenges that tend to occur when discourse analysis is misapplied or done poorly. Discourse analysis can be highly flexible and is best used when anchored in a theoretical approach. Because discourse analysis involves subjective interpretation, training and support from a qualitative researcher with expertise in the method is required to ensure that the interpretation of the data is meaningful. Finally, discourse analysis can be time-consuming when analysing large volumes of texts.

Summary

Discourse analysis is a process whereby texts are examined and interpreted. It looks for the meanings 'behind' text in cultural and social contexts. Discourse analysis is flexible, and the researcher has scope to interpret the text(s) based on the research topic and aim(s). Having a theoretical approach assists the researcher to position the discourse in cultural and social grounding.

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CHAPTER 24: NARRATIVE ANALYSIS

Darshini Ayton and Heather Craig

Learning outcomes

Upon completion of this chapter, you should be able to:

- Define a narrative.
- Explain the process of conducting narrative analysis and describe the elements of a story produced from narrative data.
- Describe the advantages and challenges of narrative analysis.

What is narrative analysis?

In simple terms, a narrative is a story with a beginning, middle and end or outcome. Bruner[1] suggests that narratives (stories) are ways of knowing:

> Telling stories is an astonishing thing. We are a species whose main purpose is to tell each other about the expected and the surprises that upset the expected, and we do that through the stories we tell. [1(p8)]

In narrative analysis, the stories (narratives) participants tell are analysed and then ‘re-storied’, or retold, based on the research questions and frameworks of the research.[2] Narratives may be unique, or they may be representative. However, when writing a ‘group’ story, the narrative should partially describe the individuals while not specifically describing each individual.[3] Narrative analysis may focus on what the story is about (the thematic content of the story) or on the structural components of the story (structural analysis).[3]

Constructing a narrative from data

The following 2 processes can assist the researcher to identify the structure and content of the narrative[4]:

- Read and re-read the transcripts.
- Identify events in the transcripts as told by the participants – these are events that have happened.
- Identify the experiences of the participants and note any images, feelings, reactions or meanings ascribed to the experience by the participants.
- Note accounts, explanations and excuses as told by the participants.
- Identify the sequences of events, key characters, plot lines and imagery used in the narrative, and explore what this might represent (e.g. metaphors).
- Identify the beginning, middle and end of the story.

Coding for narrative analysis identifies the sequence or plot of the story. This process involves six codes that are applied to the narrative:

Abstract – a few sentences to introduce the story and give an indication of the topic.

Orientation – the who (people involved), what (situation or activity), when (time) and where (location) of the story.

Complicating action – the event that starts the story and sets up the plot.

Evaluation – sometimes called 'reflection'; how the participant interprets the plot and their commentary on why (for example) the complicating action is important or not resolved.

Resolution – the final part of the plot that resolves the complicating action.

Coda – a section that ends the story and completes the plot.

Following is a narrative sequence based on the author's story of being diagnosed with multiple sclerosis. When interviewing participants for the purpose of narrative analysis, the researcher needs to ask a question that elicits a narrative from the participant. For example, in this narrative, the question from the researcher could have been: 'Tell me the story of how you were diagnosed with multiple sclerosis'. This invites the participant to give a narrative response with a beginning (symptoms), middle (seeking help) and (hopefully) end (the diagnosis). In the example, the author (Ayton) has coded the 6 elements of her story.

> We were at the movies on a Saturday night – watching *The Simpsons* movie with some friends. I remember sitting there feeling like I had sand in my left shoe. My toes felt gritty and weird. It was a weird sensation but I thought it would pass. My husband and I went home and when I woke up the next morning, the sensation was up to my waist. The sensation was like pins and needles – the type you get when you fall asleep on your arm and limit blood circulation. My skin was buzzing slightly. I was starting to freak out at this stage. I was wondering if I had a brain tumour. **[Orientation] [Abstract]**
>
> I went to work on Monday morning and, by this stage, the sensation was quite strong and was in both my legs and my torso up to my chest. It was uncomfortable but not painful. It was alarming, though. I was working at a university and my boss was a general practitioner. I told her about my symptoms and she said it could be stress, and to have a bath and breath in and out into a paper bag. When I got home that night I tried doing what she told me, but it didn't help. I had made an appointment with my normal GP for the next day.

> When I saw her she thought it could be neurological and gave me a referral to see a private neurologist. She also asked me to get more bloods done. However, the earliest appointment was in 3 weeks. I was starting to feel like I was going crazy and didn't feel like I could wait that long. **[Complicating action]**
>
> The next day I went to work but walked over to the hospital that was next to the university. I sat in the emergency department for a few hours and was seen by a registrar, who did the same blood tests as my GP. He didn't seem to think there was anything wrong with me and said while my white blood-cell count was slightly elevated, it wasn't enough to suggest that anything was wrong. He sent me home with instructions to come back if it got worse.
>
> Over the next few days, the sensation kept getting stronger. It got to the point where I felt I could cut off my leg and not feel it. I felt like some crazy marshmallow person and felt spongy and weird even though my body looked the same.
>
> I couldn't stand it any longer and so I stumbled back to the emergency department on Monday morning. I was seen by a different registrar and remember thinking that he was very good looking. He looked like he could be a character on *Grey's Anatomy*. He started doing some tests on me, including ones that tested my skin sensation. While he was doing the tests, I was recounting my experiences of the last week and said that I felt like I was going crazy. He looked me in the eye and said, "I believe you", and I promptly burst into tears. He called a neuro registrar – a lovely young woman. I remember she asked me to stand with my feet together and to close my eyes. I fell backwards straight away and was so shocked! She also asked me to walk as though I was balancing on a tightrope. I put one foot in front of the other but I couldn't swing my other leg around without falling over. I was amazed and scared at the same time. She admitted me straight away. I got my first MRI – a very traumatic experience. **[Evaluation]**
>
> My husband stayed with me that night as I was so freaked out. I had never been admitted to a hospital before. We huddled together on the hospital bed. Needless to say, we didn't get much sleep. I just kept hearing all the different beeps and alarms that are typical of a hospital ward. At 7 am the next morning the neuro registrar I had met the night before entered with a senior consultant. They explained that I had transverse myelitis and that I had lesions on my spine and brain that were causing the symptoms. They were going to start me on methylprednisolone and I was going to stay in the hospital until the end of the week. **[Resolution]**
>
> I was so relieved that it wasn't a brain tumour. However, both my husband and I were trained in biomedicine. When the neurologist was describing the lesions my husband asked – is this multiple sclerosis? The neurologist looked a bit surprised and then said – it could be, but I needed another "attack" before a diagnosis could be made. There was no way to tell if, and when, this would happen. And so the waiting game began. **[Coda]**

Another example can be found in Wang[5], who applied narrative analysis to Hannah Gadsby's *Nanette* (a show on Netflix).

Narrative analysis can be used to put together the various elements of data in a coherent and interesting narrative, and to provide explanations.[6] The researcher recursively moves between the data and the emerging narrative. As the story is written, the researcher examines the data and develops or refines the story if the events or actions do not align with the plot that is developing.[6]

The story that is developed by the researcher would not be the same as one the participant(s) would construct if they wrote their own story. The story is constructed by the researcher and is therefore shaped by the researcher's personal views, experiences and priorities (i.e. the research objectives). Furthermore, in the case of in-depth interviews, the story will be influenced by the dynamic and collaborative interactions between the researcher and participants as data is collected.[6] The narrative will also differ from that which a different researcher might put together if they conducted a similar study. However, despite this subjectivity, the narrative analysis does provide a credible interpretation of participants' experiences, with quotes providing examples in the participants' own 'voice'.[6] So, while the analysis and subsequent story should be close to the data and 'fit' it well, the narrative also adds meaning and order that is not evident from the raw data.[6]

Advantages and challenges of narrative analysis

Narrative analysis provides the stories of participants in narrative form to enable comparison between and across key story elements. These narratives provide a holistic understanding of lived experience and can be a powerful way to create policy change. However, narrative analysis can be a slow process and the researcher needs to be able to pay attention to subtle details and interpret the story overall.[6]

Table 24.1 provides 2 examples of research using narrative analysis.

Table 24.1. Examples of narrative analysis

Title	**Changing bodies, changing narratives and the consequences of tellability: a case study of becoming disabled through sport**[7]	**Lifechangers and Lifesavers: Pets in the Redemption Narratives of Homeless People**[8]
CC Licence		
First author	Smith, 2007	Irvine, 2013
Aim	To explore these connections by focusing upon the life story of one individual called Jamie (a pseudonym) who experienced a spinal cord injury (SCI) and became disabled through playing the sport of rugby union football.	'Examines personal narratives in which homeless and formerly homeless people construct their companion animals as having changed or saved their lives' [abstract]
Data collection	Life history interviews– the participant was interviewed 3 times and asked to tell his life story in his own words.	Qualitative interviews with people who were homeless and owned a pet.
Participants	1 participant	5 participants
Analysis	Structural narrative analysis	Personal narrative analysis or socio-narratology.

Title	**Changing bodies, changing narratives and the consequences of tellability: a case study of becoming disabled through sport**[7]	**Lifechangers and Lifesavers: Pets in the Redemption Narratives of Homeless People**[8]
Results	The story is told through a sequence of structures: • Jamie: context and background • Spinal cord injury, the body-self, and restitution • Spinal cord injury, the body-self, and chaos • Disability and deprivation of opportunity • Disability and infiltrated consciousness • Impairment and impairment effects • Reflections	Two participant stories are provided as narratives for constructing animals as life changers, and three participant stories illustrate the narrative of constructing animals as lifesavers.

Summary

Narrative analysis, broadly speaking, is the process of making sense of stories. The coding process seeks to identify key elements of the sequence of the story to identify the beginning (abstract and orientation), middle (complicating action and evaluation) and end (resolution and coda). Although highly interpretive, narrative analysis is a valid method of providing a credible interpretation of the participants' experiences.

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CHAPTER 25: GROUNDED THEORY ANALYSIS

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe grounded theory analysis.
- Understand how to conduct grounded theory analysis.
- Identify the strengths and limitations of grounded theory analysis.

What is grounded theory?

Grounded theory is both a study design (see Chapter 10) and an approach to data analysis. Grounded theory aims to provide an explanation from the data about a phenomenon or concept. As noted in Chapter 10, there are methodological differences in the research design of grounded theory approaches, and hence different processes of analysis align with the specific methodological approach undertaken. Researchers need to ensure that the methodological and analysis approach are aligned.

Table 10.1 in Chapter 10 outlines three grounded theory approaches: Classical grounded theory, Straussian grounded theory and Constructivst grounded theory.[1] In this chapter we expand on these approaches, specific to the analysis of data.

How to do grounded theory analysis

Classical grounded theory

The main focus of classical grounded theory as devised by Glaser and Strauss[2] is to develop a theory that explains the participants' stories or behaviours. The three steps of Classical grounded theory take the data from the abstract to interconnected ideas. Classical grounded theory is positioned within the positivist paradigm, and the steps for coding and analysis outlined here are objective and systematic:

Open coding is, as the name suggests, typically unfocused and seeks to explore all elements of the data. The transcript is divided into comparable sections (e.g. comparing similar descriptions of the phenomena) and these are given a code. This enables the researcher to group the codes, to create categories. As new phenomena, incidents or situations are identified in the data, they are compared to the categories and are either combined into an existing category or a new category is developed. This form of coding leads to the identification of what is called the 'core category', which is the most frequently occurring category that explains most of the data.[1, 3]

Selective coding is a step in which the researcher focuses on the core category and codes data to this core category. The purpose is to expand the core category and determine how it relates to other categories; to validate and test the relationships; and to continue refining and developing the core category. Selective coding continues until the core code is 'saturated'; that is, no new data changes the core code. This may require moving back and forth between codes or categories within transcripts to continue to look for how the codes may relate to each other, or collecting more data to continue to develop the core category. Codes and categories are then integrated, which leads to the development of the theory.[1, 3]

Theoretical coding is a step in which the researcher creates a theoretical outline of how the categories developed in the earlier rounds of coding relate to each other. The researcher may choose to organise and categorise codes using the Six Cs model: causes, contexts, contingencies, consequences, covariance and conditions.[4] It is important to include memos alongside the codes in this step. Memos are the researcher's thoughts and ideas about the analysis, written during the research (following data collection, while reading the transcription and throughout the coding process).[1]

Straussian grounded theory

Straussian grounded theory was developed by Strauss and Corbin,[5] and is considered methodological (pragmatic and post-positivist) rather than ontological and epistemological, and this is its main difference from classical grounded theory. The coding process is as follows:

Open coding is the first level of coding and involves breaking down the data into smaller sections; this is usually done through line-by-line coding, to identify concepts and key phrases. The researcher typically applies codes to 'who', 'what', 'where', 'when', and 'how' in the text as a first round of coding.

Axial coding is the second level of coding, which links the data conceptually. Axial coding refines and aligns the open codes and identifies relationships or links between the codes. It seeks to pull the codes back into the categories of the 'conditions' of the data, looking for conditions, actions or interactions and consequences. This is where the core codes emerge.[6]

Selective coding is the third level of coding, in which the researcher selects and integrates the axial codes into a higher level of conceptual meaning. This coding step then leads to theory development.[4]

Constructivist grounded theory

The main focus of constructivist grounded theory, developed initially by Kathy Charmaz[7], sought to move away from the positivist and post-positivist paradigms of other grounded theory approaches to recognise that reality, and consequently the research process, is socially constructed. It uses two main stages in coding:

Initial coding seeks to remain close to the data. Some researchers conduct word-by-word coding, which is helpful when coding documents as it focuses the researcher on words and their meanings. Researchers typically conduct line-by-line coding. It is during this initial coding stage that the researcher seeks to code for participants' meanings, feelings and actions, and the consequences of the actions. The focus is on the process, how it can be defined and how the process develops. During initial coding, the constant comparative method is used to compare the codes within the same interview, to explore whether and how the codes align or diverge. Then codes are compared across interviews of similar phenomena or experiences.[6,7]

Focused coding is more directed and selective than initial coding, and focuses on synthesising and explaining larger segments of the text. The most frequent codes are applied to these larger segments of text to explore whether they can be maintained consistently and make analytical sense.

Note that initial and focused coding are not linear processes; the researcher often needs to move back and forth between the two approaches.[7] This is because the researcher may have coded the first three transcripts with initial coding and then focused coding, and then in coding transcript four, a new concept becomes more evident in the data. The researcher will then go back to the earlier transcripts to explore if the concept can be identified.[7]

Axial coding, when used in constructivist grounded theory searches for links between experiences that have been categorised. This process leads to more categories, subcategories and links, and is part of the focused coding step. For example, in research involving older people who had experienced a fall, some of the older people explicitly used the word 'fall' while others avoided the word and instead used words such as 'stumbled', 'tripped' or 'went over'. When looking for links between these different ways of talking about falls, the researchers found that participants who identified as 'being old' (which had nothing to do with chronological age!) were more likely to use the word 'fall', whereas participants who rejected the label of being old were more like to use synonyms. People who did not use the word fall explained the reason for the fall as 'I was rushing', and 'I wasn't wearing the right shoes'. Axial coding in this instance examines the socially constructed reality of the participant, such as their biographical details, social conditions, reasons for sharing, who was present and the assumed consequences of describing their fall.[8, 9]

Theoretical coding follows focused coding and is a more emergent process in constructivist grounded theory when compared to other forms of grounded theory analysis.[6] Theoretical coding is the conceptualisation of how the focused codes may be integrated into a theory – basically into an analytical story.[7] Charmaz cautions that theoretical codes may lead the researcher to believe there is objectivity to the analysis, and hence advises to use theoretical coding only if it will sharpen and clarify the analysis.[7]

A contemporary example of grounded theory is Dr Brené Brown's TED Talk, titled *The Power of Vulnerability*.[9] At about the 6-minute mark, Brown describes her process of analysis. She describes having divided her data set between participants who had a strong sense of worthiness and those who struggled for it. She then conducted a constant comparative analysis between the two data sets, seeking to understand participants' conceptions of vulnerability and shame. This process of constant comparison is a key element in grounded theory analysis.

Advantages and disadvantages of grounded theory analysis

Grounded theory analysis is rigorous and can lead to the formation of robust theory as it develops from the micro to the macro layers of data. However, the process can be time and resource intensive, particularly with the concurrent data collection and analysis required in theory generation (see Chapter 10: Grounded Theory). The complexity of the interplay between the different phases of data analysis and can be particularly daunting for students and new researchers, and the theory generated can be insubstantial if insufficient data is collected and analysed.[5] Table 25.1 provides examples of two grounded theory studies.

Table 25.1. Examples of grounded theory

Title	**'"Voluntary" in quotation marks': a conceptual model of psychological pressure in mental healthcare based on a grounded theory analysis of interviews with service users**[10]	**Outsiders in the experts' world: a grounded theory study of consumers and the social world of health care**[11]
CC Licence	CC BY 4.0	CC BY 4.0
First author and year	Potthoff, 2022	Chamberlaine-Salaun, 2020
Aim/ research question	'To develop a conceptual model of psychological pressure based on the perspectives of service users.' (p3)	'To identify and explain processes of interaction between consumers and health professionals that are not bound by specific health professions, health settings, or health conditions.' (p2)
Study design	Grounded theory	Grounded theory

Title	**'"Voluntary" in quotation marks': a conceptual model of psychological pressure in mental healthcare based on a grounded theory analysis of interviews with service users**[10]	**Outsiders in the experts' world: a grounded theory study of consumers and the social world of health care**[11]
Data collection	Semi-structured interviews with 14 mental health service users having self-reported psychiatric diagnosis and prior experience with coercion in mental health care	Demographic questionnaires, interviews, consumer diaries, digital storytelling, observations, and field notes
Analysis and coding approach	Grounded theory according to Strauss and Corbin[12], using open and inductive approaches, followed by axial coding and selective coding	Essential grounded theory methods as ascribed by Birks and Mills[13] (constructivist grounded theory). Initial coding, concurrent data generation or collection and analysis, constant comparative analysis, intermediate coding, theoretical sampling, selecting a core category, advanced coding and theoretical integration, and writing memos and theoretical sensitivity.
Results	A contextual model of psychological pressure was constructed. (see Figure 2 in the article): • elements of the model • aims of communication • pressure to improve adherence to recommended treatment • pressure to improve adherence to social norms • ways of communicating • explicit statements • nonverbal communication • things that go unsaid • contexts of communication • the quality of the personal relationship • the institutional setting • the material surroundings • convergences between the parties'understanding of mental disorder	Key findings from this study relate to the culture shock that participants experienced when they unexpectedly entered the social world of health care, and the social categorisation of roles within that world that result in them having to learn a new role and establish a presence to receive tailored care.

Summary

Grounded theory aims to develop theory about a phenomenon. The three main forms of grounded theory stem from different ontological and epistemiological positions: classical grounded theory, Straussian grounded theory and constructivst grounded theory. Researchers need to ensure that their research design aligns with the analytical approach undertaken.

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RIGOUR

CHAPTER 26: RIGOUR

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the concepts of rigour and trustworthiness in qualitative research.
- Describe strategies for dependability, credibility, confirmability and transferability in qualitative research.
- Define reflexivity and describe types of reflexivity

What is rigour?

In qualitative research, rigour, or trustworthiness, refers to how researchers demonstrate the quality of their research.[1, 2] Rigour is an umbrella term for several strategies and approaches that recognise the influence on qualitative research by multiple realities; for example, of the researcher during data collection and analysis, and of the participant. The research process is shaped by multiple elements, including research skills, the social and research environment and the community setting.[2]

Research is considered rigorous or trustworthy when members of the research community are confident in the study's methods, the data and its interpretation.[3] As mentioned in Chapters 1 and 2, quantitative and qualitative research are founded on different research paradigms and, hence, quality in research cannot be addressed in the same way for both types of research studies. Table 26.1 provides a comparison overview of the approaches of quantitative and qualitative research in ensuring quality in research.

Table 26.1: Comparison of quantitative and qualitative approaches to ensuring quality in research

Qualitative research - Concept	**Qualitative research - Definition**	**Quantitative research - concept**	**Quantitative research - Definition**
Dependability	Consistency in the research and the ability for another researcher to achieve the same results with the same research process. Dependability is demonstrated through detailing the changes and context of the research setting. This includes any changes that may occur in the setting, and description and explanation of how these changes may have affected the research process.[3]	Reliability	The extent to which results are consistent over time and an accurate representation of the study population and an assessment of whether the results of a study can be reproduced under a similar methodology.[4,5]
Credibility	Confidence in the truth of the findings.[3]	Validity	An assessment of whether the research measures what it was meant to measure, or how truthful the results are.[4,5]
Confirmability	The extent by which the findings of a study are shaped by the respondents and not research bias, motivation or interest.[3]	Objectivity	Strategies to reduce bias in research.[1]
Transferability	Provides sufficient information about the context and process of the research to enable another person to determine if their context is similar and therefore the findings can be applied to the setting.[6]	Generalisability	The extent to which the findings from the research sample can be applied to the broader population.[7]
Authenticity	Demonstrates the range of participant realities, and provides rich and detailed descriptions of these realities, using quotes and narratives.[3]		

Below is an overview of the main approaches to rigour in qualitative research. For each of the approaches, examples of how rigour was demonstrated are provided from the author's PhD thesis.

Approaches to dependability

Dependability requires the researcher to provide an account of changes to the research process and setting.[3] The main approach to dependability is an audit trail.

- **Audit trail** – the researcher records or takes notes on the conduct of the research and the process of reaching conclusions from the data. The audit trail includes information on the data collection and data analysis, including decision-making and interpretations of the data that influence the study's results.[8,9]

> The interview questions for this study evolved as the study progressed, and accordingly, the process was iterative. I spent 12 months collecting data, and as my understanding and responsiveness to my participants and to the culture and ethos of the various churches developed, so did my line of questioning. For example, in the early interviews for phase 2, I included questions regarding the qualifications a church leader might look for in hiring someone to undertake health promotion activities. This question was dropped after the first couple of interviews, as it was clear that church leaders did not necessarily view their activities as health promoting and therefore did not perceive the relevance of this question. By 'being church', they were health promoting, and therefore activities that were health promoting were not easily separated from other activities that were part of the core mission of the church[10(pp93–4)]

Approaches to credibility

Credibility requires the researcher to demonstrate the truth or confidence in the findings. The main approaches to credibility include triangulation, prolonged engagement, persistent observation, negative case analysis and member checking.[3]

- **Triangulation** – the assembly of data and interpretations from multiple methods (methods triangulation), researchers (research triangulation), theory (theory triangulation) and data sources (different participant groups).[9] Refer to Chapter 28 for a detailed discussion of this process.
- **Prolonged engagement** – the requirement for researchers to spend sufficient time with participants and/or within the research context to familiarise them with the research setting, to build trust and rapport with participants and to recognise and correct any misinformation.[9]

> Prolonged engagement with churches was also achieved through the case study phase as the ten case study churches were involved in more than one phase of data collection. These ten churches were the case studies in which significant time was spent conducting interviews and focus groups, and attending activities and programs. Subsequently, there were many instances where I interacted with the same people on more than one occasion, thereby facilitating the development of interactive and deeper relationships with participants[10 (pp.94–5)]

- **Persistent observation** – the identification of characteristics and elements that are most relevant to the problem or issue under study, and upon which the research will focus in detail.[9]

> In the following chapters, I present my analysis of the world of churches in which I was immersed as I conducted fieldwork. I describe the processes of church practice and action, and explore how this can be conceptualised into health promotion action[10 (p97)]

- **Negative case analysis** – the process of finding and discussing data that contradicts the study's main findings. Negative case analysis demonstrates that nuance and granularity in perspectives of both shared and divergent opinions have been examined, enhancing the quality of the interpretation of the data.

> Although I did not use negative case selection, the Catholic churches in this study acted as examples of the 'low engagement'[10 (p97)]

- **Member checking** – the presentation of data analysis, interpretations and conclusions of the research to members of the participant groups. This enables participants or people with shared identity with the participants to provide their perspectives on the research.[9]

> Throughout my candidature – during data collection and analysis, and in the construction of my results chapters – I engaged with a number of Christians, both paid church staff members and volunteers, to test my thoughts and concepts. These people were not participants in the study, but they were embedded in the cultural and social context of churches in Victoria. They were able to challenge and also affirm my thinking and so contributed to a process of member checking[10(p96)]

Approaches to confirmability

Confirmability is demonstrated by grounding the results in the data from participants.[3] This can be achieved through the use of quotes, specifying the number of participants and data sources and providing details of the data collection.

- **Quotes** from participants are used to demonstrate that the themes are generated from the data. The results section of the thesis chapters commences with a story based on the field notes or recordings, with extensive quotes from participants presented throughout.[10]
- **The number of participants** in the study provides the context for where the data is 'sourced' from for the results and interpretation. Table 26.2 is reproduced with permission from the Author's thesis and details the data sources for the project. This also contributes to establishing how triangulation across data sources and methods was achieved.
- **Details of data collection** – Table 26.2 provides detailed information about the processes of data collection, including dates and locations but the duration of each research encounter was not specified.

Table 26.2 Data sources for the PhD research project of the Author.

Study phase	**Date**	**Data source**	**Data collection**	**Participant numbers**
Phase 1 - Exploration	April - Oct 2009 Jan-Mar 2010	Documents Qualitative interviews	Annual reports of funding agencies, local government councils and church affiliated organisations, strategic plans of primary care partnerships. In-depth interviews with local church leaders and individuals from church affiliated organisations in Victoria	5 participants from local churches 5 participants from church affiliated organisations
Phase 2 - Description	April - June 2010	Qualitative telephone interviews	Qualitative semi-structured telephone interviews with church leaders of 25 Victorian churches	25 church ministers
Phase 3 - Case studies	July - Dec 2010	Qualitative Interviews Focus groups Observation Document analysis	Face-to-face qualitative in-depth interviews with the church staff and/or key volunteers of 10 case study churches. Focus groups with church volunteers. Direct observation of case study churches in their conduct of health promotion activities. Annual reports and/or church newsletters	37 participants 10 focus groups 17 direct observations 12 document analyses

Approaches to transferability

To enable the transferability of qualitative research, researchers need to provide information about the context and the setting. A key approach for transferability is thick description.[6]

- **Thick description** – detailed explanations and descriptions of the research questions are provided, including about the research setting, contextual factors and changes to the research setting.[9]

> I chose to include the Catholic Church because it is the largest Christian group in Australia and is an example of a traditional church. The Protestant group were represented through the Uniting, Anglican Baptist and Church of Christ denominations. The Uniting Church denomination is unique to Australia and was formed in 1977 through the merging of the Methodist, Presbyterian and Congregationalist denominations. The Church of Christ denomination was chosen to represent a contemporary less hierarchical denomination in comparison to the other protestant denominations. The last group, the Salvation Army, was chosen because of its high profile in social justice and social welfare, therefore offering different perspectives on the role and activities of the church in health promotion[10(pp82–3)]

What is reflexivity?

Reflexivity is the process in which researchers engage to explore and explain how their subjectivity (or bias) has influenced the research.[12] Researchers engage in reflexive practices to ensure and demonstrate rigour, quality and, ultimately, trustworthiness in their research.[13] The researcher is the instrument of data collection and data analysis, and hence awareness of what has influenced their approach and conduct of the research – and being able to articulate them – is vital in the creation of knowledge. One important element is researcher positionality (see Chapter 27), which acknowledges the characteristics, interests, beliefs and personal experiences of the researcher and how this influences the research process. Table 26.3 outlines different types of reflexivity, with examples from the author's thesis.

Table 26.3: Types of reflexivity

Reflexivity type	**Examples from the author's thesis**[10]
Personal – reflections on the researcher's personal expectations, assumptions, biases and reactions to the research contexts, participants and data.	'It was with hesitant steps that I entered the field for my research. I was known in some of these church communities, and my background and experience in churches was what drove me to do this research. As mentioned above, I identified as an insider to this research as I shared experiences, religious affiliation and language with the research participants. In undertaking this research, I was required to be true in what I captured and interpreted, and reflexive in acknowledging my own biases that may have coloured my approach and interpretations.'(p92)
Interpersonal – reflections on how relationships influence the research process.	'My time in the field was peppered with statements such as "Oh, you know this person?" or "I don't need to explain this church terminology to you." I identified myself as an insider and by positioning myself in this way my participants treated me as someone who shared their beliefs.'(p78)
Methodological – reflections on how decisions were made regarding the study's methods and methodological approach, and the implications of these.	'I sought to understand what it meant to "be church" and how this played out in health promoting practices in their local community...The church is the social context. The aim of the inquiry is to understand and re-examine the constructions that the participants and I, as the researcher, hold in relation to the local church as a setting and partner for health promotion.'

Reflexivity type	Examples from the author's thesis[10]
Contextual – reflections on how the research context shapes and influences the research process.	'This experience from the field involved a shared experience of a church service, however during this process the participants and I became acutely aware of our differences in social position. I was attending my own church service afterwards and had dressed according to the middle class norms of this service. The attendees at Redgum Church of Christ were experiencing poverty and health issues and therefore their dress and manner reflected their circumstances in life. Despite being an insider in some aspects (religious background, familiarity with church culture and practices), there were social facets that were not shared with my participants including generational, socio-economic and ethnic differences.' (p96)

Summary

The quality of qualitative research is measured through the rigour or trustworthiness of the research, demonstrated through a range of strategies in the processes of data collection, analysis, reporting and reflexivity.

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CHAPTER 27: RESEARCHER POSITIONALITY

Danielle Berkovic

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the definition and dimensions of positionality.
- Describe insider (emic) and outsider (etic) research and their differences.
- Articulate your positionality in your research projects.

What is positionality?

Human perception is subjective: it can differ markedly between people who, when looking at the same scene, will observe different things.[1] Positionality describes an individual's worldview and the position that they adopt about research and its context.[2] Positionality encompasses beliefs about reality (ontology), knowledge (epistemology) and values (axiology), which contribute to how researchers approach their work.[3] Beliefs can be influenced by parts of our identity that are fixed (e.g. age and ethnicity) and parts of our identity that are fluid (e.g. political views, geographical location and life history). The positionality that researchers bring to their work, and the personal experiences through which their positionality is shaped, can influence the data collection and analysis.[2] Secules et al.[4] summarise 6 dimensions of positionality; this chapter adds the 7th dimension of axiology (Table 27.1).

Table 27.1: Dimensions of positionality

Dimension of positionality	**Reflection prompts**
Research questions	What research do you choose to do, and why?

Dimension of positionality	**Reflection prompts**
Epistemology	How you know what you know? How does this knowledge relate to your qualifications, work experience and life experience?
Ontology	What can you observe as a researcher?
Axiology	What research do you value, and why?
Methodology	How do you make methodological choices?
Researcher-as-instrument	How do you relate to research participants? How is this shaped by your life experiences? Religion? Family composition? Ethnic background?
Communication	How do you present yourself in writing and other communications?

How does the researcher describe their positionality?

Researchers may undertake exercises in reflexivity to understand and articulate their positionality. Reflexivity is a process by which researchers acknowledge and disclose themselves within their research, seeking to understand their part in it, or their influence upon it (see Chapter 26).[5] Positionality and reflexivity suggest that the researcher is not separate from the health and social worlds they study. The use of a reflexive approach to inform positionality acknowledges that health and social research are not separate from wider society and the individual researcher. A reflexive approach suggests that, rather than trying to eliminate their effect or influence, researchers should acknowledge and disclose themselves in their work, with the aim of understanding their influence upon, and within, the research process.[2] Table 27.2 provides examples of positionality statements included in health and social care research articles.

Table 27.2: Examples of positionality statements

Article title	**Relational embeddedness and socially motivated case screening in the practice of law in rural china**[6]	**Low-income Black mothers parenting adolescents in the mass incarceration era: the long reach of criminalization**[7]	**Associations between learning assistants, passing introductory physics, and equity: a quantitative critical race theory investigation**[8]
CC Licence			CC BY 4.0
Positionality statement	'My status as a native Chinese speaker, familiarity with the local dialect, and intimate knowledge of the surrounding communities facilitated the efforts to cultivate rapport with the legal workers in the offices.' (p931)	'Both authors are middle- to upper-middle-class white women—one is a mother, the other is not. A commitment to antiracist, intersectional, and feminist principles guides our research efforts, and we conducted this work with an awareness of the politics, dangers, and limitations of affluent white academics writing about the lives of low-income Black Americans.' (p204)	'I identify as a White, cisgender, heterosexual, continuing-generation (CG) man with a colour vision deficiency. I was raised in a pair of lower-income households but I now earn an upper-middle class income… my experiences working with marginalized students, particularly those whom I have had the honor to mentor as researchers, have motivated my attempts to use my position and privilege to dismantle oppressive power structures. As someone who seeks to be an ally it is easy to overlook my own privileges. I try to broaden my perspective through feedback from those with more diverse lived experiences than my own.' (p5)

An example of a researcher's positionality and its influence on their work

Smales writes about their potential influence on their research with young people experiencing out-of-home care.[9] In the methods section they include a description with a subheading, 'The researcher', namely that they had 'lived in a resident care unit and other forms of care for four years… and [have] had ongoing experience working within the out of home care system'.[9] The researcher acknowledges that their lived experience shaped the interview guide, based on understanding the knowledge gaps in this area of research. Smales also describes interacting with participants on a deeper level, through shared experience that provided additional meaning and context to the study. They acknowledged that the shared experiences between the researcher and participants was likely to influence the data collection and analysis, but sought to ensure that ethical, moral and professional processes were followed, so as to minimise bias in the reporting of results.

Emic and etic perspectives

Researcher positionality is discussed in the literature as a clear distinction between insider (emic) and outsider (etic) perspectives. Insiders are considered part of the community within which the research is conducted, while outsiders are considered to be outside of the group being studied.[10] Some researchers argue that the emic and etic perspectives are two ends of a positionality continuum along which researchers move back and forth during the research process, rather than distinguishing binary, insider-outsider perspectives. [11]

The two categories of etic and emic remain largely theoretical, and the conversations about practically applying the theories can be challenging. For example, having either an exclusively etic or exclusively emic approach when conducting 'outsider' research is paradoxical. On the one hand, an etic approach to data collection would mean that the researcher is oblivious to how their presence, behaviours, attitudes or methodological decisions influence insider responses. On the other hand, an exclusively emic approach would mean the researcher internalises the preconceptions and assumptions of research the participants, and therefore compromises their ability to be objective or to communicate the research findings.[12]

How does a researcher know if they are an insider or outsider?

Bracketing is a method used in qualitative research to identify, examine and mitigate researcher preconceptions that may influence the research process.[13] Bracketing works by the researcher explicitly noting their own beliefs and interactions with the research topic, in an attempt to remain impartial throughout the research process. Bracketing promotes methodological rigour and trustworthiness in the conclusions drawn from qualitative research. While bracketing is widely used to identify similarities between researchers and participants to epistemologically distance the researchers from their assumptions, an emerging method, diffraction, describes how researchers proactively engage within the research context, and their differences from participants.[4] This approach encourages researchers to interrogate aspects of their influence that are unpredictable or unknown, thereby leading to research practices that are socially just and ethical. Diffraction identifies the material realities and differences between the researchers and participants, to ontologically anticipate and rectify issues such as 'Othering'.

Articles in which researchers discuss their experiences with bracketing include Berkovic et al. and Dörfler et al.[13, 14]

In addition to bracketing, researchers Austin and Sutton[15] outline 4 questions that researchers can ask themselves to commence the reflection process:

- **Why am I interested in this topic?** Try to identify what is driving your enthusiasm, energy and interest in researching this subject.
- **What do I think I am going to find?** Seek to identify any preconceptions or assumptions you may have about your research, through honest reflection on what you expect to find in your data. You can then *bracket* those assumptions to enable the participants' voices to be heard.
- **What am I getting out of this?** Consider how your circumstances affect your interest in your research question/s or outcomes, and the amount of data you will need to collect and analyse. This question is particularly important if you have a pre-existing relationship with the research topic or participants.
- **What do others in my professional community think of this work – and of me?** Research is part of a complex social world. The influences within that world can shape your views and expectations of yourself and your work. Acknowledging this influence and its potential effects on personal behaviour will help to facilitate greater self-scrutiny throughout the research process.

Strengths and limitations of emic and etic perspectives

Conducting research as an insider (from an emic perspective) may be advantageous because the researcher has established knowledge of the research topic and is immersed in its population. This may ease recruitment efforts and, during data collection, participants may be less cautious or guarded than they would be with an outsider researcher. However, being an insider can affect how the researcher is perceived, the information that participants provide and the analysis of the data. Participants may assume that the insider researcher will judge their responses to questions because of their shared identity, and may even seek to impress or agree with the researcher, based on their perceived connection rather than their true beliefs.[16]

Summary

Qualitative researchers need to articulate their positionality. Qualitative researchers can be primarily insiders (with an emic perspective), or they may be outsiders (with an etic perspective). Being an emic or etic researcher each has strengths and limitations, but there are several examples in the literature with strategies to help navigate these.

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CHAPTER 28: TRIANGULATION

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the definition of triangulation.
- Describe the four types of triangulation.
- Understand how to conduct triangulation.
- Identify the strengths and limitations of triangulation.

What is triangulation?

Triangulation is the combination or blending of more than one participant group, researcher, theory and/or method in the same research. Its purpose is to understand the phenomenon under study[1] by determining consistency, or 'truth'.[1] Triangulation can be used to demonstrate the rigour, validity and credibility of research findings.[2] While the purpose of triangulation is not to confirm results, but rather to understand differences, it can be difficult to explain inconsistent results when discussing the research undertaken.

There are four main types of triangulation[2]:

- **Theoretical triangulation** is the use of more than one theory to guide the research process. For example, a researcher might analyse data on family violence by applying feminist and critical theory, and they might also apply structural functionalist theory (see Section 1) when examining family violence as part of a complex system. By applying different theories, the data is able to be interrogated through theoretical lenses, which can lead to deeper understanding of the findings and greater nuance than a single theory might support.
- **Researcher triangulation** is the use of multiple (two or more) researchers to collect and / or analyse data. The researchers may have different disciplinary backgrounds and experiences, and will

also bring their professional and personal interpretations to the data. For example, research approaches to consumer and community involvement (or patient and public involvement) might advocate for patients to be involved in the analysis of data, to include patient perspectives in the interpretation of the data. In a study developing a 'BroSupPORT' portal and examining issues facing men with prostate cancer,[3] researchers found that health professionals were not sure that a Patient Reported Outcome comparator tool would be helpful in prompting health-seeking behaviour, but participants with prostate cancer welcomed such a tool. Focusing a patient lens on data in this study was important because it was able to highlight differences between perspectives of health professionals and patient participants. If only health professionals had been consulted the tool would not have been considered helpful and would have been ruled out as an option for the portal.

- **Methodological triangulation** is the use of multiple (two or more) methods to collect and analyse data**.** The data collection methods might include focus groups, interviews, photovoice, observations, field notes and more. In essence, it is bringing together the various methods used to collect data and can provide a more nuanced explanation of results. Methodological triangulation can include quantitative methods to support or harmonise results. Using quantitative and qualitative methods together enables the research to answer the questions of 'what' and 'why' (see Chapter 11: Mixed Methods). The BroSupPort portal study[3] is a good example of methodological triangulation because it used a combination of workshops, interviews and focus groups to collect data.
- **Data triangulation** uses more than one data source and / or method of analysis to interrogate the data. Data sources may include interviews with people in a range of roles in an organisation, rather than only those in one particular role. Data analyses might include data from both inductive and deductive perspectives. Data triangulation might also include different data sources, such as qualitative (e.g. interviews) and quantitative (e.g. surveys). In the BroSupPORT portal study[3] data were gathered at workshops, focus groups and interviews. Surveys, mind maps, River of Life activities and problem trees (in printed form), along with field notes taken at each workshop, were used to collect data. A range of techniques was used to analyse the data including, but not limited to, descriptive content analysis.

Table 28.1 provides examples of the four main types of triangulation. Other types of triangulation, such as 'time' and 'space'[3], are not covered in this chapter because they are used less often.

Table 28.1: Examples of triangulation

Title	Avicii's S.O.S.: a psychobiographical approach and corpus-based discourse analysis on suicidal ideation[5]	Groping around in the dark for adequate COPD management: a qualitative study on experiences in long-term care[6]	Combining worlds: a mixed method for understanding learning spaces[7]	Multiple triangulation and collaborative research using qualitative methods to explore decision making in pre-hospital emergency care[8]
CC Licence	CC BY-NC-ND 4.0	CC BY 4.0	CC BY 4.0	CC BY 4.0
First author and year	Yeh, 2022	Lundell, 2020	McCrone, 2023	Johnson, 2017
Aim/ research question	What linguistic patterns can be found in Avicii's songs based on his career timeline; that is, early, middle and late career? Was there any evidence of first-person pronoun usage and linguistic indicators of negative emotions that suggest suicidal risk factors? Could linguistic evidence reveal suicidal ideation prior to his untimely death?(p215)	To explore aspects of importance in long-term care facilities for providing interventions according to the treatment guidelines for people with COPD, from the perspective of healthcare professionals(p2)	To investigate student pedagogic engagement in transitions between formal, timetabled and informal, non-timetabled learning space in a departmental setting(p2)	To describe the methodological approach employed in this study in order to share lessons on collaboration in multi-method research across multiple sites and investigators(p1)
Study design	Psychobiographical research	Qualitative	Convergent mixed methods	Qualitative
Type of triangulation	Theoretical	Researcher - Three authors read and discussed subcategories and categories	Methodological - Quantitative and qualitative methods	Data

Title	Avicii's S.O.S.: a psychobiographical approach and corpus-based discourse analysis on suicidal ideation[5]	Groping around in the dark for adequate COPD management: a qualitative study on experiences in long-term care[6]	Combining worlds: a mixed method for understanding learning spaces[7]	Multiple triangulation and collaborative research using qualitative methods to explore decision making in pre-hospital emergency care[8]
Data collection	Collection of songs and written works	Semi structured, face-to-face Interviews	Quantitative: space occupancy monitoring data. Qualitative: ethnographic observations, field interviews, in-depth interviews	Semi-structured interviews with key ambulance service staff, non–participant field observation of paramedics' day-to-day working practices, paramedic focus groups, service user focus groups, stakeholder feedback workshops
Methods of analysis	Corpus-based discourse analysis	Content analysis	Quantitative: analysis of room usages Qualitative: analysis of patterns, interpretive analysis	Thematic analysis (workshops were quantitatively analysed for paired comparisons)
Theoretical approach	Disengagement theory, interpersonal psychological theory, the need to belong	Not stated	Hermeneutical phenomenological approach	Systemic influences on decision-making
Results	See Table 8 on page 231	There was a considerable gap between treatment guidelines for COPD and the COPD management in municipal healthcare.(p8)	Occupancy data informed data-driven decisions about campus space allocation from timetabling analytics. Person–space and person–person interaction were captured. Field interviews led to understanding student intent behind the observed behaviour. In-depth interviews explained why the learning spaces were being used in certain ways.	The use of multiple methods, sources and investigators to obtain data across sites was insightful; it added to the complexity of the design and embodied time penalties. This is considered to have been more than offset by the benefits arising from continuous collaboration between academic researchers, the ambulance service, trusts and service user representatives, and was a valuable feature of the research process. (p6)

How to conduct triangulation

How triangulation is conducted depends on the type of triangulation.

- **Theoretical triangulation** requires an introduction to each theory and can be written as a literature review. The theories are described and then compared, to elicit inferences that will form the basis of data interpretation. For example, a feminist theory will inform data collection in such a way that girls and women (and women's marginalised groups) will be deliberately sought out and included in the research study. Analysis would include a focus on gender identity, patriarchal oppression, diversity of culture and background, and would seek to demonstrate women's points of view through a feminist lens. If, for example, a study is about women patients, the data collection and analysis would focus on how or whether women are represented in the data, and how women are medically treated by healthcare practitioners. Women's own perspectives would be sought and analysed, to understand their perspectives.
- **Researcher triangulation** is often described in the type of data being analysed, and can often be read in the researcher's statement of positionality or in the reflexivity section of a journal paper or report[9]. Some forms of thematic analysis (not reflexive thematic analysis) requires more than one investigator to read, re-read, code and re-code interviews or focus groups. When it is not a requirement of the method of analysis, triangulation should still be considered, in order to address concerns about the rigour, validity and credibility of findings of a single researcher. Including more than one researcher and participant can leads to greater divergence and the potential for nuanced findings.
- **Methodological triangulation** is used often in the literature. A decision is made about how to conduct the research, on the basis of the research question or aim. Often in mixed methods research, a qualitative component seeks to answer the question, 'Why?' and the quantitative component seeks to test a hypothesis or answer the question, 'What?'. However, many qualitative methods might be included, such as interviews, focus groups, newspaper clippings, to answer the research question(s). When using methodological triangulation, the researcher is looking to expand their understanding of the findings. For example, if a survey and interviews are the mixed methods used in a study, the researcher would seek to compare and contrast the findings of both methods, to gain a comprehensive understanding of the phenomenon, and then would describe how the findings support or diverge in answering the research question(s). Thus, a study exploring barriers and enablers in the implementation of the 6-PACK falls prevention program[10] incorporated a cluster randomised control trial, economic and program evaluations, and surveys and focus groups. The findings were triangulated and results suggested that regular, practical face-to-face education and training for nurses were key to successful falls prevention program implementation in acute hospitals, as were provision of equipment; audit, reminders and feedback; leadership and champions; and the provision of falls data .
- **Data triangulation** involves using and analysing more than one participant group. It is often considered an aspect of methodological triangulation because different methods usually involve more than one source of data. Data collection needs to be well-defined and conducted. Once the data from all participant groups has been examined, the findings are compared and contrasted to assist in answering the research question(s).

It's important to remember that triangulation can involve more than one type of triangulation, and this is often the case with mixed-methods research. For example, in mixed-methods research, methodological, investigator and data triangulation may be used to demonstrate the full findings of the research. While Table 28.1 has listed each type separately, examining some of the example papers will show that there is more than one type of triangulation in the studies. Strict adherence to only one triangulation type can make researching the phenomenon more difficult.

Advantages and challenges of triangulation

Comparing and contrasting theories, data sources, methods and data analyses can ensure strong reliability and validity in research results. However, this can also be time-consuming and resource-intensive. Attention needs to be paid to the nuances of the research, to provide holistic explanations. There are times when triangulation may not be considered necessary, and this also needs to be understood when addressing the research question. For example, if the purpose of the research is to develop a new theory, there may be no need to include more than one method, data point or theoretical foundation.

Summary

Triangulation is the use of more than one data source, investigator, theory or method in the same research. There are four main triangulation types: each provides a means for examining the research from different perspectives and for ensuring the rigour, validity and credibility of findings.

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ETHICS

CHAPTER 29: RECRUITMENT AND SAMPLING

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe the main types of sampling.
- Describe recruitment approaches.
- Understand how to conduct recruitment and sampling.
- Identify the strengths and limitations of recruitment and sampling.

What is sampling?

Sampling is defined as selecting a suitable group of people (population) for a study.[1] Inviting people to the study who have the information to address the research question is a key consideration in sampling. Sampling is guided by the research question and will also influence data collection.

In qualitative research, different forms of non-random sampling, also known as non-probability sampling (not everyone has the chance of being selected), are utilised.[1] Using non-random sampling means the likelihood of a potential research participant being selected is not known in advance. This form is limited in generalisability; however, it aligns with qualitative research principles of sampling for meaning rather than frequency. Qualitative researchers tend to say that qualitative research is not generalisable, but is representative.[1] While qualitative studies often include non-random sampling, simple random sampling can be conducted when it is important to select a random set of participants from a large population, in which everyone has the same chance of being selected. This could be done by randomly selecting names from a telephone list or voter registration roll.

There are many ways to select a sample (sampling techniques). Among these are:

Snowball sampling, whereby study participants recruit or refer people they know to the study. This method is commonly used when potential participants can be hard to find through other means but potential participants are likely known to each other. For example, drug users or patients with rare diseases are likely to know others like themselves. This method may pose challenges for privacy because people may not want to share their contacts.[2]

Convenience sampling, in which study participants are those most available to participate in the study. Participants may be those who are easily accessible to the researchers – such as a practitioner who is a member of a professional organisation and uses that organisation to recruit participants or patients at a hospital where the researcher works. This method can introduce bias because participants are drawn from within the researcher's own networks or spheres of influence.[2]

Purposive sampling, also known as purposeful sampling or selective sampling, involves the selection of participants on the basis of their ability to provide in-depth and detailed information about the phenomenon under investigation. For example, a study on the experience of working in a public hospital as a frontline emergency nurse during the COVID-19 pandemic requires participants to be nurses, working in an emergency department, having worked during the pandemic and at a public hospital. A general practitioner, for example, could not provide in-depth information on the phenomenon being investigated. This method may present challenges in locating potential participants because it can be difficult to find participants who are able to provide in-depth information about the phenomenon being studied.[2]

Quota sampling is sometimes referred to as purposive sampling with more structure. Categories that are important to the study and for which there is likely to be some variation are identified and then subgroups are identified on the basis of each category. The researcher decides how many people to include from each subgroup and collects data from that number of participants in each subgroup. This method requires the investigator to have prior information about the sample. For example, in a study researching students and their experience of attending university, many subgroups need to be considered; for example, those living on or off campus, the course of study, faculty or discipline, age, gender identity, ethnicity and more. This method can present a challenge to fill quotas for each category identified.[2]

Snowball, convenience purposive and quota sampling are the most commonly used techniques for sampling in qualitative research. Other, less commonly used techniques include stratified sampling, theoretical sampling, extreme case sampling, typical case sampling, systemic sampling and intensity sampling. The technique used will depend on the research aim and questions.

Sample size in qualitative research

There are no clear guidelines for sample sizing in qualitative research. While researchers often propose a sample size, in general it is not decided on prior to data collection, but rather when data saturation occurs. Data saturation is a controversial concept because it is usually considered the point at which no new data is identified in interviews or focus groups. Some qualitative researchers, such as

Braun and Clarke[4] hold that data saturation can never be fully achieved because each participant will have something new to add to the data. For other researchers, data saturation is an acceptable concept, and is often given as 8–17 participants.[1,3] While 15 might be a proposed sample size for a study involving interviews, when the researcher has completed 10 interviews they may feel they have reached saturation as far as new themes or ideas are concerned. It is important to remember that sample size is not used to generalise and validate findings[5], but rather to ensure in-depth understandings of the phenomenon under investigation.

Criteria for sampling

Another consideration in sampling is determining the inclusion and exclusion criteria for the study. This is a standard practice in qualitative research and is used to define who will and will not be able to participate in the study.[6] For example, inclusion criteria might include gender identity, age and health diagnosis. People who do not meet the inclusion criteria would not be eligible to participate in the study. Exclusion criteria are more than simply the opposite of inclusion criteria; they cover specific factors such as not being able to provide informed consent, using a specific type of medication, having a certain diagnosis and more.[6] Inclusion and exclusion criteria are broad, and should not be so narrow that they limit the characteristics of participants who can be recruited to the study.

Well-developed inclusion and exclusion criteria and well-considered sampling methods will assist researchers with the next step, recruitment to the study.

What is recruitment?

Broadly speaking, recruitment to a research study involves presenting potential participants with detailed information about the research to help them decide on whether to participate in the study. The information presented during recruitment contributes to the consent process. Researchers who initiate participant recruitment should have a basic knowledge about the research and be part of the study team.

Before any research is to commence, the study must have ethical approval from a human research ethics committee. For academic researchers, this is the university's human research ethics committee. For researchers outside the academic setting, it is the organisation that has been identified as the review agency. For example, research conducted within a hospital setting is reviewed by the hospital's research ethics committee or panel. Research ethics committees review applications against the benchmarks set out in the *National Statement on Ethical Conduct in Human Research*.

As part of their data collection activities, researchers need to consider how they will invite research participants (recruitment) and the process of consent (see Chapter 30).

Recruitment methods need to take account of whether participant contact information is available and if there is permission to use it for the purpose of the research. Having email, phone or in-person (e.g. at a clinic) information will enable the researchers to correspond directly with potential participants, to invite them to participate in the research. Most researchers do not have the contact information of potential participants or are not able to contact them for the purpose of the research. In this instance, more passive methods of recruitment are needed and need to take into account settings frequented by potential participants, in-person or online. Passive methods of recruitment include advertising on social media, posting flyers on clinic noticeboards to advertise the research, asking clinics, sporting clubs, social clubs, schools, professional organisations, patient groups and other agencies to distrubute printed newsletters or to send emails on behalf of the researcher. The author has been involved in many studies in which contact details were not available. In a hospital study examining staff perceptions of how well a program was implemented, the hospital sent out invitations to potential participants (hospital staff) on behalf of the researcher. Staff who wished to participate were able to contact the investigators independently. In other instances where no contact details were available, the author advertised for participants with the assistance of peak bodies and community networks.

Recruiting participants through social media is increasingly common, but researchers need to be mindful about privacy and public availability of information. For example, potential participants may believe their comments in response to a recruitment advertisement on a social media platform are private, when in fact the information they share is available or visible to all users on that platform, or to the public.

Problems that may be encountered during recruitment include (but are not limited to) participants who are not fluent in English, participants who are hard to find and participants who do not trust research. Researchers need to consider these challenges in their recruitment activities and adjust them as necessary. Adjustments may include providing documents translated into the preferred language(s) of potential participants, recruiting research staff who speak the language, being mindful of the gender identity of research staff (e.g. women participants from some cultural backgrounds may prefer to deal with women researchers) and ensuring the research purpose is clearly communicated.

Incentives for research participants

Sometimes recruitment can be enhanced by providing an incentive for participants. This approach must be approved by the human research ethics committee before being offered to participants. Examples of reasonable incentives include providing reimbursement for parking at a hospital, offering a gift/shopping card or a coffee voucher for a nearby café, in recognition of time spent participating in the study. Incentives should not be excessive and therefore potentially coercive. The National Health and Medical Research Council (NHMRC) provides guidance on incentives in research.

Examples of sampling and recruitment methods are presented in Table 29.1. Notice how often multiple recruitment methods are used.

Table 29.1: Examples of sampling and recruitment

Title	**Recruitment of refugees for health research: a qualitative study to add refugees' perspectives**[9]	**Benefits of dance for Parkinson's: the music, the moves, and the company**[10]	**Managing employee well-being: a qualitative study exploring job and personal resources of at-risk employees**[11]	**Frontline healthcare workers' experiences with personal protective equipment during the COVID-19 pandemic in the UK: a rapid qualitative appraisal**[12]
First author and year	Gabriel, 2017	Jola, 2022	Gauche, 2017	Hoernke, 2021
CC Licence	CC BY 4.0	CC BY 4.0	CC BY 4.0	CC BY-NC 4.0
Aim/ research question	To document refugee participants' opinions on factors that may impact refugees' willingness to participate in health research (p2)	To explore whether music is a contributing factor of Parkinson's dance classes that benefits individuals with an immediate change in their motor ability after dancing (p4)	To investigate the experience of job and personal resources from the perspectives of employees identified as at risk of burnout (p1)	To determine (a) frontline HCWs' experiences following local level (i.e. trust) and national level (i.e. government) PPE guidance; (b) concerns and fears among HCWs regarding PPE in the context of the COVID-19 pandemic; and (c) how these experiences and concerns affected HCWs' perceived ability to deliver care during the pandemic (p2)
Study design	Not stated – qualitative study	Mixed methods Qualitative and quantitative	Phenomenological study; guided by social constructivism paradigm	Rapid qualitative appraisal, mixed methods
Sampling/ recruitment type	Two community healthcare centres (convenience and non-random), cold calls to health-clinic patients, invitations to personal contacts of the research assistants, recruitment at refugee-focused community centres and snowball sampling	Participants were recruited from 6 locations with established dance programs for people with Parkinson's (purposive sampling)	Purposive and convenience sampling: selected from an annual organisational climate survey, and based on accessibility or proximity to the research	Purposive and snowball sampling: recruited from critical care, emergency and respiratory departments as well as redeployed staff from primary, secondary and tertiary care settings
Data collection	Focus groups	Semi-structured interviews	Semi-structured interviews	In-depth interviews, policy reviews, rapid evidence synthesis of 39 newspaper articles

Title	Recruitment of refugees for health research: a qualitative study to add refugees' perspectives[9]	Benefits of dance for Parkinson's: the music, the moves, and the company[10]	Managing employee well-being: a qualitative study exploring job and personal resources of at-risk employees[11]	Frontline healthcare workers' experiences with personal protective equipment during the COVID-19 pandemic in the UK: a rapid qualitative appraisal[12]
Coding analysis approach	Thematic analysis	Thematic analysis	Thematic analysis	Framework method, demographic, discourse and sentiment analysis
Results	Twenty-three variables were identified that impact on refugee willingness to participate in research. The 3 main factors identified were: do not conduct research with refugees shortly after their arrival in the host country; the voluntary nature of the research must be clearly communicated; and clearly communicate that there are no consequences for not participating in the research.	Music was reported as helpful in the dance class as was the social contact.	Both job and personal resources were factors influencing employee well-being and burnout.	Inadequate provision of PPE, inconsistent guidance and lack of training on its use presented challenges to HCWs. HCWs persisted in delivering care despite the negative physical effects, practical problems, lack of protected time for breaks and communication barriers associated with wearing PPE. HCWs developed their own informal communication channels to share information, trained each other and bought their own PPE. (p10)

Strengths and challenges

Each sampling and recruitment method has strengths and challenges. The one chosen depends on the study's research question(s) and aim(s). Choosing the appropriate methods will bring rigour to the research, while choosing inappropriate methods will reduce rigour and affect the research results. Consider a study in which women's experience of episiotomy is being sought.[7] It may be possible to recruit many women based on how relatively easy the birth was, or only a few women based on how willing the women are to talk about the use of forceps during delivery. Or consider a descriptive qualitative study in which up to 40 participants are recruited to provide slightly more generalisable results about an experience with a health service.[8] Each sampling and recruitment method is valid, depending on what is being researched.

Summary

Sampling refers to the selection of a suitable group of people from a broader population, to participate in a study. Selecting the people suitable for the research study is important because that will affect the study's findings. There are many ways to sample, and these depend on the research being undertaken as well as the availability of participants. Recruitment refers to providing potential participants with information about the research and gaining their agreement to participate. There are many recruitment methods, and the one(s) chosen depend on the research being undertaken as well as participant agreement to become involved. Issues of privacy, confidentiality and consent need to be fully considered when sampling and recruiting participants to a research study.

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CHAPTER 30: ETHICAL PRINCIPLES AND CONSENT

Danielle Berkovic

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the 4 ethical principles of autonomy, beneficence, non-maleficence and justice.
- Identify key challenges of informed consent in qualitative research.
- Articulate future directions for informed consent in emerging qualitative study designs.

What is consent?

In research, consent means that human participants enter research freely, with all information provided about the research, and that consent is given before entering the research.[1] The principle of informed consent is formalised to ensure that relationships between the researcher and those participating in the research are based on trust and integrity and to safeguard people's freedom to decide whether or not to participate in research.[1] There are 4 ethical principles that researchers must adhere to in health and social care research: (1) autonomy, (2) beneficence, (3) non-maleficence and (4) justice.[2] Consent needs to cover each of these elements.

The origins of consent

After the Second World War, when it was discovered that doctors had conducted pseudoscientific medical experiments on prisoners in Nazi Concentration Camps, the Nuremberg Code for research on human subjects was established. The Code is composed of 10 principles, centred on the consent and autonomy of research participants, rather than researchers' objectives. The first principle of the Nuremberg Code is that "the voluntary consent of the human subject is absolutely essential"[3].

History is fraught with problems involving consent. One of the best-known studies is the Syphilis Study at Tuskegee.[4] In 1932, the United States (US) Public Health Service began a study in Tuskegee, Alabama to record the natural history of syphilis in a socioeconomically deprived area known to have the highest rate of syphilis in the US at that time. The study initially recruited 600 Black men. Participants were not given the opportunity for informed consent; In fact, the researchers misled participants by telling the men that they were being treated for 'bad blood'. The researchers persuaded the men to participate in exchange for free medical treatment, free meals and burial insurance. By 1943, when penicillin was discovered as an effective treatment for syphilis, participants in the study were not told about or offered this treatment. Seven men in the study died directly as a result of syphilis, and more than 100 are thought to have died from syphilis-related complications.[4]

Today, consent is one of the most important considerations when recruiting participants for health and social care research. The consent requirement serves the important function of safeguarding participants from harmful interventions, and the provision of information is considered a prerequisite for potential participants to make rational decisions concerning their involvement in research.[5]

Autonomy

Autonomy means that all persons have intrinsic and unconditional worth, and therefore should have the power to make rational decisions and moral choices. Autonomy enshrines individual participants' rights for self-determination. To maintain research participants' autonomy, researchers must ensure that consent is **informed**. This means that prospective participants must be provided with detailed information about what their participation will entail, with no undue influence.[2]

Informed consent

According to the Declaration of Helsinki,[6] developed by the World Medical Association as a statement of ethical principles for medical research involving human participants, adequate information for informed consent must be comprehensible and meet the following criteria:

- The information should be given both verbally and in writing.
- The purpose and design of the research, what it means to participate, the advantages and disadvantages of participation, plans for the broader study overall, voluntary participation, and the unimpeded opportunity to withdraw, must be outlined to every participant.[7]

The term 'informed consent' infers the past tense, or a completed process. This suggests that all information is known and described at the onset of the study, which is a much clearer process in quantitative research than in qualitative research. This is because, as discussed in the data collection and analysis sections of this textbook (section 3 and section 4), qualitative research is often iterative and evolves as the research progresses. Some information about the research may therefore not be known at the start of the study.[8] To ensure that participants are provided with adequate opportunity to make autonomous and informed decisions about their participation, the researcher can, for example, send the participant a list of questions before the data collection takes place. Prospective participants can consider the tangential topics that might ensue during the course of the study, and make an informed decision about their participation.

In her article, 'The concept of informed consent in qualitative research',[9] Dr Byrne describes semi-structured interviews regarding compliance with antihypertensive medication. After a few interviews, the researcher identified the need to investigate participants' sexual function, as sexual dysfunction is a common side effect of these medications that can contribute to non-compliance. The researcher had not included the subject matter of sexual dysfunction in the consent form initially provided to prospective participants but had they known this private topic would arise, they may not have opted to consent. This study exemplifies the dynamic aspects of qualitative research that require researchers' continuing consideration of informed consent, in order to protect research participants. No participants withdrew from the study, but the researcher reflected on the unforeseen discomfort caused to participants, in contradiction to the principle of non-maleficence.

Beneficence

Beneficence means that researchers must act in the best interests of their participants – to their **benefit**. It supports several moral rules to protect and defend the rights of participants, and to remove conditions that will cause harm.[2] The language of beneficence is positive; the principle calls for more than the avoidance of harm: to purposely benefit research participants and to promote their welfare. Researchers consider beneficence by:

- Assessing the risks of harm and the potential benefits of research to participants and to the wider community.
- Being sensitive to the welfare and interests of participants involved in their research.
- Reflecting on the social and cultural implications of their work.

Non-maleficence

Non-maleficence demonstrates the ethical tenet to **do no harm** to participants.[2] The practical application of non-maleficence is for the researcher to weigh up the potential benefits of the research versus the potential burden on participants, to ensure that this balance is appropriate and to choose the best research design and level of involvement for participants.

Until the 21st century, the concept of 'do no harm' was primarily discussed among quantitative researchers following experiments conducted on humans and the risk of unforeseen physical and psychological harm. In contrast, the harms appear to be minimal in qualitative research when researchers are talking to participants, as opposed to executing an intervention. However, while the risk of physical harm is less prominent in qualitative research, the risk of psychological discomfort is indeed present.[10] Some qualitative research is also interventional (see Chapter 7 on Action Research), and therefore non-maleficence must also be considered in this context.

Justice

In general, justice is interpreted as the fair, equitable and appropriate treatment of research participants.[2] Research that is just considers that:

- The scope and objectives of the proposed research, the selection, exclusion and inclusion of participants are fair.
- The process of recruiting participants is fair.
- There is no unfair burden on research participants.
- There is fair distribution of the benefits of participation in research.
- There is no exploitation of participants in the conduct of research.
- There is fair access to the benefits of research.

Informed consent in qualitative research

Houghton and colleagues have outlined 5 ethical challenges within the 4 principles of consent, specific to qualitative research: (1) informed consent processes, (2) the participant–researcher relationship, (3) continuously monitoring the risk-benefit ratio of the research, (4) confidentiality and (5) the dual role of the clinician-researcher.[11]

Informed consent processes

As described earlier in this chapter, the traditional, one-off process of informed consent is not always feasible in qualitative research, since the researchers may not be able to predict the direction of an interview or focus group, based on the interpretivist nature of this approach. If previously unanticipated information is discussed in the process of collecting data, the researcher should reiterate that the participant has the right to withdraw from the study at any time. By reminding participants of this right, the researcher is bringing the voluntary nature of autonomy and informed consent to the forefront and enshrining participants' right to informed consent.

It can be challenging for researchers to know from whom consent is required. For example, ethnographic studies (Chapter 9) often involve participant observation (Chapter 15). The question is whether the researcher needs to gain consent from everyone being observed. What about people who are observed incidentally but are not part of the study? In her ethnographic study, Ethical conduct and the nurse ethnographer: consideration of an ethic of care,[12] Pauline Griffiths initially attempted to obtain written informed consent from hospital patients while they were acutely unwell. Upon being approached patients were apprehensive and concerned that they were about to experience additional medical intervention. It was subsequently decided (in conjunction with the university and hospital human research ethic boards) to seek verbal informed consent from certain patients who were not as unwell as others. This decision was based on the principle of beneficence, and the fact that the researchers believed that written consent was causing some participants needless anxiety.

In addition to the participants who are intended to be observed, conducting observational studies in a public setting can pose other ethical challenges. There may be other people, such as visitors, who become part of the observations, even if the intention is to only observe specific participants in the research. The challenge lies in deciding from whom to obtain informed consent and by what means.[11]

The relationship between the researcher and the participant

The relationship between the researcher and the participant is not as clear-cut in some qualitative research settings as it is in quantitative research. When data is collected over a period of time, there is the opportunity for participants and researchers to build a relationship. As the research progresses and relationships grow, researchers must remain aware of the presence and nature of power, particularly power imbalances between themselves and participants (and the potential effect of this on the participant), in accordance with the principle of justice. Xu and colleagues, have reflected on this in an article examining their experiences of obtaining informed consent in qualitative research.[13] They identified that the researcher–participant relationship should be discussed as part of the process of informed consent in long-term qualitative studies, so that the researcher and the participant can decide together on a mutual assessment of suitability for research participation.[13]

Risk-benefit ratio

Adhering to the principles of beneficence and non-maleficence involves calculating the level and extent of risk, balanced with the potential benefits of research participation. It is important for researchers to convey these principles to participants. That way, if unexpected topics arise within an interview or focus group discussion, participants and researchers can have a conversation about whether this may cause harm or distress, or whether the benefits of participation outweigh the potential harm.[11] In essence, it is important that the researcher is mindful of the effects of the research on the participant and should take appropriate steps to minimise associated risks.

Confidentiality

There are two main considerations for confidentiality in the context of qualitative research: when there are multiple participants in a focus group, and when detailed descriptions are used to report participant characteristics within a study.[14] With regard to participant characteristics, researchers may need to use pseudonyms and to be selective when describing defining characteristics of participants that could reveal their identities. With regard to focus group confidentiality, the researcher should direct participants not to discuss the focus group (including other participants and topics discussed) outside of the data collection setting. At the same time, the researcher must stress that it is impossible to guarantee focus group anonymity.

When it is difficult to gain informed consent

Up to this point, informed consent has been discussed in the context of potential participants who are cognitively intact. However, many people who participate in research are from groups considered vulnerable, or who may not have the capacity to provide informed consent. Some examples include, but are not limited to[15]:

- Pregnant people
- People with cognitive impairment, intellectual disability, or mental illness such as dementia or schizophrenia
- People with impaired capacity for communication, including children
- People who are in hospital or reliant on others for care
- People who are incarcerated, or people on parole
- Children living in out-of-home care or foster care.

These populations should not be excluded from research based on their potentially limited capacity to provide consent. Researchers have designed consent frameworks and checklists to facilitate participation for these population groups. Following is an example of older people living with dementia.

Informed consent for people living with dementia

Dewing's consent framework for older people living with dementia[16] prompts researchers to be mindful during qualitative data collection of possible expressions of verbal, non-verbal and behavioural discontent, disengagement and discomfort. This framework emphasises consent as well as the concept of assent, which describes the ability to indicate a meaningful choice and a minimal level of understanding by those who lack the capacity to provide obvious verbal or written consent.

Table 30.1: Dewing's process consent framework

Stage	**What is involved?**
Preparation and background	• Gaining permission to access the person if they are in a location where this is necessary • Finding out about the person • Establishing a basis for consent and understanding the person's ability to provide consent
Initial consent	• Considering consent and assent • Using a range of written or verbal prompts to enhance understanding • Maintaining notes as evidence
Ongoing consent	• Monitoring • Revisiting consent
Feedback and support	• Providing feedback to the person, staff or family following data collection • Assisting the person transition back to their usual environment

Data derived from Process Consent and Research with Older Persons Living with Dementia[16]*. Not available for reuse under CC BY NC.*

Emerging challenges

Emerging data collection methods in qualitative research do not involve clear-cut participant involvement. Examples include participant observation (Chapter 15) and social media research (Chapter 16), as well as challenges that arise when working with vulnerable and hard-to-reach populations (Chapter 33). A group of researchers aiming to identify considerations for making informed choices about engaging in qualitative research in underrepresented populations identified 9 core values to consider.[17]

Conclusion

The 4 ethical principles of research are autonomy, beneficence, non-maleficence and justice. Informed consent must be included in each of these principles. Consent can be complex in qualitative research; researchers must consider their relationship with the participant, the risk-benefit ratio and the processes of continuous consent. Emerging populations and research designs have also given rise to new methods of consent, which require consideration prior to conducting research.

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CHAPTER 31: ETHICAL CONSIDERATIONS IN CONDUCTING RESEARCH WITH HARD-TO-REACH POPULATIONS

Tatiana Corrales

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand some of the factors that make populations hard to reach.
- Understand some of the ethical challenges associated with research involving hard-to-reach populations.
- Develop study protocols to mitigate some of the ethical challenges and to empower 'hard-to-reach' populations to participate in research.

Who and what are hard–to–reach populations?

The term 'hard to reach' is not well defined, but in general is used to refer to groups or populations that are difficult to engage in research.[1] The factors that make a population hard to reach are varied and may reflect *institutional barriers* (e.g. gatekeeping by service providers or government bodies) and/or *individual characteristics* of people within that population (e.g. homelessness, substance abuse, age, the presence of disabilities, or people who highly dependent on medical care).[1,2,3] Due to their hidden nature, these populations are often excluded from research. This chapter focuses on the factors that can make certain populations hard to reach and the ethical implications of not including vulnerable groups in research.

'Hard-to-reach' populations are typically considered vulnerable, marginalised and/or disenfranchised. Normally, hard-to-reach populations are those that exist outside of the mainstream, such as people who are homeless, children in Out-of-Home Care (OOHC), people in prison and people experiencing multiple forms of disadvantage or hardship.[3] Hard-to-reach populations can be characterised by significant histories of trauma. Their interactions with systems of care and control have often exacerbated their trauma, leading to increased wariness and suspicion of systems, services and institutions, including universities.[3,4,5]

There are also certain personal characteristics, including age (specifically children) and the presence of intellectual disabilities or cognitive impairments that can lead to groups being considered vulnerable and, consequently, hard to reach.[4,6,7,8]

Contested terminology

While terms like 'vulnerable', 'marginalised' and 'disadvantaged' are commonly used to describe hard-to-reach populations, these terms are often ill-defined and contested.[3,6] Vulnerability is not a static construct: its definition depends on context and perspective. From a research governance perspective (i.e. research ethics), vulnerability is equated with risk – risk to the vulnerable individual and risk to the organisation.[7,9] This focus on managing risk creates its own set of challenges, including significant barriers that ultimately exclude certain cohorts of people from research.

However, vulnerability – particularly when it is grounded in trauma – can coexist with risks that require management or control. For example, children and young people who have experienced maltreatment are considered highly vulnerable. These same children may exhibit challenging behaviours, including antisocial and criminal activity.[10] Vulnerability can therefore elicit compassion and protection, but only when it conforms to certain stereotypes of what it means to be vulnerable.[3]

The attributions applied to vulnerable people may not reflect how people define themselves. The term 'vulnerability', for example, can connote weakness and frailty, or the need for protection. It can also be used to imply that vulnerable people lack the capacity for self-protection and personal agency.[4,6,11] Similarly, the term 'marginalised' has connotations of personal responsibility or personal failure.[12] However, marginalisation is a process of exclusion from the mainstream, driven by entrenched systemic and structural inequities.[13]

The language we use to describe research participants is important and has implications for participants' willingness to engage with our research. It may not be that populations are 'hard to reach' but that our way of thinking about and doing research needs to be more flexible, creative and inclusive.[8]

Table 31.1 provides a non-exhaustive list of groups that are typically considered vulnerable and consequently hard to reach. It is important to note that many of the characteristics in the table are not mutually exclusive. In fact, it is the *intersection* of multiple individual characteristics with institutional barriers that render certain populations hidden and silenced.

Table 31.1: Hard-to-reach populations and factors that increase perceived risks of research participation

Population	**Perceived risks and vulnerabilities**
Children (0–18 years old)	Cognitive immaturity Legally unable to provide free and informed consent (up to certain age thresholds) Potential for distress and/or traumatisation perceived as unacceptably high
Children in statutory Out-of-Home Care (OOHC; includes foster, kinship, and residential care)	Under the guardianship of the state – participation is contingent on approval from child protection services Significant trauma histories place this group at an increased risk of distress and/or re-traumatisation Presence of mental health challenges, intellectual disabilities, neurodivergence (e.g. Autism Spectrum Disorder, Attention-Deficit/ Hyperactivity Disorder) and/or behavioural difficulties[14]
Children under the supervision of youth justice systems	Similar characteristics to children in OOHC Require approval from youth justice departments Where children are detained, approval from the detention centre is also required
People experiencing homelessness	High risk of distress and re-traumatisation Presence of mental health difficulties and/or substance abuse histories Perceived unsafe living environments
People experiencing significant mental health difficulties	High risk of distress and re-traumatisation Capacity to provide free and informed consent may be compromised
People living with disabilities (intellectual and/or physical)	For people with intellectual disabilities, capacity to provide free and informed consent may be limited or restricted. May be dependent on others to assist with communication. Raises concerns of coercion.
People with dementia	As above
People from culturally and linguistically diverse backgrounds (including recently arrived immigrants and refugees)	Capacity to provide free and informed consent may be influenced by challenges with English proficiency. The use of interpreters can raise concerns about judgement and stigma within a community, particularly if the research is touching on sensitive topics (e.g. child protection intervention, reproductive health, family violence)[15,16]
First Nations People	High risk of distress and re-traumatisation through culturally unsafe and inappropriate research methodologies Risks about how data will be interpreted and disseminated – with/without community consultation? Risk of inappropriate interpretations of data if community not involved in collection and analysis of data.

Population	**Perceived risks and vulnerabilities**
People with substance abuse challenges	Safety concerns (for participants and researchers) Capacity to provide free and informed consent may be compromised
Victim-survivors (child abuse, domestic and family violence)	High risk of distress and re-traumatisation Participant safety a key concern – need to ensure that participation in the study does not increase the risk of violence by intimate partners
People in custodial settings (prisons, immigration detention)	High risk of distress and re-traumatisation Safety (of participants and the researcher) Real of perceived coercion to participate in research
People who are highly dependent on medical care and/or are hospitalised	Risk of real or perceived coercion due to fear that medical treatment will be withheld Inability to walk away from the hospital setting (for hospitalised patients)
People who are pregnant	Perceived risks vary by nature of the study: Medical research – perceived risk of procedures that may harm the foetus (not the necessarily the mother) Social science research – perceived risk of causing distress.

As the information in Table 31.1 shows, from a research governance perspective vulnerability is framed through a lens of risk: that participants will experience distress and trauma, that the safety of participants and researchers is at risk and that there is potential for unethical conduct if the correct protocols are not in place to ensure participants are able to provide free and informed consent.

Ensuring that risks are properly managed is an important element of all research. However, when vulnerability is so narrowly equated with risk, people's agency – their right to determine whether they want to participate in research – is eroded. In attempting to *protect* vulnerable participants from unethical practices, we run the risk of excluding their voices from research, policy and practice.[3,7]

Institutional barriers

A group's perceived vulnerability can also be used by institutions – including research ethics committees, service providers and statutory bodies (e.g. child protection, criminal legal systems) – to limit access to participants. This is commonly referred to as 'gatekeeping'.[3,7,9]

Often it is important to rely on the discretion of people who have a deep knowledge and understanding of the group that is being approached to participate in research. As researchers, we may not always understand the complexity of the lives of participants. Or we may be unprepared for the ways in which participants respond to the research. 'Gatekeepers' can provide important information to ensure that participants are approached with sensitivity.

However, gatekeeping can also be a form of control, grounded in paternalistic ideals. This is particularly evident with populations that are deemed simultaneously vulnerable and risky or dangerous. Box 31.1 provides an example of gatekeeping by statutory bodies on a project exploring the service needs and experiences of mothers in prison.

Box 31.1: Barriers to recruiting criminalised women who have been pregnant and/or given birth in prison

This project involved in-depth interviews and focus groups with a range of stakeholders, including prison staff, lawyers, service providers and women with lived experience. Initially, ethics approval was sought to interview women in custody. Access to prisons was limited during multiple extended lockdowns during the COVID-19 pandemic. Further, the corrections department's policies limited how criminalised women – including those on community-based orders or who had been released on parole – could participate in the study. For example, they could not be reimbursed for their time participating in the study. Women in custody could be invited to participate in the study, but their involvement had to be facilitated through the prison, and interviews had to occur online. This raised ethical, methodological and logistical concerns. For example, recruitment would need to be undertaken by prison staff as the researcher was not allowed on site. This meant that there was no way to guard against selection bias, or to minimise the potential for perceived coercion. It was also impossible to guarantee women's privacy during online interviews conducted within a custodial setting. This was especially concerning given the focus of the study on women's experience of the 'care' they had received from the prison system during pregnancy and following childbirth. As none of these factors could be guaranteed, and as the prospect of future extended lockdowns remained the researchers decided to recruit women in the community, rather than attempting to access women in custody. The result was that the study did not capture the experiences of women who were in custody during the period of the study.

Based on an unpublished research project undertaken by Tatiana Corrales (2021–2023)

Research involving vulnerable populations sometimes entails balancing competing ethical and practical considerations. From a practical perspective, there are often external constraints linked to funding and reporting timelines, that limit the amount of time that can be spent on recruitment activities. In these situations, it is sometimes necessary to compromise certain elements of the study – in this case, giving voice to women in custody – in order to safeguard the rights of vulnerable participants.

Gatekeeping may not represent an attempt to prevent certain groups of people from participating in research. The reasons for gatekeeping are varied and in general are intended to protect vulnerable groups from exploitation.[9] However, whether intentionally or unintentionally, gatekeeping can contribute to a population being hard to reach' This, in turn, can result in certain groups being excluded from research, thereby diminishing their voices and making them increasingly hard to reach, in an endless loop.

The ethics of research with hard–to–reach populations

In Australia, the ethical conduct of human research is grounded in the principles of merit and integrity, justice, beneficence and respect.[17]

There is a tension inherent in seeking to balance these principles. Ensuring that participants are not exposed to, or directly caused, harm as a result of research is fundamentally important. However, participants also have the right to decide whether they want to participate in research. This is embodied in the principle of respect, which states that 'respect for human beings involves giving due scope, throughout the research process, to the capacity of human beings to make their own decisions.'[17(p11)] As researchers, we have an ethical obligation to support vulnerable groups to be active participants in research.

Ethical research involves more than just managing risks. It is about genuine engagement with communities and research participants, based on respect for their autonomy, dignity and expertise in their own lives. The inclusion of people with lived experience in research project – from conceptualisation to dissemination of findings – can be a powerful means of empowering vulnerable populations to be heard.[18] The slogan 'nothing about us without us'[18,19] highlights the importance of genuine engagement, ensuring that people with lived experienced are consulted and included in every stage of research.

Additional ethical considerations with hard–to–reach populations

- As far as practicable, engage people with lived experience early in the research process – preferably before you design the study.
- Include adequate and appropriate remuneration for lived-experience consultants and participants in the research budget. Consultants should be paid for their time as experts; research participants should be compensated for their time in a way that reflects their contribution. Participants should also be reimbursed for the cost of travel. Paying participants is a contentious area of research ethics. Some research ethics committees are not comfortable with high-value payments to participants, due to the risk that this will act as an inducement to participation, thereby limiting a participant's capacity to provide *free* and voluntary consent. What constitutes a 'high-value' payment can be arbitrary, but in our research, $80 and $100 payments have been considered excessive by multiple ethics committees. However, high-value payments can be ethically justified as a means of recruiting and retaining research participants, and as a gesture that participants' views are valued.
- Develop thorough research protocols that explain how participant distress and participant safety, as well as researcher distress and safety, will be managed. Additional considerations may be needed, depending on the nature of the population. For example, when undertaking research with families

involved in the child protection system, it is important to consider:
    - the potential for extreme levels of distress among participants, including threats of suicide
    - legal obligations on the research team to report suspected child maltreatment to relevant authorities, and how this will be managed
    - how the research team will manage participant disclosures of harm perpetrated against them.
- Ethics should always be about more than managing risk. Ethical research with hard-to-reach populations is fundamentally about valuing the perspectives of people who are often excluded from research. It is about respecting their autonomy to choose whether they want to participate in a study, and about creating safe spaces that will enable their participation.
- There are unique considerations that apply to research with or about First Nations Peoples. Chapter 19 explores this in more detail.

Summary

Undertaking research with hard-to-reach populations can be challenging. Despite these challenges, it is important that researchers attempt to engage with these populations as they have too often been rendered invisible in research and policy discussions. Rather than only seeing their vulnerability and marginalisation as evidence of risk, we should be working to empower the silenced and invisible members of society to contribute to and participate in research. The experiences and perspectives of hard-to-reach populations are valuable in their own right. They also have the power to broaden our understanding and develop more creative and meaningful solutions to entrenched structural problems.

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CHAPTER 32: LOOKING AFTER YOURSELF

Danielle Berkovic

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe the emotional burden of qualitative research.
- Identify strategies to cope with the emotional responses of participants in qualitative research.
- Learn how to look after yourself during the qualitative research process.

Why do qualitative researchers need to look after themselves?

As described throughout this textbook, qualitative research for health and social care spans many disciplines and topics. Each individual researcher brings their own lens and experiences to the qualitative landscape, and some research topics may require the researcher to undertake emotional work. This type of research can be highly demanding in terms of mental, emotional or physical energy, at the expense of the researcher's health or wellbeing.[1] For example, Chapters 9 and 10 describe two potentially emotionally charged phenomenological and ethnographical studies: one investigating abused mothers' lived experiences and another seeking to understand the perspectives of women who use drugs intravenously.

What types of emotions might qualitative researchers experience?

The Economic & Social Research Council (ESCR), the ESCR National Centre for Research Methods and Qualiti (all UK-based organisations) led the Commissioned Inquiry into the Risk to Well-being of Researchers in Qualitative Research.[2] They identified six emotional and psychological 'risks' that qualitative researchers should be aware of (Table 32.1):

Table 32.1: Six risks to qualitative researchers

Emotional and psychological risks to qualitative researchers	**Definitions and examples**
Role conflict	During data collection (particularly interviews), the researcher may incorporate elements of self-disclosure to the participant, drawing the researcher and participant into an unexpected dynamic. This can inadvertently lead to the researcher acting as a health or social care provider, or a friend. Conversely, the participant may also disclose more personal detail than is required for the purposes of the research, which can also lead to the researcher acting as a friend and feeling conflicted about their role.
Anxiety	Data collection with participants who have experienced trauma can cause the researcher emotional or moral unease. The researcher may empathise with the participant to the extent that it causes the researcher discomfort.
Isolation	Working in unfamiliar settings can heighten a researcher's sense of isolation; for example, during an extended period of data collection in an unfamiliar country. The research topic itself can also have an isolating effect on the researcher.
Resistance	Some participants can be uncooperative or obstructive to the research process, and gatekeepers may represent barriers to access.
The unanticipated long-term impact of research	The long-term mental toll that can come from research spanning several years
Staying emotionally and psychologically safe	The emotional strain of having to deal with distressing research encounters can be acute. This not only applies to the researcher collecting the data, but also to those who are tangential to the research, such as interview transcribers.

The role of bracketing

Given the emotional and psychological risks, it is important for those undertaking qualitative research to understand their positionality (see Chapter 26) with regard to the research topic. Researchers should undertake a bracketing exercise (described in Chapter 26) to identify their personal strengths and weaknesses, and potential biases, so they might learn about the types of research that have potential to cause distress. Fenge and colleagues found that researchers with social work or psychology backgrounds who conduct research in the same field can especially benefit from identifying their positionality when working with high-risk populations, such as sex offenders in the criminal justice system or survivors of family violence.[3]

How to look after yourself

Table 32.2 presents some tips and tricks offered by Rager[4] for how researchers might look after themselves in the three stages of the research process.

Table 32.2: Coping strategies for researchers

Ways of coping	**Explanation**	**Example articles**
Journal writing	The researcher writes their thoughts and feelings about their research. Writing has been acknowledged as an effective reflective exercise and is commonly used in psychology research.	Anticipating doing a study with dying patients: an autoethnography on researcher wellbeing[5] CC BY NC A researcher's reflective account of conducting qualitative research with people who are dying, with journal writing suggested as a means of dealing with their conflicting role between researcher and confidant.
Peer debriefing	The researcher confides in a colleague or someone in the workplace whom they trust about how the research is affecting their health and wellbeing. This relationship can be established as an informal catch-up, or at regular intervals.	The mental health of people doing qualitative research: getting serious about risks and remedies[6] CC BY-NC 4.0 Describes the importance of workplaces and communities openly sharing the potential challenges of undertaking qualitative research, and learning from each other about what works in caring for the self.
Personal counselling	The researcher talks to others – counsellor, colleagues, friends or family – about maintaining personal boundaries in their research.	The safety of researchers and participants in primary care qualitative research[7] © British Journal of General Practice and not available for reuse under CC BY-NC Describes a general practitioner's experiences with conducting qualitative research and their involvement in a counselling program to identify and manage their emotions.
Member checking	Member checking enables the researcher to touch base with participants after data collection, thereby creating a sense of closure at the end of the research.	Member checking: can benefits be gained similar to group therapy?[8] CC BY-NC-SA 4.0 Describes the therapeutic benefits of member checking for both the researcher and participants.

Ways of coping	**Explanation**	**Example articles**
Maintaining work–life balance	Social and emotional support networks when conducting research are key, in addition to social events, hobbies, exercise, etc.	Blurring boundaries: balancing between distance and proximity in qualitative research studies with vulnerable participants[9] CC BY 4.0 Reports on the experiences of social science researchers conducting various types of qualitative research projects and what they did to take care of themselves; maintaining a work–life balance was key.

Summary

It is important for researchers to look after themselves, especially while undertaking qualitative research that is emotionally challenging. There are different techniques researchers can use to help them cope with research that is personally challenging, including finding the self-care methods that work for them.

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CHAPTER 33: CONFIDENTIALITY AND PRIVACY

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe confidentiality and privacy.
- Understand how to ensure confidentiality and privacy in research.
- Identify the strengths and limitations of confidentiality and privacy.

What is confidentiality?

Confidentiality is an agreement to keep something private or secret. In research, it follows on from consent in that seeks to protect participants' identifiable data. When participants provide informed consent to the researcher, an agreement is formed that the participant's identifying information will not be available to anyone outside the research team unless specifically agreed to.[1]

Identifying information includes names, personal information and responses to the research. Any private information about a participant that they do not want shared with others is considered confidential.[2] Researchers should provide the highest level of confidentiality, which includes defaulting data status to anonymous, ensuring participants provide informed consent and enabling participants to review and correct their data.[2]

There are many laws, regulations and conventions that must be adhered to when conducting research, and confidentiality is covered under these legal requirements. In Australia, these include federal legislation such as *The Privacy Act 1988* (Cth), and state and territory regulations that apply where the research is conducted, such as *The Health Records Act 2001* (Vic.). *The National Statement on Ethical Conduct in Human Research* (2007) (National Statement)[3] sets out guidelines for research with humans, in accordance with the *National Health and Medical Research Council Act 1992* (Cth).

Universities, hospitals and other healthcare organisations have ethical guidelines for research, protocols for research governance and human research ethics committees, all of which include confidentiality and privacy as an important consideration. For example, Monash University has published *A Guide to Good Research Practice*[4], which provides staff and students with the latest national and international guidance for ethical and responsible conduct in research. The Australian departments of Defence and Veterans Affairs have a joint human research ethics committee to approve any research undertaken with or about current and past defence personnel and their families. Private organisations such as Bellberry Ltd[5] act as human research ethics committees for researchers who are conducting their research outside the academic and hospital sectors. When research studies are approved by a research ethics committee, the confidentiality considerations are fully scrutinised.

The importance of ensuring confidentiality cannot be overstated for researchers and healthcare practitioners, and there are many ethical challenges associated with confidentiality. An example is a paper by Duncan and colleagues[6], in which a researcher interviewed a 15-year-old participant. The researcher assured the young man that his answers were confidential, and the participant told the researcher that he did not want his mother to know about the interview. During the interview, however, the participant disclosed issues with adhering to medication that caused the researcher to question whether these issues should be disclosed to the participant's mother and treating physician.

After lengthy discussion with the research team and examining all possible options, the researcher telephoned the young man and suggested that he tell his mother about the medication adherence issue. The ethics committee that approved the research was also notified of this ethical grey area and how it was resolved. Ultimately, the research team remained unsure that they had made the correct decision about maintaining confidentiality. They were not sure whose interests were being served by maintaining confidentiality. It is important that researchers are acutely aware of issues regarding confidentiality and autonomy when undertaking research with young people and hard-to-reach groups (see Chapter 31).

In a study by Veness and colleagues, more than 8000 public complaints to regulators, citing concerns about healthcare providers and confidentiality, were examined. The study found that mental health practitioners had significantly higher rates of complaints than other health practitioners about confidentiality.[7] The authors suggested that this may be due to the frequency with which mental health practitioners discuss patient care with others. They also suggest, however, that the findings may be indicative of practitioners' failure to explain the limits of confidentiality. Confidentiality with focus groups is discussed later in the chapter.

Families can also influence confidentiality arrangements, such as when participants have not given permission to share their confidential genetic information with family members. An example is a study by Dheensa and colleagues[8], in which researchers encounter a participant with prostate cancer and a family history of breast cancer. The researchers needed to consider if and how information about the BRCA2 mutation could be confidentially communicated to the participant's sister. In the same example, a research participant could breach confidentiality if they shared health information about another person with a heathcare professional without that person's consent.

The number of people recruited to a study can also play a role in undermining confidentiality. In a study with younger people[9], Taylor and colleagues found the number of participants recruited to the study was considered too small by some specific departments that were involved in recruitment. The concern was that participants could be identified on the basis of their responses, and the departments refused to participate in the study.

While confidentiality can appear to be straightforward, as with any ethical issue, there are many ambiguities and nuances that researchers need to be able to work through successfully.

What is privacy?

In research, information privacy is the right to control how one's personal information is collected, used or disclosed. Privacy is acknowledged as a fundamental human right in Australia.[10] According to *The Privacy Act 1988* (Cth), personal information includes but is not limited to any personal information that a health service provider collects, including health records, wishes about future health services, genetic information and research data.

When conducting research, the primary concern is ensuring participants' involvement in research is protected and the appropriate settings are considered for recruitment, enrolment and data collection.[1] Researchers need to collect some personal information from participants, but human research ethics committees usually recommend that the only data collected should be that which is necessary for the research. Exemptions from specific requirements of the Privacy Act may be approved by a human research ethics committee; however, such exemptions are rarely sought for qualitative research studies because participants usually participate with the understanding that their information and status will remain private as written in the patient information and consent form provided to participants. Privacy can be ensured by only collecting personal information that is necessary for the study, and collecting that information in a considered manner. Up-to-date data systems, policies and document management protocols can ensure the quality of privacy in research.

In a systematic review of the perception of respect for and dignity of inpatients[11], the authors found that violations of patients' dignity and privacy were fairly routine. One example of a privacy violation included providing a patient list to third parties for religious visits, without consent.[11] While this may be a regular practice, it is also a violation of privacy if the patient has not consented.

Perdue University in the United States has developed an excellent infographic[1] that explains the differences between confidentiality, privacy and anonymity.

Strengths and limitations of confidentiality and privacy

Confidentiality and privacy are enshrined in research activities as being of the utmost importance to researchers and participants. When done properly, participants can be assured that their private information will not be shared without their consent, and they will not be identifiable in research results. A high level of concern for confidentiality and privacy can lead to greater trust between researchers and participants. Australian government organisations such as the Australian Bureau of Statistics and the Australian Institute of Health and Welfare (AIHW) use the Five Safes Framework[12], an internationally recognised approach to considering strategic, privacy, security, ethical and operational risks. The Framework is produced in Table 33.1. While not all research data needs this level of scrutiny for privacy and confidentiality, the Framework is a good starting point for considering whether research data is private and secure.

Table 33.1: The Five Safes Framework

Dimension	**Meaning**	**Potential risks to be mitigated**
Projects	Is the use of the data appropriate? AIHW Interpretation: Use of the data is legal, ethical and the project is expected to deliver public benefit.	• Breach of data supplier requirements • Breach of AIHW Ethics Committee collection/project approval conditions • Project is not expected to deliver public benefits commensurate with risk • Project design unlikely to meet stated objectives • Consent arrangements are unlawful • Using AIHW data for this project is outside community expectations.
People	Can the users be trusted to use it in an appropriate manner? AIHW Interpretation: Researchers have the knowledge, skills and incentives to act in accordance with required standards of behaviour.	Users of the data: • are subject to a conflict of interest • are subject to incentives to breach terms and conditions • are inexpert in the subject matter • have insufficient statistical skills to analyse the data effectively • and/or their organisation are unlikely to be able to manage data breach risks effectively • and/or their organisation have a history of breaching terms and conditions.

Dimension	**Meaning**	**Potential risks to be mitigated**
Data	Is there a disclosure risk in the data itself? AIHW Interpretation: Data has been treated appropriately to minimise the potential for identification of individuals or organisations.	• Identifiers are not removed • Data include variables not required for the project • Data include records not required for the project • Data treatments are insufficient to prevent disclosure of personal information (Privacy Act) • Data treatments are insufficient to prevent attribute disclosure • Data treatments are insufficient to prevent identification of an information subject (AIHW Act s.29).
Settings	Does the access facility prevent unauthorised use? AIHW Interpretation: There are practical controls on the way the data is accessed – both from a technology perspective and considering the physical environment.	Data are: • lost, intercepted or disclosed during transmission to the setting (data/ privacy breach) • subject to unauthorised access at the setting (data/privacy breach) • used for purposes beyond those approved (including linking to other data) • removed from the approved setting • not destroyed on completion of the project.
Output	Are the statistical results non-disclosive? AIHW Interpretation: A final check can be required to minimise risk when releasing the findings of the project.	• Outputs do not meet confidentiality requirements • Outputs are released without required data supplier approval • Output treatments are inconsistent with those of data already released.

Confidentiality has limitations. Researchers must respect the promise of confidentiality while disseminating results that participants may fear might identify them. It is not uncommon for researchers to discover that participant concerns around privacy and confidentiality are barriers to recruitment.[13]

Focus groups pose an increased risk to privacy and confidentiality because participants may identify themselves and provide private information in the group setting. Focus group guidelines (see Chapter 14) about privacy and confidentiality should be made clear before discussion commences.

Some of the limitations of privacy include the use of digital platforms. Data leaks and the ability to identify participants are potential risks.[14] With more research being conducted online and recruitment taking place through social media, there is greater risk of privacy breaches. Recruitment through a social network on Facebook (Meta), for example, poses many issues for privacy because internet provider (IP) addresses could be used to identify participants, and the phrases people use in their posts and comments could be searched to identify participants.[15]

Summary

Confidentiality and privacy are core ethical principles for researchers and must be clearly discussed with participants. Regulations must be followed, and approval must be sought and provided by human research ethics committees. While there are limitations to confidentiality and privacy, when researchers follow regulations and guidelines, they can assure participants that their information will be safe.

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CHAPTER 34: DATA STORAGE AND ACCESS

Danielle Berkovic

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the importance of data storage and access in the context of qualitative research.
- Identify the types of data that require considered management processes.

Why do data storage and access matter?

Managing qualitative data requires designated structures and systems, for two main reasons: (1) to protect participants' privacy, confidentiality and anonymity, and (2) to organise data in a way that makes it easily accessible and retrievable. [1] Data may include, but may not be limited to, consent forms and demography of participants, interview and/or focus group transcripts, audiotapes or videotapes, researcher notes and other types of data described in Section 3 (e.g. River of Life drawings and diagrams, social media data). Storing qualitative data appropriately enables researchers to manage data that may have been accumulated in various forms, at different points in time and across multiple locations for different research purposes, all while maintaining the security of the data. It is therefore recommended that researchers establish appropriate data management protocols at the outset of a research project and use a reflective process to better systemise their data (see Table 34.1).

Data storage policies

Researchers should be mindful of their university's or institution's data management policies. In Australia, the National Health and Medical Research Council (NHMRC) provide guidelines supporting the Australian Code for the Responsible Conduct of Research, and researchers are required to adhere to the access and storage policies outlined in the document. For example, the Code states that researchers must 'retain clear, accurate, secure and complete records of all research including research data and primary materials'. [2] The NHMRC outlines two key reasons for appropriately storing data:

- **Retention and publication:** Enable the justification of the outcome of the research and facilitates sharing of the published findings. Primary qualitative data may be of cultural or historical value, or provide important insight into certain communities, so researchers should consider appropriate avenues through which to store their data. Published data also often requires some type of metadata, and although this is less applicable to qualitative research, data collection tools such as interview guides or researcher reflections may be appropriate to keep.
- **Managing confidential and other sensitive information:** Unless specified otherwise in the participant information sheet, prospective research participants usually participate in research with guaranteed endeavours to protect their anonymity. Researchers are responsible for enshrining this right by appropriately storing consent forms with names either in a locked filing cabinet or scanned and in a password-protected folder. Individual universities and institutions will have their own policies about this and it is always important to check this at the outset of your research when coming up with your data storage and access policies. What can also come under this is allocating pseudonyms for participants in interview transcripts.

Universities and other research institutions have policies that explain how qualitative data must be stored, the length of time that it should be stored for, and guidelines on when electronic archives are to be erased and physical archives are to be destroyed. In particular, electronic data should be stored on a secure server that is only accessible by the researchers named on the ethics application. Some Human Research Ethics Councils will not approve studies that use servers and/or storage services located outside of Australia, for example, Dropbox. These are standard research governance policies, which researchers must be aware of, and vital step in the research process that research ethics committees will also consider prior to approval. In addition, most universities or other research institutions will mandate that data storage and management processes are detailed in the participant information sheet or consent forms provided to prospective participants. [3] What to do with these sheets, in addition to other research materials, is provided in Table 34.1, based on the authors' experiences in conducting qualitative research.

Table 34.1: Examples of data storage and access protocols

Research materials or data	**Storage and access considerations**	**Example storage and access solutions**
Consent forms	• Consent forms usually contain the participant's name and can sometimes include their contact information. • Consent forms often explain the research context, and therefore are revealing of participants' experiences, which the participant may prefer to keep private outside of the research.	• If the consent form is a hard copy version, the researcher should place it in a locked filing cabinet at the designated research facility. The researcher should also scan the consent form and store it digitally in a folder that is protected and only accessible by the named researchers. The same process applies to electronic consent forms.
Audio and video recordings	• Audio and video recordings usually contain the participant's name (assuming that an interviewer, for example, refers to the participant by their name at least once). • Audio and video recordings may also detail private information that the participant is only disclosing for the purposes of the interview or focus group.	• The researcher should download the audio and/or video recording onto a computer and delete the recording from the original device. • The researcher should save the file in a folder that is protected and only accessible by the named researchers.
Transcripts	• Transcripts usually contain the participant's name, assuming that the interviewer refers to the participant at least once in the recording. • Transcripts may also detail private information that the participant is only disclosing for the purposes of the interview.	• The researcher should save the transcripts in a folder that is protected and only accessible by the named researchers. • Transcripts should be de-identified by replacing participants' names with numbers or pseudonyms.
Field notes	• Depending on what the researcher is detailing at the time, field notes may contain identifying information about research participants who are being observed.	• The researcher should save the notes in a folder that is protected and only accessible by the named researchers.
Researcher reflections	• Depending on what the researcher is reflecting upon, their reflections may contain identifying information about participants.	• The researcher should re-read their reflections to ensure that there is no potentially identifying information about participants. If there is no identifying participant information, the researcher may choose to store this data as it best assists them. • If the reflections contain identifying information, the researcher should save the transcripts in a folder that is protected and only accessible by the named researchers.

Differences between sharing 'raw' qualitative and

quantitative data

As qualitative research gains prominence and is increasingly published in high-impact journals, the concept of data sharing is being discussed among journal editors, manuscript reviewers and researchers. Raw qualitative data – data that has not yet been analysed or aggregated – is distinct from raw quantitative data; how to adequately share qualitative data without compromising participant anonymity is a key consideration. Four challenges and potential solutions for sharing qualitative data are described here:[4]

- **Qualitative data is unique:** Qualitative data lends itself to generating new theoretical or practical insights about a phenomenon of interest, in greater detail than is possible through quantitative research. This qualitative data is usually not collected in linear fashion. Thus, the measure of reliability in quantitative research (e.g. producing the statistical code used to analyse anonymised data) does not translate to qualitative data. Instead, researchers may describe verification strategies for how analytic codes were developed, produce reporting checklists or calculate inter-rater reliability for comparing similarities between data coders.
- **Reproducible research and qualitative data:** The iterative nature of qualitative data collection, analysis and interpretation means that the process of data verification is challenging. This is dissimilar to quantitative research, where enough detail about the methods should be described to ensure it is independently reproducible. This concept is not transferrable to qualitative research; for example, even if an interview or focus group is audio-recorded, the recording cannot show the body language of participants, which may contribute data on their emotional response to a particular topic of discussion. Sharing qualitative data for reproducibility purposes is unlikely to produce the same results, as each population group, and even the same population group on a different day, are likely to contribute different data.
- **Preserving the anonymity of participants:** Maintaining participants' anonymity is a pillar of qualitative research ethics, and so all data collected would need to be de-identified prior to sharing. Although this may be possible, it places undue burden on the participant to ask that their entire de-identified transcript be made publicly available, as their experiences alone may be identifying, or at least sensitive. De-identifying data for the purpose of data sharing also introduces unnecessary potential for human error and inconsistency, which in turn risks the participants' privacy and the broader population's confidence to participate in qualitative research. Certain types of studies are at particular risk of deductive disclosure, especially where participants are from easily identifiable minority groups or specialised professions. Instead of a data-sharing policy, researchers could be required to follow procedures that enhance transparency; for example, disclosing the transcription methods employed and the processes for analytic code development and determination of the final themes in the study's findings). Supporting the study's findings with an adequate number of quotes in research publications is also key.
- **Other unintended consequences of qualitative data sharing:** The burden of organising qualitative data to the extent that it is ready for external review is likely to exceed the time and effort required to write a report for publication. Given that qualitative research aims to convey people's

experiences, it could be argued that the researcher's energy should first and foremost focus on displaying the data and interpreting its meaning. Journals should consider the possibility that, in response to data-sharing policies, participants and researchers may alter their questions and responses, similarly to how participants might alter their behaviour to be considered more 'desirable' if they are being observed by a researcher.

Summary

Ensuring that qualitative data is managed, stored and appropriately accessible is a key part of the research process, and should be considered by researchers at the outset of the project.

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WRITING QUALITATIVE RESEARCH

CHAPTER 35: COMMUNICATING YOUR FINDINGS

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the important elements to include when communicating your qualitative research.
- Describe approaches to presenting qualitative data.

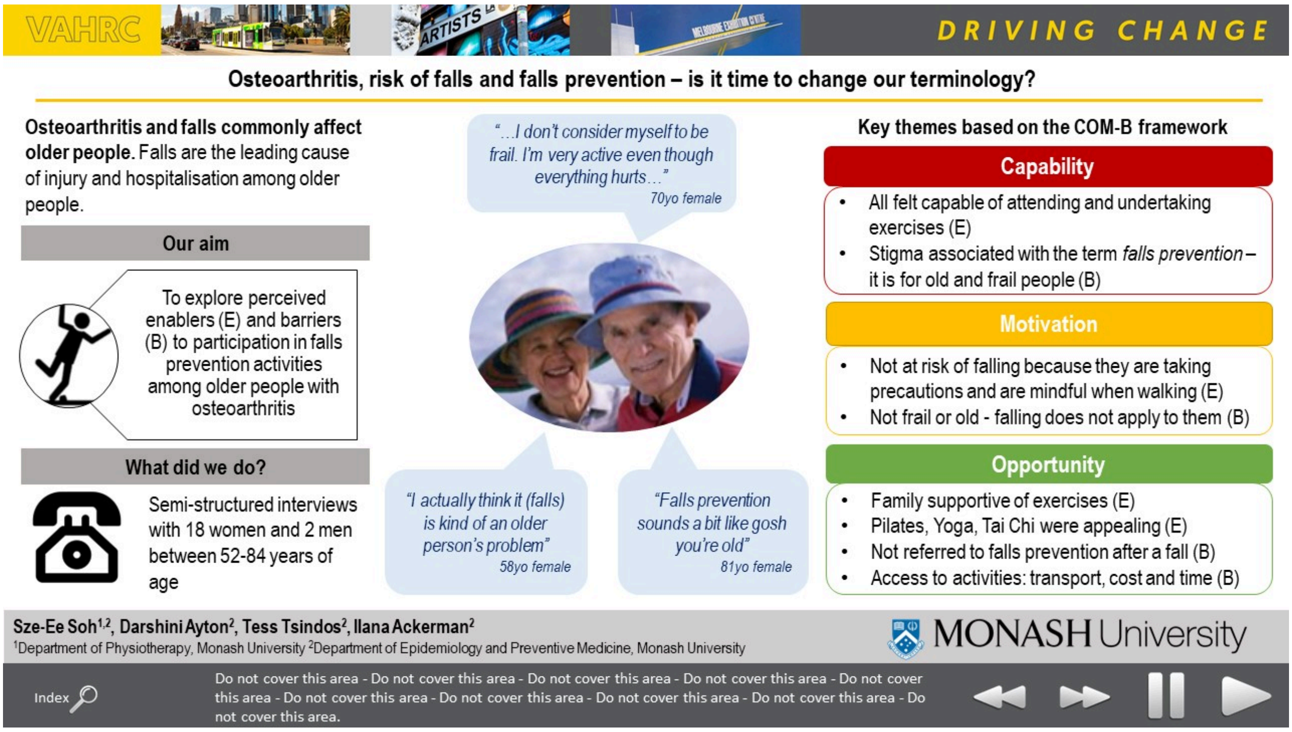
Formats for communicating qualitative research

It is not uncommon for qualitative researchers to complete data collection and analysis and then to be overwhelmed by the amount of data that has been collected. Presenting data in a meaningful way can be a challenge. Unlike quantitative research, which can use tables, charts and figures to succinctly present research results, qualitative research typically requires a narrative to describe and explain the themes and findings of the research, which may involve the presentation of quotes to illustrate the themes or findings (see Chapter 26).

The main formats for communicating qualitative research are:

- **Research thesis** – in Australia, examples include honours thesis (approximately 10 months of research, resulting in 10,000–15,000 words); masters thesis (12–24 months of research, 10,000–30,000 words) and doctor of philosophy (PhD) thesis (3–4 years of research, 60,000–90,000 words and may include publications). The benefits of presenting research in a thesis include having the space (word count) and flexibility to write about the qualitative research process and results. For example, in Chapter 26, all the examples about how to write about rigour were from a PhD thesis, which demonstrates that the student was able to write about rigour in greater detail than would have been possible in other formats.

- **Conference presentation** – typically, the background, methods, results and discussion/ implications of the research need to be demonstrated within a 10–20-minute presentation. Depending on the study, it can be challenging to present all the research in such a short time, and hence researchers often choose to address just one or two of the study's research questions and focus on the results that address these.
- **Poster** – a conference poster provides the opportunity to present study results visually, in charts and figures, and to incorporate quotes from participants to illustrate. As with the conference presentation, a poster is limited to providing a high-level summary rather than much detail (see Figure 35.1 as an example).



VAHRC

DRIVING CHANGE

Osteoarthritis, risk of falls and falls prevention – is it time to change our terminology?

Osteoarthritis and falls commonly affect older people. Falls are the leading cause of injury and hospitalisation among older people.

Our aim

To explore perceived enablers (E) and barriers (B) to participation in falls prevention activities among older people with osteoarthritis

What did we do?

Semi-structured interviews with 18 women and 2 men between 52-84 years of age

"…I don't consider myself to be frail. I'm very active even though everything hurts…" 70yo female

"I actually think it (falls) is kind of an older person's problem" 58yo female

"Falls prevention sounds a bit like gosh you're old" 81yo female

Key themes based on the COM-B framework

Capability

- All felt capable of attending and undertaking exercises (E)
- Stigma associated with the term *falls prevention* – it is for old and frail people (B)

Motivation

- Not at risk of falling because they are taking precautions and are mindful when walking (E)
- Not frail or old - falling does not apply to them (B)

Opportunity

- Family supportive of exercises (E)
- Pilates, Yoga, Tai Chi were appealing (E)
- Not referred to falls prevention after a fall (B)
- Access to activities: transport, cost and time (B)

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Do not cover this area - Do not cover this area - Do not cover this area - Do not cover this area - Do not cover this area - Do not cover this area - Do not cover this area - Do not cover this area - Do not cover this area - Do not cover this area.

Figure 35.1: A poster presented at the Victorian Allied Health Research Conference in 2019. Used with permission from the authors.[1]

- **Academic journal or book publication** – most researchers wish to publish their research in academic journals and books. Journal requirements differ between disciplines. Throughout the chapters of this textbook, we have provided links to published qualitative research across health and social care journals. These articles demonstrate the diversity of qualitative research in published form. Every journal provides an outline of its focus and scope (see 'About the Journal' on the journal's homepage), including the types of research it is interested in publishing. The Instructions to Authors page guides prospective authors on the types of articles the journal publishes (e.g. original research, opinion, short reports, letters to the editor), word limits, guides to writing style and formatting requirements. Examples of journal websites that provide journal information and author guidance include:

  - Health and Social Care in the Community (see the About and Contribute sections)
  - BMJ
  - Australian Social Work (see the About this Journal and Submit an Article sections)
  - Public Health

Styling and formatting qualitative research for publication

The main structure for presenting research in any form is known as IMRAD, which stands for introduction, methods, results and discussion. An outline of each of these sections is provided here, tailored specifically to the presentation of qualitative research:

Introduction

The introduction covers the *why* of the research by describing the background, research problem, brief literature review, the framework or theory (optional) and posits the research aim and/or question and/or objectives. See, for example:

- Misconceptions and the acceptance of evidence-based non-surgical interventions for knee osteoarthritis. A qualitative study[2]
- Barriers and challenges affecting the contemporary church's engagement in health promotion[3]

Methods

The methods section details the research process (when, where and how the was study done), including the research design and philosophical underpinnings, research setting, population, participant selection, recruitment, data collection, analysis, reflexivity and ethical considerations and approval. As discussed in Chapter 26, it is important to provide enough information about the methods so that the reader can make sense of the results. A useful process, particularly in providing information about data collection, is to include a table showing how data was collected, including relevant activities or questions. See, for example:

- Co-designing a patient support portal with health professionals and men with prostate cancer: an action research study[4] (see Table 1)
- Barriers and enablers to intervention uptake and health reporting in a water intervention trial in rural India: a qualitative explanatory study[5] (see Tables 1 and 2)
- The primary care experience of adults with chronic obstructive pulmonary disease (COPD). An interpretative phenomenological inquiry.[6] (The methods section includes a good example of how to write about reflexivity and researcher positionality.)

Results

The results section explains and interprets the data generated from the research. The first part of the results section describes the participants (demographics), dates when data were collected and duration of interviews, focus groups or observations. The next part presents the themes of the study with a narrative, explains the themes of the study and provides supporting quotes. There are several ways themes can be presented: in diagrammatic form, tabular form and/or in narrative form throughout the paper. The decision of how to present the results depend on the journal's word limit and table requirements. In general, if the word limit is low (up to 3000 words), then quotes tend to be presented in tables. If the word limit is higher (up to 8000 words), then quotes can be woven throughout the results section. See, for example:

- When immunosuppression and COVID-19 intersect: an exploratory qualitative study of young lung transplant recipient perceptions of daily life during a pandemic[7] (See supplementary table 1 for the themes and quotes. The results are presented in a narrative format, with an explanation of the theme with quotes in the text.)
- 'I literally had no support': barriers and facilitators to supporting the psychosocial wellbeing of young people with mental illness in Tasmania, Australia[8] (Figure 1 is a diagram with an overview of the themes.)

As you may observe in the examples given, qualitative researchers do not use percentages when describing themes. Since data collection is flexible and adaptable to the participant group, not all participants may be asked the same questions in the same way. Hence, it is not a structured form of data collection that enables percentages to be presented. While researchers may indicate the number of participants who described a particular experience, they rarely quantify this further; rather, they seek to describe, compare and contrast participants' responses, using words such as *some, others, most, all, a few*.

Choosing quotes

The quotes in the narrative presentation and the tables should illustrate the study's themes. This includes providing ordinary quotes, unexpected quotes, hard-to-classify quotes (or negative case quotes) and minor quotes to illustrate minor themes.

Editing quotes

Quotes from the transcript may be hard to follow and messy to read. Researchers tend to edit quotes for clarity, while being careful to not change the meaning of the quote.

For example, this original, unpublished quote from the 6-PACK pre-implementation study is lengthy, with some statements that are irrelevant to the study's findings[9]:

> To some extent, some falls are unpreventable… But the majority of times, things can be done to prevent them. Accidents don't just [happen], you're walking down the street [and] your high heel breaks, you fall. You can't say you're going to prevent that… I think sometimes with some of

> the elderly that, yes, they're elderly and they're demented, but we should be aware that they're a higher risk of falling and implement things so [they don't fall]. Having the buzzer close by, having adequate lighting, having adequate railing and stuff around [will help prevent falls]. [unpublished quote]

The same example has been edited; it uses ellipses (...) to indicate when a sentence has been redacted and square brackets to indicate when the researcher has inserted their own words to provide clarity:

> To some extent, some falls are unpreventable... But in the majority of times, things can be done to prevent them... yes, they're elderly and [have dementia], but we should be aware that they're a higher risk of falling and implement things so [they don't fall]. Having the buzzer close by, having adequate lighting, having adequate railing and stuff around [will help prevent falls]. [unpublished quote]

Presenting the quotes

If the quote is 40 words or longer, it should be presented as a 'block quote', which is an indented paragraph placed after the description of the quote. If the quote is just a few words, it can be integrated into a descriptive paragraph. This can be seen on page 9 of the article by Ayton and colleagues on the pre-implementation study of the 6-PACK falls prevention intervention.[9] The **bold** text in the block quote following indicates the theme and the ***bold text in italics*** indicates a subtheme. Quotes in *italic*s (or within a single quotation mark) are woven into the explanation of the theme. The final quote is presented separate from the main text as it is longer and brings together the points that have been made in the descriptive paragraph.[9]

> **Engaging staff in falls prevention.** As highlighted by one senior staff participant, staff engagement is important and can be facilitated through 'engaging hearts and minds'—both the emotional and logical aspects of falls prevention. Nurses described feeling *guilty*, *stressed* and *distressed* when a patient under their care experienced a fall. They also described the *worry* experienced if a patient suffered a fall-related injury. The ***emotional impact of a patient fall*** was seen as something that could be a motivating factor. A senior staff member at one hospital highlighted that nurses responded to interventions that ***emphasised the benefit to the patient***. This also had implications for sustaining the project long term:
>
>> If you always promote it as best for the patient and patient-focused you'll get staff on-board, and continuing to help drive the program. You've got to be able to sell it to them... first of all say this is going to be so much better for your patient outcomes. (SS1, H1)[9(p10)]

Discussion

The discussion section revisits the study's aims, research questions and objectives and then presents the implications of the results within the context of the broader academic literature base. The discussion also includes the strengths and limitations of the study, and implications of the study or future research directions. In some social science journals and book, the results and discussion sections may be combined. See, for example:

- Boundary breaches: the body, sex and sexuality after stoma surgery[10] (The results and discussion are presented together with concluding remarks at the end.)
- Exploring the partnership networks of churches and church-affiliated organisations in health promotion[2] (The results and discussion are combined, including the section on strengths and limitations, with a conclusion at the end. This paper also provides a good example of the use of diagrams.)

In the discussion section, it is important to demonstrate that the research questions and aims have been addressed. Some researchers adopt their research questions as subheadings in the discussion. The discussion positions the research within the research discipline and published research, and presents research implications.

Considerations in determining publication of qualitative research

- **Explore different journal types.** Look at the reference list you have included in your paper and note which journals are mentioned often. This will provide a good rationale for submitting to one of those journals.
- **Research the journal.** Once you have chosen a journal to submit to, consider whether it has published qualitative research. Does it have reviewers or an editorial board member who is experienced in qualitative research? Read the author guidelines closely for guidance on submitting qualitative research, in terms of word limits, presentation style and reporting tools required (see Chapter 36 for details on reporting tools).
- **Check the journal's data–sharing requirements.** Consider whether you can ethically meet these requirements. For example, *Plos ONE* requires authors to make their raw, de-identified data available (see https://journals.plos.org/plosone/s/data-availability)
- **Find an example to guide your submission.** After you have identified the journal you wish to submit your paper to, find a qualitative research article that has been recently published in that journal (it does not need to be in the same topic area as your research). Use this article as a template to guide how you prepare your introduction, methods, results, discussion and conclusion.
- **Persevere.** It is not unusual to have to submit to a few journals before finding the right home for your article. Take on reviewer feedback (see Chapter 37) and seek advice from colleagues and peers about where to submit.

Summary

Communicating qualitative research requires the researcher to consider the form of communication and to tailor the data, results and presentation to suit the format (thesis, conference presentation, journal paper) and the needs of the audience. When presenting qualitative research, typically the IMRAD format is followed. Considering how to present data – whether in narrative form or using tables and diagrams – is often contingent on the journal's requirements.

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CHAPTER 36: REPORTING TOOLS

Tess Tsindos

Learning outcomes

Upon completion of this chapter, you should be able to:

- Describe the main reporting tools used in qualitative research.
- Understand how to use the main reporting tools.
- Identify the strengths and limitations of each reporting tool.

What is a qualitative reporting tool?

Generally speaking, a tool is something that helps someone complete a task. Qualitative reporting tools are usually checklists or frameworks that help researchers demonstrate to publishing journals that they have followed a comprehensive process in reporting on their research. Qualitative reporting tools provide detailed information on the research team, study methods, context of the study, findings, data analysis and interpretations. Although using these tools could be considered unnecessary, they can help in planning the study as well as with reflexivity.

The main reporting tools used in qualitative research

There are three main reporting tools academic journals use to ensure comprehensive reporting and transparency in reporting qualitative results. These are the Consolidated Criteria for Reporting Qualitative Research (COREQ),[1] the Standards for Reporting Qualitative Research (SRQR)[2], and the Johanna Briggs Checklist for Qualitative Research (JBI).[3] A fourth tool, the Critical Appraisal Skills Programme (CASP), a qualitative research checklist,[4] is also helpful for researchers, although not required by journals. While using these checklists might seem onerous, they are very helpful in focusing the researcher on improved reporting of qualitative research.

COREQ

The COREQ[1] is a 32-item checklist that is designed to help researchers report on their results. It is divided into three domains: research team and reflexivity (8 items), study design (15 items), and analysis and findings (9 items). Many journals request the author(s) complete this checklist and submit it with their manuscript. While it is a lengthy checklist, it is not difficult to complete. The first step in completing the tool is to ensure the manuscript is submitted with line numbers; this is easily done by clicking 'Line numbers' in the layout tab in Microsoft Word. Once the lines are numbered, the researcher is able to refer to the line number(s) containing the information being requested. Once completed, the checklist should be uploaded to the journal site as a separate document.

Strengths and limitations of COREQ

A strength of COREQ is that qualitative research is clearly and transparently presented. Reviews of COREQ have highlighted ambiguity in reporting, which could be due to the subjective nature of the items; ethical concerns not being adequately addressed in the checklist; and while the checklist might be completed, the research may still be of poor quality.[5]

SRQR

The SRQR[2] consists of 21 items and 'aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research'(p1245). It includes the article title and abstract; problem formulation and research question; research design and methods of data collection and analysis; results, interpretation, discussion and integration; and other information. The checklist is completed along the same lines as COREQ, by providing answers based on line numbers. Once completed, the checklist is uploaded to the journal site as a separate document.

Strengths and limitations of the SRQR

Strengths of the SRQR are that it is moderate in length, highly transparent in purpose and claims to consider all qualitative research methodologies equally. The tool was developed through a systematic consideration of existing tools and is appropriate for use by experienced qualitative researchers. Limitations are that it is unclear whether SRQR truly considers all qualitative methodologies equally[10]and that it does not explicitly mention a conceptual framework.[6]

JBI

JBI[3] provides a means for assessing the quality of a study for the possibility of bias in design, conduct and analysis. It comprises 10 questions that researchers answer about aspects of the research, such as congruity between the stated philosophical perspective and the research methodology, whether conclusions from the research flow from the analysis and interpretation of the data. The tool does not ask for line numbers as evidence; rather, it provides checkboxes to confirm items. This checklist is often used as supporting evidence for systematic reviews (evidence synthesis).

Strengths and limitations of JBI

JBI's focus on congruity of results is considered both a strength and a limitation.[7-9] This brings attention to the study's philosophical perspective, methodology, research questions and researcher reflexivity but comes at the expense of comprehensiveness. Brevity, ease of use and clarity mean that JBI can be used by less experienced researchers.[9]

CASP

CASP comprises 10 questions divided into three categories: Are the results of the study valid? What are the results? Will the results help locally?[4] This checklist was designed to be used as an educational pedagogic tool, and is used for quality appraisal in health-related qualitative evidence syntheses.

Strengths and limitations of CASP

CASP has been described as of the most commonly used checklist or criteria-based tools for quality appraisal in health and social care-related qualitative evidence syntheses.[8] CASP comprises only 10 items and has been criticised for not including items that provide a rationale for sample size and recall bias, and relatively minimal use of the participant voice.[8] A further limitation is that the tool may prioritise a quantification of quality over content, which can lead to questionable interpretations of quality. Another limitation is that although it is promoted as a good tool for novice researchers, in fact the researchers need help in determining what constitutes good quality qualitative research.[8] A new question about the study's underlying theoretical, ontological and epistemological frameworks could be incorporated to strengthen the tool.[9]

Summary

Four qualitative reporting tools have been introduced with brief discussion of how to use them. Each is tool has its uses, and journals usually request one of these tools be completed when submitting a manuscript for publication. Each tool has strengths and limitations. The overarching limitation is that requiring all researchers to adhere to a single standard is restrictive for such a broad field of enquiry. However, all research should be transparently reported, and each tool presents a solid way of reviewing qualitative research to ensure a study has been rigorously appraised.

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CHAPTER 37: THE JOURNAL REVIEW PROCESS

Darshini Ayton

Learning outcomes

Upon completion of this chapter, you should be able to:

- Understand the review process for manuscripts submitted for publication in academic journals.
- Prepare responses to common misconceptions about qualitative research that may be evident in reviewers' comments.

Submitting a manuscript for publication

When a researcher has completed writing up their qualitative research, it is time to prepare to submit the research to the journal they have identified as suitable for its publication. The submission process can be time-consuming; typically, it involves the following steps:

- Preparing all the relevant documents for review. Each journal provides instructions for submission, which may include:
    - A cover letter to the editor, explaining the focus of the manuscript, the proposed format (e.g. original research article) and why it should be published in this particular journal.
    - A title page providing details about the authors and their affiliations.
    - An anonymised version of the manuscript. This will require the researcher to strip the paper of all identifying information, including author names and affiliations, and names of approving human research ethics committees. Depending on the journal, tables and figures may be placed at the end of this document or submitted as separate files and formats.
    - A separate file with all the tables and another with the figures (depending on journal requirements).

    - Supplementary data documents, such coding trees, interview guides, additional tables with themes and quotes, and the completed qualitative research reporting tool (see Chapter 36), submitted for review but not for publication.
- Creating an author account on the journal's submission portal (if this is the first time you are submitting to this journal).
- Completing of an author profile, including institution details, main areas of research and keywords describing research areas (e.g. methods, topic areas)
- Creating a new submission for the manuscript in the submission portal. This typically involves:
    - Entering the full title of the manuscript, including a short title.
    - Entering the abstract into the journal's submission portal (not as a document upload).
    - Selecting the type of manuscript (original research article, short report, letter to the editor).
    - Selecting keywords to describe the structure of the manuscript (methods, topic area, population group).
    - Uploading the relevant documents for review (see point 1).
    - Listing all authors in the correct order, including their names, titles, institutions and email addresses.
    - Uploading a publishing agreement, including the signatures of all authors agreeing to the submission.
    - Declaring all funding sources for the research.
    - Declaring conflicts of interest for each member of authorship team (this is sometimes included in the publishing agreement and funding declaration).
    - Proposing at least two peer-reviewers who may be suitable to review the manuscript.
- Confirming the submission. The submission system or portal then generates a single PDF file including all the documents; the submitting author is then required to review and approve this file to confirm the submission.

The peer-review process

When a manuscript has been submitted for consideration, usually the journal's administrative team will invite an editor to handle the submission. Every journal has its own protocols for submission, so the handling editor may be the editor-in-chief, managing editor, associate editor or other personnel who may accept or reject the submission. The first task of the editor is to read all the prepared documents and the cover letter, and to decide whether the manuscript fits within the scope of the journal and warrants peer review. If the editor's immediate decision is to reject the submission, this is known as a *desk rejection*.

If the editor believes the manuscript fits the scope of the journal and warrants further review, they will invite peer reviewers. Peer reviewers usually receive an email inviting them to review the manuscript, with a short abstract embedded within the email. This enables the peer reviewers to determine whether they have the expertise to review the article. However, even if a peer reviewer is confident about the methods or the topic area, this does not guarantee that they will accept the invitation to review. Recent research has indicated that 70% of invited peer reviewers decline the request.[1] There are many reasons for this, including a lack of training, lack of time and the unpaid nature of the role.[1, 2] Journals typically require at least 2 peer reviewers per article, and in some cases this may be 5 or 6. Hence, the editor may send out 20 or more invitations to review an article before securing the required number of peer reviewers. In the journal submission system, there is a section indicating the status of the article; if the editor is finding it difficult to find peer reviewers, the status may remain at 'awaiting peer review assignment' (or something similar) for a few months.

The role of peer reviewers

Peer review has a long history in academic publishing. The role of the peer reviewer is to provide a critique of a manuscript, to ensure quality and rigour, and to assist the journal editors in their publishing decision.[3] Once the peer reviewer has accepted an assignment, they are provided with the collated PDF of all the submitted documents. Reviewers are required to log into a different section of the journal submission portal, and are asked to indicate whether the paper meets certain requirements (e.g. is written well; is of interest to the journal's readership; statistical tests are relevant and have been correctly performed). The peer reviewer is required to read the manuscript and supporting documents, and to provide a report to the editor and authors. Usually, this begins with an overall summary of the paper and then feedback and questions on each section of the paper. The peer reviewer is required to recommend whether the article should be accepted as is, revised with minor revisions, revised with major revisions or rejected. The peer reviewer can also submit comments to the editor, which are not seen by the authors. Peer reviewers are usually given 2–3 weeks to provide their review. While the peer reviewers are undertaking their review, the status in the submission portal is usually listed as 'awaiting peer review reports'. Once the reports have been provided, the editor decides whether to accept the manuscript, invite the authors to revise it (either minor or major revision), or to reject it. This decision is based on the editor's assessment of the reports and the peer-reviewers' recommendations.

Strengths and limitations of the peer–review process

Peer reviews can strengthen a research article by highlighting areas where further explanation is required. In qualitative research, this may include advice on the structure of the results and whether the quotes illustrate the themes well. This author has received excellent advice from peer reviewers on how to coherently integrate theory into results and how to meaningfully discuss the research within the broader context of the literature. However, there is limited evidence on whether peer review leads to the publication of high-quality research. Many concerns have been raised regarding the system and infrastructure for submission, the varied roles and responsibilities of peer reviewers, the quality of peer-review reports and potential bias on the part of peer reviewers (which journals attempt to minimise through the use of anonymised review).[3] Read about some of the debates on the role of peer review:

- The limitations to our understanding of peer review[3]
- The evolving crisis of the peer-review process[1]

For the researcher, anonymised peer review has the advantages and limitations of diversity in the reports and the different opinions of the peer reviewers.

Responding to peer review

Regardless of the editor's decision to accept, revise or reject the paper, an email is sent to the authors with the results of the peer review. If the paper is rejected, reports from peer reviewers can still be helpful in strengthening the paper for the next submission. If the paper requires minor or major revision, then the author team will need to respond to each of the peer-reviewers' points and demonstrate how they have addressed these in their revised manuscript, or provide a rationale as to why a change is not required.

Usually, authors approach the response to reviewers in one of 2 ways:

1. Separately list the reviewer's comment, question or suggestion, followed by a written response.
2. Tabulate the response, with columns for the reviewer's comment, question or suggestion, the authors' response and changes that have been made in the manuscript.

Table 37.1 is an example of the tabulated format for addressing peer-reviewer feedback, although usually the last column is titled 'Changes to the manuscript'. This table is an aggregate of feedback received by the author over years of publishing qualitative research and does not relate to any particular paper or peer reviewer.

Table 37.1: Common peer-reviewer feedback and example responses

Reviewer 1	**Author response**	**Resources to support the response**
The small sample size for this qualitative study is not generalisable.	Qualitative research does not seek to be generalisable. Instead, qualitative research seeks to provide depth of insight on the topic and research questions posed. The participants in this study are representative of the broader population with this condition. [The author could demonstrate this point with statistics from other studies in terms of characteristics of the study population.]	Chapter 2 Chapter 26 Doing reflexive TA[4]

Reviewer 1	**Author response**	**Resources to support the response**
The researchers should report the inter-coder reliability for the analysis.	Inter-coder reliability does not align with the rigour underpinnings of qualitative research. This research employed thematic or grounded theory, which does not lend itself to inter-coder reliability. These approaches to analysis focus on the interpretation of the data rather than the frequency of the data. [Inter-coder reliability may be used for content analysis.]	Intercoder reliability in qualitative research: debates and practical guidelines[5] Why don't we advocate multiple-coders and inter-rater reliability for reflexive TA[4]
The issue of data saturation is not addressed.	Data saturation is a contentious topic in qualitative research. We undertook reflexive thematic analysis, which does not endorse data saturation as a practice.[6] [Applied thematic analysis does use data saturation.[7,8]]	Resources against data saturation Thematic analysis: the good, the bad and the ugly[9] Resource on data saturation A simple method to assess and report thematic saturation in qualitative research[8]
The authors should state WHY they chose the [theory/ model/ framework] to enable future readers to get an understanding of arguments for choosing such a [theory/ model/ framework].	We have expanded the description of [theory/model/ framework] in the methods, including linking the [theory/ model/framework] to our research questions [or objectives]. We have also provided references to other studies that have adopted this [theory/model/ framework].	
How did you decide on the questions to ask in the focus group interview and semi-structured interview? Please describe its process in the part of 'Materials and methods'.	We have expanded the description of the interview [or focus group] guide development, including how questions were generated, based on the literature and our work with our consumer [or patient] advisory group. We have detailed how the questions evolved after piloting and throughout the data collection period. We have provided a table in the supplementary materials of the interview [or focus group] questions, mapped to our research questions.	

Process for addressing peer–reviewers' comments

Peer reviewers' reports are typically provided to the corresponding author, or may be sent to all authors by email. It can be confronting to read reviewers' feedback and difficult to formulate a meaningful response. Taking time to read and digest peer-reviewers' reports before preparing a response can be a helpful start. Typically, journals provide a deadline for authors to submit their response and amended documents. If this timeframe is not achievable, it is advisable to let the journal know that more time is needed.

1. Follow the journal's guidelines on how to prepare the amended manuscript. Some journals ask for changes to be tracked (using the Track Changes function in Microsoft Word), and for 2 versions to be uploaded: a tracked-changes version and a 'clean' version. Other journals ask for changes to be highlighted in the text, using the text highlighting tool.
2. Prepare a separate document to respond to the peer reviewers. Start by thanking the reviewers for the time they have taken to review the manuscript and for the feedback they have provided. Then respond to each of the reviewers' points in a table or document (see for example Table 37.1).
3. Be clear and concise, and provide evidence for your decision in the response. If appropriate, integrate this evidence into the manuscript.
4. Do not make changes to the manuscript that do not relate to reviewer or editor feedback.
5. Ensure all the changes are made across all the documents that are being submitted for re-review.
6. Ask a co-author or colleague read the response, to check for tone and clarity.
7. Resubmit the manuscript and supporting documents through the journal submission portal. It is common for papers to be sent to the same peer reviewers for a response, but new reviewers may be invited for an independent round of review.
8. Be aware that responding to reviewers' comments and resubmitting an article does not guarantee that it will be accepted.

Summary

Submitting a manuscript for publication can take time, as does the peer-review process. Ensure you have read the journal's submission guidelines thoroughly, and allocate sufficient time for the submission process. There are advantages and limitations to the peer-review process, but regardless, this is the current process used in academic journal publishing. Responding to reviewers' reports is an important part of the process towards publication, and can help to strengthen a paper before publication.

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Reviews were structured around considerations of the intended audience of the book and examined the comprehensiveness, accuracy, and relevance of the content. Reviews were also focused on relevance longevity, clarity, consistency, organization structure flow, grammatical errors, and cultural relevance.

The authors and the publication team would like to thank the reviewers for the time, care, and commitment they contributed to the project. We recognise that peer reviewing is a generous act of service on their part. This book would not be the robust, valuable resource that it is were it not for their feedback and input.

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VERSION HISTORY

This page provides a record of edits and changes made to this book since its initial publication. Whenever edits or updates are made in the text, we provide a record and description of those changes here. If the change is minor, the version number increases by 0.1. If the edits involve substantial updates, the version number increases to the next full number.

Scope note: Version notes are limited to changes in content. Corrections to spelling, grammar, the fixing of broken links etc. will not warrant a version note. As this book is being published in parts, the initial publication of each new section will also not trigger a version note.

Version	**Date**	**Change**	**Affected section**
2	30/6/2023	Table 3.1 replaced with text from para 7 to para 10.	Chapter three